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The Potential and Limits of Mental Health Service User Involvement

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degree of PhD

University of Glasgow

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ABSTRACT

User involvement in the planning and management of health and social services has been a key social policy theme of the 1990s. For users of mental health services in particular, such involvement has often been seen as offering an opportunity both to reconstruct mental health services on the basis of users' wishes and more equal relationships with professionals, and also to challenge the stigma which surrounds mental ill-health and contributes to the social exclusion experienced by many users. Yet the apparent consensus that user involvement is a 'good thing' can obscure the different, and sometimes contradictory, agendas underpinning such involvement, while also minimising the obstacles to involvement.

This thesis will attempt to assess the potential and limits of mental health service user involvement in terms of the challenge that different forms of involvement pose to dominant ideologies of mental ill-health, to the professional domination of services and to the stigma and oppression associated with mental ill-health. This will involve a critical evaluation of the major factors - economic, political, and ideological - which have driven such user involvement over the past ten years, as the basis for an exploration of the attitudes towards, and experience of, involvement by service users and workers in five focus groups and nine community-based mental health projects across central Scotland. A central concern of the thesis will be to critically engage with recent characterisations of the mental health users' movement as a 'new social movement'.

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INTRODUCTION

The late 1980s and early 1990s saw the emergence within government policy-making, mainstream academic discussion and health and social welfare practice of a theme which, if not entirely new in health and welfare discourses, had, since the Seeborn Report more than two decades earlier, been a very muted one - the theme of service user involvement in health and social services. For one group of service users in particular, viz., users of mental health services, who were often seen in both popular and psychiatric discourse as incapable by definition of making decisions about their lives and the services they received, the implications of such involvement seemed potentially enormous. It appeared to offer a way of gaining some control over their lives, with involvement in community care consultations, for example, providing an opportunity to influence policy-makers in the development of mainstream services; involvement in the management and development of community-based services allowing the development of more holistic and needs-led services in contrast to the mainstream psychiatric services which were often experienced as oppressive by users; and collective involvement, including campaigning activities, allowing users to challenge the devalued status of people with mental health problems as well as the material inequalities and social exclusion associated with that status.

Alongside the awareness of the possibilities presented by this new development, however, the 1990s also saw a growing sense of unease on the part of many health and welfare practitioners, academics and service users themselves concerning the apparently conflicting and sometimes contradictory agendas underpinning user involvement. Contributing to this unease was the fact that in common with earlier themes in social policy, such as the emphasis on 'participation' in the 1960s or on 'community' in the 1980s, the notion of user involvement (and the point applies with even greater force to the related concept of 'empowerment') seemed to appeal to *all* sections of the political spectrum, having its roots in the consumerism of the New Right on the one hand and the new movements of disabled people, older people and mental health service users on the other.

The aim of this thesis is to explore and 'unpack' these contradictions of mental health service user involvement, with a view to evaluating the nature of the challenge posed by such involvement in respect of the three areas of ideology; mental health services; and stigma and structural oppression:

- i) *Ideology*. The very notion of people with mental health problems playing an active role in the development of services and in wider campaigning activities clashes sharply with the extremely negative characterisation of people with mental health problems inherent in biomedical ideology on the one hand with its view of mental ill-health as disabling, all-pervasive illness on the one hand and populist ideologies of mental ill-health with their emphasis on 'dangerousness' on the other. While the notion of user involvement in mental health services implies to a greater or lesser degree a rejection of both of these ideologies, what is less clear is the extent to which that rejection is based on a developing counter-ideology, an emerging paradigm of mental ill-health, analogous to the social model of disability which has played such an important role in the development of the disability movement. An aim of the thesis therefore is to explore the nature and extent of the challenge posed by mental health service user involvement to dominant ideologies of mental ill-health.
- ii) *Mental health services*. Historically, people with mental health problems have had little, if any control, over the kind of services they receive. The corollary of the 'invalidation of the self' which, as Goffman observed more than three decades ago, often accompanies a diagnosis of mental ill-health is the all-pervasive power of the mental health professional, above all the psychiatrist, over the treatment of the patient (Goffman, 1961). What then are the implications of user involvement in the development and management of services both for the content of these services and also for relationships between workers and service users? What role, if any, is there for mental health professionals within user-controlled services? Is it important that workers themselves should have experienced mental health problems - the 'wounded healer' model (Rippere and Williams, 1996)? And how necessary or useful is professional training? A second aim of the thesis, then, is to explore the implications of user involvement for community-based services and for relationships with mental health workers.

iii) *Stigma and structural oppression.* Traditionally, people with mental health problems have experienced a degree of stigma and social exclusion the all-encompassing nature of which arguably exceeds that experienced by any other oppressed group. Over the past decade, service users, organised in to the mental health users movement, have begun to mount a collective challenge to that stigma and exclusion. What is the nature of this challenge? How comparable is the oppression of mental health service users to other forms of oppression? What are the prospects for a collective user movement? And how useful are attempts to characterise that movement as a 'new social movement'? The third aim of the thesis therefore is to evaluate the nature and capacity of collective user involvement to challenge the stigma and oppression experienced by a majority of mental health service users.

In sum, then, the overriding aim of the thesis is to evaluate the *potential* and the *limits* of mental health service user involvement in terms of the challenge posed by such involvement in each of the above three areas. The basis for that evaluation is a series of individual interviews conducted between January 1996 and March, 1997 with fifty service users and eighteen workers in nine community-based mental health projects across Central Scotland, with issues emerging from these interviews forming the basis for a further five group discussions in other parts of the Central belt.

The fact that the thesis is primarily *exploratory* in nature, as opposed to being either *evaluative* on the one hand (did the level of involvement claimed match the reality?) or *comparative* on the other (why did one project have a higher degree of involvement than another?), suggested that respondents should be users (and workers) with some experience of involvement who were able to reflect on the issues and dilemmas to which involvement gives rise. It was this criterion, rather than a desire for a 'representative' sample, which guided the selection of the projects, groups and respondents who contributed to the study and in that sense the study may be seen as a critical exploration of the views and experiences of a section of the 'cadre' of the mental health users' movement in Scotland.

In terms of the structure of the current thesis, that exploration begins with a literature review in chapters one to three which seeks to evaluate the contribution, both theoretical and practical, to user involvement from three main sources: consumerism; professional models of involvement; and the more radical models developed by users and their allies. Following Draper (1996) I have dubbed the first two sources 'user involvement from above' and the third 'user involvement from below', in recognition both of their different origins and also of the very different forms of involvement they envisage. Chapter three will also include an exploration of the nature of the discrimination and disadvantage experienced by the majority of people with mental health problems and critically evaluate attempts to characterise collective responses to the oppression of service users in term of 'new social movement' (NSM) theory.

In chapter four, the methodology underpinning the thesis is outlined and discussed. In contrast to much current social theorising which accepts postmodern notions regarding the end of 'grand narratives' and the relativity of 'truths', the classical Marxist underpinnings of the thesis are explained, with a discussion of the concept of *totality* on the one hand and an underlying philosophical stance best described as *realist* on the other. This chapter will explore the implications of such a stance for the conduct of the research process, for the evaluation of different 'knowledges' and more generally for what is sometimes referred to as 'emancipatory research'.

Chapter five will provide a brief description of the nine projects and five focus groups, as well as some discussion of respondent characteristics, such as age and gender.

A discussion of respondents' preferred terminology for people with mental health problems will form the starting point for an exploration in chapter six of ideological shifts and trends within the users' movement and the potential significance of such shifts, in terms of the challenge they pose to dominant ideologies. At the same time, while the importance of language in the struggle against oppression is acknowledged, the centrality accorded to language within postmodernist accounts is rejected and the significance of other, more material, factors noted. On the basis of the discussion of

preferred terminology, the chapter continues the critique begun in chapter three of attempts to apply a model of 'identity politics' to the mental health users' movement.

As noted above, mental health services have historically been characterised by a near total domination by psychiatry and related professions, at the expense of the views and experiences of service users. In chapter seven, the overwhelming rejection of such professional domination by respondents in this study will be discussed and will provide the basis for an exploration of the kinds of skills and qualities that respondents felt workers should possess; of the value or otherwise of professional training; and of the view, again popular within much contemporary social theorising based on notions of identity, that mental health workers should themselves have experienced mental health problems, since only those who have experienced a particular oppression are capable of both understanding and resisting it.

Chapter eight will move from an exploration of attitudes *towards* user involvement to a consideration of the actual experience *of* involvement which took place in these projects, with Arnstein's 'ladder of participation' providing a framework for exploring the *forms* of involvement which existed within the nine projects. Variations between projects will be noted and the second half of the chapter will explore the factors which user and worker respondents felt *constrained* such involvement on the one hand and conversely, the factors which *promoted* it on the other.

Given the relative newness and fragility of the mental health users' movement, it is perhaps not surprising that there have been few attempts to date to explore the issues and dilemmas to which mental health service user involvement sometimes gives rise. Yet in several of these projects, major dilemmas *had* arisen from time to time and as many respondents recognised, it was only by openly addressing such dilemmas that they could be overcome and involvement strengthened. In chapter nine, the most common issues and dilemmas will be explored and an attempt made to assess their significance for the future of user involvement.

In chapter three, the characterisation by some commentators of mental health service users as a 'new social movement' was noted. One aspect of this characterisation - an emphasis on issues of *identity* - was explored in chapters three and six. In chapter ten, two other elements of that characterisation - an emphasis on cultural/ideological issues rather than material issues on the one hand and a reluctance to engage in class-based alliances on the other - will be critically evaluated against the experience of the groups and projects, as will the more general issue of the capacity of people with mental health problems to engage in collective, campaigning activity.

The final chapter will attempt to draw together the threads of the above arguments into an overall assessment of the potential and limits of mental health user involvement in respect of the challenge such involvement poses to dominant ideologies of mental ill-health, to the professional domination of mental health services and to the stigma and oppression experienced by many users. The election of a New Labour Government in May, 1997 has led some theorists sympathetic to new social movement approaches to revise that thesis to suggest that 'change from above' may now be a more realistic prospect than under previous Labour governments, a suggestion that will be critically evaluated in the middle part of this chapter on the basis of the experience of the first two years of that government. Finally, 'new social movement' theory has emerged in response to the perceived inability of class-based analysis, and particularly Marxism, to explain the social movements which have emerged over the past three decades. Given that Marxist concepts underpin much of the critique of 'new social movement' theorising throughout the current thesis, the final section of this chapter will briefly sketch out some of the ways in which Marxism might seek to make sense of the oppression experienced by mental health service users and point to strategies for challenging that oppression.

Consumerism: the sovereign service user?

As predicted by some commentators, 'user empowerment' has proved to be a central theme of social policy throughout the 1990s (Clarke and Stewart, 1992). While the suggestion that the role to be played by service users would form 'the ideological territory over which future election battles will be fought' (*Guardian*, 1/11/95) can with hindsight be seen to be an exaggeration, it is nevertheless true that the relationship of service users to a range of 'welfare' services, including education, health and social services continues to be as central to political debate under New Labour as under previous Conservative administrations (Ellison and Pierson, 1998).

For users of mental health services in particular, it is tempting to see the past 10 years as having brought about a qualitative change in the way in which their views are perceived. A leading member of the organisation Survivors Speak Out has noted, for example, that the 1983 Mental Health Act was developed largely without the direct involvement of users/survivors, a neglect which, he argues, would be unlikely if not impossible today, since the users' movement would not allow it (Campbell, 1996).

As several writers have noted, however (Payne, 1995; Sheppard, 1995; Adams, 1996), as with other key community care concepts the apparent consensus about the importance of user empowerment or user involvement (terms which, I shall argue later, are not synonymous) can conceal real differences of values, ideologies and objectives. In a discussion of the concept of partnership, for example, Braye and Preston-Shoot have argued that

The apparent consensus about partnership as an uncontroversial 'good thing' masks what is in fact a complex and varied aetiology in which several influential factors are combined. (Braye and Preston-Shoot, 1995).

A similar observation might be made in respect of concepts such as empowerment and indeed the concept of 'the user' itself. The uncritical way in which these terms are often employed to connote quite different things suggests that Raymond Williams' acerbic description of 'community' as 'a warmly persuasive word' that '...never seems to be used unfavourably, and never seems to be given any positive opposing or distinguishing term' (Williams, 1976: 65-66) might also apply to user empowerment. In fact, as Mayo notes in her discussion of community, it is precisely this persuasive quality which gives that term its ideological usefulness, in that it conceals the fact that

community has been used in different ways over time. And it has been used within the context of alternative sociological approaches and competing political orientations. These fundamental differences are key ... It is not just that the term has been used ambiguously; it has been contested, fought over and appropriated for different uses and interests to justify different politics, policies and practices (Mayo, 1994:48).

In this chapter and the two which follow, I shall argue that, like community, the concept of user involvement (which in the context of this thesis will refer mainly to mental health service user involvement) also needs to be 'unpacked' or 'unravelling' (Taylor et al, 1992) to separate out the quite different - and sometimes contradictory - ideologies which underpin it. Drawing on the work of a number of writers associated to a greater or lesser extent with the critical social policy tradition (Williams, 1991; Taylor, 1996), I shall contend that in discussions of user involvement and empowerment, there has often been a blurring of several quite different agendas: a *consumerist* agenda, the main concern of which is the reduction in the role of the State in the provision of welfare and the promotion of private services; a *professional* agenda, which is driven primarily by professional social work academics and practitioners who see in user empowerment both a continuation of social work's traditional emphasis on client self-determination and also a basis for a more empowering social work in the future (Ramon, 1991; Parsloe and Stevenson, 1993; Adams, 1996); and a more *radical* agenda, derived at least in part from the 'new social welfare movements' that have grown up over the last decade (Williams, 1992),

including the mental health users' movement. Each of these agendas will be examined in turn.

At the same time, I shall argue that previous critiques of the consumerist model of user involvement themselves suffer from a number of important limitations, both in their analysis of consumerism and also in their prescriptions for challenging the discrimination and oppression experienced by many service users. Consequently, an aim of these three chapters will also be to develop an analysis of user involvement which goes beyond existing critiques and which draws in part on classical Marxist categories to develop a fuller evaluation of the limits and potential of user involvement. This analysis will then be applied and developed in subsequent chapters in respect of the research into the ideologies and activities of mental health service users in Scotland which forms the basis of the current thesis.

CONSUMERISM AND WELFARE

'Consumerism' has...become an officially-approved fashion. In hospitals, schemes, advice and information services and many other aspects of public administration managers are being exhorted to pay more attention to consumer wishes, offer customers wider choice, and develop techniques for 'marketing' their particular service.'(Pollit, 1987: 43)

Notions of consumer sovereignty are as old as capitalism itself. Historically, one of the key ideological justifications for a free market system has been precisely that it is responsive to the wishes of consumers. In the 1980s, however, consumerism as an element of New Right ideology (George and Wilding, 1994) experienced an extraordinary renaissance which involved not only its official promulgation as a core element of government policy, notably in Britain and the USA, but also its acceptance more widely by a rightward-moving Western intelligentsia influenced by ideas of postmodernism and postindustrialism (Keat, Whiteley and Abercrombie, 1994). While the term 'consumerism' is used in a variety of ways, the following two-part definition,

suggested by Keat and his colleagues, usefully encapsulates the core senses in which the term has been employed in relation to publicly provided services :

- 1...The production of such goods and services should be organised in ways that significantly mirror or parallel those involved in a free market economy, for example through the use of mechanisms enabling competition between rival producers, of contractually specified forms of exchange, and so on;
2. ...The 'consumers' of those goods and services should enjoy the kind of relationship with their 'producers' that may be thought to obtain between actual consumers and producers in a free market economy, and hence, for example, that these goods and services should satisfy their consumers' preferences, be responsive to their demands, and so on - depending on how that relationship is understood. (Keat et al, 1994 : 2).

By the end of the decade, the dramatic collapse of the state capitalist economies of Eastern Europe and Russia saw that enthusiasm for such a market-based consumerism spread to the new governments of these regimes, leading some academic commentators to suggest that what we were witnessing in the triumph of liberal democracy and the market was 'the end of history' (Fukuyama, 1992).

With hindsight (and in fact, as more far-sighted commentators pointed out at the time e.g. Callinicos, 1991), such claims signally failed to grasp the dynamics of the changes which were taking place. For one thing, at the same time as the economies of Russia and Eastern Europe were collapsing, so too were the major Western capitalist economies moving back into slump and crisis (Harman, 1995); for another, whatever genuine *mass* popularity such ideas may have enjoyed in the 1980s (in itself a matter of considerable debate (Mayo, 1994: 3), support for the market among the British population underwent a considerable decline in the 1990s, reflected both in opinion polls (with one 1993 poll, for example, showing only 18% supporting privatisation (*Guardian* ,17/1/93) and widespread interest in popular critiques of government policies based on market economics

Such ideas have a continuing importance however, for two reasons. On the one hand, consumerist ideas have been incorporated into law and policy relating to the delivery of health and social services, notably through the NHS and Community Care Act, 1990, which is likely to provide the framework for such services for the foreseeable future. While the Act itself is very brief and short on specifics, both the White Paper 'Caring for People' on which it is based and subsequent policy guidance have been explicit in arguing that the extension of consumer (i.e. user and carer) choice provides the underpinning rationale for the community care reforms. Secondly, these ideas, as well as a more general acceptance of market principles are now part of the intellectual furniture of all the main political parties in Britain, including the current New Labour government (Blair, 1998). For that reason, they require a thorough exploration and evaluation.

This will involve, firstly, locating the new consumerism in its historical and ideological context, focusing on the problems it sought to address and the solutions it offered. Secondly, I shall examine the relevance of consumerist principles to public services, through an examination of what Potter suggests are the five core principles of consumerism: *access, choice, information, redress and representation* (Potter, 1988). Thirdly, I shall suggest that while the critiques of consumerism developed by Potter and other critics of consumerism are useful as far as they go, they suffer from a number of weaknesses both in the analyses they offer and in their prescriptions for service users seeking to move beyond consumerist analyses.

THE ROOTS OF THE NEW CONSUMERISM

The period from the end of the Second World War until the early 1970s was one of sustained economic growth unparalleled in the history of Western capitalism (Kidron, 1968). Within Britain, that economic stability was reflected in the political sphere by the dominance of 'Butskellism', an ideological acceptance by both of the main political parties of certain assumptions rooted in the writings of Keynes (in relation to management of the economy) and the principles of the Beveridge Report (in relation to welfare) (George and Miller, 1994; Timmins, 1995).

That consensus was rudely shattered by the re-emergence of economic crisis on a world scale in the mid-1970s. At a stroke the old Keynesian solutions seemed redundant and the late 1970s saw the growing influence of a new 'economic evangelism' (Keegan, 1984), central to which was the notion that interference in market forces, whether by over-powerful trade unions or by over-blown welfare states (the 'Nanny State', as Mrs Thatcher was prone to describe it) was at the root not only of Britain's economic problems but also of the current social and political malaise. Thus, as Clarke has noted, this emerging 'New Right' ideology comprised both an *economic* dimension, based on neo-liberalism, and a *moral* dimension, based on neo-conservatism (Clarke, 1998).

While these ideas also underpinned some of the policies of the Wilson-Callaghan administrations of 1974-79, it was the election of a Conservative Government in 1979 under Margaret Thatcher which saw the most concerted attempt to translate this new ideology into Government policy. In relation to welfare, the argument of the New Right was that as well as being socially, morally and economically damaging, the Welfare State was also ineffective and inefficient and that three areas in particular required urgent and thorough reform:

- i) The existence of huge welfare bureaucracies ;
- ii) The domination of professionals ;
- iii) The power of public sector trade unions .

The New Right's view of the Welfare State of the early 1980s is neatly summarised by George and Wilding as follows :

Politicians have limited power. Consumers have less. Producer power rules. The result is services and systems geared rather to producer interests than to the public interest and the needs of service users. There is no natural corrective mechanisms which ensure service change in response to changing needs or

proven deficiencies. Too many powerful people have an interest in perpetuating the status quo (George and Wilding, 1994 : 28).

How then was this welfare 'bureauprofessionalism' (Newman and Clarke, 1994) to be tackled? In essence, by the same market forces which were to be applied to the economy as a whole. Thus, the 'rolling back of the State' would take place through a combination of privatisation and the restructuring of health and welfare through the introduction of market forces; the power of professionals would be curbed through an alliance between managers committed to 'new managerial' ideology and the customers of public services (Clarke, Cochrane and McLaughlin, 1994; James, 1994); and the public sector trade unions would be weakened by a combination of anti-union legislation, greater involvement in service by private and voluntary sector providers (where trade union organisation was weaker) and, again, by the development of alliances between managers and 'customers' *against* workers. As Carpenter has noted the divisions of workers as providers and as users which became apparent during the Winter of Discontent has been elaborated into a critique and reorganisation of public provision under the doctrines of the 'new public management' (Carpenter, 1994: 86-87).

Underpinning this ideological dislike of the welfare state was a view that excessive state expenditure was hindering economic growth, and there seems little doubt that the desire to cut state spending provided a major motivation for the community care reforms (Biggs, 1990). In particular, it is clear that the growth in public sector expenditure on private residential care for elderly people - from £10 million in 1979 to £459 million by early 1986- which was highlighted by the Audit Commission Report of 1986, and the need for a pragmatic response to this expenditure, with its perceived negative consequences for economic growth, provided a key impetus for the setting up of the Griffiths Committee in 1987 (Means and Smith, 1998). This priority was also reflected in the remit provided to the committee :

to review the way in which public funds are used to support community care policy and to advise me on the options for action that would improve the use of

these funds as a contribution to more effective community care (Griffiths, 1988).

Far from perceiving any contradiction between the goal of reducing public expenditure on the one hand and increasing consumer choice on the other, the Griffiths Report and the subsequent White Paper *Caring for People* (Department of Health, 1989) both accepted that the central role of the State as provider of welfare limited choice and argued for a 'mixed economy of welfare' in which the State would play an increasingly residual role, with the primary caring role being carried out by 'family, friends and neighbours' on the one hand, with an increased role for voluntary and private organisations on the other. The mechanism for this shift, now incorporated into the NHS and Community Care Act, 1990, would be a split between purchasers and providers, the effect of which would be to create a kind of internal market of care. Both the White Paper, the Act, and subsequent policy guidance can be said to reflect the principles of consumerism, in that a repeatedly stated aim is the desire to improve consumer choice and service flexibility. In a much-cited passage which was seized on by a number of social policy commentators as evidencing the 'progressive' content of the legislation, a key guidance document stated that

The rationale for this reorganisation is the empowerment of users and carers...this redressing of the balance of power is the best guarantee of a continuing improvement in the quality of services (Department of Health, 1991).

The next section of this chapter will draw on the framework developed by Potter (1988) and referred to above to critically evaluate the claim that the extension of market forces to welfare services (through the creation of a mixed economy of care) *does* in fact increase choice for service users.

EVALUATING CONSUMERISM

Access

Potter defines access as 'the cardinal consumer principle'. In the ideal model of consumerism, there should be no barriers between the customer and the product he/she wishes to purchase. By contrast, the *inaccessibility* of public services - geographical, cultural and structural - has formed a central plank of the critique of local government in particular and of the welfare state in general over the past 15 years, both from the political Right and also from some sections of the Left and Centre-Left.

Thus, the bureaucratic and over-centralised nature of local authority services was the subject of an influential critique in the early 1980s which saw the solution in the creation of decentralised 'patch' services, located in people's own neighbourhoods and based on principles of localisation; greater autonomy for local teams; integration of patch workers; a community orientation; and participation (Hadley and Hatch, 1981; Barclay, 1982; Beresford and Croft, 1986).

In addition, for people with disabilities, a major weakness of state welfare agencies has often been their lack of *physical* accessibility. The point is graphically made by the photograph on the jacket of Oliver's *The Politics of Disablement* which shows a disabled man in a wheelchair being prevented from gaining access to a polling station by a flight of stairs. Even where services do exist and are accessible, they have often tended to reinforce the isolation and segregation of people with disabilities from the rest of the community (Oliver, 1990).

Finally, Fiona Williams has drawn attention to the *gendered* and *racialised* nature of welfare services and the way in which assumptions, for example, about the role of the extended family within the Asian community or the lack of child care provision within welfare agencies creates a range of barriers to services for women, black people and other oppressed groups. (Williams, 1989; Bowes and Sim, 1991).

To what extent then can a market-based consumerism develop more accessible services ? As Potter notes, consumerist contributions to the debate about access have tended to focus on two points. Firstly, they emphasise the need for clear and explicit criteria about how services are to be rationed: equity demands, for example, that people should know how to go about purchasing their council house. Similarly, the emphasis of the Major Government on published Charters, such as the Citizens' Charter, might also be seen as a way of improving access.

Secondly, proponents of consumerism stress the need for greater *openness* within public services, involving perhaps decentralised services - what one model of consumerism, drawing on the ideas of the management theorists Peters and Waterman, has described as 'getting closer to the public' (Peters and Waterman, 1982; Local Government Training Board, 1987).

Clearly both of these points are concerned with improving what might be termed *procedural* access, through increasing awareness of the criteria by which public services are to be rationed. In this respect, they typify the concern of consumerist approaches with *procedural* rights, as opposed to *social* rights, such as the right, for example, to a place in a supported accommodation project or the right of a service user to have a personal advocate (Barnes, 1997; Clarke, 1998). Consequently, they may be of rather limited value to service users.

In other respects, it could be argued that the application of consumerist principles to welfare services, rather than increasing access, will actually reduce it.

Thus, given that consumers of social services in particular are typically poor (Townsend and Whitehead, 1988; Borrie, 1995; Becker, 1997), it is difficult to see how they will access the private welfare services which will play an increasing role within the 'mixed economy of care'. As Walsh notes :

The empowerment of citizens to enable them to operate effectively in a market environment depends upon giving them the necessary resources, capacity, information. In practice, there is little in the proposals for public sector change

that acts to enhance the user's resources. The distribution of initial resources plays little part in the debate (Walsh, 1995 : 196-7).

The historical association of welfare services with poverty and social control has also been a factor in discouraging their use by those who could afford to go elsewhere (Jordan, 1984; Clarke, 1993). Again, however, the increased residualisation of these and other local authority services entailed in the community care reforms (most clearly seen in the way that council housing, for example, has increasingly become 'special needs housing') is likely to increase this stigma and make people even less willing to use them.

A final limitation of the consumerist principle of access to public services noted by Potter is that, in contrast to the 'supermarket' model which underpins much consumerist thinking, those who *pay* for welfare services are not necessarily those who *use* them :

Deciding *who* shall have access to *what* is a political responsibility and one that in local government is clearly the province of elected members. (Potter, 1988 : 151)

It was of course precisely to address this issue that successive Conservative administrations sought to encourage a closer link between the purchase and use of services through different forms of privatisation and quasi- privatisation, based on a combination of a 'contract culture' and residualised public services. As Walsh has noted

The concept that is emerging is that of the citizen as individual consumer, contracting with the state (Walsh , 1995: 190-91).

The clearest example of such direct contracting is contained in the 1996 Community Care (Direct Payments) Act which allows disabled people to purchase their own services. While research suggests that the scheme has proved popular with many

disabled people, particularly when measured against the appalling level and quality of services which disabled people have been offered historically (Oliver and Barnes, 1998), such individual contracting, whether it takes the form of nursery vouchers or direct payments is, as Walsh notes 'an inadequate basis for the effective operation of the public sector' (ibid.). There must also be concern that, as well as undermining local democratic control of services, the apparent increase in access to services to which it gives rise may prove to be short-lived (with the possibility of 'top-up' payments being introduced, for example) and limited to more able groups of disabled people.

Choice

The need to promote consumer choice in health and social services, and the failure of public sector welfare to do so, has provided the explicit rationale for the introduction of the 'mixed economy of care'. The effect of introducing competition into health and social services, it has been argued, will be to increase service flexibility and diversity, leading to improved quality of care and allowing people to stay at home where appropriate (Griffiths, 1988; White Paper, 1989).

Once again, the attractions of this argument to users of health and social services are obvious. A major finding of the study of the views of 516 users of mental health services by Rogers and her colleagues for example was that many would prefer 'talking treatments', such as counselling and psychotherapy, to drug-based treatments, were such talking treatments to be made available (Rogers, Pilgrim and Lacey, 1993). Given, however, that a move towards the privatisation of welfare will *reduce* choice for those who wish to use public services, there is clearly an assumption here that the introduction of market mechanisms into welfare, coupled with an expanded role for the voluntary sector, will create this diversity (Biggs, 1990). It is this assumption which I wish to explore in this section, through a consideration of the following five aspects of choice: choice as a valued good in relation to other valued goods; consumerist assumptions about the expression of preferences; choice and 'quasi - markets'; inequality and choice; choice and 'involuntary customers'.

i) Choice as a valued good.

Choice is perhaps the core value of consumerism. However, choice as a valued good has to be balanced against other valued goods, and it may be that the importance attached to 'shopping around' may be greater among the affluent middle - classes than among less well-off sections of society .

As Harman suggests

Claims of consumer sovereignty rest on the assumption that there is something intrinsically good about a situation where people have continually to provide for their consumption in a privatised way . But for most working - class families shopping is not some enjoyable and liberated exercise in consumer sovereignty but a burden which has to be met, often by traipsing round shops and supermarkets looking for affordable goods (Harman, 1989: 28).

If such limitations apply to models of consumer sovereignty in the commercial sphere, they are likely to have even greater application in the sphere of welfare. For those dependent on public transport for example, the geographical proximity of a school or hospital may be of greater importance than the 'right' to send one's child to a school on the other side of town or to be treated at a specialist centre requiring many hours of travelling. Similarly, continuity of care is something which is highly valued both by professionals and consumers of elderly residential care services; given, however, that in 1986, high levels of bankruptcy meant that the average life of a private home was 3 years, the increase in choice resulting from the greater role of the private sector may be at the expense of an even more prized good (Biggs, 1990).

More generally, as Coote notes in respect of the use of 'Exit' strategies (Hirschman, 1970) as a means of exercising choice:

Consumerism relies on individual choice as a means of empowerment . But choice may be illusory or irrelevant in the public sector ...In some cases, users may not want to 'take their custom elsewhere'. For example, a young man with

a broken leg just wants to get his bones set. An elderly woman in a residential home may not want to pack her bags and go elsewhere, preferring to stay in familiar but improved surroundings (Coote , 1994 : 192).

Empirical support for this hypothesis comes from a study of user and carer group involvement in community care planning by Means and his colleagues who found that

People we talked to had difficulty relating the idea [of increased choice - IF] to the reality of their experience of services . Many said that while choice was important, a guaranteed minimum level of service delivery was more of a priority (Means et al , 1994 : 170)

Finally, *pace* Margaret Thatcher's assertion that 'there is no such thing as society', the exercise of *individual* choice, for example, the right to buy one's own council house, will often be at the expense of a prized *collective* good, in this case an adequate supply of affordable housing. It is not at all clear that a majority of people believe that individual choice should always be given priority over the collective. On the contrary, throughout the 1980s and 1990s, the annual British Social Attitudes study consistently found a large majority strongly in favour of state provision in areas such as health and welfare (German, 1993).

ii) Consumerist assumptions about the 'expression of preferences'.

A different criticism of the application of the concept of consumer sovereignty to health and social services , focusing on its intellectual rather than its value assumptions, was suggested by Richard Titmuss (Titmuss, 1968). Central to consumerism is the notion of the 'rational consumer'. As Hutton has argued, market economics (of which consumerism is a central component) rests on an a set of assumptions about the way the world works, one of which is that 'all human conduct can be reduced to a ranking of economic choices, in which costs and benefits are accurately and consistently weighed up against each other'(Hutton, 1996: 227). As applied to the commercial sphere, this notion is fraught with difficulties, which has led some economists to argue that it should be abandoned (Kahnemann, 1993, cited in Hutton, 1996). Applied to

health and welfare, Titmuss argues, these difficulties render the concept inoperable since typically, the patient is not in a position to make an effective choice between different types of treatment, and where he or she does, if the wrong choice is made, they are unable to take the item back, as the supermarket model would suggest.

Pilgrim and Rogers make a similar point in respect of psychiatric care :

Customers of health care do not have the same access to clinical knowledge as health care professionals, who have many years of training and experience on which to base their choices. Informed consent, in which the benefits and negative effects of treatment are made available to patients, has only recently been acknowledged as an area which needs attention (Pilgrim and Rogers, 1993: 166).

Clearly, this particular criticism of consumerism needs to be handled with some care. The wholesale denial of the views and experiences of users of mental health services, for example, under the cloak of professional knowledge and expertise will be a recurrent theme throughout this thesis and it may be that this criticism has greater application in respect of certain areas of organic medicine, such as heart surgery, than in respect of mental health. That said, there are also many areas of health and social welfare where the notion of the 'rational consumer' simply does not fit, either because of a physical or mental impairment such as dementia, or because the service user simply does not have access to the information which would help him or her to make a rational decision.

iii) Choice and 'quasi -markets'.

A third element of this critique of the ability of market forces to increase choice in the sphere of welfare derives from the theory of 'quasi-markets', as developed by Le Grand and his colleagues (Le Grand and Bartlett, 1993; Bartlett et al, 1994). According to their argument, the introduction of internal markets into the NHS and personal social services has created 'quasi-markets ' which differ from conventional markets in a number of important respects.

Firstly, it is suggested, the community care reforms have been primarily concerned with the issue of choice and value for money for the *purchaser*. Typically, however, the purchaser in these markets is not the patient or client but rather the NHS Trust or the fund-holding GP or the local authority social work department. The effect is to create a number of barriers to choice. In respect of social services, for example, the client is dependent on his or her care manager for empowerment; while in future years it may be possible for clients to change or reject care managers, there are no moves in this direction at present (Means , Hoyes, Lart and Taylor, 1994) .

Secondly, Le Grand suggests, while genuine choice depends on there being many providers, there is a danger that competition will be reduced by the domination of monopoly or near monopoly providers. One factor fuelling this process is the fact that while the development of different types of contracts such as 'spot contracts' may allow for a degree of individual choice, economies of scale are likely to lead purchasers to agree to block contracts; as Payne comments, 'By setting a block contract, the local authority may rule out other choices for users, who have to accept the provider with the contract ' (Payne , 1995 : 205) .

iv) Inequality and choice.

A core assumption of consumerist ideology is that through the exercise of the purchasing power of consumers, providers will be forced to develop services which are more responsive to the needs of their customers. Market competition will ensure that those which fail to do so will be forced out by their more efficient rivals .

In fact, as we have seen in the above section, the creation of a 'surrogate consumerism', controlled by a new layer of bureaucracy within health and social services, severely qualifies the extent to which these reforms increase choice. (Walsh, 1994: 194) .

Furthermore, the widespread social and economic inequality which forms the context for these reforms and which disproportionately affects some 'community care' groups - such as elderly people or people with mental health problems - has implications not only for access to services, as we saw above, but also for choice and the development

of a range of services. With the focus of social policy and legislative debate since the Griffiths Report on the 'supply' side of welfare, reflected in the central concept of a 'mixed economy of care', less attention has been paid to the 'demand' side, in terms of the purchasing power of consumers. Yet as Braye and Preston-Shoot point out

There is an inevitable mismatch between the image of a consumer with money to spend and the reality of disempowered and discriminated - against groups (Braye and Preston - Shoot, 1995: 27).

It was of course precisely the failure of the market to meet the needs of these groups which lead to the creation of a welfare state in the first place; and given the fact that many consumers of health and social services are unlikely to be able to take advantage of whatever new private provision becomes available, it is difficult to see how a reduction in publicly provided services on the one hand and an assessment and care management approach which, in the absence of sufficient resources, is likely to be experienced as a form of 'means testing' can be seen as an extension of choice (McLean, 1989; Biggs, 1990; Victor, 1991).

v) Choice and 'involuntary customers'.

As the preceding discussion suggests, the concept of the 'customer' needs to be 'deconstructed' before it can be meaningfully applied to health and welfare services. Not only is it the case, however, that consumers of these services often lack the purchasing power to significantly affect the quality of services. More fundamentally, relative to other citizens, they are often additionally disadvantaged or oppressed, either through a disabling condition such as schizophrenia or dementia or more frequently through the stigmatising social construction attached to their particular status or condition. Not surprisingly, then, recipients of certain health and welfare services are often ambivalent in their responses to these services, particularly when they are delivered on a compulsory basis. Within the mental health users' movement, such ambivalence is reflected in the debate over terminology (a debate to which I shall return in chapter six):

Consumer tends to be rejected because of its connotations with Tory consumerism but also because consumer implies you are getting something of value. The majority of people in the users' movement do not feel they have consumed anything of value and many say quite clearly that the real consumers of mental health services are relatives, the police and the state (Rogers and Pilgrim, 1991: 136).

Or more succinctly:

Survivors of the mental health system are no more consumers of mental health services than cockroaches are consumers of Rentokil (Barker and Peck, 1987)

The issue of the relative powerlessness of service users, in relation both to professional power and also structural oppression, will be explored more fully in chapter three. It is clear, however, that the presence of 'control' as well as 'care' elements in areas of health and social services mean that notions of 'choice' may have more limited application in respect of these service users.

Information

The provision of information to service users is seen by most commentators as the 'bottom line' of user involvement. In her consideration of the dimensions of empowerment through 'voice' strategies for example (Hirschman, 1970), Taylor locates information on the bottom rung of a hierarchy of levels of involvement (ranking below consultation, influence, partnership and control) (Taylor et al, 1992). Similarly Potter suggests that without information about the standards of services that authorities aim to provide; about users' rights and responsibilities; about decision making processes; about why decisions are taken and what these decisions actually are, then 'consumers are merely whistling in the dark' (Potter, 1988: 153).

Historically, of course, health and social services have not always been characterised by such openness. The secrecy often associated with large bureaucratic organisations

on the one hand (exemplified by recent debates over 'whistleblowing', Hunt, 1995) and the dominance of professional power on the other have conspired to ensure that patients and clients have often been left in the dark regarding decisions which have crucial implications for their health and welfare:

People aren't given clear information on the options available, whether the medication will prevent relapse or what the side effects are. You aren't in a position to make a judgement without knowing what the full pros and cons are. (Mental health service user, cited in Beresford and Croft, 1993: 67).

It is perhaps in respect of information-giving that the consumerist contribution appears strongest. In John Major's Citizens' Charter, for example, considerable stress was placed on making information available:

Full, accurate information should be readily available in plain language, about what services are being provided. Targets should be published, along with full and audited information about the results achieved. Wherever possible, information should be in comparable form so there is pressure to emulate the best (Prime Minister, 1991: 5).

In addition, two aspects of the community care changes should, in theory, improve the flow of information to service users.

Firstly, local authority social work departments are encouraged to publicise the policy changes and the services they offer as widely as possible. Thus, the policy guidance following the 1990 Act defines the first stage of the care management process as *publishing information* with a view to informing potential service users 'about the needs for which care agencies accept the responsibility to offer assistance and the range of services currently available' (SSI, 1991:11). Such information should highlight the values and principles on which decisions are based, should be ethnically sensitive and should avoid jargon and confusing terminology.

Secondly, through its emphasis *inter alia* on needs led assessment, the Act and subsequent guidance is also concerned with encouraging professionals to work with clients in a more collaborative way, which should involve more sharing of information. One study of professional power in the Health service has suggested that the 'new managerialism' might be an important catalyst in this process, since it identified a strong commitment on the part of general managers to consumerism and found that they perceived themselves as having a role to play in stimulating professional staff to treat clients as customers rather than patients (Strong and Robinson, 1990).

While such openness is to be welcomed, in practice the capacity of consumerism to empower service users through the provision of information may be more limited than it appears at first sight.

Firstly, there are practical and organisational issues. Simply making information available to service users is no guarantee that they will receive it and/or make use of it. Payne cites one survey of twelve local authorities which looked at their achievements in the area of information-giving. Published material had been made available in most, but had little effect on users, who were still poorly informed about assessment and charging. Lack of consultation with users' groups regarding the design of the information and a failure to appreciate the way in which users often looked to lower-level staff, such as home helps, for information were two factors which undermined the effectiveness of information-giving (Payne, 1995: 186-187).

If such a failure to appreciate the complexities of making information available stems at least in part from the rather simplistic model of 'the customer' which underpins consumerist strategies and the limitations of this model when applied to users of health and social services, then these same limitations also relate to a second point affecting the use of information, viz., the involuntary nature of many service users' relationships with social services and with psychiatric services in particular. As Means et al point out in their discussions of empowerment and 'quasi-markets':

Information flow is constrained by the fact that many choices are made under duress (mental health) or in crisis (Means et al, 1994: 177) .

It is precisely at such times, when 'exit' is not an option and 'voice' is often least heard, that the need for clear and accurate information is most pressing. As writers from the disability movement and the mental health users' movement have forcefully argued, however, the provision of information at such times cannot be left to the goodwill of professionals but requires on the one hand a framework of rights to both information and services and on the other a forceful advocacy movement to ensure that these rights are enforced (Lindow, 1995; Campbell and Oliver, 1996) . Such considerations, however, move the discussion from a consumerist discourse, in which the language of power, oppression and rights is generally absent into a citizenship discourse in which they form the core currency (Beresford and Croft, 1993) .

Reference to rights brings us to the third qualification on the ability of consumerist information-giving strategies to empower clients. In previous sections, I have referred to the fact that many users of health and social services are poor and therefore dependent on publicly-provided, rather than private, health and social services. Where such public services are severely underfunded, however, as the evidence suggests they have been in recent years (Glennister and Hills, 1998), then the publication of information may take on a different significance .On the one hand, rather than being a means of *raising* expectations about what is available, it may become a means of *dampening down* such expectations. Payne, for example, suggests that the aim of publishing information

is not to seek out cases so they can be assessed and put in priority order but to define in advance what agencies will deal with. This may be an attempt to make clear at an early stage to the public that services will be limited (Payne, 1995: 75).

Where, however, expectations *are* raised and users, individually or collectively, *do* become more assertive in demanding their rights, then it remains to be seen whether

the commitment on the part of government and local authorities to making information available will remain as strong. Means et al refer to such a scenario when they observe that

perhaps one of the dilemmas of a rights-based approach to empowerment in a hostile climate is that it risks provoking resource holders to limit the information they make available to service users and to curtail their use of discretion (Means et al, 1994: 175).

Nor is such a scenario purely hypothetical. In 1992, the *Guardian* newspaper reported the existence of a confidential circular from the Chief Inspector of the SSI to local authorities warning them not to advise older people and disabled people of their rights under the new system unless the money was available to deliver the services - an example of the way in which the consumerist commitment to making information available can be undermined by a greater commitment to a reduction in public expenditure (cited in Langan and Clarke, 1994: 86).

Overall then, it could be argued that while consumerist approaches *may* increase the amount of information available to service users, the impact of such information provision is likely to be rather limited. As Walsh comments, in a discussion of the Citizen's Charter:

The main emphasis of the charter movement is upon the information element in choice; there is little reference to resources or ability. Movements that are aimed precisely at empowering the disadvantaged, such as advocacy systems, have received little support...Without empowerment of the citizen, the development of citizen rights will be procedural rather than substantial (Walsh, 1994: 197).

Redress

Historically, users of both social services and health services have enjoyed very limited rights of redress when dissatisfied with the service provided. The stigma associated with use of welfare services on the one hand and the dominance of professional power on the other have often meant that expressions of dissatisfaction have tended to be devalued or dismissed. Potter cites the views of some social service staff that complaints were made largely by 'malcontents and misfits who have problems other than the ones complained of' (Potter, 1988: 154), while Hugman notes the use by professionals of terms such as 'unco-operative', 'manipulative', 'obstructive' and 'ungrateful' to label clients who complained about services:

Each of these terms is the occupational response to a service user whose actions resist in some way the professional definition of the means, the scope, the goals or the values with which the service user is being expected to comply. The weakness of individual resistance lies in the potential of these ascriptions as a means of undermining the service user through moral devaluations (Hugman, 1991: 135).

Consumerism seeks to address this lack of redress in two main ways : firstly, by requiring local authorities to set up complaints procedures under the NHS and Community Care Act (by contrast, there is no such statutory requirement on health authorities, although they are encouraged to set up similar mechanisms via the Patients' Charter); secondly, through the mechanism of contract compliance. To what extent will these developments secure effective redress ?

In a discussion of complaints procedures under the 1990 Act, McClay suggests that to be effective, a complaints procedure must contain four key elements: people must know how to complain; they must know to whom they should complain; they must have confidence that their complaints will be dealt with; and where appropriate, they should be able to obtain redress (McClay, 1994: 153). While relatively little research

has been undertaken to ascertain the extent to which local authority complaints procedures are meeting these requirements, the evidence that does exist gives few grounds for optimism: a major postal survey conducted by the SSI in England, for example, found that the majority of clients were dissatisfied with both the length of time taken to respond to their complaint and with the outcome of their complaint (cited in McClay, *ibid.*: 164).

While in part such dissatisfaction may be due to teething troubles, it may also reflect wider issues relating to the differences highlighted above between the sovereign consumer of consumerist ideology and the experience of being a user of a stigmatised service, faced with the reality of professional power. While, for reasons already discussed, one aim of consumerist approaches is to reduce professional power, in practice if service users are not *supported* in complaining, by means of independent advocacy, for example, then the *formal* criteria for complaining which McClay identifies may count for little (Beresford and Croft, 1993 : 52).

Given these characteristics of 'welfare bureau professionalism' (Langan and Clarke, 1994), it might be supposed that the growing use of private and voluntary providers which the Act encourages will offer service users greater scope for redress. It is, however, far from clear that this will be the case.

For while the remit of the Inspection Units set up under the 1990 Act extends to both private *and* local authority providers of residential care, this is not true of complaints procedures which apply only to services provided by the local authority. In effect, this means that redress for users of private or voluntary services arranged through a care manager will depend on a number of factors over which they may have limited control including, for example, their relationship with their care manager (with whom they may have only limited contact); the effectiveness of contract monitoring; and the extent to which the contract agreed between the local authority and the care provider addresses their needs in the first place (Biggs, 1990/91; Shaw, I., 1995).

Here as elsewhere, it seems that service users are 'quasi-customers' rather than sovereign consumers. Nor is more recent legislation likely to extend service user power in this area. In the consultation document issued to accompany the Community Care (Direct Payments) Bill in its passage through Parliament, for example, for example, the then Government was emphatic that users who were awarded direct payments to permit them to purchase their own services would not have access to local authority complaints procedures :

The recipients will not be able to use this procedure to complain about services purchased using direct payments as these will not be the responsibility of the local authority. Nor will personal assistants employed by payments recipients have access to this complaints procedure. *Recipients themselves will need to deal with any disputes arising with the personal assistants they employ or contract with* (Department of Health, 1995 - my emphasis - IF).

Given what has been said above regarding the powerlessness and vulnerability of service users in the face of organisational and professional power, it may be that the overall effect of reducing local authority provision and extending the contract culture in this way may be to limit even further the scope for effective redress on the part of these users.

Representation

The fifth consumerist principle identified by Potter is *representation*.

Taken literally, she suggests it means 'simply that the views of consumers should be adequately represented to decision-makers at all points in the system where decisions are taken concerning their interests' (Potter, 1988: 154). This section will focus on the extent to which the Act creates new opportunities for such representation, while the related but distinct issue of the *representativeness* of service users' organisation will be discussed in chapter three.

Historically, opportunities for users of health and social services to make their views known to decision makers have been extremely limited. Beyond the usual mechanisms of representative democracy (from which compulsorily detained psychiatric patients, for example, are excluded, regardless of their state of mind at the particular time), their views have usually been represented either by professionals or by voluntary organisations which, in the case of people with learning disabilities and mental health problems in particular, have tended to be dominated by carers (who are often parents) (Oliver, 1990). In a critical discussion of research into the views of psychiatric in-patients, for example, Rogers and her colleagues comment that 'the customers' view might well be important to the researchers, but the equally important notion that "the customer is always right" is not conceded' (Rogers et al, 1993: 10).

Consequently it is perhaps this dimension of the community care reforms more than any other which has been seen by writers in the critical social policy tradition (Williams, 1989; Taylor, 1996) as offering possibilities for the empowerment of users and carers. In an article exploring what he describes as 'the janus face of community care legislation', for example, Levick has argued that 'the underlying philosophy of self - determination here, while not codified in law, is a potentially transformative vehicle for user sovereignty in decision making' (Levick, 1992). Both the requirement for individual users' views to be represented in needs-led assessment at one end of the process and the collective representation of users and carers in the formulation of community care plans at the other are seen as offering scope for a strategy which aims to exploit the 'radical possibilities' in the community care legislation (Ibid.) Similar arguments have been made by Coote in respect of 'democratic' models of quality assurance (Coote, 1994).

In fact, the experience of the actual operation of the NHS and Community Care Act since 1991 lends support to Carpenter's view that there has been a 'tendency to greatly exaggerate the progressive aspects of the reforms' (Carpenter, 1994: 71). Firstly, given the power differentials between users and professionals already referred to (as well as the physical or mental impairment which the user may have), it is difficult to see how individual users' views can be 'adequately represented' either within the process of

needs-led assessment or in the community care planning process without the provision of the necessary **access** and **support**, such as properly resourced independent advocacy services, provision of transport to meetings, and increased training (Beresford and Croft, 1993: 150). Neither the Act, however, nor the subsequent policy guidance provide for these supports.

Secondly, those who enthuse about the possibilities for increasing user representation through the mechanisms created by the community care legislation frequently neglect the financial context in which the reforms have been introduced, a context in which involvement in the ways referred to above *may* enhance a user's sense of being listened to but where the needs identified in the assessment will often not be met (especially since there is no legal requirement on local authorities to do so) and where the 'right to assessment' may often amount to little more than a mechanism for means-testing and the rationing of scarce resources (McLean, 1989; Biggs, 1990/91). As one generally positive analysis of user perspectives on community care assessments concluded

Without the resources - new or recycled - to meet needs identified in assessments in which users and carers have an increasing say, disillusion may set in. At the end of the day, users and carers are likely to judge community care assessments more on their outcomes than on how they are conducted (Brace, 1994: 75).

Thirdly, while an effect of the reforms has been to highlight the needs of undervalued groups such as informal carers who previously were often 'invisible' to policy-makers and social services and has led to the development of new and increasingly powerful representative organisations of users and carers (Ferguson, 1995; Twigg and Atkin, 1995), it could be argued that given the limited and essentially individualised forms of representation envisaged in the Act (in needs-led assessment, complaints procedures and consultation on community care plans), the development of such self-organisation has often happened *despite*, rather than *because* of, the community care reforms (Carpenter, 1994: 73).

Finally, there is a more general issue regarding the role of representation within consumerist models. Whatever the merits of individual representation within community care assessments or group representation within community care plans, few people would see such representation as a satisfactory *substitute* for traditional mechanisms of representative democracy, such as elected local councils, or as an adequate means of overcoming the limitations of these mechanisms (limitations, incidentally, which were recognised by critics on the Marxist Left both much earlier and at a qualitatively deeper level than consumerist critics have so far achieved e.g. Miliband, 1984; Draper, 1977). Yet it does appear to be the case that the overall effect of the introduction of market forces into public services has been to *reduce* the level of representation and accountability within these services. In a powerful polemic, Hutton, for example, has argued that

Lines of democratic accountability have been broken as schools, hospitals and housing have been removed from their former control by local government or Parliament and placed under the management of new trusts and agencies. By 1996, the *Guardian* has estimated, there will be a staggering 7,700 new quangos ...dispersing some £54 billion of public money. This is a bizarre achievement for a regime committed to removing the burden of government - a triumph of double-speak that Orwell would have admired (Hutton, 1996: 4-5).

What this criticism points to is the tendency inherent in consumerism to replace the figure of the *citizen* with civil and political rights with that of the *consumer*, whose rights exist mainly in relation to the purchase of commodities, in this case health and social services (Beresford and Croft, 1995). As we have seen above, however, there are major difficulties involved in constructing users of health and social services as 'customers' or 'consumers', while the widespread social, political and economic discrimination and disadvantage experienced, for example, by users of mental health services (an area which will be explored in depth in chapter three) means that a perspective which focuses solely on their relationship with services is seriously inadequate.

CONSUMPTION OR PRODUCTION?

Potter's influential analysis provides a useful framework on which to hang a critique of consumerist approaches to user involvement. Even that analysis, however, suffers from a number of important theoretical weaknesses, two of which will be addressed here.

Firstly, there is the absence, noted by Clarke (1998), within her five criteria of consumerism of the issue of *resources* or *money*. Yet as the above discussion has demonstrated, service users in general and users of social services and mental health services in particular, are frequently poor and with limited buying power. Any critique of consumerist models of user involvement which fails to take this into account is seriously weakened by this omission.

There is also, however, a second, more profound, objection to Potter's critique which also applies to other critiques of consumerism, including some of those from writers associated with the critical social policy tradition. Potter's method (which I have by and large followed in the above discussion) is to treat the five criteria of consumerism as essentially unproblematic and then explore their limitations when applied to public services. The problem with this approach, however, is that it leaves unchallenged the consumerist or New Right view of the market as driven by consumer preferences, except when 'interfered' with by trade unions or 'excessive' State regulation. Yet as Titmuss demonstrated in a classic study three decades ago, the idea that by the expression of their preferences in the market place, consumers are able to ensure quality of service in a way that would not be possible in a publicly regulated system is a myth. A comparison of public and commercial markets in blood, for example, led him to conclude:

In commercial blood markets the consumer is not king. He has less freedom to live unharmed; little choice in determining price; is more subject to shortages in supply; is less free from bureaucratisation; has fewer opportunities to express

altruism; and exercises fewer checks and controls in relation to consumption, quality and external costs. Far from being sovereign, he is often exploited (Titmuss, 1970).

One reason for this is the existence of monopoly. In the discussion earlier of choice and quasi-markets, reference was made to the possibility or even likelihood of a small number of suppliers beginning to dominate the market in social care and so restricting user choices. In reality, of course, such domination of the market by a tiny number of providers is precisely the experience of consumers in most areas of the commercial market - something which enthusiasts for the market often choose to ignore. Thus, for example, with regard to the much-vaunted 'supermarket model' of the market, the irony is that supermarket shoppers in Britain and most other Western countries have remarkably *little* choice, with five companies in 1989 accounting for 74 percent of packaged grocery sales, and one estimate suggesting that by 1995, three supermarket chains would dominate three quarters of food retailing in Britain (Harman, 1989: 27). Similarly, in the area of mental health, developing 'user-led' services is not simply a matter of increasing consumer power, through more widespread advocacy services or higher benefit levels. Rather it involves recognising and being prepared to challenge the dominance of the giant pharmaceutical companies, with the sales of a drug such as Prozac, for example, manufactured by Eli Lilly, exceeding \$1.3 billion annually, making it the second most commonly prescribed drug in the USA, prescribed to more than 10 million people world-wide (Breggin and Breggin, 1995).

Given their commitment to the market, it is perhaps unsurprising that the dominance of such 'producer-led' services is almost invariably overlooked by New Right advocates of consumerism in public services. What is more surprising is the fact that critics of the New Right also frequently fail to make this criticism, something which may reflect the extent to which sections of both the academic and political Left in the 1980s and 1990s were prepared to accept the argument that 'there was no alternative' to the market, influenced as they were by a mixture of postmodernism, Fukuyama's 'end of history thesis' and the 'New Times' analysis associated with the now defunct journal *Marxism*

Today (Hall and Jacques, 1989; for a critique of some of these trends see Sivananden, 1989; Callinicos, 1989; Callinicos, 1995).

CONCLUSION

This chapter has attempted to provide a critical evaluation of the capacity of consumerist approaches to welfare to empower users of health and social services. As the dominant ideology of the 1980s (as well as the model of user involvement enshrined in legislation), the influence of consumerist approaches should not be underestimated. However, through a consideration of the areas of access, choice, information, redress and representation, I have argued that the emphasis of consumerist approaches on *procedural*, rather than *substantive* rights; the *minimalist* forms of user involvement which they envisage; and the problems involved in constructing users of health and social services as 'customers' means that not only that the capacity of such approaches to empower such service users is often limited but that in important respects the introduction of market forces into welfare will actually *reduce* choice for users. I have also suggested that existing critiques of consumerism have often been limited by an acceptance of some of its core tenets, in particular an acceptance of the view that the market extends choice.

In the next two chapters, two of these critiques - the professional social work critique in chapter two, the more radical critique linked to the mental health users' movement in chapter three - will be explored in much greater detail and the opportunities they offer to the users of mental health services in particular both for greater involvement in services and also for challenging the stigma and discrimination they experience will be critically evaluated.

‘Good Intentions’: professional social work and user involvement.

Dissatisfaction with consumerist models of service user involvement has given rise to a number of critiques which have attempted to overcome some of the limitations of consumerism identified in chapter one. One of the most influential of these critiques has rested on a distinction between a *consumerist* approach and a *democratic* approach. The key elements of the democratic approach are defined by Beresford and Croft in the following way:

The democratic approach is about more than having a voice in services, however important that is. It's also concerned with how we are treated and regarded more generally and with having greater say and control over the whole of our lives. The idea of empowerment is central to the democratic approach. Its objectives are civil rights and equality of opportunity...If the consumerist approach is essentially service-led, beginning with the service providers' needs, not the consumers', the democratic approach is *citizen*-led. It is concerned with people having the chance to speak directly for themselves. The two approaches to involvement have different origins and objectives (Beresford and Croft, 1993: 9).

Thus, it is a feature of the democratic approach that people are not perceived solely in relation to the services they use - as consumers - but in a much broader, more holistic way, as *citizens* whose impairment or disability ought not be a bar to them enjoying the same range of civil and social rights as any other citizen. In contrast to consumerism, then, there is a consciously *political* dimension to this model which involves recognising the structural roots of the discrimination and disadvantage experienced by many service users.

Secondly, the reference to people speaking directly for themselves highlights another important aspect of this approach, viz., the recognition that, as noted in the discussion on representation in chapter one, historically people with disabilities or people with mental health problems have often been spoken *for*, whether by carers or professionals or paternalist organisations, and have had their needs and wishes defined by others. Hence, the democratic approach lays great stress on helping such users to 'find a voice', through advocacy, self-advocacy and the development of self-organisation.

The distinction between consumerist and democratic approaches is a useful one then, in that it recognises the wider social and political context in which health and social services are delivered, and also the need for a *political* response on the part of service users if the discrimination and disadvantage which they experience is to be challenged.

In other respects, however, the distinction is less useful. Firstly, there is a lack of precision about what the 'democratic' model which Beresford and Croft counterpose to the consumerist model actually involves. Given that *empowerment* is a term much favoured within New Right discourses, it is difficult to see how this can be a defining characteristic of this approach (a point acknowledged by Beresford and Croft in a later article (1995)). The points made in chapter one regarding the difficulties surrounding the use of concepts such as 'community' and partnership' have, if anything, even greater application in relation to empowerment. Thus, in terms similar to those employed by Mayo in the previous chapter, Ward and Mullender have argued that

'empowerment' has become the current bandwagon term in social work and is being used to justify what are, in fact, varying ideological and political positions. Because it creates a vogue image and an aura of moral superiority, it affords protection against criticism. Yet the term lacks specificity and glosses over significant differences. It acts as a 'social aerosol', covering up the disturbing smell of conflict and conceptual division (Ward and Mullender, 1991 : 21) .

Yet beyond an ambivalence towards market-driven consumerism, it is sometimes difficult to see what such 'empowerment' approaches amount to.

Secondly, despite their correct insistence that 'user involvement' is a *political* issue, in that it highlights the need for service users to address the lack of power in their lives, Beresford and Croft's writings tend to be curiously abstract and even apolitical in that nowhere do they address the issue of exactly *how* service users are to overcome their lack of power. They neglect, in other words, the issue of *agency* (Callinicos, 1989). While they are explicit in rejecting a revolutionary socialist strategy for overcoming the oppression experienced by service users, at no point in their widely-read text on citizen involvement is there any reference *either* to the potential role of political parties, such as the Labour Party, in challenging that oppression *or* to the limitations of such reformist strategies. The result is a strategy and set of goals for citizen involvement that come dangerously close to pessimism and fatalism and that seem unlikely to inspire service users who wish to challenge their oppression:

It's a journey that's both far-reaching and small-scale. It isn't the bloody revolution which promises to change everything and leaves us excluded just the same. It isn't the prescriptive policy that's meant to improve our lot, but stigmatises and leaves us dependent. It doesn't mean we must make giant strides. There's probably something wrong if we are trying to. We don't have to feel guilty about the modesty of our progress. The smallest steps will take use forward, as long as we are heading in the light direction. Our final goal may still seem light years away (Beresford and Croft, 1993: 220).

In chapter three, I shall explore more fully the extent of the discrimination and inequality experienced by mental health service users. Given the extent of that discrimination and inequality, however, and the anger and militancy which characterises some sections of the mental health users movement, it seems unlikely that they will be content to settle for the extremely modest goals and timid strategies proposed by Beresford and Croft.

The silence of these and other writers on the issue of agency means that in practice responsibility for bringing about change is assumed to lie either with the State, whether in the form of welfare professionals and/or enlightened local authorities, who are seen as having the responsibility for providing support for user involvement; or with service users themselves, despite their acknowledged lack of power.

In effect, there is an eliding of two agendas here: on the one hand, a *professional-led* agenda, driven mainly by social work professionals and academics who have embraced the notion of user involvement for reasons that will be explored below (with the text by Borerford and Croft referred to above, for example, being published as part of a 'practical social work' series); on the other, a *radical* agenda, linked to a greater or lesser extent to the 'new social welfare movements' (Williams, 1992) that have sprung up over the last ten to fifteen to challenge the discrimination and disadvantage experienced by service users. While there is often considerable overlap of both personnel and ideas between these two approaches, there remains nevertheless an important difference in terms of goals and strategies between even the most radical social work and what are now commonly (if, as I shall argue later, misleadingly) described as 'new social movements' which gets lost in the notion of a 'democratic' approach to user involvement.

In this thesis, therefore, I shall employ the three-fold distinction of *consumerist*, *professional-led*, and *radical* approaches to user involvement. For the remainder of this chapter, I shall explore professional-led (specifically, professional social work-led) approaches before considering radical approaches in the next chapter. After an initial discussion of the historical antecedents of user involvement in social work theory and practice, I shall critically evaluate four social work rationales for such user involvement - ethical; corporatist; educational/therapeutic; and radical social work.

'THE CLIENT SPEAKS'

Professional models of user involvement tend to find their main support from within the social work profession, and more specifically, from social work academics. *Prima*

facie, this seems paradoxical. As Clarke has argued, 'Professionalism has been placed on the defensive by the assertion of customer-centred models of provision' (Clarke, 1996: 53). Given that social work has historically been far less secure in its professional identity than the older professions such as medicine or nursing, one might have assumed that social work would feel most threatened by an increased role for clients/users. The implications of service user involvement for notions of professionalism will be discussed more fully below in the section on radical social work. At this stage, however, three reasons may be suggested for this social work response.

On the one hand, since its inception in the late nineteenth century, a central concern of social work has been with the maintenance of social cohesion on the one hand and the avoidance of social exclusion on the other (Clarke, 1993; Becker, 1997). The idea of *participation*, therefore, is one that recurs time and again within social work literature, albeit in a range of guises, beginning with the Charity Organisation Society and the University Settlement Movement of the late Victorian era, through to the emphasis in the Seebohm Report of the late 1960s on citizen participation (Seebohm, 1968; Steadman-Jones, 1971; Lewis, 1995). For one leading contemporary social work academic, the recent emphasis on user-involvement is both a development of this tradition and also an opportunity to remedy earlier omissions :

Recent events provide the greatest challenge social services departments have faced since their inception, since they lay bare their value base. They provide an opportunity for departments to achieve the kinds of relationships with clients and with the public which Seebohm envisaged but which has been distorted by the demands flowing from a large organisation. Now there is a second chance (Parsloe, 1988: 90).

Secondly, alongside both the conservative social work tradition of the nineteenth century and the 1960s social democratic tradition of Kilbrandon and Seebohm is a more radical strand which has been concerned both with emphasising the structural roots of clients' problems and with challenging the 'professionalisation' of social work.

which is seen as an attempt to increase the distance between client and worker (Bailey and Brake, 1975; Simpkin, 1982). While as a movement radical social work reached its zenith in the 1970s before declining in the 1980s (Langan, 1993), its legacy can be still seen both in the emphasis within the Diploma in Social Work on anti-discriminatory and anti-racist practice (CCETSW, 1995; Thompson, 1998) and also in the support for user involvement (Barnes, Prior and Thomas, 1990). No comparable movements can be found in the more conservative health-related professions (with the partial exception of anti-psychiatry which I shall discuss in chapter three).

A third, more self-interested, explanation can also be offered for social work's interest in user involvement. As a number of commentators have noted, the 1980s and 1990s have seen the social work profession being subjected to a number of challenges, from both left *and* right, leading to what one writer has called 'a crisis in care' (Clarke, 1993). This prolonged crisis has led some critics to argue that

It would appear that until the political climate changes and there is a widespread revulsion against current trends and social inequalities, social work might continue as an occupation but perish as a caring and liberal profession (Jones and Novak, 1993: 210-211)

In this situation, the interest in user empowerment has been seen by some people as an attempt by leading social work professionals to 'colonise' this new development, as a vehicle for 're-inventing' and 're-presenting' the social work profession in a new, more positive light. Jack, for example, has argued that

It is important to consider the empowerment debate within its social and political context - it is after all about power and the defence of sectional interests. As such the debate should be seen as part of a wider process in which professionals are involved in defending their own interests and not simply as a debate about a technique which professionals employ in the interests of service users (Jack, 1995 : 13).

Certainly, as the radical social work tradition referred to above recognised, an uncritical acceptance of the helping and participative pretensions of social work and community work can both obscure their important social control functions (Bailey and Brake, 1975; Donzelot, 1982) as well as creating an illusion of change where none in fact is taking place, the 'good intentions' noted by Marsh and Fisher in their study of partnerships in social work (1992).

Thus, involvement and participation within professional models of user involvement, rather than being seen as necessarily radical on the one hand or unambiguously 'good things' on the other, need to be unpacked, in common with the other core concepts discussed earlier. This will involve exploring some of the main rationales for participation within professional social work discourses viz., the *ethical* rationale - participation as a value in itself; the *corporatist* rationale - participation as an element in the planning process *and/or* as a 'strategy for legitimisation'; the *educational /therapeutic* rationale, the focus of which is on the benefits of the *process* of participation, rather than on the outcomes; and *radical social work*, with its attempt to challenge the professional distance between worker and client.

The ethical rationale.

Within the social work and community work literature, participation is often justified on ethical grounds, either as a core value in itself or as an extension of the principles of respect for persons and client self-determination. Thus, in their discussion of community social work, for example, two of the most prominent writers in the professional community work tradition (on which see Twelvetrees, 1990) describe participation as a 'fundamental principle':

Involving clients and local people in decisions about priorities and how services are delivered would seem to be axiomatic to community social work. Either social work seeks to engage with the community or it does not, and if it does it has to deliberately open its doors, put its goods on display, encourage response and debate, begin to share power (Henderson and Thomas, 1987: 10).

While 'participation' is more frequently referred to as a core value in the community work, rather than the social work, literature, nevertheless the idea of participation is also reflected in a range of traditional social work values such as *mutuality* and *self-determination* (Hugman and Smith, 1995). Such a value stance would seem to be both an essential prerequisite for genuine user involvement and also an important counter to the paternalism which has historically pervaded health and social services. As a *basis* for user involvement, it suffers from important limitations.

Firstly, terms such as 'participation' and 'self-determination' are so broad that, like community, they can mean very different things to different people (Horne, 1987). In an example of the 'elasticity' of social work values, Ramon has argued that 'empowerment is not an additional value since it is adequately covered by that of self-determination when the latter is taken seriously' (Ramon, 1991: 16). A danger of such elasticity is that it becomes possible for workers simply to change the language they used to describe their practice, while the practice remains essentially the same. In a paper entitled 'Can social work empower?', for example, Browne argues that 'If we talk about empowering users of social services... we are talking about enabling them in some way' (Browne, 1995).

There are two problems with this kind of argument. Firstly, it adds to the existing terminological confusion. The 'enabling' - as opposed to 'provider' - role of social work departments and of local authorities is central to consumerist ideology and can therefore hardly be used to define the empowerment approaches. Secondly, as the 'enabling' role of social workers is widely accepted by mainstream social work literature and has been for decades (see e.g. Baker, 1975), it is not clear what advantages, if any, derive from re-packaging this role as 'empowerment'. As Ward and Mullender comment, there is a danger that, used in this way, empowerment simply becomes a 'professional Newspeak' which 'allows anyone to rewrite accounts of their practice without fundamentally changing the way it is experienced by service users' (Ward and Mullender, 1991: 22).

Secondly, given that definition is in the last resort a matter of power (Rojek et al, 1988), in respect of such 'slippery' terms, it is the definitions of professional groups, rather than of service users, that are likely to become accepted. A consequence is that the significance of issues of power and conflict is likely to be minimised. As Barker and Peck note:

workers often hold a consensual view of the world which leads them to assume compatibility between this new vocabulary and the old, yet in our view the words sometimes represent world views in conflict (Barker and Peck, 1987:1).

Thus, the forms of user involvement which flow from such empowerment approaches may be of a very limited type and fit quite comfortably into a classical social work paradigm. A good example of this is to be found in a discussion of empowerment by two prominent social work academics:

We realise that for many people and especially for community workers, empowerment implies an increase in political power. We do not use it in this sense but rather to describe work with individuals and families within a relatively circumscribed context, that of their need for formal community services (Parsloe and Stevenson, 1993: 6-7).

It is perhaps not surprising then, given the influence of such interpretations of 'empowerment', that studies of user involvement have found a huge gap between what professionals *claim* to be doing to involve service users and the reality, described by Marsh and Fisher as 'the DATA effect - we **Do All This Already**', when in fact, they do not (Marsh and Fisher, 1992). Reporting on another study which reached similar findings, Shemmings and Shemmings conclude:

We consider it unwise to leave it to managers and professionals to define terms such as 'empowerment' and 'partnership', for they are too apt to do it in ways that suit their own professional interests (1995).

As Donnison has noted, a 'shared' acceptance of these values is likely to count for little when there is a conflict of interest between those with power and those without:

A good case could be made for consulting people on moral grounds of courtesy or humanity, or just on grounds of political expediency. But consultation promised for these reasons rarely confers real power on the poorest people when hard decisions have to be made about scarce resources. That's why they are poor: powerful people can afford to neglect them (Donnison, 1991).

In fact, it is precisely such a neglect of issues of power, underpinned by a consensual world-view, which typically characterises traditional social work approaches to user involvement, in contrast to more radical approaches whose starting-point is often the inequalities in power and resources between users, professionals and services.

The corporatist rationale

If the *ethical* case for participation is inadequate, then, for some commentators, often from the Fabian tradition, the *corporatist* case is much stronger. Donnison's writings provide a good example of this approach. According to Donnison, effective policies can only be arrived at if the views of the potential recipients of these policies are taken into account and they are involved in the consultation process; otherwise the policy-makers are likely to 'get it wrong', resulting in disruption or opposition at the implementation stage (Donnison, *ibid.*). Participation, therefore, is a means not of avoiding conflict but of bringing it into forums where it can be 'managed' (Donnison, 1973, cited in Cockburn, 1977). In this view, the real threat to representative democracy comes not from popular participation or from conflict but rather from a *lack* of participation - from *apathy* - which in the long run will result in a loss of legitimisation of democratic institutions and their decline into disrepute.

While such an approach may seem preferable on both moral and technical grounds to *no* consultation, its focus on *means* rather than *ends* leaves this form of participation

open to accusations of manipulation. In her study of the introduction of corporate management and community development approaches in Lambeth in the 1970s, for example, Cockburn concluded that, far from pulling in opposite directions, community development and corporate management approaches were 'the tough and tender aspects of one principle: management' (Cockburn, 1977: 2).

Such a danger is in fact evident in Donnison's own writings. In his introduction to a study of community development in Strathclyde, for example (Barr, 1991), after a discussion about the value of 'the community-based way of working', Donnison continues

Frank Kitson (then a Brigadier but later General Sir Frank) was laying down similar principles for soldiers in his book *Low Intensity Operations* nearly 20 years ago. Lord Scarman, after the Brixton riots, gave the same advice to the police: crime prevention has to be a community- based, hearts and minds operation or it is worthless (Ibid.).

Given that the role of British troops in Northern Ireland or of the police on the streets of Brixton are matters of considerable political debate, to portray such issues as essentially 'technical' matters by focusing on means rather than ends is to ignore their politically contested nature and suggests that participation is being employed here in what might be seen as a manipulative fashion.

The recognition that such manipulation is also a danger in user involvement in health and social services is evident in Shemmings and Shemmings' amended version of Arnstein's Ladder of Citizen Participation (Arnstein, 1969):

- Rung 8 : Citizen Control
- Rung 7 : Delegated Power
- Rung 6 : Partnership
- Rung 5 : Consultation
- Rung 4 : Involvement

Rung 3 : Keeping fully informed

Rung 2 : Placation

Rung 1 : Manipulation

As they comment 'Although the bottom two rungs are not examples of true participation, they are included because they can sometimes masquerade as such', and cite as examples, situations where people are invited along without being permitted to speak or where decisions have been made in advance (Shemmings and Shemmings, 1995 : 53).

An example of such manipulation in relation to user involvement is provided by Payne when he notes that involvement by service-users in the development of community care plans might be seen as a means of ensuring that the right types of services are developed but also that users are made aware of financial constraints from the outset and are less likely to object at a later stage (Payne, 1995).

The educational/therapeutic rationale.

Whereas corporatist rationales for participation are primarily concerned with securing a desired *outcome*, the focus of educational/ therapeutic models of participation is on the *process* of participation itself. Examples of this approach include some models of community development, particularly those influenced by adult education and social work theory . Henderson and Thomas suggest that what these models share is

an explicit interest in improving interpersonal and inter-group relations rather than environmental or social-structural conditions, and an appreciation of the gains to individual functioning that comes from involvement in community activities (Henderson and Thomas, 1987: 325).

A similar emphasis on the therapeutic benefits of participation can be found in the group psychotherapy and therapeutic community traditions developed during and after the Second World War by W.R. Bion and Maxwell Jones respectively (Sedgewick,

1982), places where groups of therapists and patients worked together to attempt to create an environment where traditional models of institutional authority were broken down and patients participated in the government of their hospital community.

More generally, an emphasis on the social work *process*, as opposed to an emphasis on outcomes, was a core element of Butrym's rejoinder to the radical critics of social work in the mid-1970s (Butrym, 1976).

A concern with the *process* of collective involvement has in fact also been a feature of much radical and revolutionary thought, from Marx to Freire (Marx and Engels, 1970; Friere, 1984). For Marx, for example, it was only through the process of collective struggle to change society, and above all in a revolution, that workers learned to break with the old ideas of racism, sexism, and feelings of inferiority which otherwise played such a key role in perpetuating the status quo:

This revolution is necessary, therefore, not only because the *ruling* class cannot be overthrown in any other way, but also because the class *overthrowing* it can only in a revolution succeed in ridding itself of all the muck of ages and become fitted to found society anew (Marx, and Engels, 1970: 95).

That said, however, for these thinkers, whatever benefits might derive from participation *per se* in terms of heightened political consciousness and increased confidence, without a thorough transformation of the political and economic structures which create and maintain a variety of oppressions, such gains would necessarily be short-lived. By contrast, within professionally-led models of user involvement, by definition the goals are likely to be much narrower and may not include structural change; power differentials may be concealed (Chamberlin, 1988); and, as Beresford and Croft argue, there is a danger that therapies based on participation can in themselves become oppressive:

Where 'participation' becomes therapy or training... the truly therapeutic benefits of empowerment are lost. If people are to have a real choice in

whether they become involved... involvement should not be conceived in therapeutic terms (Beresford and Croft, 1993: 109).

Radical social work

The final rationale for challenging service users' lack of power over services comes from the radical social work tradition referred to earlier. In one sense, locating radical social work within a chapter on *professional* social work approaches to user involvement is misleading since a critique of the trend towards professionalism within social work was a central plank of this particular current (Langan, 1993). It is also the case that the links between radical social work on the one hand and the movements and struggles taking place in the wider world of the 1970s on the other - both trade union struggles and the struggle against various forms of oppression - were often close and on occasion fed into each other.

Nevertheless, the distinction between even the most radical social work practice and the struggles of movements against oppression, such as the disability movement and the mental health users' movement, to be discussed in the next chapter, is an important one and relates back to the issue of agency referred to above. For both the *location* of social workers and community workers within bureaucratic welfare agencies which are often far from radical and their relative *lack of power* to challenge structural inequality mean that they are often poorly placed to act either as agents of change or even as catalysts of change. It is these factors above all which resulted in radical social work theory's frequently-noted failure to develop a radical praxis. Corrigan and Leonard's 'Marxist' approach for example, sometimes seemed to amount to little more than an exercise in consciousness raising (1978) while the experience of the Community Development Project suggested that more sustained attempts to develop radical community work approaches would often founder on the opposition of hostile local authorities who did not take kindly to their employees encouraging community opposition to their policies (Loney, 1983).

That said, the critique developed through core texts such as Bailey and Brake (1975) and Simpkin (1982) was an important one and deserves to be defended both against conservative critics such as Butrym (1976) and Davies (1995) who wish to remove or at least reduce social work's wider commitment to challenging social inequality and also against critics influenced by postmodernism such as Rojek, Peacock and Collins (1988) who seek to portray class, in the form of 'classism' (Thompson, 1998) as just one more form of oppression. In terms of its relevance to current debates around user involvement, the legacy of radical social work can be seen in three main areas:

i) Material inequality.

The recognition of the material inequality experienced by many users of social services and mental health services forms the starting point for radical social work. As Bailey and Brake argue:

Radical social work...is essentially understanding the position of the oppressed in the context of the economic and social structure they live in. A socialist perspective is, for us, the most human approach for social workers (Bailey and Brake, 1975: 9)

As we saw in chapter one, such an understanding continues to inform the critique of consumerism's attempts to portray such users as 'customers'. In addition, the emphasis on the determining influence of *structure* on the one hand and *class* on the other also has contemporary relevance as a rejoinder to postmodern theorists who tend to dissolve structures, and particularly class structures, into a stew of 'identities' which often appear to be entirely subjective and freely chosen (Williams, 1996; Woodward, 1997; for a critique, see Ferguson and Lavalette, 1999).

ii) The critique of professionalism.

The second area where radical social work has relevance to current discussions of user involvement in respect of notions of professionalism. Radical social work theorists saw the professionalisation of social work as on the one hand an attempt to place the interests of social workers as an occupational group *above* the interests of clients and

on the other to create distance between social workers and their clients through an emphasis on professional knowledge and expertise (Payne, 1996). By contrast, radical social work emphasised the *commonalities* between workers and clients on the one hand and the value of *clients'* knowledge and experience on the other.

The relationship between workers and service users will be explored in depth in chapter seven of this thesis. However, it is worth noting at this stage that the issue of the *common* experience of workers and clients is a very live one within the mental health users' movement, reflected for example in the 'wounded healer' model of helper (Rippere and Williams, 1986), while the assault on professional knowledge and expertise has gained considerable theoretical support over the last two decades from the postmodern deluge of the last decade.

iii) 'Empowerment'.

Earlier in this chapter, I criticised the amorphousness and ambiguity of the term 'empowerment' and pointed to some of the limitations of its use. At the same time, the recognition of the controlling aspects of health and welfare practice on the one hand and a desire to challenge the lack of power of clients and users of mental health services on the one hand marks a significant step forward from traditional social work notions which emphasise the consensual and helping aspects of social work. Again, the roots of these ideas are to be found in radical social work:

Radical social work sought to generate a wider awareness of the power that social workers had by virtue of their access to information and resources that were not readily available to service users. 'Empowerment' was the process of transferring this power into the hands of the people who were systematically denied it within the framework of the welfare state (Langan and Lee 1989: 9).

CONCLUSION

In a classic critique of bureaucratic socialism, the late American Marxist writer Hal Draper made a distinction between what he called *socialism from above*- primarily the social-democratic and Stalinist traditions, which saw social change being handed down

from above- and *socialism from below*, socialism arising out of the struggles of ordinary working-class people, which Draper saw as much closer to Marx's own view of socialism as the self-emancipation of the working-class (Draper, 1996).

In similar vein, it is possible to make a distinction between user involvement *from above* - the consumerist and professional-led models discussed in chapters one and two - and user involvement *from below*- arising from the activities of service users themselves (Ferguson, 1997). As the discussion in chapters one and two suggested, while models of user involvement from above have been important and influential, at best they have often led to minimalist forms of involvement and to improvements in procedural rights, at worst to purely cosmetic changes in practice (in the case of professional-led models) and to increased inequality (in the case of consumerist models). By contrast, user involvement from below - by which I mean that initiated and developed by service users themselves, sometimes with the support of professional workers, sometimes arising out of movements such as the mental health users' movement - has often gone much further both in challenging dominant ideologies of mental ill- health and also in challenging professional/user relationships. Chapter three will involve a critical examination of the limits and potential of such user involvement from below, through an exploration of the experience, activities and ideas of users involved in the mental health users' movement.

The challenge from below: the Mental Health Users' Movement.

An important feature of the political scene in Britain and elsewhere over the past decade has been the growth in self-organisation amongst groups of people, such as people with disabilities or older people, who are particularly dependent on the services of the welfare state and who in the past have often been 'represented' by others, usually in the form of established charities (Oliver, 1990). The focus of this chapter will be on the growth and nature of such self-organisation amongst mental health service users. in what is usually referred to as the mental health users' movement (Campbell, 1996).

In relation to the wider theme of user involvement, the contribution of the users' movement differs in important respects from both consumerist and professional approaches. Firstly, in contrast to the 'top-down' nature of both of these approaches, service users themselves have often played a central role in both initiating and developing movement activities. Secondly, whereas, with the partial exception of community development approaches, the focus of the first two approaches has been overwhelmingly on the involvement of *individual* users, a common feature of movement activities has been their *collective* focus. Finally, while both professional and consumerist approaches have at best tended to lead to minimalist forms of involvement and to improvements in procedural rights, by contrast, user involvement from below has often gone much further both in the challenge it presents to professional/user relationships and also to dominant ideologies of mental ill- health. A central aim of the current thesis will be to evaluate the potential and limits of this challenge.

While no single set of ideas dominates the users' movement (Rogers and Pilgrim, 1991) there is evidence in recent years of the growing influence amongst some user groups of *identity politics*, based on the idea that all mental health service users share a

common interest which overrides any other interest or division (Aronowitz, 1992; Smith, 1994). An emphasis on shared identity is also evident in the characterisation by some academic commentators of the users' movement as a 'new social movement' (Rogers and Pilgrim, 1991; Barnes and Shardlow, 1996; Rogers and Pilgrim, 1996). The implication of describing movements such as the disability movement or the mental health users' movement in this way is that they differ from 'older' social movements such as the trade union movement in key respects, such as a far greater preoccupation with issues of identity; a stress on autonomy; and a lack of concern with material or class-based issues (Scott, 1990; Mayo, 1994; Campbell and Oliver, 1996; Barnes, 1997).

In the second half of this chapter, I wish to explore and evaluate this characterisation of the mental health users' movement as a 'new social movement' (or occasionally 'new social welfare movement', Williams, 1992), whether the term is used in a *descriptive* sense (to suggest that the movement in practice is more concerned with cultural than material issues for example), or in a *prescriptive* sense, (to imply a particular strategic direction for service users wishing to challenge their oppression). In particular, I wish to question the notion underpinning much social movement theorising that a politics of identity offers the best way forward for mental health service users wishing to challenge stigma and discrimination.

Before that, however, and as a basis for that discussion, the first part of the chapter will explore the nature of the discrimination and disadvantage experienced by mental health service users, with a view to assessing on the one hand the extent to which all mental health service users can be said to share a common experience and identity, and on the other, the ways in which such discrimination both resembles and differs from the structural oppression experienced by women, gays and blacks.

Before commencing this analysis, a brief note on terminology is necessary. There is no agreed term within the mental health users' movement for people who use mental health services, with terms such as user, service user, survivor and even madperson being used (the last reflecting the idea that it is possible for groups of oppressed

people to 'reappropriate' the language of the oppressor). The issue of terminology will be explored in some detail in chapter six. In this chapter, however, I shall employ the term user or service user, both for the sake of consistency and also because it is still the most widely used term, while acknowledging that many people with mental health problems strongly object to the term.

MENTAL ILL-HEALTH AND OPPRESSION

While the disability movement has had some success in recent years in winning the argument that 'disability' is often socially constructed, rather than being the inevitable product of mental or physical impairment (Barton, 1996; Oliver, 1996; Oliver and Barnes, 1998), the continuing dominance of the biomedical model of mental health means that many of the problems experienced by people with mental health problems, such as poverty, unemployment and social isolation, are still more likely to be seen as the 'natural' consequence of mental ill-health.

Yet while mental health problems clearly *do* impair the functioning of people experiencing them, structural factors are often at least as significant, and sometimes more so. In this section, three aspects of such structural oppression will be examined: the impact of stigma; the medical model of mental illness; and exclusion from the labour market.

Stigma

The starting-point for any examination of the experience of people with mental health problems is an acknowledgement of the all-pervading stigma which they experience. Reviewing the American experience, for example, Warner has argued that

It is obvious that mental patients are still highly stigmatised. Branded as 'psychos' in popular parlance, they encounter great hardship in finding employment and generate fear as to their dangerousness. Citizens fight to exclude psychiatric treatment facilities and living quarters for the mentally ill

from their neighbourhoods. The status afforded the mentally ill is the very lowest - lower than that of ex-convicts or the retarded (*sic* - IF) (Warner, 1994: 180).

In most respects, the picture in Britain is similar . A recent national survey of the views of mental health workers by the Health Education Authority, for example, found that the two most common reasons given by their patients for experiencing discrimination were being labelled mentally ill and racism (followed by ageism and homophobia) (1998). Another general population survey carried out by the Scottish Association for Mental health found that 48% of those interviewed concurred with the statement that 'If I was suffering mental health problems, I wouldn't want anyone to know about it' (SAMH, 1999).

It could of course be argued (and frequently is) that, rather than reflecting stigma and discrimination, such attitudes towards people with mental health problems reflect a realistic perception of the danger that they pose to other members of society. While this discourse of 'dangerousness' is currently an influential one, it rests on extremely dubious foundations.

Thus, the conclusion of the most recent and most comprehensive research into the danger posed by people with mental health problems living in the community is that public fear of random killings by such individuals is based on myth (*Guardian*, December 12, 1997). The research, carried out for the Department of Health at Manchester University, found that arbitrary attacks, such as that carried out on the musician Jonathon Zito, are rare. People are almost three times more likely to be killed by a stranger who is not mentally ill than one who is. Of 408 homicide convictions in one year, only twelve per cent were carried out by people who 'had been in contact with mental health services' during the twelve months preceding their offence, with the overwhelming majority of homicides by mentally ill people involving not strangers but family members. By contrast, over 1,000 people with mental health problems are likely to kill themselves each year. Very similar findings were arrived at by the Boyd Inquiry.

set up by the last government in the wake of a number of homicides involving people with mental health problems (Confidential Inquiry, 1994).

All such homicides are tragic both for the victims and their families and for the perpetrators and their relatives. What inquiries into their causes tend to highlight, however (e.g. Blom-Cooper, Hally and Murphy, 1995), is less the innate dangerousness of people with mental health problems than the chronic and scandalous under-resourcing of mental health services on the one hand and the lack of proper co-ordination between services on the other (Larkin, 1995). It is, however, the issue of dangerousness and not resources that is emphasised both in the media and in social policy discussion. Among the findings of the Boyd Inquiry for example were the following: that less than one homicide a month involves someone with mental health problems; that a quarter of these involved the killing of small children by depressed mothers; that three-quarters of the thirty four individuals involved were felt to be receiving the appropriate level of support and supervision by professionals involved with them; that very few had defaulted on their medication; and that only a third had a diagnosis of schizophrenia. Despite this, these findings were reported in the popular press with headlines such as 'One murder a fortnight by mentally ill' (*Daily Telegraph*, 17 August, 1994), 'Scandal of loonies freed to kill' (*Daily Star*, 18 August, 1994), and 'Free to kill', (*The Sun*, 18 August, 1994) (Crepaz-Keay, 1996).

The fact that it is the alleged dangerousness of people with mental health problems that forms the central theme of both media and government attention, rather than the scandal of under-resourcing, suggests a process of scapegoating involving the creation of a moral panic is at work, the effect of which is to divert attention away from the lack of services for people with mental health problems and which plays a role analogous to that played by other ideologies, such as racism:

Racism offers white workers the comfort of believing themselves part of the dominant group; it also provides, in times of crisis, a ready-made scapegoat, in the shape of the oppressed group (Callinicos, 1992: 21).

In similar fashion, the stigmatising of people with mental health problems as 'dangerous' by the tabloid press can provide those who do not experience such problems with a sense of superiority in belonging to the 'normal' majority, even though their lives may be empty and impoverished in other respects.

The practical expression of this stigma is twofold: at an informal level, it leads to the exclusion of people with mental health problems from employment, housing and many areas of social contact; at a social policy level, it has led in recent years to an emphasis on the need to *control* the behaviour of people with mental health problems, with such control usually involving an emphasis on the taking of powerful medication and greater compulsion in the community, rather than a focus on the factors which create or worsen mental health problems in the first place and the kind of services that could reduce mental distress.

The biomedical model of mental ill-health.

A second source of the oppression of people with mental health problems is the dominance of the biomedical model of mental ill-health. At the heart of this model is the notion that such ill-health is an 'illness', in essence no different from physical illness, the roots of which lie in biology rather than in social factors and in response to which physical treatments, in the form of drugs, ECT, or even brain surgery, constitute the first, if not the only, course of action.

The dominance of this model is a reflection of three main factors. Firstly, there is the 150-year old professional and institutional hegemony of the psychiatric profession over all matters relating to mental distress (Busfield, 1986). Different psychiatrists, of course, will vary in the role that they attribute to biological factors, and there is evidence that in general British psychiatrists are more willing to consider the role of social factors than their US counterparts (Clare, 1980; Rowe, 1993). Nevertheless, an acceptance of the *primary* role of biological factors in the aetiology of mental ill-health continues to characterise most psychiatric practice. As noted in chapter one, underpinning and reinforcing this dominance is the power of the pharmaceutical

companies. A casual glance at the advertisements in any issue of the British Journal of Psychiatry vividly illustrates the role played by these companies in framing psychiatric response to problems of mental ill-health.

A second factor contributing to the dominance of psychiatry in matters relating to mental health is the *ideological* role played by psychiatry in individualising mental distress and deflecting attention away from the role of structural factors both in the production of mental ill-health and in responses to it. The fact for example that working-class women with children are four times more likely to experience clinical depression than their middle-class counterparts is obscured by seeing depression as primarily an individual or biological problem (Brown and Harris, 1978).

Finally, there is the fact, neglected by some radical critiques of psychiatry, that in some respects at least, mental ill-health *does* resemble physical illness, both at a philosophical level (Sedgewick, 1982) and in terms of its impact on social functioning. In his study of psychiatry and political economy, for example, the Marxist psychiatrist Richard Warner, while recognising some of the limitations of psychiatric classifications, argues that

Schizophrenia, nevertheless, fulfils any criteria we might wish to establish to define an illness. It is a non-volitional and generally maladaptive condition which decreases the person's functional capacity and which may be identified by a reasonably circumscribed set of characteristic features (Warner, 1994: 4)

Given the current popularity on both sides of the Atlantic of 'Third Way' perspectives which emphasise the 'employability' of disabled citizens as a means of reducing welfare benefits and coercing individuals back into the workforce (Blair, 1998; Giddens, 1998; Ellison, 1998), the recognition that mental ill-health is often disabling and incapacitating needs to be emphasised , alongside the need to challenge the discrimination that keeps those who have experienced mental health problems out of the workforce.

That said, there is no doubt that many service users do experience the medical model as a source of oppression, something that has never been recognised by the dominant social democratic political tradition in Britain, as represented in the Labour Party, which as Goodwin has noted, has never seriously questioned the legitimacy of psychiatry. (Goodwin, 1990). The potential for oppression is linked to what Pilgrim and Rogers describe as the dominant features of modern Western psychiatry, viz., the emphasis on *diagnosis* on the one hand and *biological* explanations of mental distress on the other, along with biological treatments (Pilgrim and Rogers, 1993). Each of these aspects will be briefly considered.

i) The emphasis on diagnosis.

Psychiatry's emphasis on diagnosis has been criticised on several fronts over the past four decades. The main elements of that critique - its over-emphasis on *symptoms* of 'illness' in the absence of clear physical *signs* (Szasz, 1972); its 'medicalisation' of human distress (Laing, 1964); the doubtful scientific validity of many psychiatric classifications, including schizophrenia (Boyle, 1991) - are now so well-known as to require only a brief restatement here. In terms of the *oppression* of people with mental health problems, however, two aspects of that emphasis on diagnosis are particularly significant and merit fuller discussion.

Firstly, there is the emphasis on the *symptoms* of mental-ill health at the expense of the person's own account of his or her emotional distress, resulting in what Goffman referred to as the 'invalidation of the self' (Goffman, 1961). Such invalidation has often involved a dismissal by professionals and lay people of the thoughts, feelings and wishes of people with mental health problems:

The most frequent complaint among people who have received mental health services is that nobody listens. Traditional stereotypes combine with current ideas about mental distress, causing a situation in which mental health professionals are trained to ignore the content of what service users say (Lindow, 1995: 206).

Secondly, as well as frequently resulting in a disregard of the thoughts, wishes and feelings of the mentally distressed individual, the wider social impact of diagnosis, in the form of 'labelling' is often to exclude the individual with mental health problems from employment, housing and many areas of social activity.

Such labelling is normally a by-product of psychiatric diagnosis rather than the deliberate intention of individual psychiatrists, let alone of the profession as a whole. In 1998, for example, the Royal College of Psychiatrists actually launched a campaign entitled 'Challenging Stigma', making many of the points that have been outlined above. The fact, however, that several users groups, including the All Wales User and Survivor Network, felt moved to demonstrate *against* this campaign on the grounds of its hypocrisy, claiming that psychiatrists were responsible for creating the stigma in the first place through labelling people as mentally ill, suggests that not all users accept the profession's commitment to challenging stigma as genuine. According to a spokesperson, ' They systematically present us as dangerous nutters to justify coercive treatment' (*Community Care*, 29 October, 1998).

Clearly the stigmatisation of people with mental health problems, as 'nutters' or 'loonies' is often far more extreme amongst the general population than amongst the psychiatric profession and both the impact of this stigma, as well as its roots, will be discussed more fully below. At the same time, the labelling involved in psychiatric diagnosis is one factor which contributes, albeit inadvertently, to the stigma.

ii) Biological problems, biological solutions.

A second aspect of the medical model often experienced as oppressive by people with mental health problems is its emphasis on biological factors in both the aetiology of, and responses to, mental ill-health. Whether this takes the form of the search for the 'schizophrenic gene' on the one hand or the 'magic bullet' which act as a cure-all on the other, the effect is to downplay the role of structural factors in producing and

sustaining mental ill-health on the one hand and the possibility of holistic or political responses to mental ill-health on the other (Rose et al, 1984).

Moreover, while many people with mental health problems *do* find drug treatments helpful in relieving the symptoms of mental ill-health, there is also a substantial minority who do not. In their study of 516 recent service users, for example, Rogers, Pilgrim and Lacey found that while just over half the sample found major tranquillisers helpful or very helpful, more than a quarter described them as either harmful or very harmful (Rogers, Pilgrim and Lacey, 1993: 132). Critics have also pointed to the alleged ineffectiveness and potential harmfulness of psychiatric medication (as well as of interventions such as ECT). Pilgrim , for example, argues that

With estimates of the effectiveness of medication as low as 20% for patients diagnosed as schizophrenic (Crow et al, 1986) alongside the high probability of reported iatrogenic tardive dyskinesia (an irreversible disorder of motor control which is a frequently observed side-effect of neuroleptic medication), it seems that the majority of patients are being exposed to a damaging and ineffective intervention (Pilgrim, 1990 : 227-228 ; see also Breggin, 1993).

Despite these limitations, it is drug treatments, rather than 'talking treatments' or social treatments which are likely to be at the heart of the current government's revised 'care in the community' policy, including the possibility of their compulsory administration to those who are deemed to be a risk to themselves or the public (*Guardian*, December 9, 1998).

Exclusion from the labour market

A third aspect of the oppression of people with mental health problems is their exclusion from the labour market. A survey carried out in the mid-1980s found that, where work applicants demonstrated equal experience and training, employers

discriminated against those who 'confessed' to having had a mental health problem at some time in the past (cited in Rogers et al, 1993).

Once again, such discrimination cannot be justified solely by reference to the impact of mental ill-health on an individual's capacity to work. There is considerable evidence that given proper support, many people with histories of mental health problems are quite capable of maintaining employment. The success of the model of rehabilitation developed by the International Clubhouse movement, for example, whatever limitations it may have (Perkins, 1997), attests to the employment potential of people with mental health problems (Oliver et al, 1996). The argument that it is social, economic and political factors rather than impairment *per se* that affects the employment prospects of people with mental health problems is also supported by research evidence. On the basis of a review of the research literature on employment and mental health, Warner has argued that there is a relationship between the booms and slumps of the capitalist economy on the one hand and the employment of people with mental health problems on the other. Higher recovery rates occur during periods of economic upturn, which suggests that when there is a shortage of labour, there is a much more positive attitude towards employing former patients. Hence his definition of schizophrenia as ' an illness which is shaped, to a large extent, by political economy' (Warner, 1994: 1).

The strength of Warner's argument is that, without ignoring or downplaying the often devastating impact of mental ill-health, he sees the problems of poverty and social isolation experienced by people with mental health problems not as the inevitable consequences of mental ill-health but rather as the consequence of a particular social and economic order. In similar vein, Sedgewick argues that any strategy for mental health services

must come, above all, from the realisation that some of the most basic needs of the mentally disabled- above all, the needs for housing, for occupation and for community - are not satisfied by the market system of allocation which operates under capitalism.... The crisis of mental-health provision ...is simply

the crisis of the normal social order in relation to any of its members who lack the wage-based ticket of entry into its palace of commodities (Sedgewick, 1982: 239).

What this suggests is that while mental health problems may from time to time affect an individual's ability to maintain employment, stigmatising attitudes on the part of employers, a lack of supported employment schemes and the demands on the labour process within capitalism (which, in the form of stress, affects far larger numbers of workers than those labelled as mentally ill) are more significant factors.

A note of caution is necessary, however. Given that employers have often used a history of mental health problems as a basis for refusing employment to someone who is well-qualified to undertake a particular post, the users' movement and its supporters have understandably been keen to emphasise the *potential* of service users to undertake employment, rather than the limiting effects of their mental health problems. However, at a time when social democratic governments on both sides of the Atlantic are pursuing varieties of 'workfare' schemes as a means both of reducing their welfare bill - including spending on disability benefits - and also attacking 'welfare dependency' (Ellison, 1998), protecting the right of mentally disabled people *not* to work takes on a new significance. Rogers and her colleagues, for example, found that nine per cent of the 516 respondents in their study identified 'work stress' or some aspect of their employment as the primary factor leading to a crisis (Rogers et al, 1993: 91).

The above discussion of the impact of stigma, of the role of the biomedical model of mental health and of the effects of exclusion from the labour market strongly suggests that many of the problems experienced by people with mental health problems cannot be seen as the 'natural' consequences of poor mental health but rather are often the product of structural discrimination and oppression. I shall argue below that this oppression differs in important respects from the oppression suffered by black people and women. It is none the less real for that, however, and it is at least in part in response to this discrimination and oppression that the current mental health users'

movement has developed over the past fifteen years or so (Barnes, 1997). It is to a consideration of this movement that we shall now turn.

MENTAL HEALTH SERVICE USERS - A 'NEW SOCIAL MOVEMENT'?

While the nature of the mental health users' movement makes it difficult to estimate the actual numbers of users or former users involved, one activist has estimated that the number of user groups has grown from around a dozen in the mid-1980s to around 350 nationwide by the mid-1990s (Campbell, 1996). Not all of these groups are campaigning groups. In her account of the movement, for example, Lindow classifies them as *reactive* (advocacy projects, campaigning organisations), *alternative* (crisis centres, user-controlled projects) and *creative* (including Hearing Voices groups or Survivors' Poetry) (Lindow, 1995). What is likely to characterise all, or most of them, however is the active involvement of users or former users in activities which to some degree challenge dominant, negative stereotypes of people with mental health problems.

This involvement of users or former users is one feature which distinguishes the current movement from earlier mental health movements, such as the anti-psychiatry movement of the late 1960s and early 1970s, based on the ideas and activities of R.D. Laing. As Kotowicz has noted, while Laing and his colleagues in the 1960s may have given people with schizophrenia a 'voice', British anti-psychiatry (in contrast to radical mental health movements elsewhere, such as Italy) was based very much on a small number of radical psychiatrists and other professionals, with little if any involvement by patients themselves (with the Mental Health Patients' Union , for example, not being set up until 1973) (Kotowicz, 1997).

As noted in the introduction to this chapter, the involvement of numbers of users in challenging the discrimination and oppression experienced by users is also a factor which has led some academic writers who are sympathetic to the movement to conceptualise it as a 'new social movement', similar to the gay movement or the women's movement. Pilgrim and Rogers for example have argued that

...user dissatisfaction has now reached a point that, in terms of numbers and organisations, it constitutes a nascent 'new social movement'. Social movements can be defined as certain groups engaged in informal efforts in order to promote their interests in opposition to dominant forms of power and organisation preferred by the State (Toch, 1965). 'New' social movements can be distinguished conceptually from 'old' social movements in that they are further removed from the arena of production than the latter. Additionally, rather than seeking to defend existing social and property rights from erosion by the state, they seek to establish new agendas and conquer new territory (Pilgrim and Rogers, 1993).

In similar vein, on the basis of research into users' groups in England, Barnes and Shardlow have argued that

A potentially useful sociological perspective which we are starting to apply in the context of the research on which this article is based is that of new social movement theory...Disability theorists (e.g. Oliver, 1990; Shakespeare, 1993) have applied NSM theory to disabled people's movements, but with the exception of Rogers and Pilgrim (1991), there has been little use of this body of work in relation to the mental health user movement (Barnes and Shardlow, 1996: 130).

Insofar as describing mental health users as a social movement refers to the development of *collective* organisation amongst users and to their involvement in activities which to some degree at least are *oppositional* in nature, the term seems appropriate and unobjectionable. One leading social movement theorist, for example, has argued that

The proper analogy for a social movement is neither a party nor a union but a political campaign. What we call a social movement consists in a series of demands or challenges to power-holders in the name of a social category that lacks an established political position (Tilly, cited in Foweraker, 1995).

The extent to which users can and do challenge power-holders will be considered more fully below. The characterisation, however, by Pilgrim and Rogers on the one hand and Barnes and Shardlow on the other, of the users' movement as a *new* social movement has a different, more contentious meaning.

Firstly, it implies a preoccupation with issues of *identity*, which Foweraker identifies as the defining feature of new social movement theory (Foweraker, 1995). Secondly, it suggests a focus on *cultural* or *ideological* issues rather than material issues. Thirdly, it implies that *class-based* politics have limited relevance in challenging the discrimination and oppression experienced by users. The rest of this chapter will explore the extent to which these ideas are helpful in describing and analysing the users' movement on the one hand and in providing a theoretical and strategic basis for that movement's development on the other.

A shared identity?

In respect of identity, there is little doubt that personal experience, rather than an altruistic concern with the issue of mental ill-health, is the most common reason for people becoming involved in the mental health users' movement. Barnes and Shardlow, for example, note that

Our research suggests that the factors which provide the strongest motivation to participate in mental health user groups are the shared experiences of distress and of being a recipient of mental health services - of being a 'patient' (Barnes and Shardlow, 1996: 130).

Similarly, the single most important feature of the MHUM identified by Rogers and Pilgrim and described by them as 'the identifying characteristic of the users' movement in Britain' was an emphasis on the *experience* of being a psychiatric patient and the need for that experience to be recognised and validated. This finding is reinforced both by the subsequent (and much more extensive research) conducted by

Rogers, Pilgrim and Lacey (1993) as well as by the writings of users such as Sassoon and Lindow, who emphasise 'the validation of the user's view' (Sassoon and Lindow, 1995).

Two points can be made about personal experience as a basis for involvement. On the one hand, given the stigma and social isolation experienced by people with mental health problems, the existence of a movement or at least of groups of other people who have been through similar experiences and who are able to recognise and validate each other's experience can be an enormously importance source of confidence and social support. As one user respondent in the present study commented , referring to the role of the drop-in centre in which he was involved

Of course, other people's attitudes to mental health, that's responsible for a lot of the loneliness of members you know , that's why places like this are set up ...it's a refuge for people. They come here, they know this place is open and it's a kind of insurance for them so whether they come in or no, they know the place is open to 9 o'clock at night so if they get into any trouble they know they can come here come in the door and there's a friendly face here for them and that's really what we're about.

What this suggests, however, is that the emphasis on a common user identity identified by Barnes and others, rather than being something which is fixed or static, may vary according to the extent to which service users feel accepted or rejected in the world outside. In this connection, there is evidence, despite the continuing stigmatisation of people with mental health problems, that attitudes have changed in recent years. A review of the SAMH study on attitudes to mental health mentioned above noted , for example, that

one surprising and reassuring fact to emerge is the level of awareness that exists. Virtually all respondents (98%) recognise that 'anyone can suffer from mental health problems' while a similar proportion (96%) agree that you should not use terms like 'loony' or 'nutter'. Over three quarters of the survey group

expressed a willingness to work alongside someone with mental health problems (*The Herald*, 5/10/98).

A second point on the issue of identity is that while experience often provides an initial basis for involvement, by itself it does not lead to the development of a strategy for challenging oppression, a point also noted by Pilgrim and Rogers on the one hand (1991) and Barnes and Shardlow (1996) on the other. In part, this is because experience is necessarily subjective, in part because not all users share the same experience, any more than physically impaired people do. Class differences, for example, are likely to result in very different experiences for different users. Challenging the notion that all disabled people share a common identity, for example, Stack, in discussing the disability movement from a Marxist perspective, has argued that

As with all movements of the oppressed, there is a class basis to it. If Rupert Murdoch had a disabled child, that child would face very few obstacles in its life compared not just to me or working class disabled people but to most able bodied people. Much of the oppression and discrimination people face is based in the workplace (Stack, 1995:15).

Class is also a major division amongst mental health service users. Not only do the politicians, businesspeople and celebrities who pay £3, 000 a week to have their mental health problems treated at the private Priory group of hospitals, for example, enjoy forms of care and treatment beyond the wildest dreams of most people who become mentally unwell but they are also unlikely to experience the day to day concerns and worries of having to survive on benefits or of struggling to access either acute psychiatric services or patchy and under-resourced community-based services which is the fate of most service users. Nor is there much evidence that it has a profound or lasting effects on lifestyle or career prospects, in contrast to the kind of employment discrimination experienced by poorer service users discussed above (Observer, 10/1/99)

Yet while there has been a growing recognition within the literature in recent years of the relationship between mental ill-health and 'race' on the one hand (Fernando, 1996) and mental ill-health and women's oppression on the other (Busfield, 1996), the profound impact of class differences at every stage of the process of mental ill-health has often been neglected, even in the more radical literature. Thus, for example, as Sedgewick noted, *Social Class and Mental Illness*, the pioneering work by Hollingshead and Redlich published in the late 1950s which looked at the ways in which a person's social class affected the kind of psychiatric treatment they received, was completely ignored by all the major anti-psychiatric writers (Sedgewick, 1982: 278). As a recent survey of the research literature has demonstrated, however, far from all people with mental health problems sharing a common experience, almost every aspect of mental ill-health from its inception to its treatment is coloured by class (Henderson et al, 1998). Thus, schizophrenia is diagnosed five times more often in low socio-economic status compared with high socio-economic status adolescents - in other words, before 'social drift' may have occurred; in respect of unemployment, a 1993 study found that the unemployment rate is the most effective predictor of psychiatric admission; while in respect of depression, as noted above, an important finding of the classic study by Brown and Harris (1978) was that working-class women with children were four times more likely to experience depression than their middle-class counterparts (Henderson et al, 1998).

To stress the importance of class and other structural factors such as 'race' and gender, is not, of course, to deny the possibility that biological factors may play a predisposing role in the development of certain psychotic conditions, as Warner argues, let alone in organic conditions such as epilepsy or Alzheimers (Warner, 1994). Nor is to ignore the obvious fact that poor mental ill-health affects individuals from all classes. It does mean however that not only are poor and working-class people more likely to suffer from mental ill-health but that the implications of being mentally ill are much more severe. The centrality of *material* issues for most service users was one of the major conclusions of the study of 516 service users carried out by Roger, Pilgrim and Lacey:

If users' views reported in this book were replicated and implemented at the level of policy, then the current emphasis on physical 'treatments' would be drastically reduced. It would be replaced by two types of professional activity: the first would be in terms of being listened to and responded to empathetically...the second would be in terms of the recognition of the centrality of social needs...Given that recovery from mental health problems is a function of social opportunities, particularly as regards accommodation and employment, policy-makers might place housing and income maintenance at the centre of their thoughts (Rogers et al, 1993: 183-4).

A politics of identity?

It is clear then, not least from the research of Rogers et al, that material issues *do* loom large in the lives of the majority of service users. Similarly, Barnes and Shardlow acknowledge the significance of structural factors, including class, in shaping the experience of service users. At the same time, on the basis of their research, they argue that mental health service users

have not developed a strategic approach to addressing the structural and legal factors which do, in practice, mean that the position of people with mental health problems as citizens is affected (Barnes and Shardlow, 1996: 131).

It is that failure to address structural issues on the one hand and their finding that there was little evidence of the groups in their study allying themselves with class based movements on the other, that leads them to conclude that such groups

may perhaps be better understood as examples of 'new social movements' whose objectives are cultural and ideological rather than structural and material (Barnes and Shardlow, 1996:127).

In respect of challenging structural oppression, a core tenet of new social movement theory, reinforced by the assumptions of postmodernism and poststructuralism, is that not only do all members of an oppressed group share a common interest and identity which overrides all other divisions but also that the primary responsibility for challenging that oppression lies with the members of that group. As Smith has argued in a critique of 'new social movement' analyses

Key to this strategy for social change, which has been carried to its logical extreme more recently through the development of 'identity politics', is the idea that only those experiencing a particular form of oppression can either define it or fight against it (Smith, 1994: 3).

In an example of such identity politics, Mike Oliver, a leading disability theorist and activist has argued that ' If we are going to transform ourselves and society, it is only we as disabled people who can do the necessary intellectual work' and has criticised a range of disabled political activists from the Italian Marxist Antonio Gramsci to New Labour's Education Secretary David Blunkett for failing to 'embrace their impairments as part of a politics of personal identity' - in Gramsci's case at least, for seeing class, rather than disability, as the central divide within capitalism (Oliver, 1996: 14).

Oliver's characterisation of the disability movement as a new social movement has been challenged by other disability activists (Shakespeare, 1993; Stack, 1995). The characterisation of the mental health users' movement in this way is , if anything, even more questionable.

Firstly, while people with mental health problems do experience oppression in many aspects of their lives, their oppression differs in important respects from that experienced by, say, women or blacks. Historically, both women's oppression and the oppression of black people have been central to the functioning of capitalism in a way that the oppression of people with mental health problems has not. Women's oppression, for example, is rooted in the capitalist family and in the way in which women can serve as a cheaper section of the workforce (German, 1989). Racism has

its roots in the experience of colonialism and slavery and in the way in which it can be still used by the ruling class as a tool to 'divide and rule' workers (Callinicos, 1993). By contrast, the relatively small number of people who experience severe mental health problems such as schizophrenia and manic depression (as opposed to painful but often less incapacitating conditions such as anxiety or depression) as well as the often hidden and transient nature of such problems means that the oppression they experience is much less systematic than that experienced by blacks and women and, from the point of view of the ruling class, much less significant as a tool to 'divide and rule'.

Secondly, while there has been a growth in user self-organisation and confidence over the past decade, there are a number of factors which are likely to limit that growth. The basis for any movement of oppressed people is a willingness on the part of individuals who belong to that group to stand up and challenge existing portrayals of that group - to 'come out', in the language of the gay movement. Yet, as Barnes and Shardlow note, the difficulties of doing so for people with mental health problems may be of a qualitatively different order:

making one's identity as a user of services visible may not be easy because of the stigma attached to such a status. In the case of people whose shared identity centres around their use of mental health services there are particular problems associated not only with the status of service user, but with the fear of madness (Barnes and Shardlow, 1996: 115).

The disincentives for people with mental health problems to 'come out' as part of a users' movement are considerable and include the implications for employment, housing and social relationships discussed earlier. While it may be possible for those who are in particular occupations or who are employed within voluntary organisations in the mental health field to do so, in general, even within the so-called 'caring professions' such as statutory social work, an admission of a mental health problem is likely to lead to the individual being treated with suspicion (Community Care, 17 September, 1998). Given that the majority of people with mental health problems are likely to be poor or working-class, the attractions of being a movement activist are

likely to be limited. The comments of one writer regarding the difficulties of 'coming-out' for working-class gays and lesbians seem apposite:

Obviously in a society where normalised heterosexuality and the family are pushed as the only valid expression of sexuality, individual 'coming out' is more or less the only way to reject dominant values and live as an out gay person. However, the vast majority of working-class people who experience lesbian or gay feelings cannot go through this individualised process because they do not have the necessary levels of independence, support and confidence to do so (Field, 1995:37-38).

There is another parallel with the position of gays, which may inhibit involvement in a users' movement. While sexism, racism and disablism are usually forms of oppression based upon visible, physical characteristics, many mental health problems, such as depression or eating disorders or milder forms of schizophrenia can be concealed or controlled through medication. Given the high costs of 'coming out', many may prefer to keep their mental health problems hidden - especially since, again unlike these other forms of oppression, they may be intermittent in nature.

A fourth issue is the impact of mental health problems in themselves and the implications of these problems for sustaining and developing collective organisation. As one activist within the main Scottish users' organisation, Scottish Users Network, put it in this study:

We face all the usual pressures that apply to any organisation but with an extra layer - our own mental health problems. The pressures mean that feelings can be more difficult to handle - that can create instability.

Further, as the earlier discussions on terminology and identity indicate, 'claiming' a mental health identity may not be the same as claiming a gay or a black identity. For many people, having a mental health problem is likely to be something they want to leave behind: while the spirit of 'glad to be mad' is a proud and defiant retort to the

ignorance of stigma and discrimination, there is little evidence that most users of mental health services would, given a choice, opt to have mental health problems.

Finally, some of the dilemmas inherent in the notion of a shared mental health identity were highlighted by a report in *Community Care* magazine of a demonstration in the autumn of 1998 by several users organisations, including the All Wales User and Survivor Network, against the Royal College of Psychiatrists' launch of a 'Challenging Stigma' campaign (*Community Care*, 29 October, 1998). With justification, one might argue, these groups were criticising what they saw as the hypocrisy of the RCP campaign on the basis that both individual psychiatrists and psychiatry as a profession had played a major role in both creating and sustaining this stigma over the decades. What was potentially problematic about this demonstration, however, was that, as the photograph accompanying the report showed, it took place beneath a statue of Sir Winston Churchill, the rationale being that as Churchill himself was a well-known sufferer from depression, he therefore shared a common interest with these service users. Leaving aside Churchill's well-documented attitude towards oppressed groups in general (including *inter alia* his ministerial involvement in the shooting down of striking Welsh miners in 1911 and his public admiration throughout the 1930s for Mussolini's fascists), as Ponting has revealed in his biography of Churchill, he was also throughout his life a convinced eugenicist who, while a member of the 1906-14 Liberal government, went so far as to advocate the compulsory sterilisation of 100,000 of the 'mentally enfeebled' and the herding of many more into concentration camps as a basis for protecting the purity of the British 'race' (Ponting, 1994). While the example may be an extreme one, it does make the point that class interests will often be a far more compelling basis for a shared identity than characteristics such as mental ill-health or physical impairment.

Challenging structural oppression

The fact that identity politics may have limited relevance for mental health service users does not mean that such users are therefore incapable of successfully challenging the structural oppression which they experience. On the contrary, there may be

alternative explanations for the failure of these groups identified by Pilgrim and Rogers on the one hand and Barnes and Shardlow on the other to address the structural issues which, by common consent, play a major role in shaping the experience of many service users. It is possible, for example, that this failure is a *contingent* rather than an essential feature of the users' movement, perhaps linked to the lack of confidence or political experience of group members: debating the most 'user-friendly' term for people with mental health problems may seem a less daunting option than struggling to defend community-based services in the face of local authority cutbacks.

Similarly, the failure of mental health users' groups to ally themselves with class based movements may be partly explained by the extremely low level of trade union struggle in Britain in recent years; the involvement of the gay movement during the 1984-85 miners' strike in Britain suggests that when the level of struggle rises, the importance of such links may be more obvious (Field, 1995; Pagel, 1988).

A major aim of the current thesis will be to explore these and other factors as part of a wider evaluation of the nature and extent of the challenge posed by what I have described as 'user involvement from below', as will the capacity of 'new social movement' theory to make sense of that challenge. This will involve an exploration of issues of language and identity in chapter six; issues of user involvement in mental health services in chapters seven to nine; and the potential of users to *collectively* challenge structural oppression in chapter ten. Before then, however, it is necessary to outline and discuss the methodological issues underpinning this thesis as well as providing a description of the individuals, groups and projects who participated in it. These issues will form the subject matter of chapters four and five.

Methodology: paradigms and process.

In exploring the potential and limits of mental health service user involvement, three overarching operational questions were of particular significance. These were:

- What role can users of mental health services play in the planning, provision and management of community-based mental health services ?
- What implications might such user involvement have for professional workers and professional-led services ?
- To what extent do mental health users in Scotland constitute a 'new social movement'?

Answering these questions is not, of course, a simple technical matter of data collection and analysis but rather involves issues of epistemology, ontology and methodology (what are sometimes referred to as *paradigm* issues, following Kuhn, 1962). It also involves ethical issues and issues of methodology in the narrower sense of process, method and technique. The first part of this chapter will explore each of these areas in relation to the current thesis while the second part will consider the ways in which such philosophical, ethical and methodological issues were addressed at each stage of the research process.

PARADIGM ISSUES

Crabtree and Miller's discussion of the role of paradigms in relation to research methods provides a useful starting point for exploring the first of the above issues (Crabtree and Miller, 1992). They define a paradigm as follows:

A paradigm represents a patterned set of assumptions concerning reality (ontology), knowledge of that reality (epistemology) and the particular ways of knowing about that reality (methodology) (Guba, 1990). These assumptions and the ways for knowing are untested givens and determine how one engages and comes to understand the world. Each investigator must decide what assumptions are acceptable and appropriate for the topic of interest and then use methods with the selected paradigm (Crabtree and Miller, 1992: 8).

Following Habermas, they go on to suggest that at least three research paradigms exist:

- i) *Materialistic enquiry*. This paradigm, they suggest, is most commonly represented by positivism and the biomedical model. It tends to be associated with the use of quantitative methods. For Crabtree and Miller, the materialist inquirer values progress, stresses the primacy of method, seeks an ultimate truth of reality. 'The materialist inquirer climbs a linear ladder to an ultimate objective truth' (Ibid:10).
- ii) *Constructivism*. By contrast, the constructivist paradigm, also known as *naturalistic enquiry* or *hermeneutics*, is employed where human constructions, such as cultural life, are under investigation. This knowledge is usually supplied through qualitative methods. In the constructivist paradigm, 'no ultimate truth exists; context-bound constructions are all part of the larger universe of stories' (Ibid.). Postmodernist approaches to research, as well as some feminist approaches, are the most important current examples of this paradigm.
- iii) *Critical/ecological enquiry*. The third paradigm referred to by Crabtree and Miller derives from the work of the ecological theorist Gregory Bateson and focuses on issues of domination, the distribution of power and associated inequalities. The critical/ecological enquirer, they suggest 'seeks to move from the false consciousness of present experience and ideology to a more empowered and emancipated consciousness by reducing the illusions through the process of historical review and the juxtapositioning of materialistic and interpretive inquiry' (Ibid.: 11-12) Its use, they suggest, is most appropriate for political engagement and the study of systems.

Crabtree and Miller's outline of these three paradigms is not without its flaws. Their rather crude equation of positivism with materialism, for example, is one that many contemporary Marxists would reject (see e.g. Rees, 1998). Similarly the suggestion that particular paradigms are associated with particular approaches, although popular with both feminist and postmodernist researchers, is an unhelpful one. As Silverman has argued

The polarities around which the qualitative/quantitative distinction have been based need (to use the fashionable term) to be deconstructed. Why should we assume, for instance, that we have to choose between qualitative and quantitative methods? Why can we focus only on 'meanings' but not 'structure' or on 'micro' but not 'macro' processes? Why should case study researchers assume that there is something intrinsically purer in 'naturally occurring data' (Silverman, 1993: 23)

That said, Crabtree and Miller's outline does give a fair representation of the major competing frameworks within contemporary social theory. Of the three paradigms, it is the third - the critical/ecological paradigm - which most closely resembles the approach adopted in this thesis, both in its emphasis on a critical approach to the subject under investigation - not least, the deconstruction of *experience* - and in its location of user involvement within wider frameworks of oppression and domination. In other words, in contrast to postmodernist approaches which simply *present* consumer views, the views of users and professionals will be critically analysed on the basis of the literature review and of a broadly Marxist understanding of oppression.

Such ecological or systems approaches also have their weaknesses, however. Firstly, their emphasis on equilibrium make them compatible with thoroughly conservative views of society which reinforce, rather than challenge, relations of oppression and domination (as in the works of Talcott Parsons, for example - for a critique of Parsons, see Mills, 1959). Secondly, their failure to acknowledge or explain power differentials between different systems at best can lead to a vague pluralism, at worst to victim-blaming (a central point in the feminist critique of systemic family therapy).

Thirdly, there is a timeless, abstract quality to much systems thinking which often makes it incapable of grasping the processes of concrete historical change. Finally, it lacks an ontology and from that perspective, is vulnerable to postmodern relativism in which no discourse has any more validity than any other. If therefore, the reality of users' experience is to be fully captured and explained, a critical/ecological paradigm by itself is insufficient. In this thesis, two other concepts - *totality* and *realism* - will be employed throughout (though usually implicitly rather than explicitly) to provide the additional theoretical underpinning:

Totality.

A central argument running throughout the thesis and already explicit in chapters one to three is that the phenomenon of mental health user involvement cannot be understood in isolation but needs to be located within a wider political, social and economic context which is shaped by a range of competing forces, interests and agendas. Such a perspective relies on the notion of the world (or more specifically, capitalist society) as a totality, developed by the Hungarian Marxist George Lukacs. Rees summarises Lukacs's concept as follows:

Totality refers to the insistence that the various seemingly separate elements of which the world is composed are in fact related to one another. ...Poverty and crime, unemployment and suicide, art and business, language and history, engineering and sociology cannot be understood in isolation, but only as part of a totality. Moreover, once we bring these terms into relation with each other, their meaning is transformed....In a dialectical system, the entire nature of the part is determined by its relationships with the other parts and so with the whole. The part makes the whole and the whole makes the parts (Rees, 1998: 5).

The concept of totality has sometimes gained rather a bad name, in part as a result of its treatment at the hands of vulgar Marxists to suggest that elements of culture or social life are simply 'reducible' to an economic base. In fact , as Rees continues,

One important point to note about this approach is that it is, by its very nature, opposed to reductionism. It does not abolish the role of the individual in favour of the whole, the collective or any other such abstraction. [On the contrary]...a dialectical approach is radically opposed to any form of reductionism because it presupposes the part and the whole are not mutually reducible to each other. The parts and the whole mutually condition, or *mediate*, each other. And a mediated totality cannot form part of a reductionist philosophy because by definition, reductionism collapses one element of a totality into another without taking account of its specific characteristics (Ibid.)

So, for example, while economic trends in the 1980s may have led to the increasing withdrawal of the State from the provision of social welfare in favour of market forces, and while such trends were a key element in the shift towards consumerism in health and social services, to suggest that mental health user involvement can be 'reduced to' or is simply a 'reflection' of these trends, does damage to a complex and many-faceted process of change, which requires a detailed analysis of the sort that I have tried to provide in chapter one.

This approach stands in direct opposition to currently popular postmodernist approaches, in two main respects: i) in its assertion that the world can be understood as a totality. Postmodernism's starting point by contrast is its 'incredulity towards grand narratives', and its insistence that only 'local narratives' are possible, that user involvement, for example can only be understood in its own terms ii) in its rejection of the notion, central to postmodernism, that all discourses are equally valid. Some social work writers sympathetic to postmodernism often tend to assume that this view will lead to greater tolerance of difference and diversity. For Howe, for example,

If there are no universal truths, then difference should not only be tolerated, it should also be celebrated as a reflection of the polymorphous, non-unitary and non-consensual nature of much of the social world (Howe. 1994).

In fact, the implications of there being 'no privileged discourse' for oppressed groups seem much less sanguine and it is not at all clear why the absence of 'universal truths' should be celebrated, as Howe suggests. For if all discourses are equally valid, then presumably there is no basis for distinguishing between the accounts of the black victim and his racist attacker, of the abused wife and her abusing partner, or, in respect of the current thesis, of a mental health users' movement and a biomedical psychiatry. A core assumption in the thesis, therefore, is that not only do agendas or discourses differ both in power and influence, depending in part on the interests they represent, but also in their capacity to empower, with some agendas tending to actively *disempower* service users. To use once the example referred to above but this time with a different emphasis, considered in isolation, the involvement of service users in the management of mental health services appears to be unequivocally 'a good thing', a mechanism for empowerment; however, in a context where the government and the State, influenced by free-market ideologies, are seeking to withdraw from the provision of social welfare, 'user-led' services may sometimes be little more than a crude euphemism for the dumping of services onto people with mental health problems.

Realism.

The second assumption underpinning this thesis concerns the nature of knowledge. A variety of factors, both social and ideological, have contributed over the past two decades to the now widely accepted view (amongst social theorists at least) that our knowledge of the world is neither objective, universal or absolute but is subjective, fragmented and relative. Chief among the ideological roots of this perspective are Foucault's view that the will to truth is merely a form of the will to power; the postmodern view that no discourse is more valid than any other; and the growth of an identity politics which insists that only those who experience a particular form of oppression can have real knowledge of it. As an example of the latter, Oliver has

argued that only disabled people are capable of producing theoretical knowledge which can assist in the struggle against their oppression:

If we are going to transform ourselves and society, it is only we as disabled people who can do the necessary intellectual work (Oliver, 1996:5).

This is not a view which will be adopted in this thesis. It is undoubtedly the case that ideas of every sort - from natural science, social science, philosophy and so on - have often been used to justify oppression. One need only think of the use of eugenics theory to justify the extermination of disabled and mentally ill people in the Nazi concentration camps or more recently the role of genetic theory to 'explain' differences in educational attainment between blacks and whites in the USA (Murray, 1995) to recognise the myriad ways in which supposedly 'scientific' knowledge has contributed to oppression. But to proceed from the fact that ideologies have often been used in an oppressive fashion to the assertion that *any* knowledge produced by those not experiencing a particular oppression is *ipso facto* flawed is both profoundly pessimistic in denying the possibility of human empathy, and also implies a unanimity of view and a shared experience amongst the oppressed which is clearly lacking. Rogers and Pilgrim's early study of the British mental health users' movement shows that far from there being such unanimity amongst users' groups, there was a wide range of different perspectives. The same is true of writings from within the disability movement (e.g. Barton, 1996). In terms of shared experience, for example, the late Princess Diana was both a lone parent and a person with mental health problems but since the implications of these roles for her, as well as most other aspects of her life and day to day experience, were so different from that of the majority of members of both of these groups, it would be difficult to argue that she shared a common identity with them.

In this thesis, by contrast, the underpinning philosophy will be *realism* - the view that 'social phenomena exist not only in the mind but also in the objective world - and that there are some lawful and reasonably stable relationships to be found among them' (Miles and Huberman, 1994: 4). This assumes that while the choice of research approaches and methodologies will depend on the area being explored, with

quantitative approaches best suited to some areas and qualitative approaches to others, nevertheless the aim of research is to produce 'true' statements about the area under investigation. To some extent, this approach goes against the grain of much contemporary social work and social policy research where as Oakley has noted

Qualitative methods are seen to be more suited to the exploration of individual experiences - the representation of subjectivity within academic discourse and to facilitate (in practice if not in theory) a non-hierarchical organisation of the research process...conversely, quantitative methods ...are cited as instituting the hegemony of the researcher and as reducing personal experience to the anonymity of mere numbers (Oakley, 1989).

In fact, as Oakley herself demonstrates in her use of quantitative methods, there is no basis for the notion that one methodological approach is inherently more radical or emancipatory than another. Qualitative methods are quite capable of being used in an exploitative and manipulative fashion while quantitative methods can produce radical, or even revolutionary, research. As an example of the former, one need only consider the way in which focus groups, a qualitative method *par excellence* are increasingly used by both government and big business as a tool for manipulating public opinion and consumer demand. By contrast, the use of quantitative methods in the Black Report in the 1980s to expose health inequalities or, a century earlier, by Marx in his study of factory conditions in 19th century Britain, shows that quantitative approaches can produce research findings which have potentially subversive implications. In general, then, this thesis will follow Rogers and Pilgrim in seeing *outcome* rather than *process* as the defining feature of emancipatory research. Their approach, they claim,

was consistent with a critical and emancipatory research framework in which those subordinated to dominant interests are given a voice...In line with such a framework, we were concerned to use knowledge to encourage social change and not merely to document some aspect of social reality (Rogers and Pilgrim, 1995).

That said, there is clearly considerable potential for oppressive practice within the *process* of research (as well as much evidence of actual oppression), notably in the relationship between researcher and researched. A minimum aim of the current research, therefore was not to *disempower* participants who had already had sufficient experience in their lives of feeling disempowered by both mental health professionals and, in some cases, by researchers; more positively, where possible, one aim of the research was to actively *empower* participants, both individually and collectively. The specific ways in which this was done will be outlined in the account of the research process below.

Finally, the realist worldview outlined above suggests that within qualitative as within quantitative research, issues of the validity and reliability of the findings are important. While this may seem to be stating the obvious, in fact, researchers working within particular feminist or postmodernist methodologies often see a concern with such issues as inappropriate. Two feminist researchers, Stanley and Wise, for example, describe 'objectivity' as

an excuse for a power relationship every bit as obscene as the power relationship that leads women to be sexually assaulted, murdered and otherwise treated as mere objects. The assault on our minds, the removal from existence of our experiences as valid and true, is every bit as questionable (1983: 169).

While accepting that there are numerous instances of researchers oppressing or exploiting their research 'subjects', consciously or otherwise, (Davidson and Layder, 1994), there are two major problem with seeing the 'experience' of women or other oppressed groups as a hallowed given which cannot be subjected to critical analysis, in the way that Stanley and Wise imply. Firstly, by definition, experience is subjective and everyone's experience is different. One person's experience of schizophrenia for example may be very different from another's, depending on such factors as their previous personal history, age, class and the resources available to them. Secondly, 'experience' is not simply what happens to people but how they make sense of what has happened to them

(Everitt et al, 1994). Some women, for example, may make sense of their experience of domestic violence by concluding that men have a right to treat women in this way, as some service users may rationalise their experience through a belief that 'the psychiatrist always knows best'. Rather than seeing such 'discourses' however, as equivalent to those which challenge male or psychiatric oppression, it is necessary to look at where such interpretations come from, and why some interpretations seem more persuasive at some times than at others. Underpinning this approach is the view that thoughts, ideas and feelings do not exist or develop in a vacuum but are linked in complex ways to social and economic structures and processes. In the words of the Italian Marxist Antonio Labriola (1966: 108) 'Ideas do not fall from heaven and nothing comes to us in a dream'.

In terms of the methodology to be adopted in this thesis, this will involve the pursuit of what Hammersley has called ' a subtle form of realism' based on the following three elements:

1. Validity is identified with confidence in our knowledge but not certainty.
2. Reality is assumed to be independent of the claims that researchers make about it.
3. Reality is always viewed through particular perspectives; hence our accounts *represent* reality, they do *not* reproduce it (Hammersley, 1992: 50-51).

More generally, it means that the views of service user and worker respondents will not simply be *presented*, but will be subjected to a critical analysis in the way suggested above.

THE RESEARCH PROCESS: AN OUTLINE.

In this section, I shall draw on Arber's outline of the research process (Arber, 1993) as a framework for exploring the issues - practical, theoretical, ethical, methodological - which arose at each stage of this research.

Conceptualising the issues.

Two processes in particular were important in conceptualising the issues which would form the basis of the research. On the one hand, the literature review undertaken during 1995-96 and the discussion within supervision of issues arising from that literature review; on the other, the pilot study involving members of Renfrewshire Association for Mental Health, undertaken during the month of October, 1996. The main focus of this section will be on issues arising from the pilot study but since these issues also formed the basis of much discussion within supervision, reference will be made to these discussions where appropriate.

At the time when the pilot study was carried out, Renfrewshire Association for Mental Health (RAMH) was a small voluntary organisation providing a range of services for people with mental health problems and their carers in designated areas of Paisley (it has since grown considerably). Although not 'user-led' in the sense that users formed a majority on the Executive, there was at least one service user on the Executive and there did appear to be a genuine attempt on the part of staff and management to increase the level of involvement, through the organisation of a specific working party on user involvement, for example and the setting up of a users' committee. Access to potential respondents was eased by the fact that I had been a member of the RAMH Executive for two years, had been involved in RAMH workshops on user involvement, and therefore knew staff, as well as several service users, fairly well. It was also geographically convenient to Paisley University. For all these reasons, it seemed a suitable project to act as a pilot for the study.

As a result of a poster being placed in the day centre area of the Association's offices, a meeting took place involving myself and eight service users, all of whom agreed to participate in a group discussion around issues facing people with mental health problems and the idea of a users' movement, while four of the eight also consented to be involved in individual interviews focusing on their experience of, and attitudes towards, user involvement in mental health services.

Factors influencing choice of research tools will be discussed more fully below, but at this stage a semi-structured interview schedule for the individual interviews and an interview schedule for the group interview seemed the most appropriate mechanisms for exploring issues such as the feelings, ideas and experiences of service users in relation to user involvement - issues which were essentially qualitative but about which a substantial literature already existed, therefore lessening the need for a more open, unstructured, exploratory approach.

The focus of the individual interviews was on exploring the extent to which service users had been involved in decision-making processes within both medical services and RAMH, while the group interview concentrated on problems of living faced by service users living in the community and on the extent to which a mental health users' movement might offer a way for addressing or challenging these problems (Appendices A and B).

Issues arising from the pilot study.

The pilot study raised issues of both content and process. The major content issue (which emerged through discussion in supervision) was that part one of the individual questionnaire which addressed the experience of involvement in traditional psychiatric services was producing responses which, while intrinsically interesting, were often not relevant to the topic under investigation, viz., the limits and potential of user involvement. This created two potential problems. On the one hand, much of the material being produced in response to questions in this section was already fairly well known (such as the limits of the medical model, side effects of medication, etc.). On the other, there was a danger of the research being skewed away from an *exploratory* focus towards a *comparative* focus on user involvement in traditional medical v. community based services. Consequently, this section was dropped from the revised individual questionnaire. Otherwise, the questions in both the individual and group interviews seemed mainly clear and relevant.

A second content issue was the *length* of both the individual and the group interviews. Some respondents complained that the interviews (of approximately an hour's duration) were placing too many demands on their concentration, especially where respondents were on medication. In the revised version, therefore, the number of questions was reduced (Appendix C).

In addition to these content issues, three major ethical issues arose at this stage of the research.

i) Researcher self-disclosure. Given that a central focus of the research was the ways in which stigma can be challenged and, flowing from that, the need to break down barriers between service users and professionals, the question of whether and how any mental health problems experienced by myself as researcher should be referred to seemed an appropriate issue to address. On the one hand, as the first section of this chapter made clear, the philosophical stance adopted in this thesis involves a rejection of the view that only those experiencing a particular problem or form of oppression can understand or empathise with others experiencing that oppression. On the other, the dangers of self-disclosure between worker and service user, not least in terms of shifting the focus of attention away from the user to the worker, are often emphasised in the social work literature (see e.g. Lishman, 1995). In the event, however, I felt it appropriate to make reference to a period of poor mental health some years previously. Having done this verbally (and, with hindsight, unsatisfactorily) during the pilot study, I thereafter made reference to this in the introductory letter sent out to projects and focus groups (Appendix E).

ii) Mental health of workers. As well as interviewing RAMH service users individually and in a group, interviews were also arranged with two RAMH staff with a view to exploring their perspectives on the limits and potential of user involvement. In the event, only one of these interviews took place, which meant that the worker interview schedule had to be piloted on two workers from another organisation (Glasgow Association for Mental Health). Reflecting current debates about the importance of workers in mental health projects being service users or former service users themselves, one question within the schedule was 'How important is it that workers themselves have personal experience of mental health problems?'. Initially, it

had been my intention to follow this up with a probe concerning whether or not that worker was or had been a service user. It quickly became clear during the pilot interviews, however, that it would be quite unethical for a researcher to 'out' workers in this manner (in contrast to user respondents who had agreed to be interviewed on the basis of being users) Consequently in the revised interview schedule, if workers wished to volunteer such information, the opportunity was provided for them to do so but equally they were free not to do so, should they so chose (a point noted and commented on favourably by a worker in one project who felt that it indicated respect) (Appendix D).

iii) Exploitation of service users by researchers. An opportunity was provided for RAMH service users to evaluate both the process and the content of the individual and group interviews through a small questionnaire and a plenary discussion. In general, feedback was favourable. One experienced local activist, however, made the point that she had frequently participated in consultations carried out by statutory bodies such as health or social work, had given of her time and experience, and had often heard nothing more regarding the results of that research. She therefore questioned the value of involvement in this project. This is a legitimate concern and a specific example of a more general point made by Barnes regarding the involvement of service users in research:

Consumer research...has been criticised by some users of services not only for its failure to achieve results but also for placing users in a passive, respondent position, equivalent to the position they have experienced as clients of services. The powerlessness is seen to relate to all stages of the research process: determining what is to be researched, the process of data collection and the interpretation and analysis of results (Barnes, 1995: 229).

After consideration, a commitment was made by myself to ensure that the pilot group were informed of the progress of the research both at a transitional stage and at the final stage of the fieldwork, in the latter case through the convening of a conference

involving all respondents who had been involved in the research. As well as providing respondents with an opportunity to hear and comment on some of the issues arising from the research, such a conference would also provide opportunities for service users to network across Scotland and so could contribute to the development of the users' movement. This initially rather tentative proposal was included in the letter sent out thereafter to all projects involved in the research and eventually developed into the respondent validation exercise, to be discussed below.

The issue of exploitation of service users by researchers was raised again at the next stage of the research by members of Scottish Users Network who agreed to participate on the basis that they would receive payment. Given the increasing tendency for respondents in research projects to receive payment for being involved, there seemed no insuperable objections to this (other than the point raised by a supervisor that, were this to become the norm, it could seriously hinder the development of user-based research). In the event, SUN members accepted that as a PhD researcher, I did not have access to funds for payment, and when an attempt to secure funds for this purpose from two major mental health charities failed, agreed to participate on the basis of the reciprocal involvement referred to above.

Emancipatory research?

The ethical issues discussed in the previous section highlight the need as a minimum not to add to the oppression of service users, either through the process of the research or in the way in which outcomes are used. But to what extent can or should research seek to go beyond this modest goal? The idea of *emancipatory research* has become popular in recent years, particularly amongst those who are active in the 'new social movements'. Oliver defines emancipatory research in the following way:

This disillusion with existing research paradigms has raised the issue of developing an alternative emancipatory approach in order to make disability research both more relevant to the lives of disabled people and more influential in improving their material circumstances. The two key fundamentals on which

such an approach must be based are empowerment and reciprocity (Oliver, 1996: 141).

More broadly, Morris defines emancipatory research as 'research which seeks to further the interests of the 'researched' (Morris, 1992, cited in Oliver, 1996: 128). In this broader sense, the current research has some claim to be an example of emancipatory research insofar as it is concerned both in its focus and in its approach with empowering service users. That said, to what extent and in what ways should such research involve service users as *actors* in the research process? The issue arose in the course of the pilot project when the group of service user respondents expressed an interest in remaining involved in the research. Two major options for involvement presented themselves: i) involvement in the process of data collection ii) involvement in the process of data analysis. Discussion of these options formed the basis of a paper prepared for a supervision session (October, 1996), the main points of which will be summarised below.

i) Involvement in data collection.

One form of user involvement considered at this stage was that at least some of the data collection could be undertaken by users themselves e.g. through conducting some of the individual interviews. Rogers, Pilgrim and Lacey in their study of users' views of services, for example, felt that there were some advantages in using untrained interviewers, though these seemed to be volunteers, students and mental health workers, rather than users themselves (Rogers, Pilgrim and Lacey, 1993). In respect of the current research, some positives of involving service users in data collection were that it would :

- a) Empower users who were involved through the development of new skills and experiences.
- b) Contribute to developing contacts between different groups of users.
- c) potentially yield richer data, in that being interviewed by another user might feel less threatening .
- d) Facilitate access to projects.
- e) For PhD purposes, provide originality in methodology.

On the negative side, however, it was felt that this form of involvement might :

- a) Place additional demands on the already limited time of a part-time PhD researcher, through the requirement for support, training, finance, logistics, and the need to develop new, more structured research instruments.
- b) potentially yield less rich data, as a result of the lack of skill/experience of the interviewers.
- c) Give false and confusing messages to users regarding ownership of the project and the accountability of the researcher.
- d) Lead to a focus on process at the expense of the purpose of the research.

ii) Involvement in data analysis.

A second option considered at this stage was involvement of service users at the data analysis stage of the research. As noted above, a group of users were already involved in the pilot stage of the research. A suggestion floated with this group which met with a positive response was for a small conference or seminar after the data collection has been completed, both to discuss interim findings with those who have been involved and thus contribute to the data analysis but also to put groups of users in touch with each other and thus in a small way to contribute to the development of a users' movement. This would seem compatible both with the ethical considerations discussed above and the requirements of the PhD.

It was this latter suggestion (in the form of the respondent validation exercise referred to above) which seemed to best meet most of the ethical, methodological and practical requirements and which be discussed more fully in the final section of this chapter.

'Designing the sample' (Arber, 1993).

The aim of the project was to explore the limits and the potential of mental health user involvement. Sample design therefore was dictated by this overarching objective, operationalised into the three research questions which introduced this chapter, viz.

- What role can users of mental health services play in the planning, provision and management of community-based mental health services ?
- What implications might such user involvement have for professional workers and professional-led services ?
- To what extent do mental health users in Scotland constitute a 'new social movement' ?

Clearly, if one wishes to explore the *potential* of user involvement, then it is necessary to look at organisations and projects where such involvement is at a relatively high level and to speak to service users who have experience of involvement in the management and development of services . Again, if one wishes to explore the implications of that involvement for mental health workers, then it is necessary to explore the experience and ideas of project workers as well as service users. Finally, without prejudging the involvement of projects in campaigning activities, exploring 'movement' issues is likely to be more fruitful if at least some of the projects and individuals involved have some experience of collective advocacy.

As regards the 'representativeness' of the sample, Arber has made the point that

Where the researcher's aim is to generate theory and a wider understanding of social processes or social actions, the representativeness of the sample may be of less importance and the best sampling strategy may be focused or judgemental sampling (Arber, 1993: 71).

In practice, this led to a decision to focus on between eight and twelve community-based mental health projects spread across central Scotland which professed a high degree of user involvement and which reflected the various aspects of users activity identified by Lindow - cultural, service-providing and campaigning (Lindow, 1995). Within each of these projects, the aim would be to interview between six and eight service users (as well as two workers) who had some experience of involvement in

decision-making processes within the organisation. It was hoped that these numbers would be sufficient to achieve 'saturation point' in terms of new information (though as Maykut and Morehouse point out 'practically speaking, the sampling concepts of saturation of information and diminishing returns may have to be balanced with limitations of time, money and other factors that impinge upon the research enterprise', Maykut and Morehouse, 1994: 63).

In addition, an attempt would be made to set up a further five focus groups to explore wider 'movement' issues and any other issues arising out of the individual interviews.

In the end, a total of fifty service users and eighteen workers were involved in individual interviews over the nine projects, though respondents in one project - Saheliya, an Edinburgh-based project for ethnic minority women with mental health problems- were interviewed as a group, with the researcher using the individual questionnaire. In part, this was because the women felt more comfortable in a group setting where they could assist each other, with language for example; in part, because some women did not wish to be interviewed alone by a white male researcher. While interviewing the women individually might have produced fuller or at least different results, reflecting a minority ethnic perspective within the research on the one hand and respecting the women's' wishes on the other was more important.

In addition, five focus groups took place, involving a further thirty users and two workers. In all, therefore, a total of eighty service users and twenty workers were involved in the research. Given that the majority of these service users could be described as 'activists' within their projects rather than simply consumers of services, the sample has some claim to be 'representative' in terms of representing the views and experience of the 'cadre' of the users' movement in central Scotland, in the sense of those individuals with the greatest experience of involvement.

Selecting methods.

As with sample design, so too the choice of methods flowed primarily from the topic under investigation, rather than from a predisposition towards a particular paradigm. The research aims combine elements of what Crabtree and Miller describe as *qualitative description* on the one hand (‘what is going on here? What is the nature of the phenomenon? What are the dimensions of the concept? What variations exist? What meanings/practices occur in lived experience?’) and *interpretive explanation generation* on the other (‘What is happening here? What patterns exist? How do phenomena differ and relate to each other? How does it work? How did/something occur/happen?’) (Crabtree and Miller (1992: 6). To address these issues, a primarily qualitative approach seemed most appropriate. Hence, the decision to rely mainly on two qualitative research tools: semi-structured interviews and focus groups. A third tool - observation - was also attempted in the initial visits but was soon discarded, in part due to the difficulties inherent in observing processes of user involvement, in part due to the time constraints on a part-time researcher. As Morgan comments

With regard to practicality, some processes, such as attitude formation and decision-making, are inherently unobservable, and some kinds of behaviour are either too private or habit-ridden to offer much opportunity for meaningful observation. With regard to efficiency, there are many topics in which the effort required by participant observation would be excessive or in which the need for rapid data gathering would supersede the need for the depth and detail of participant observation. In each of these cases, focus groups could well be the preferred method (Morgan, 1997:10).

The individual interviews addressed five main areas: identity and terminology; aims, strengths and weaknesses of the particular project; user involvement within the project; relationship with paid workers; and biographical information. Individual interviews varied in length between thirty minutes and two hours with the average interview lasting around an hour. The majority of these interviews yielded rich and

relevant data, reflecting the projects selected, lessons learned from the pilot project in terms of length and content of questionnaire, and perhaps some residual interviewing skills from the researcher's previous life (though on the differences between social work interviews and research interviews, see Fuller and Petch, 1994). One indication of the degree of respondent engagement with, and enthusiasm for, the research project is that just under forty of the respondents voluntarily attended the respondent validation exercise held in Paisley University in June, 1998.

Areas covered by the focus groups (which were conducted following the completion of all the individual interviews) were the problems experienced by service users living in the community; the extent to which the group had resorted to collective, campaigning activities to address these problems, as well as attitudes more generally towards a 'users' movement'; attitudes towards the elements of an 'ideal' mental health service; and also the exploration in greater depth of issues arising from the individual interviews, such as the relative significance of terminology. The tool employed here was an *interview guide*, based around a small number of topics rather than a more structured *interview schedule* (Appendix F; on this distinction, see Maykut and Morehouse, 1994). On average, these discussions lasted an hour and a half and were taped (unlike the individual interviews where recording was by means of note-taking). For a variety of reasons, including the very wide variations in campaigning experience between groups, variations in the numbers attending with only three in the smallest group and twelve in the largest, lack of awareness of alternative services, and occasional organisational mix-ups, these were perhaps less fruitful than the individual interviews. Nevertheless, they did yield particularly useful insights into issues around campaigning which will be explored in depth in chapter ten of the thesis.

In some respects, the approach adopted reflected aspects of a 'grounded theory' approach (Strauss and Corbin, 1990): thus, for example, data analysis proceeded concurrently with data collection; as mentioned, one aim of the focus groups was to explore issues arising through the individual interviews; and the projects were selected as the research developed, rather than all being chosen *a priori*. On the other hand, use of this approach was limited both by the general philosophical/political stance of

the researcher outlined above and by the fact that a considerable literature on user involvement already exists, suggesting the use of semi-structured interviews, rather than the unstructured interviews more common within a grounded theory paradigm (Fielding, 1993).

Finally, while the use of quantitative approaches was generally not indicated either by the research aims or by the numbers involved, some 'mixing of methods' (Brannan, 1992) did take place in that, where appropriate, attitude rating scales were included in the interview schedule, in order to permit more general statements to be made about users' views (Procter, 1993). Thus, for example, prior to looking specifically at the degree of user involvement in a particular project, respondents were asked to respond to the statement that "Professionally-trained mental health workers are the best people to decide the kind of services that users of mental health services should receive' on a five-point scale from 'strongly agree' to 'strongly disagree'. At the end of that section, they were presented with the statement 'All mental health services should be run only by users or former users' and asked to respond in similar fashion. These sections were subsequently analysed using SPSS for Windows and were helpful in clarifying what respondents perceived to be both the *limits* and the *potential* of user involvement. Given the numbers involved, however, they should be seen as offering a fairly crude guide to respondents' views, rather than a statistically precise representation.

Computer-based analysis

Three main software packages have been employed in the organisation and analysis of the data gathered in the course of the current research: *i) Microsoft Word 6*. Notes from the individual interviews were transcribed using Word 6, with hard copies then being sent to respondents for corrections or amendments and the file kept on disc.

(The focus group discussions were taped and transcribed by a secretary, also using Word 6). *ii) SPSS for Windows*. As noted above, some use of this quantitative data analysis package was made in respect of the rating scales used in the individual interviews. *iii) QSR NUD-IST Version3*. This popular package for analysis of

qualitative data was used from the pilot study through to the final stage of the data analysis .

Lyn Richards, one of the inventors of QSR NUD-IST, has suggested that the package represents an advance on previous manual methods of qualitative analysis in three main areas:

i) Unlimited data management.

QSR NUD-IST places no limits on the varieties or volumes of documents that can be stored. Thus, 'off-line' documents, referring to material not held on computer, as well as 'on-line' documents can be stored. In the current research, 66 documents comprising all the individual interviews and focus groups were stored in one NUD-IST project (with the pilot project being held separately).

ii) Unlimited coding.

There are no limits to the number of codes that can be created, with one document being indexed at different points ('nodes'), text coded as many times as its meanings require, and memos attached to index nodes permitting the researcher to develop ideas as he/she progresses and also see the way in which ideas have developed. Again, in the current project, a total 262 nodes or categories were created.

iii) Theorizing.

Its flexible retrieval and indexing system provides the researcher with a powerful tool for interrogating the data. I shall say more about this function below (Richards, 1995).

The use of a package such as QSR NUD-IST is not, of course, a substitute for analysis. As Coffey and Atkinson comment

It should be evident that coding data for use with computing programs and the retrieval of coded segments of text is not, in our view, analysis. At root, it is a way of organising data in order to search them...Qualitative data is not enhanced if researchers decide they will take their data and "put it through the computer", as if that substituted for the intellectual work of analysis (Coffey and Atkinson, 1996: 172).

That said, the experience of the current research is that a package such as QSR NUD-IST provides an extremely convenient way of 'interrogating' the data as a basis for theory-building and development in the way that Richards suggests. In this research, such interrogation took two main forms:

1) Text-retrieval or lexical searches.

The initial form of data analysis involved a 'top-down' search for particular themes, based on a reading of the transcribed interviews and usually driven by issues arising from the literature. Thus, for example, a search for the word 'oppression' came up with no finds, suggesting that new social movement politics and ideologies have perhaps had a limited impact on this group of users - a possibility that was then explored further through looking at the uses of the word 'madperson'. By contrast, there were several references to the negative 'culture' of the users' movement, which on further exploration sometimes occurred beside terms such as 'backstabbing' or 'fragmented'. This provided a basis for exploring the extent to which this culture was linked to the mental health problems of those involved or reflected wider issues within the 'movements' (such as lack of power, for example).

While this procedure bears some resemblance to *content analysis* (Krippendorff, 1980), in this case particular terms were used primarily as a 'springboard' for the exploration of particular themes and the concern was less with the frequency of occurrence of a particular term than with its meaning and associations.

Such text-searches, while not providing an analysis in themselves, when linked with themes arising from the literature review, often provided important pointers to potentially rich seams within the data. The speed and comprehensiveness of such searches, as compared to either manual searches or word processor searches, enormously facilitated the exploration of the data.

ii) 'Grounded' searches.

A second training session in the use of QSR NUD-IST in December 1997 suggested that a more 'grounded' analysis of the data would be helpful to ensure that all the major themes were being identified and that literature-driven searches were not blinding the researcher to other potential themes in the data. This involved recoding around twenty five of the most substantial interviews, this time making the unit of NUD-IST textual analysis the line rather than the paragraph, with a view to achieving a more 'fine-grained' analysis, and systematically coding these interviews on a line by line basis. The effect was two-fold: on the one hand, the creation of dozens of new nodes, which were more precise than some of the previous nodes had been; on the other, a degree of confirmation that by and large the themes that had been identified in the initial analysis were the correct ones.

The strength of QSR-NUDIST as a system for helping to generate theory is concisely summed up by Coffey and Atkinson in the following way:

At the heart of the theory-building procedures in NUD-IST is the fact that all codes are arranged into hierarchically structured trees. In contrast to the simplest systems of coding, therefore, NUD-IST arranges codes in relation with one another, with orders of generality or specificity. In working with the data, adding or modifying codes and coding schemes, one is therefore simultaneously modifying the structure of inter-related codes. The process of coding (in NUD-IST terminology, indexing) is not simply a mechanism for searching and retrieving chunks of data; it is also the conceptual framework indicated by the index system itself. The arrangement of codes into hierarchical relationships is not automatic: the analyst must specify the relationship with other codes (Coffey and Atkinson, 1996: 178).

Reliability, validity and qualitative research.

Even if a study genuinely had no exploitative objective, and merely attempted to give voice to an oppressed group, it would not follow that the researcher's claims to knowledge were automatically more valid than anyone else's. It is possible to be both well-intentioned and wrong (Davidson and Layder, 1994: 183).

In the discussion of research paradigms in the first part of this chapter, the view that issues of reliability and validity have no place in qualitative research was noted and rejected. In this final section of the chapter, the ways in which such issues have been addressed in the current research will be discussed.

A useful starting-point is Silverman's observation that a 'scientific' approach to research is not synonymous with a positivist approach:

It is an increasingly accepted view that work becomes scientific by adopting methods of study *appropriate* to its subject matter. Sociology is thus scientific to the extent that it uses appropriate methods and is rigorous, critical and objective in its handling of data (Silverman, 1993: 144).

The implications of this view will be considered firstly in relation to the concept of reliability, then in relation to validity.

i) Reliability in qualitative research.

In respect of the current research, three issues involving reliability seem particularly relevant: research tools; numbers; and 'trustworthiness' of findings.

a) Research tools. In a text on surveys in social research, de Vaus defines a reliable measurement as 'one where we obtain the same result on repeated occasions' (DeVaus, 1991:54). He notes further that ' A question may be unreliable due to bad wording; a person may understand the question differently on different occasions...It is

wise to avoid questions about which people are unlikely to have an opinion or knowledge, or at least to provide 'do not know' or 'cannot decide' responses' (Ibid.).

While de Vaus' strictures are directed primarily at quantitative researchers, they also have relevance for qualitative researchers. Thus, in the current research, one objective of the pilot study described above was to ensure that the questions were clear and understandable. While in general this objective was met, some additional questions in the revised interview schedule failed to meet this criteria. Thus, question D6, in the individual interview schedule 'Mental health workers can only empower users if they themselves have power within their organisations' tended to be met by blank expressions, while some (though not all) respondents failed to see the relevance of question D5, 'Paid workers in mental health projects should belong to a trade union'. Clearly such lack of clarity has a bearing on the value of the responses in these cases.

b) Numbers. In quantitative research, sample size is an important consideration in terms of the statistical significance of the findings and the extent to which they are generalisable. Qualitative research, by contrast, is often more concerned with the *meaning* of a particular phenomenon and is less concerned with numbers involved. Does this mean then that numbers are irrelevant in qualitative research? In the current study, would the findings have been as significant (or otherwise) if three or four projects rather than nine projects and five focus groups had been involved? Once again, the answer must be that it depends primarily on the purpose of the study. While in some cases intensive involvement in a single case study can yield findings which clearly generalise beyond that single example (Goffman's *Asylums* comes to mind), in others, a focus on a single case may produce findings that are so case specific as to have limited value. One experienced qualitative researcher argues that

For me, the answer is that numbers do matter, but that we need to work out and demonstrate just what their salience is in our analysis...The significance of numbers is not a given, nor can it be deduced or treated in a purely statistical manner, nor is it always the most relevant aspect of the analysis. These are matters of analytical interpretation which need to be worked out and understood afresh each time (Mason, 1994: 104).

In the present study, the concept of *saturation* (Glaser and Strauss, 1967) was a useful one in respect of the projects visited, in that after visiting six or seven projects, very little original data or fresh insights were emerging. The same is true of the five focus groups, though here Morgan's 'rule of thumb' that projects should consist of three to five focus groups was taken into account, the basis being 'that more groups seldom provide meaningful new insights' (Morgan, 1997: 43).

c) '*Trustworthiness*'. Within the qualitative research literature , concepts such as *trustworthiness* or *credibility* or *authenticity* tend to replace the concept of reliability (Denzin and Lincoln, 1994). The basis for this is the recognition that qualitative data - in the form of interviews, for example - cannot be treated simply as 'reports' to be counted or measured, but reflect complex views of reality which need to be analysed or 'deconstructed'. The danger, of course, is that such research is then seen as purely subjective. How, if at all, can such a danger be avoided?

Within the literature, a number of suggestions have been put forward including multiple methods of data collection; building an audit trail; and working within a team (Maykut and Morehouse, 1994). At the end of the day, of course, the issue is one of the extent to which the researcher is justified in imposing the interpretation that he or she does on the 'raw data'.

In the current study, an attempt to establish such 'trustworthiness' has been made in a number of ways: through the 'transparency' of the research process itself ; through comparing and contrasting the views of respondents in different projects to build up a convincing picture; through adopting a 'grounded' approach to analysis in the manner described in the section above; and through a continual process of movement back and forward between analysis of interviews, the literature review and the ideological, social and material context in which mental health service users find themselves. While such an approach bears some resemblance to the method of discourse analysis derived from the work of Foucault (Potter and Wetherill, 1994), whereas that method typically involves seeing all discourses as valid and self-contained , the critical/ecological approach adopted here implicitly draws on Gramsci's concept of *contradictory*

consciousness in seeking to make sense of respondents' statements through locating them in a wider ideological and structural context (Gramsci, 1971).

ii) Validity.

By validity, I mean truth; interpreted as the extent to which an account accurately represents the social phenomena to which it refers (Hammersley, 1990: 57).

An argument running through this chapter has been that 'experience' or 'discourse' cannot simply be presented as 'truth' but rather needs to be contextualised and critically understood. Thus in respect of the current research, to simply present service users' views in an anecdotal fashion might or might not be interesting in and of itself but would do little to further our understanding of the phenomenon of user involvement. While quantitative researchers have produced fairly rigorous techniques for checking the validity of quantitative data, validity is a more difficult concept within the qualitative paradigm. How can the data in the current study for example be shown to be plausible and credible and go beyond mere anecdote?

In discussing this question, Silverman identifies three approaches to validation : triangulation; analytic induction; and respondent validation; (Silverman, 1993: 156-170). *Triangulation* involves using multiple sources of data collection and different methods as part of the methodology. Within the current study, for example, data was gathered from individual interviews (with both users and workers), focus groups and documentary material both from individual projects and from the wider user movement; while data gathered was mainly qualitative, some use was also made of quantitative materials and approaches. Through a dialogue between this material and the literature review, the aim is to build a convincing, many-sided picture of user involvement. While the use of triangulation is clearly a sensible approach, it does, however, have its limits. As Hammersley and Atkinson point out:

one should not adopt a naively 'optimistic' view that the aggregation of data from different sources will unproblematically add up to produce a more complete picture (1983:199).

Analytic Induction. Silverman's preferred approach, is a form of hypothesis testing, involving the search for deviant cases and the use of the constant comparative method. While the current study did not adhere rigorously to this approach, there are nevertheless strong similarities between the use of QSR NUD-IST to generate codes outlined above and the constant comparative method, as outlined by Maykut and Morehouse:

The constant comparative method of analyzing qualitative data combines inductive category coding with a simultaneous comparison of all units of meaning obtained (Glaser and Strauss, 1967). As each new unit of meaning is selected for analysis, it is compared to all other units of meaning and subsequently grouped (categorized and coded) with similar units of meaning. If there are no similar units of meaning, a new category is formed. In this process there is room for continuous refinement: initial categories are changed, merged or omitted; new categories are generated; and new relationships can be discovered (Morehouse and Maykut, 1994: 134).

Respondent validation. This approach, developed by Bloor (Bloor, 1978) involves researchers going back to their research subjects with their tentative results and refining these in the light of their reactions. As noted earlier, respondent validation was employed in the present study when, at the end of the fieldwork phase and following the completion of the initial data analysis, just under forty respondents attended a half-day seminar in June, 1998 at Paisley University to hear and comment on some of the initial findings. This involved an initial thirty minute presentation of some of the main findings in respect of terminology, issues and dilemmas in user involvement, and the potential for collective activity, followed by a large group discussion. Thereafter, respondents went into three small groups, led by trained facilitators, to explore issues for building a users' movement, and reported back their findings to a plenary session

While respondents comments were generally confirming of the findings, important new points were also made about the need to make a clear distinction between 'user-led' and 'user-controlled' organisations (with the first often involving a degree of tokenism) while in the course of the day, a consensus also began to emerge regarding the often limited value of user involvement in statutory 'consultation exercises' (such as those undertaken by health boards and social work departments) and the need to channel more energy into the building of a users' movement.

As well as providing respondents with the opportunity to make specific comments on the findings, the event was also an example of 'emancipatory research' in stimulating 'networking' amongst those present, with representatives of Scottish Users' Network making the offer to hold a follow-up day later in the summer to carry forward the issues discussed at this event.

As Silverman comments, such 'empowerment' is not synonymous with validation and the exercise described above should not be seen as providing a 'definitive' validation of the data. What it did, do, however - and the point potentially holds for respondent validation in general - was to provide new insights into some aspects of that data.

A final suggestion by Silverman (following Bryman, 1988) is that the process of generalising findings should relate less to *populations* than to *theoretical propositions*:

As our understanding of social processes improves, we are increasingly able to choose cases on theoretical grounds - for instance, because the case offers a crucial test of a theory (Silverman, 1993: 160).

The point is particularly apposite in respect of the present study, one aim of which, for example, is to explore the extent to which mental health users can be said to constitute a new social movement. Prior to addressing that issue, however, and the other issues reflected in the overarching questions which introduced this chapter, it is necessary to

outline the characteristics of the projects, groups and respondents who provided the information on which this study is based.

Characteristics of Projects, Groups and Individuals.

As mentioned in the previous chapter, a total of nine community-based mental health projects across Central Scotland were visited between January, 1996 and February, 1997 and individual interviews conducted with fifty service users and eighteen workers. In addition, towards the end of this period, focus groups were organised in five other areas of Central Scotland involving a further thirty users. In this chapter, I shall outline the characteristics of the projects visited and then discuss some characteristics of the individual respondents, such as age and gender, based on the biographical information which they provided. The chapter will conclude with a brief description of each of the focus groups.

THE PROJECTS

Scottish Users Network

Scottish Users Network (SUN) was set up with the involvement of service users in 1987. Its main aim, in the words of its most recent three-year plan, is 'to set up ways for users throughout Scotland to meet each other to discuss common problems and interests and to come up with preferred policies and solutions' (SUN 3-Year Plan, 1996). Its remit is, therefore, national and in that sense it is probably the nearest Scottish equivalent to the English-based users' organisation, Survivors' Speak Out. At the time of the study, its main funding came from the Scottish Office and the Mental Health Foundation, which permitted SUN to employ a part-time co-ordinator and a part-time development worker since 1995. Also at the time of the study, SUN was located within the Edinburgh offices of the Scottish Council for Voluntary Organisations (SCVO) which also provided a line management function, administrative and financial systems.

The 1996 Plan identified the following as the main areas of current and/or future activity:

i) Internal Organisation.

SUN has undergone a number of major changes over the past three years, the most important of which was the shift to becoming a funded organisation employing staff and the subsequent involvement of SCVO in a managerial and administrative support function. This has led to the need to develop both new internal administrative systems and also mutually satisfactory ways of working with the parent organisation.

ii) Consultation

As the main national users' organisation, SUN is regularly required to respond to Scottish Office consultation documents relating to legislative and policy initiatives, such as the Framework for Mental Health Services in Scotland. In addition, it consults with users and users groups throughout Scotland through a variety of mechanisms including substantial involvement in the organisation of the annual Scottish Users' Conference.

iii) Publications

In line with its general objectives SUN has produced a number of publications, including a report on user group consultation on the Mental Health (Patients in the Community) Act, 1995 and a Scottish User Group Directory, giving details of user groups throughout Scotland.

iv) Campaigning

The 1996 Plan explicitly commits SUN to 'pursue campaigns as instructed by the membership and in the wider movement' Following a resolution passed at the 1996 AGM, the main campaign in which SUN has recently been involved is against government cuts in local authority funding.

Issues

In his report to the 1996 AGM, the secretary identified the need to establish collective responsibility on the Executive and also the impact of poor attendance of Executive members as two of the major difficulties faced by the organisation over the preceding year. Both of these points were also raised during individual interviews by Executive

members and staff and were seen as reflecting wider issues relating in part to the history of SUN. Other issues which were identified included the need for a *regional* structure to create greater representation and accountability and also the issue of user-workers.

Saheliya

Saheliya is a community-based mental health project for minority ethnic women in Edinburgh. It was set up in 1992 with the appointment of a development worker whose initial task was to identify the mental health needs of black and minority ethnic women and how these needs could be met in a culturally appropriate and sensitive manner. Since then, on the basis of MISG funding and (since 1997) National Lottery Funding, the project has expanded considerably to employ four full-time project workers, two administrators and several sessional workers. The project's main aims are to provide culturally appropriate and ethnically sensitive services to minority ethnic women with mental health problems and to raise awareness within existing services with a view to them becoming more accessible to these women (Saheliya Annual Report, 1996-97).

Saheliya offers a wide range of preventative and support services including: counselling and one-to-one support; group support, including discussion groups and activity based groups; complementary therapies including massage therapy and reflexology; and a befriending scheme. In addition, Saheliya staff provide a training input into a range of professional, further education and higher education courses as well as being represented on numerous statutory and non-statutory bodies concerned with mental health issues.

Issues

Funding was identified as a major problem by both staff and users. On the one hand, the fact that the project is funded by a yearly MISG grant made it difficult to engage in long-term planning. On the other, like many of the other projects covered in this research, Saheliya has been faced by the threat of financial cuts in recent years and the 1996-97 Report devoted space to photographs and descriptions of campaigning activities Saheliya staff and users had been involved in to counter this threat. More generally, it was also noted that the lack of funding meant that the services of the project could not always be available at the right time.

The inadequacies of the statutory mental health services were an issue for all of the projects in this study but particularly so for Saheliya, given the failure of these services to address the specific needs of black and ethnic minority women. The issue therefore of separate versus commonly provided services was one which came up in several of the discussions.

The fact that there are only two meeting rooms in the existing premises was also identified as a problem, especially where people wanted to talk about confidential issues. Service users felt that the location of the project (on the ground floor of an elegant Georgian Terrace) was a limitation in that various activities, such as physical exercises , could not take place due to complaints from business neighbours. Finally, Saheliya is distinctive not only in being the only project of its kind in Scotland but also in the organisation of its staff group which is based on a collective rather than a hierarchical model of decision-making. While staff felt very positive about this model of operation, some service users felt that it occasionally created difficulties in respect of accountability and user involvement .

Stepping Stones.

Stepping Stones is a community-based mental health resource serving the Clydebank area. Its origins lie in a befriending scheme initiated by the local Social Work Department in 1989. In 1994 the members' committee was successful in its application for Mental Illness Specific Grant Funding and Stepping Stones currently employs a development worker, two project workers and an administrative/clerical worker, as well as a range of sessional staff. According to its application for MISG funding, the aims of the organisation are 'to promote good mental health and prevent deterioration of mental health by supporting those affected by mental ill-health'. It seeks to do this by promoting social, educational and recreational activities, reducing social isolation and seeking to reduce stigma.

Consistent with the holistic approach to mental health outlined above, Stepping Stones offers a wide range of individual and group activities geared to improving the well-being of clients and members. At an individual level, these include counselling, reflexology and Shiatsu massage; at a group level, creative writing, a men's' group, drop-in activities, T'ai Chi and various others activities. As part of its commitment to challenging stigma, Stepping Stones has also been involved in organising workshops for local workers during Mental Health Awareness Week and in January 1997 was awarded a grant from West Dunbartonshire Partnership to produce publicity material highlighting general mental health issues. Some of these activities have been undertaken in partnership with the local mental health resource centre and close links with local statutory and voluntary organisations were perceived as a major strength by Stepping Stones respondents.

Issues

Since receiving MISG funding, the demands on Stepping Stones have grown considerably. According to the 1996-97 Annual Report, referrals to the project almost doubled during that year. Significantly, referrals from health service agencies accounted for 50% of the total, reflecting a much larger interest in Stepping Stones

services from NHS facilities. This can be seen as a mixed blessing. On the one hand, it reflects the growing credibility of the service and the recognition that there is a role for complementary or alternative approaches in promoting mental health. On the other hand, as the Annual Report notes, 'this overall growth in referrals has placed a heavy burden on the organisation as it struggles to respond to the increased demand with depleted resources'. Closely linked to the issue of resources was the issue of support, especially for the management committee all of whom are service users. The committee had previously been supported by a local authority community worker but when this worker left, her post had not been filled. Several respondents suggested that the health of management committee members was adversely affected from time to time by the stresses of running the organisation.

Survivors' Poetry Scotland

In contrast to most of the other projects in this study, Survivors Poetry Scotland (SPS) is part of a national organisation, Survivors Poetry, a literature and performance resource which is located in London. With origins in a politically based organisation, CAPO (Campaign Against Psychiatric Oppression), Survivors Poetry has been established since 1991. The Scottish group was formed in 1995 and operates under the auspices of Glasgow Association for Mental Health. Initially funded by underspend from GAMH budgets, the organisation is now funded on a year-by-year basis by the Greater Glasgow Community and Mental Health Services Trust, with additional funding from the Scottish Arts Council and Glasgow City Council. This funding permits the employment of two development workers and an administrative assistant, as well as the sessional employment of professional writers to work with the groups.

The aims of SPS are:

' to promote the development of a survivor-led arts group providing poetry workshops, readings, performances, music, visual arts, publishing, recording and other activities by and for survivors of the mental health system with support from professional writers and performers;

provide a safe environment where mental health users can work together to improve the quality of their writing and performance and to create opportunities for publication; provide a voice for survivors of the mental health system through performances of poetry' (SPS Developmental Study, 1996).

Main Activities

i) Public Performances and Workshops.

Public performances of members' poetry as well as poetry workshops are a central part of the activity of Survivors' Poetry. From the group's launch in August 1995 till the end of 1996, 15 performances were given in a wide range of different venues including theatres, arts centres and psychiatric hospitals.

ii) Writers' Groups

SPS supports several writers' groups, some led by visiting facilitators, some by facilitators who are themselves SPS members.

iii) Publications

As well as producing a regular magazine (NOMAD), the group has also published an anthology of survivors' poetry entitled '*sweet, sour and serious*'.

Issues

Funding was identified as a major issue within SPS, both in respect of the small size of the grant and also its award on an annual basis, which severely inhibited development. Other issues raised were the lack of accommodation and an identified base; occasional tensions surrounding the use of paid external professionals as facilitators (internal SPS facilitators are not paid); and alternative viewpoints about the future direction of SPS, linked in some cases to wider issues of control within the organisation.

The Core Club

The Core Club is a Scottish Association for Mental Health project based in a terraced house in Dumfermline in Fife. As well as being managed by SAMH, the Core Club, like Survivors Poetry, is affiliated to another national (or in this case, international) mental health organisation, the International Center for Clubhouse Development (ICCD), based in New York. The Clubhouse model which the ICCD promotes aims to provide an alternative approach to rehabilitation for people experiencing mental ill health. The model has 2 main characteristics which form the basis of the Clubhouse philosophy: the right to meaningful work and the opportunity to develop relationships (ICCD, 1994). Affiliation to the ICCD involves acceptance of these aims by the Core Club, as well as attendance at national and international conferences and functions, and receipt of a regular newsletter. The project is staffed by a project manager, two project workers and an admin. worker.

Main Activities

The work ethic is central to Clubhouse philosophy and this is reflected in the activities undertaken in the Core Club:

i) Work Units

Members are encouraged to participate in one of the three main work units within the Club - administration, maintenance or food service.

ii) Transitional Employment.

The Transitional Employment Programme offers Clubhouse members the opportunity to work in 'real' jobs with local employers on a part-time basis on a placement basis.

iii) Social/educational programme.

As well as organising social activities, the Club House also has strong links with local FE colleges and community education, with some members attending a photography class, for example.

Workers emphasised, however, that as important as the activities themselves is the process through which decisions are made about who will do what and how and indeed a visitor to the Core Club is struck both by the high level of involvement of members in the decision-making processes and also by the communal atmosphere which prevails, stemming in part from the conscious reduction of differences between staff and members.

Issues

Issues identified by respondents included the very limited nature of the current accommodation which, as with other projects, inhibited the activities that the project can undertake and also concern about possible cuts in funding. An issue identified by workers in particular was that of confidentiality, particularly where it was felt that the disclosure of information might have a damaging effect on the health of members. Confidentiality was in fact an issue for several of these projects and will be discussed in the section on 'Dilemmas' in chapter nine.

Manic Depression Fellowship Scotland

The Manic Depression Fellowship Scotland was formed in 1992, mainly by people with manic depression themselves and is part of the UK-wide Manic Depression Fellowship network. The aims of MDF Scotland are:

- to help people with manic depression, their friends, relatives and all who care
 - to promote, develop and co-ordinate a network of community based manic depression self-help groups throughout Scotland, enabling people with manic depression and their relatives and friends to meet and gain support and advice
 - to inform and educate members of the public, professionals and other agencies about the nature of the illness and the role and value of the Fellowship
 - to encourage research into all aspects of MD
- (MDFS Development Plan, 1997-2000).

Since its formation, MDFS has grown from three self help groups in 1992 to seventeen groups throughout Scotland by 1997. It now employs a full-time co-ordinator, a full-time administrator, a part-time outreach worker for Ayrshire and Arran and a part-time clerical assistant. Funding is mainly through MISG, though the Outreach worker is being funded through the local Health Board and the organisation has also received substantial grants from other bodies, notably the Tudor Trust.

Project Activities

MDFS activities during 1996-97 included the following:

i) Internal Reorganisation.

During this year, the organisation moved into new, larger premises, became a limited company and took over the Scottish membership of MDF UK. The organisation also produced a Development Plan for the period 1997-2000.

ii) Conferences.

Two major conferences were organised in different parts of Scotland, the first on Stigma, Education and Self- Management , the other on Support and Self- Management.

iii) Research.

Commenced a Scotland-wide user/carer consultation project with a view to ascertaining what users and carers want from MDFS. In addition, a Board member has been involved in research projects at Gartnavel Royal and the Royal Edinburgh Hospital aimed at developing interventions to address recurrent mood swings.

iv) Publications

Produced a booklet on ECT jointly with SAMH. In addition, the convenor has been involved with members of MDF UK in the development and production of a training programme in the self-management of manic depression.

iv) Direct service activities.

As well as providing support to self-help groups, MDFS also deals with a large number of calls from users, carers and professionals

(MDFS Annual Report, 1996-97).

From its inception, the organisation has also seen campaigning against stigma and around policy issues affecting people with MD as an important part of its work and has contributed regularly both to government consultations and also to the media generally.

Issues

Although the only one of the projects in this study which bases itself on a psychiatric classification, MDFS is strongly committed to developing self-help strategies for dealing with manic depression and much of its current activity is geared towards this end. In this connection, an issue which was highlighted by several respondents from MDFS was the difficulties of managing the illness of both staff and Board members within a user-led organisation - an issue which was also around for several of the other projects in the study.

AdvoCard

AdvoCard is an advocacy scheme for users of mental health services in North East Edinburgh which grew out of discussions within Edinburgh mental health service users' organisations in the early 1990s. According to its 1997 Annual Report, AdvoCard aims 'to increase self-determination for service users.... by providing a confidential crisis card advocacy service....AdvoCard seeks to enable people with mental health difficulties to achieve their full potential through providing support and better access to information. By taking part in our advocacy project, card holders will be encouraged to express their thoughts, feelings, preferences and ideas in relation to their own mental health needs'. AdvoCard is based in shop-front premises in Leith Walk and employs three part-time workers - a development worker, a training officer and an administrator/book-keeper. AdvoCard is a registered Scottish Charity and is funded through Mental Illness Specific Grant.

Project Activities

There are two main aspects to AdvoCard and project activities reflect this:

i) Cardholder Service.

The matching, training and support of cardholders and their representatives.

Cardholders are service users who opt to carry a 'Crisis Card' which provides minimal information about the cardholder and which is recognised by a range of mental health services including hospital services, while representatives are volunteers (who are themselves sometimes service users) who represent the cardholder in a confidential manner and on the basis of a negotiated agreement.

ii) 'Flying Advocates'.

These are more specialised representatives who are available to all cardholders and representatives and have a more detailed knowledge of patients' rights and the law relating to mental health. They can be called on where someone is seeking one-off support rather than an ongoing relationship and/or where the person's usual representative is not available.

Issues

Among the issues identified by workers and service users within AdvoCard were: the part-time basis of the service; the need to increase user participation on the Executive (at present 50%); confidentiality; and the impact on the running of the service of mental ill- health of cardholders, representatives and committee members.

Charlie Reid Centre

The Charlie Reid Centre is a community based resource in Glasgow 'for those affected by mental illness or serious mental health problems' (introductory leaflet). Funded through MISG, it is managed by the National Schizophrenia Fellowship (Scotland) and is the largest of the Fellowship's 15 projects in Scotland. As an NSF project, the Centre is governed by the mission statement of the parent organisation but

within that overall framework, each project has its own specific objectives. According to the Centre manager, the Charlie Reid Centre has four objectives:

- i) to enhance the quality of life of people with mental health problems.
- ii) to allow people to take an informed part in decision-making
- iii) to avoid unnecessary and damaging interventions
- iv) to help people access appropriate interventions (Interview with Centre manager, 10/12/97).

The project is based in the city centre and employs several staff including a centre administrator, a carers support worker, a counsellor, and a catering support worker.

Project Activities.

The Centre operates on a membership basis and in keeping with the Centre's aim of providing social and recreational support, the following activities are available:

i) Cafe

A feature of the Centre is a cafe which is also open to the general public. In addition to providing a 'normalising' atmosphere in which members can meet, it also provides training and employment opportunities for members.

ii) Groups

Centre activities are organised on a timetable basis and groups available to members include creative writing, art, a women's' group and a music group. There is also a weekly carers' group.

iii) Therapeutic activities

While all of the above activities can be seen as therapeutic, more obviously therapeutic activities on offer include Shiatsu massage; aromatherapy and reflexology; and counselling.

More generally, staff offer emotional support and benefits advice when appropriate.

Issues

As with other projects in this study, there were issues concerning lack of resources (restricting the hours that the cafe can be open, for example) and also the annual nature of funding. In addition, a major issue identified by both staff and service users

concerned the history of user involvement within the Centre, with one episode in particular being singled out as having been a 'crisis' situation. This episode will be discussed in greater detail in chapter nine.

Glasgow Advocacy Network

The Glasgow Advocacy Network has been designed to co-ordinate the development of a mental health advocacy service in the Glasgow area. Based within the offices of Glasgow Association for Mental Health (GAMH), the Network is funded through Glasgow City Council, the Community and Mental Health Trust and Glasgow Association for Mental Health. It is staffed by a Project Co-ordinator and three project workers. Its aims are to promote the civil rights of current and former users of mental health services; to facilitate patient councils and user and carer forums; and to promote good practice in planning and delivery of mental health services.

Main Activities

The main activities of the service are:

- i)* the promotion of self and citizen advocacy on an individual basis;
- ii)* the development of locality-based groups of representatives of mental health service users.
- iii)* the establishment of a structure of service users councils within several areas of the city, feeding into a Glasgow service users council. The model for these councils is the Dutch Patients' Council, established by law in every hospital in Holland and nationally funded. At present, the Network supports Patients Councils in most of the psychiatric hospitals in Glasgow.

Issues

The Network has a strong commitment to service user involvement and was the only one of the projects visited which had a policy of employing only users or former users as workers. While all those interviewed supported this policy, it did raise a number of

issues and dilemmas concerning relationships with 'non-user' staff in the parent organisation; implications for credibility with psychiatric staff on the one hand and hospital patients on the other; and the effects of illness on the running of the organisation. In respect of the issue of credibility, several respondents spoke of resistance to advocacy from psychiatrists in particular. Finally, lack of resources was identified as a problem, both in the sense of having too few workers to cover city-wide demand and also in relation to the uncertainties created by annual funding.

PROJECTS AND RESPONDENTS: ISSUES AND CHARACTERISTICS.

'Representativeness' and 'accountability'.

As Lindow and Morris have noted, the issues of representativeness and accountability are two of the most difficult in user involvement in community care services:

When a service user taking part in consultation exercises with agencies is challenged as not representative this is experienced as undermining and used to block what a person is saying. 'People have said to us :When we agree with them we are representative. When we don't they say we aren't.'" (Lindow and Morris, 1995: 56-57).

Not surprisingly, these issues also arose within the current study in relation to user involvement in projects and shall be explored at a later stage. To what extent, however, can the sample of projects and respondents in the current study be said to be representative of users more widely?

In two senses both the projects and respondents are clearly unrepresentative and deliberately so. Firstly, as discussed in the previous chapter, given that the focus of this thesis is on the *limits* and *potential* of mental health service user involvement, little would have been learned about the dilemmas to which user involvement gives rise if the sample had been based on the 'average' mental health project, in which there may be a very limited or tokenistic commitment to involvement. Therefore, *purposive*

sampling, involving mental health projects with a known or nominal commitment to a high level of user involvement seemed the most appropriate sampling strategy (even if inevitably some of the projects in the study in practice proved to have a higher commitment to involvement than others).

A second sense in which project respondents are not 'representative', in the sense of being 'typical' of all service users, is that in many cases, though not all, they tended to be playing a leading role in the management or development of their projects and sometimes within the wider movement. In that respect, this is a study of the views and experience of the 'activists', the 'cadre' of the mental health users' movement in Central Scotland. Again, this aspect of sample selection was indicated by the overall purpose of the research.

To describe the views of such activists as 'unrepresentative', in the sense of being unusual or untypical of users views more generally is misleading, however. For one thing, many of these respondents had been democratically elected to the positions that they held, as secretary or chairperson, for example, and in the cases where they had not been, the need to develop more democratic structures was widely recognised and debated. This does not mean that the issue of individuals acting undemocratically arises any less within the mental health users' movement than within any other movement, party of organisation. As Beresford and Croft comment however

Self-advocacy organisations are subject to the same limitations as others, no more, no less...Instead of using representation as an excuse to exclude people, agencies and authorities should first examine their *own* arrangements for involvement. Are they providing the necessary **access and support** to make possible broad-based involvement in their organisation? People's reluctance to get involved has much to do with the difficulties of doing so (Beresford and Croft, 1993: 149-150).

Secondly, as we shall see in the next section, in terms of personal characteristics and biography, the respondents presented a very wide cross section both of the general

population and of those with mental health problems. Finally, in terms of ideologies, as the next chapter will demonstrate and as previous studies of the users movement such as those referred to in chapter three have found, there is no single 'user view' and users espoused a very wide range of views both on mental health and on wider issues.

Characteristics of respondents.

The characteristics of the particular respondents in this study will be considered under five headings: post held within the organisation; age; diagnosis; gender; and 'race'. It should be noted that given the nature of the interviews with Saheliya respondents, noted above, they will not be included in the discussion which follows, except in respect of gender and 'race', which are consequently based on the responses of forty two individuals in eight projects.

1) Posts held within the organisation.

Of the forty two service user respondents, seven identified themselves as being either convenors or chairpersons of executive committees or management committees; four were secretaries or treasurers; and a further fourteen were committee members. The remainder identified themselves as either members or volunteers. This did not necessarily imply a lack of involvement or responsibility, however. Within the Core Club for example, which is based on a model of *direct democracy* rather than *representative democracy*, all of the members were very actively involved in decision-making processes within the organisation. That said, fifty per cent of respondents held formal positions within their organisations.

ii) Age of respondents.

In her critical appraisal of the ideas of R.D. Laing, Mitchell (1974) noted the particular attractiveness of Laing's ideas to young people with schizophrenia, since, she argued, not only did they provide a positive interpretation of schizophrenia but they also gave a theoretical justification for adolescent rebellion against the bourgeois

family. More generally, the association between youth and oppositional social movements is something of a commonplace in both academic and popular discourse. What, then, can be learned from the age patterns of respondents in this study? In fact, if 'youth' is defined as under thirty, then a relatively small number of respondents - only five out of forty two - fell into this category. At the other end of the spectrum, however, only two respondents in the entire study were over sixty. The overwhelming majority of respondents were therefore aged between thirty and sixty with the largest single group - sixteen or forty per cent - aged between forty one and fifty. Clearly then, the activists within these projects were neither youthful radicals nor were they elderly long-term psychiatric patients being discharged into the community after decades of hospitalisation. Some explanation of why this might be so is provided by Lindow in her account of her own experience of the psychiatric system:

I lost my twenties to psychiatry. I first went into a mental hospital when I was 19. I spent my thirtieth birthday in my last mental hospital so far. It took me those 11 years of going in and out of big bins and psychiatric units to realise that psychiatry had nothing to offer me. The system did me more harm than good (Lindow, 1995: 203).

It may be then that two factors tend to condition the age patterns of activists within the movement: on the one hand, the existence of a *long-term* mental health problem, rather than a single episode, which results in repeated contact with the psychiatric services, sometimes as in Lindow's case taking the form of the 'revolving-door' syndrome; on the other, a growing recognition of the *limits* of these services and a developing awareness of the need for alternatives.

iii) Diagnosis.

In this study, as in social work practice more generally (Butler and Pritchard, 1984) the issue of diagnosis is seen as less important than the impact of an individual's mental health problems on his or her social functioning. Thus, our concern will be with the *impact* of the mental health problems of leading activists on their projects and

organisations and on the users' movement more generally than with the label attached to these problems. That said, what can be learned both about the sample of respondents in this study and about the users' movement more generally from the diagnoses or labels which these respondents had been given?

Out of forty valid responses, almost half - nineteen respondents or forty eight per cent - had been labelled as having a psychotic condition, with equal numbers being labelled schizophrenic or manic depressive. Of the rest, the largest single category was anxiety or depression (eleven, or just over a quarter of the sample). Other labels included 'eating disorder' or 'nervous breakdown'. Responses to a question on the nature of their previous contact with mental health services (which, due to their diversity, have not been quantified) suggested that the full range of psychiatric interventions (other than psychosurgery) had been experienced in varying degrees by these respondents, including being sectioned under the mental health legislation; receiving ECT; being given major tranquillisers; as well as a wide range of non-medical interventions such as counselling and psychotherapy. 30 individuals or 75% of the sample had spent time in hospital.

These findings require some comment. Firstly, as the discussion above on the age patterns of respondents suggested, activists within projects or the users' movement will often be those who have had prolonged or repeated contact with the mental health services; in more medical language, those suffering from what is usually described as a chronic condition, such as schizophrenia or manic depression, rather than a single bout of mental ill-health. Secondly, the fact that almost half the sample have experienced what would be seen by psychiatrists as the more severe forms of mental ill-health (as opposed to those who are sometimes disparagingly - and misleadingly- referred to as 'the worried well') means that the views and attitudes expressed in the thesis cannot be so easily dismissed as 'unrepresentative' of those with serious mental health problems.

Does that mean, however, that the views expressed are less valid or meaningful, coming as they do from people who have experienced severe mental health problems? Perhaps the best rejoinder to this particular line of argument - and the essential stance

adopted by myself in the preparation of this thesis - was provided by Sedgewick when he wrote that

Dialogue with unreason is possible, and necessary, on terms fairly familiar to the dialogue of society with other handicaps and misfortunes. The 'lucid' intervals characteristic of most mental infirmities indeed distinguish them from the conditions of permanent communicative handicap such as deafness, sclerosis and terminal coma. 'The key' writes one chronic schizophrenic patient of his own career, 'lies in how I think of myself when I am well' (Sedgewick, 1982: 146).

Adoption of this stance meant that the fact that all of those interviewed as service users had previously experienced mental health problems did not present major methodological problems. The overwhelming majority of those interviewed were 'well' at the time of interview - partly because selection of respondents was guided by project workers - and in the few instances where this was not the case either the individual himself or herself, or other service users, or project workers, or myself as researcher quickly became aware of this and responded appropriately.

iv) Gender.

The next respondent characteristic to be considered is the gender of the respondents. This time including Saheliya respondents, a total of thirty, or sixty per cent, of respondents were female while twenty or forty per cent were male. This appears to reflect wider patterns of mental ill-health where women generally present more frequently with mental health problems than men (for a summary of the literature on this issue, see Pilgrim and Rogers, 1993). One issue which raises is the role of women within the users movement. The rather romantic notion that there is a 'natural' unity of oppressed people which means that one group of oppressed people will automatically challenge the oppression of others is not borne out by historical experience (as witnessed, for example, by recent debates over the relationship between women's oppression and disablism: Morris, 1996). At least one user respondent in this

study felt that sexism was an issue within the users' movement, though less so than previously.

v) 'Race'.

The users' movement in Scotland is an overwhelmingly white organisation. While in part this may reflect the more widespread *under*-representation of the British Asian population - the largest minority ethnic group in Scotland - within mental health services (as opposed to the *over*-representation of the British Afro-Caribbean population) (Bowes and Sim, 1991; Pilgrim and Rogers, op. cit.; Fernando, 1995), nevertheless, it does mean that the mental health problems of a significant section of the population in Scotland, and the services they receive, are perhaps not being addressed as effectively as they should be by users' organisations. It was in an attempt to ensure that this limitation was not reflected in the current thesis that Saheliya, one of the very few minority ethnic mental health projects in Scotland which also has a commitment to user involvement, was asked to participate.

THE FOCUS GROUPS

As noted in the previous chapter, the aim of the focus group discussions was to explore wider issues of collective campaigning and also to revisit some issues, such as the relative importance of language, arising out of the individual interviews. Factors affecting the choice and composition of these groups were both practical and theoretical. In a discussion of focus group design, Morgan has made the point that

Where differences in group dynamics are not an issue, practical considerations may govern the choice between strangers and acquaintances. In some cases, it may be almost impossible to recruit a full group of acquaintances (e.g. amongst service recipients); in other cases, it may be almost impossible to avoid it (e.g. organisational settings). For those circumstances, decisions should rely on the basic criterion of whether a particular group can comfortably discuss the topic in ways that are useful to the researcher (Morgan, 1997: 38).

In respect of the current thesis, three factors guided group composition and selection. Firstly, given the aims of this part of the research, already- existing groups seemed to offer the best forums for exploration of the experience of collective activity and the evaluation of such experience, rather than groups made up of individuals from different groups. Secondly, as with the projects, such groups should have a commitment to, and experience of, user involvement (as opposed to being purely recreational or social groups). Thirdly, in respect of the 'comfort' issue mentioned by Morgan, it seemed reasonable to assume that mental health service users might feel more relaxed and comfortable in the company of fellow group members than they would do in a group of strangers.

On the basis of these criteria, five groups or projects across central Scotland were contacted and agreed to participate in the research project. In the letter inviting groups to participate, it was suggested that between eight and ten members would be the optimum number of participants. While some groups did reach or even exceed this number, for a variety of reasons including ill-health on the part of group members, some were substantially smaller.

Fife Mental Health Survivors Group.

This group was formed in 1994 and has its own office in Kirkcaldy in Fife. The group has produced a mission statement which states that ' Our philosophy is that services exist for the benefit of service users. We aim to empower users and carers to take the lead and with mutual support be actively involved in the development of mental health services. We aim to facilitate co-operation, understanding and the free flow of information between everyone involved in the mental health services' (Annual Report, 1995-96). In addition to annual reports and a regular newsletter, the group has produced a number of other publications, including a discussion paper on respite care, and has been actively involved in both consultation and campaigning activities within Fife. Four group members participated in the focus group discussion.

Ayr Action

Ayr Action for Mental Health is a registered charity which came into existence in Autumn 1987. Its aims and objectives are:

1. Pressing for and providing improved facilities for those in the Ayr area with continuing mental health needs.
2. Promoting and where possible providing an advocacy service for this group of people.
3. Co-operating wherever possible with other agencies both statutory and voluntary.
4. Improving public awareness of mental health problems.

More generally the stated philosophy of the project is 'to empower our members/users through involving them in decision making, planning and building confidence in other users' (Ayr Action, 1998). The mechanism for this is a committee made up mainly of service users with responsibility for issues of policy and finance and also a members' forum who are involved in planning day to day activities within the day centre in which the project is based. Eleven members participated in this focus group.

Eastwood Mental Health Forum

The forum meets regularly in a community centre in Eastwood, just south of Glasgow. Set up four years ago with assistance from the local mental health association, one of the first activities of the group was to conduct a survey of the needs of people with mental health problems in East Renfrewshire. This acted as a stimulus to both the local Health Board and Social Work Department who conducted a much larger survey which resulted in the setting up of a mental health project within Eastwood, employing six full-time workers. The Forum has been involved in several letter-writing campaigns to the local press and has good links with both health and social work professionals and also with a local councillor. Six Forum members attended the focus group in Eastwood.

People Need People

This group is based in Falkirk and meet several days a week in a local community education centre. With the assistance of a community education worker, part of whose remit involves working with people with mental health problems, the group has developed a range of activities including vocational activities such as word-processing; discussion groups; 'alternative' models of service provision, such as "Echos", a support group for people who hear voices; and some campaigning activity, though this has usually involved individual members, rather than the group as a whole. Seven members and their support worker attended this focus group.

Edinburgh Users Forum

This group meets regularly in the offices of the Edinburgh-based CAPS Project (Consultation and Advocacy Promotion Service) and its aims, as listed in the SUN User Group Directory, are 'collective advocacy and campaigning'. In fact, group members have been very actively involved over the past two years in a range of different campaigns, including the Scottish Trade Union Congress's campaign in 1997 against cuts in local authority and community-based services. In addition, several of EUF's leading members are heavily involved either as workers or as office bearers in several other user-led projects in the Edinburgh area, such as SUN and AdvoCard. Unfortunately, due to ill-health, only two group members and a CAPS worker were able to attend this focus group.

CONCLUSION

The aim of this chapter has been both to provide a description of the projects, individuals and groups who participated in this study and also to address some of the issues which their participation raises, in respect of their 'representativeness', for example. Through 'unpacking' these individual interviews and focus group discussions, chapters six to ten will attempt to identify the nature of the challenge posed by

individual users and the users movement collectively to dominant ideologies of mental ill-health, to the current organisation of mental health services and to the structural oppression experienced by service users. The starting point for this exploration will be the issue which, as we have seen in chapter three, lies at the heart of attempts to characterise mental health service users as 'a new social movement' but which is also seen as significant by many service users themselves - the issue of *language* and *identity*.

From the Patient to the Madperson: challenging a spoiled identity.

As noted in chapter three, the description of mental health users in Britain as a 'new social movement', analogous to the women's' movement or the gay movement, is one that was first suggested by Pilgrim and Rogers in a small-scale study of users' groups in Britain in the early 1990s (Pilgrim and Rogers, 1991). More recently, the term has been taken up again in research into user activities in the English context (Barnes and Shardlow, 1996; Barnes, 1997). That chapter highlighted the centrality of notions of *identity* within NSM theory and suggested some limitations of that concept as applied to mental health service users. This chapter will seek to continue and develop that discussion within the context of this thesis. What does this research tell us about how mental health user groups address the issue of identity ? Specifically, what is the significance of current debates over the most appropriate terminology for service users? Kotowicz has argued that

Psychiatry is more than just a branch of medicine. It is a vast edifice with an ideology, an attitude, and most of all, it is a language which shapes the reality it claims to describe (Kotowicz, 1997: 12).

To what extent, then, do debates within the users' movement about language represent a challenge to the dominant psychiatric paradigm ? Given the 'spoiled identity' (Goffman, 1968) that people with mental health problems have historically carried, challenges to that identity which seek to replace it with a more positive identity might be seen as a first step in challenging the wider stigma and oppression that they experience. Historically, such challenges have often been reflected in the language of the 'movements' - in the shift from 'Negro' to 'black' in the US civil rights movement in the 1960s, for example, or from 'homosexual' (or worse) to 'gay' in the later gay rights movement. An examination of changing terminology amongst users of mental

health services may therefore provide a useful indicator to some of the issues of identity referred to above.

At the same time, a word of caution is necessary. Language *is* a political issue and political struggles have almost always involved a struggle over language (Cameron, 1995). However, in recent years, an emphasis on changing language (as in the use of 'politically correct' terminology, for example) has sometimes become a substitute for changing more basic aspects of people's lives, leading to what one writer has called ' a vast overestimation of the role of language in bringing about social change and the attempt to substitute language reform for real reform' (Molyneux, 1993).

Consequently, in this chapter, I shall be more concerned with exploring the assumptions and ideologies underpinning changing terminologies than with the actual changes themselves and in the discussion at the end of the chapter, I shall attempt to locate the discussion on terminology within the wider context of the problems that people with mental health problems experience in day to day living.

FROM THE PATIENT TO - WHAT?

The issue of user identity was addressed in the first question put to both service users and project workers in the context of individual interviews. Respondents were informed that

Throughout this interview, I'll be referring to people with mental health problems as 'users'. However, terms such as patient or client or survivor or customer are also commonly used to describe people with mental health problems. Which, if any, of these terms do you think best describes people with mental health problems and why ?

Respondents were then provided with a card with the following terms randomly written on it:

patient, client, survivor, customer, user, other.

The following table indicates respondents' preferred responses.

TABLE 1 - PREFERRED TERMINOLOGY

PREFERRED TERM	USER RESPONDENTS	WORKER RESPONDENTS
patient	4	0
user	7	4
customer	0	1
client	2	0
survivor	8	1
member	3	2
more than one	6	4
other	12	6

Given that 'patient' has been the term traditionally used to describe people with mental health problems, reflecting the dominance of the biomedical model, I shall begin by outlining responses to this term before going on to consider responses to the others.

Patient

Only 4 respondents (7 %) selected *patient* as their preferred term. Of those who did, for one respondent (who was herself a former health professional), this clearly reflected not a positive choice but rather a recognition of what she perceived to be the realities of the situation:

The overall focus is still on symptoms and illness and treatment. As someone with a mental illness, I tend to feel I've been labelled a patient for ever. I'm so against labelling - I'm just someone with an illness. (Survivors' Poetry)

For others, 'patient' was seen as an appropriate term within the hospital setting, but inappropriate in other contexts. For a worker with one project

It depends on where they are. If they're in hospital, then patient; in a social work department, a client.

For another

The term patient would only apply in the context of treatment.

In general, however, 'patient' was seen - sometimes neutrally, sometimes pejoratively - as a 'clinical' term, reflecting the biomedical model. Most respondents saw it as implying *passivity, dependence, alienation* and above all *disempowerment*.

For a member of Survivors' Poetry, the term was 'too passive' while a Stepping Stones respondent felt it was 'too dependency-oriented'. One MDFS member felt it had 'connotations that 'you'll wait while someone else does something' while for another MDFS respondent, 'patient suggests the person can't help themselves'.

For others, the term connoted what Foucault has described as 'the gaze', 'a surveillance that makes it possible to qualify, to classify and to punish. It establishes over individuals a visibility through which one differentiates and judges them' (cited in Parton, 1991: 6-7):

Patient is much more medical - it plays into the idea of seeing someone in the context of their illness, rather than as a person in their own right. (Survivors' Poetry)

I don't like patient. You're saying to someone ' You're ill, I'm here to cure you'. You're not a person, you're an illness. (Stepping Stones)

Amongst those rejecting the term, however, the most common reason given was the power imbalance it implied:

Client and patient both head towards a disempowered status. (Scottish Users' Network)

Patient? No, that's a power thing. (Core Club)

These negative connotations of the term 'patient' were repeated at a later stage of the interview when respondents were asked to identify the ways in their project differed from traditional psychiatric services:

You're classed as a person, not as a patient. You've got rights. you're allowed to voice your opinions, whether they're right or not. (Core Club)

It doesn't talk about illness and it doesn't focus on illness. It doesn't treat people as patients, we're treated as ordinary human beings. (Survivors' Poetry)

You're treated like a patient in a day hospital. You're treated as if there's something wrong with you. You're not allowed to do things for yourself - they do things for you. (Core Club)

Two comments can be made regarding the response to this term. Firstly, despite the fact that only a very small number of respondents saw this as an appropriate term to describe people with mental health problems living in the community, 'patient' continues to be the preferred terminology at the level of national health policy, used for example in the most recent mental health legislation (the Mental Health (Patients in the

Community) Act, 1995) and also in the current White Paper on Health, reflecting the continuing dominance of biomedical approaches.

Secondly, while these comments may appear to imply a rejection of the notion of mental ill- health *per se* and its associated implications for social functioning, responses to other parts of the interview schedule do not support this conclusion. It seems, rather, that what *is* being rejected is *being defined* in terms of that mental ill- health - a 'spoiled identity'. A comment by Barham and Hayward on similar comments by interviewees in their study of people with mental health problems living in the community seems particularly apposite here:

It would be a mistake however to view comments of this type as necessarily implying a *denial* of the realities of mental illness. Often enough, what is being said is that though vulnerability to illness may be a persistent feature of a person's life, it does not follow that there is a need to speak about it, and draw attention to it, all the time (Barham and Hayward, 1995: 155).

Clearly if this is the case, then it raises questions about the limits of an identity politics which continues to define people in terms of their mental ill-health, albeit with a more positive identity, a point to which I shall return later.

Customer

As discussed in chapter one, the consumerist discourse of user involvement - the user as customer - has been extremely influential within policy discussions of service user involvement over the past decade. It can with justification be described as the 'official model' of user involvement, since its prescriptions have been enshrined in the NHS and Community Care Act and in subsequent policy guidance. One might assume then that many of the users in this study would have been persuaded to see themselves as customers. In fact, in the entire study, only two interviewees responded positively to the term:

I would veer between customer and client, because people are using a service, therefore they're customers or clients. Client has a professional or business meaning but I would veer towards customer. (GANET)

I quite like customer, I like the implications. Personally, I feel that all services should be person-centred. The person in hospital or wherever is the person with the income on his head and should be seen as such. (GANET)

For other respondents, however, the term was variously seen as too commercially-orientated, politically conservative or simply inappropriate:

Customer is not appropriate- we don't have choices. (SUN)

Customer is not a word I'd use very often - usually in relation to BT. (GANET)

Customer is meaningless. If we were given sufficient money, then we might be customers. (SUN)

Survivor and customer are respectively too left-wing and too right-wing. (SUN)

It seems that the realities of users' day to day experience of lack of resources and lack of choice may outweigh attempts by government to reconstruct them as consumers of mental health services.

User

The term 'user' or 'service user' is now commonly used to refer to people who are receiving services from health and social services and was also the term used within the current fieldwork to refer to people with mental health problems who were making use

of and/or were involved in decision-making within the projects studied. How did these respondents view the term?

Overall, user was seen as the least 'loaded' term, as well as being the term which emphasised the *common* nature of mental ill-health:

In my work, I use user' - the majority of people will use services at some point.
(SUN Executive member who also worked in the mental health field)

Users. We all use, have used, will use mental health services. (SUN)

User is the least biased- it doesn't go beyond the fact that people are engaging with services and that they are of use to them. (Survivors' Poetry)

The accepted word is user. (SUN)

Personally it's user. It's difficult because people outside can think of that as drug user but within the mental health field, user explains what people are trying to get - to USE the Charlie Reid Centre, for example, not as a customer. I've worked in the mental health field for ten years now and that seems to be the preferred term of the majority. Solicitors (or prostitutes) have clients, hospitals have patients, shops have customers. (Worker, Charlie Reid Centre)

The term most used and which I'm happy with is user or service user because that clarifies and defines people who are using services. The terms are used in different contexts e.g. someone may be a client in relation to help with the DSS but is also a user of services. (GANET)

At the same time, 'user' was seen by some as providing a distinct and acceptable *non-medical* identity for people with mental health problems but without the provocative undertones which some saw 'survivor' as having:

User is a very good one. Most people refer to users now. People who use that term tend to be in organisations like this, rather than medical organisations, where it's the doctor-patient system (Stepping Stones)

I tend to stick with user - it's the term I'm most comfortable with. User is allied to the user movement and it denotes a degree of strength. (SUN)

An Executive member of SUN concisely summed up what he saw as the strengths and limitations of the term as follows:

On a more general level, we use user because it's more commonly used. It has two advantages. Firstly, it's less exclusive. Survivor implies having survived both the mental health system and also survived mental health problems. People are at different stages and some don't yet feel that they have survived their mental health problems. Emotionally, I prefer survivor but user is less exclusive - like trade unionist, it's more role-specific. Its disadvantage is that there are many services that people don't *use* at all but are *abused* by them - that's a contradiction in reality. User implies you can be an actor *and* a user of services. In that sense it can be seen as positive i.e. what we would like to be. (SUN)

To summarise then, 'user' was favoured by this group of respondents as being the most commonly used; as neutral as opposed to stigmatising on the one hand or challenging; as bestowing a positive identity; and as suggesting an element of *active* choice, in contrast to the perceived passivity of the patient role.

Another group of respondents saw the term in a very different light however. In contrast to the SUN respondent above, 'user' implied passivity:

I don't like the word user because as users we're not putting anything in. (Core Club)

User has connotations and does not allow people to escape services.... I don't like the passivity of user or the others. (Worker, Stepping Stones.)

For others it was these connotations that made it unacceptable:

As a journalist, I know that the general public don't understand 'user' - it's associated with drug abuse. (Survivors Poetry)

User is a degrading word, it's too convenient, too easy for the medics to lump everyone together into this category. (MDFS)

At the same time, there was a recognition that it had become the accepted term:

Personally, I don't like the term 'user'. I wouldn't use that term about myself. For a lot of people, it has negative connotations but politically it is the word to use. (GANET)

Survivor

For some of those respondents who disliked the term 'user', 'survivor' offered a more positive alternative.

The term I use to describe my own experience is survivor - and that's about surviving the mental health system. In my work, I use 'user' - the majority of people will use services at some point. (SUN)

Here, it's member Survivor's a good one too - you'd like to think you've come through. Mental illness is a big trauma, you like to think that you've survived. (Core Club)

I like survivor. My favourite saying is 'We're still here - we've survived.' A lot of the people who have been through this project have had horrendous pasts. But we're here, we've got here - we wouldn't be here if we hadn't.
(Stepping Stones)

The ambiguities of the term were concisely summed up by the following respondent:

If I had to plump for one term, it would be survivor.... survivor has a good ring to it. In Survivors Poetry, the word means more than just a user of mental health services. It includes anyone who has had any kind of trauma in their lives, such as abuse, and also people with disabilities. Patient and client are too passive. Customer is too commercial. However, in the Survivors Poetry Scotland letterhead, it talks about 'survivors of the mental health system'. I think that might be counter-productive. There is a possibility that some people might think it means that the whole mental health system is wrong and destructive. I don't feel that. I am a survivor of mental illness and have had positive experiences of the mental health system as well as damaging experiences. It's a strong ongoing debate. Survivor doesn't have to mean a survivor of the mental health system. I should stress that the majority of people on SPS- staff and on committees, etc. - whom I have discussed this with do not currently agree that the letterhead sub-title should be changed. The view is that very bad things do still happen within the mental health system and that the concerns of SPS about this should be flagged up in a prominent way. I agree SPS should stand up for what it believes in - but I am not sure the subtitle represents the whole picture of what SPS is really about. The issue of the letterhead sub-title is being discussed in Survivors Poetry UK-wide.

(Survivors' Poetry)

I like the word survivor. In Stepping Stones we use the word member. User has connotations and does not allow people to escape services. Survivor means that someone can have an experience of mental illness and still be involved (as opposed to ex-user). It's a positive, fighting term. (Worker, Stepping Stones)

As with 'user', however, there were those for whom the term had very different connotations:

Survivor I hate. You've survived as in you're still living but not as you should be. It implies you've come out the other end - I haven't. (Stepping Stones)

There isn't a user-friendly term for users. Survivor and customer are respectively too left-wing and too right-wing. Survivor suggests that you've survived the system, while customer would raise the hackles of any liberal-minded person. The accepted word is user. (SUN)

Survivor is too emotive and a bit misunderstood - it creates problems in communication with professionals. (SUN)

Survivor is truly cringe-worthy. Survivor can apply to everyone in different aspects of their life. We all survive difficult situations and come out at the end. (MDFS)

I don't like survivor - I see it as a slightly aggressive term, that there is a system that people have come through, That's against them. It's rather aggressive. (GANET)

I hate survivor - it's too dramatic. It reminds you of an air crash. (MDFS)

These very different responses to the term 'survivor' highlight two important issues, which will be noted here and discussed in greater depth below. Firstly, the nature of mental ill-health. As noted above, the term 'survivor' is an ambiguous one - what exactly is it that has been survived? For some respondents, it was the experience of mental ill-health itself and for this group, the term implied that they had 'come

through', had triumphed over adversity. For others, however, this was not their experience. Mental ill-health was an ongoing problem, in which periods of 'wellness' were punctuated by frequent relapses and they had little sense of having 'survived' in terms of having come out the other end. Hence, to describe themselves as 'survivors' was both painful and inappropriate.

By contrast, for another group of respondents, the term referred not to their own mental ill-health but to having survived the mental health system. In this sense, 'survivor', as some of the comments above indicate, was generally perceived to be the most political term, in that it contained an implied critique of the mental health system in general and of psychiatry in particular. In a sense then, the different responses to the term reflect on the one hand the very different experiences of the mental health system that these respondents had had and on the other, current debates within the user movement regarding the attitude that users should take towards professionals and professional treatments.

Client

The term 'client' was rarely a first choice and where it was suggested, it was normally qualified by a 'maybe' or a 'probably'. Two respondents liked the term because of its connotations within their previous professions, namely law and tourism. More generally, where it was seen positively, this was because it was seen either as a fairly neutral term or alternatively as appropriate in the specific context of counselling activities:

The two safest terms perhaps to use are members when you're within an organisation and perhaps from the main service providers point of view, the word that's mainly used nowadays is client which is a bit impersonal but it's probably a safe one... there's no stigma to it. Client, well, you could be a client of a lawyer and I think these are probably the two least offensive terms in use at the moment. (Ayr Action)

Probably user and client. It takes away from any 'patient' notion.
(Charlie Reid Centre)

Client in certain contexts, for example in a counselling or a
benefits context, when it's a relationship of client of a specific
service. (Worker, Charlie Reid Centre)

For others, however, the connotations of 'client' with social work services made it a
less acceptable term:

Client and patient both head towards a disempowered status.
(SUN)

Patient and client are too passive. (Survivors' Poetry)

Client has become quite a negative term- the social work equivalent to policing
- and is discredited (SUN)

Member

Interestingly, in the context of a discussion of identity issues, the only term to which
no respondent objected was *member*. All of the projects in the study referred to their
'members'. Whereas the other terms may be seen as conferring an identity, as defining
an individual in terms of their mental health experience, membership confers no such
permanent identity; it is less *essentialist* than the other terms (Woodward, 1997). One
chooses to join a club or organisation and one may choose to leave; one may choose
also to join a host of other organisations at the same time. Obviously for some
respondents, the use of this term was purely contextual, and outwith the organisation
they might choose to refer to themselves as users or survivors. For others, however,
to define themselves as a member of a particular project or organisation was preferable
to using any of these other terms; outwith the organisation they were just 'people'.
'Member' is also the term employed within the growing International Clubhouse

Association to which the Core Club is affiliated and a worker there explained the rationale for using the term :

Here, it's members. I'm not keen on the term user. Other than in the club, just 'people'. Member has to do with ownership and there's also no stigma. I find the term quite empowering and it doesn't say you're using 'the services' or are going to be using them all your life. Ex-patients who instigated the Core Club decided on the term.

Similar comments were made by a Stepping Stones worker:

In Stepping Stones we use the word member. User has connotations and does not allow people to escape services. Survivor means that someone can have an experience of mental illness and still be involved (as opposed to ex-user). It's a positive, fighting term. Customer is just a misuse of the term and I wouldn't use any of the others. I don't like the passivity of user or the others. Stepping Stones uses member because people weren't comfortable with the different terms. People prefer the term 'member'. (Worker, Stepping Stones)

That the use of term is becoming more widespread nationally was suggested by a comment from a speaker in one of the focus groups:

In Manchester where I come from they've actually stopped using the word 'users' because nobody liked it, they thought it was associated with people who use drugs. So they actually changed it to member, but to me, member means that you are a member of an organisation. (Edinburgh Users Forum)

Other terms.

As Table 1 indicated, almost a third of respondents either opted for a term not on the card provided or found none of the terms satisfactory. Of the terms not on the card, although they tended only to be mentioned by two or three individuals, they are

interesting in highlighting the wide range of ideas currently being debated within the users' movement in what might be seen as a transitional period for mental health services and ideologies.

On the one hand there was the term 'people with the diagnosis'. This was suggested by members of only one organisation - Manic Depression Fellowship Scotland - and was unusual in that most respondents in this study were hostile to an emphasis on diagnosis which they saw as being the basis of labelling on the one hand and as obscuring the shifting nature of mental ill-health as a process on the other.

The medical model is based on diagnosis and people are labelled and not listened to. That's changing. But where people come into a project like this, they can trust and are listened to. They're also listened to in a way that is culturally sensitive and not pathologising. (Worker, Saheliya)

It's not just the diagnosis. I think it depends on what stage they're at. I mean like this time last year you wouldn't have got this out of me. I can't speak for other people but I myself at the moment am well, I'm feeling good about myself. I'm feeling good about things in general, so I'm able to detach and talk about these things knowing this is for the greater good. But it's not necessarily the actual diagnosis although it can be - it's more where they're at themselves. (Advocard)

As the following statements make clear, however, for some MDFS members, to speak of 'someone with the diagnosis' was seen as having the advantage of separating the person from the condition in a way which the other terms did not do:

Someone who doesn't accept the medical diagnosis is in denial. It's the person who has the diagnosis. Someone with epilepsy, for example, is a person with epilepsy, not an epileptic. (MDFS)

I like 'someone with the diagnosis' because it's factual. I don't like any of the others. The main thing for me is that people should be empowered to self-manage. (MDFS)

Again, as the pen-picture of this organisation in the previous chapter indicated, within MDFS an acceptance of the validity of diagnosis was combined with a strong emphasis on self-management and the development of non-medical strategies to deal with the condition. Nevertheless, it does seem to suggest an acceptance of the value of medical diagnosis that was not always shared by other respondents.

At the other end of the linguistic spectrum, the term 'madperson' was mentioned positively by some SUN respondents:

I like to talk about 'mad bastards' and users here as 'my loonies' - one thing I like about that language is that the psychiatrists hate it. (SUN member)

There are other terms like 'mad' - equivalent to the use of 'dykes' in the gay and lesbian movement. That's the most enjoyable term - especially with psychiatrists. I think it's great to use the word 'mad' - we have 'Glad to be Mad' tee-shirts. 'Mad' also has the double -meaning of 'angry'. 'Mad' has lost much of its former stigma - 'mentally ill' and 'insane' now carry that stigma. (SUN member).

The rationale for using this term was provided by a member of Edinburgh Users' Forum:

There was all this thing about the distinction between mad and bad, like you know, these people that have murdered, and it'll say on the news that the person was sick , mentally ill. Then there's the sort of stereo-types that all people with mental illness are doing these sorts of things, so it's to distinguish between being bad and being mad, and mad isn't necessarily bad - mad could be bad or bad could be mad but it's not necessarily true, but yea, we use that

word which I must admit some people still cringe at - not within the user movement but certainly when I say to friends outside 'Oh, I'm mad. I accept it and I'm not ashamed of it', they say 'What? You're admitting that you're mad?' but I think like J. said, you take a word, that's your word.

The belief that terms of oppression can be 'appropriated' by the oppressed and turned against the oppressor is a fairly common one within a number of the 'new social movements'. The leading organisation of gay men in the USA, for example, calls itself 'Queer Nation', a deliberate 'appropriation' of a term of anti-homosexual abuse. At one level, it can be argued that such an attempt to appropriate language represents a defiant and admirable refusal to accept the stigma implicit in certain terms. A high point of the popular 1996 television series 'Taking Over the Asylum', for example, was a demonstration organised by psychiatric patients under the slogan 'We are loonies and we are proud'. Against this, it has been argued that not only does using such 'politically correct' language reflect an exaggerated belief in the power of language to change people's actual living conditions but it may also be regarded by most people as an *acceptance* of oppression, rather than a means of challenging it (Smith, 1994). In respect of mental health service users, there is the additional issue of the extent to which it is possible to embrace a 'user' identity in the same way as a gay or black identity, an issue we shall return to later.

Finally, there were those who saw no term as being particularly useful. As noted, the largest group of people were those who found none of these terms useful but even those who did opt for a particular term often did so reluctantly. The following comments are fairly typical:

When I first heard user, I thought 'crap'. It suggests taking things and not giving anything back. I would only use patient if it was technically necessary. Customer sometimes, but there's no satisfactory word. I would sometimes use participant but it's a bit long. Whenever possible, I refer to people as members. (SUN)

'People with mental health difficulties' is in some ways the best of all - it covers a wide range of people. (SUN)

I think it creates awkwardness more than anything. I mean you could go in and introduce yourself and go well hi, I'm Joe Bloggs and I'm a user of services...it's just a horrible, horrible term then you find 'somebody with a mental illness' and then you think, God, I don't want to say I've got an illness and you say 'I've got mental health problems' or 'I've got mental health difficulties'. I don't care. (Eastwood Mental Health Forum)

This is one of the debates I'm engaged in. There's no clear answer. If I had to plump for one term, it would be survivor. None of these terms are satisfactory. (Survivors Poetry)

None of these terms is adequate to describe the needs of people with mental health problems who have to turn to others for help. (Worker, AdvoCard)

The recognition, implicit in several of the above comments, that each of these terms might simply be a new 'label' which continued to define people primarily in terms of their mental health problems was something of which workers and service users in Saheliya were particularly conscious:

People who come here as users, though they may suffer from depression or anxiety or whatever, we look on them as women, we don't label them. In our culture, if someone is given a label, people will look down on them and their self-esteem will be lower. (Saheliya, worker)

THE SIGNIFICANCE OF LANGUAGE.

What conclusions can be drawn from the above discussion of changing terminology? At the most general level, the discussion appears to highlight the *transitional* nature of

both mental health services and mental health ideologies. The era of the 'career mental patient' may be over but as yet it is not clear what will replace it. As Barham and Hayward have noted

The condition of the mental patient in the asylum was marked, among other aspects, by the loss of civic agency; one of the critical tasks now is to assist in the creation of meaningful civic identities (Barham and Hayward. 1995: 157).

More specifically, two points in particular seem to stand out. On the one hand, there appears to be an overwhelming rejection by these respondents of the disempowering aspects of the biomedical model of mental ill-health, as reflected, for example, in the criticisms of the term 'patient'. It might have been assumed that with the decline of the asylum, this model would in any event become less influential but this may prove to be a questionable assumption. Certainly within the US context, far from the process of 'deinstitutionalisation' having lessened the grip of biomedical psychiatry, it has, if anything, strengthened it, reflecting in part the influence of multinational drug companies (Breggin, 1993), while in Britain, the 'hospital in the community' model of mental health community care appears to be gaining ground (Roger, Pilgrim and Lacey, 1993). At the same time, it should be noted that what is primarily being rejected by the respondents in this study is the *dominance* of this model and the *power relations* it entails, rather than biomedical involvement or expertise *per se*. As we shall see in subsequent chapters, many users saw a continuing role for mental health professionals and treatments but within a more holistic, partnership-based mental health service.

The second notable point arising from the discussion is the lack of consensus regarding a preferred term for people with mental health problems. As well as reflecting the current transitional state of mental health services and of mental health ideologies referred to above, it may also be that the lack of an agreed term reflects more profound issues about the nature of 'a mental health' identity, issues which may have implications for the applicability of identity politics in general and a social model

of health in particular to mental health users. These issues will be explored in the following section.

TOWARDS A MENTAL HEALTH IDENTITY?

In this section, I shall explore some of the difficulties associated with the notion of a 'mental health' identity before suggesting what the basis of such an identity might be.

A positive identity?

A common feature of earlier NSMs has been their inversion of a previously stigmatised or devalued characteristic, relating to skin colour or gender or sexual orientation for example, and reclaiming that characteristic as the basis for a new and positive identity. Obvious examples would include slogans such as 'Black Power' or 'Gay Pride'. A similar process has taken place within the disability movement, although as noted in chapter 3, debates have taken place between those who have seen disability as *wholly* socially constructed, and those who have argued that impairment in itself continues to be a handicap, regardless of social structures and constructs. It is much harder, however, to 'invert' mental ill-health, however conceptualised, in this way. As Sedgewick noted, for virtually all psychiatric schools, whether Freudian, Jungian or biomedical, mental ill-health in general, and psychosis in particular, is 'breakdown, sheer affliction' (Sedgewick, 1982: 98), while even R.D. Laing in his later writings argued

I never idealized mental suffering, or romanticised despair, dissolution torture or terror... I have never denied the existence of patterns of mind and conduct that are excruciating (Laing, 1985: 8-9).

Even the language of mental ill- health or mental distress is evaluative, as neither mental illness nor mental distress (the term more commonly used within the users' movement) are usually regarded as desirable or sought-after states. Within this study, there was an implicit assumption (as well as many explicit statements) on the part of

most, if not all, respondents that mental ill-health *impaired* functioning at the level of feeling, cognition, and behaviour. To repeat a comment made by an AdvoCard worker

None of these terms is adequate to describe the needs of people with mental health problems who have to turn to others for help. (Worker, AdvoCard)

Hence the limits of 'Glad to be Mad'. Mental ill-health for these respondents was a state which might be learned from but hardly one to be actively sought. One worker defined a major aim of her organisation as being

To help people with the illness and their friends and family not just to manage the illness but also to move away from it. Personally, I think it's good for people with the illness to move away from it and not become professional manic-depressives. (MDFS)

A permanent identity?

Members of other social movements have tended to base identity on an *enduring* characteristic such as skin colour or gender or disability. By contrast, for the majority of people who experience mental ill-health, it is likely to be of a *transient* nature. Even for those in this study who experienced frequent relapses, mental ill-health was nevertheless a *process* from 'good health' to 'ill-health' and back again. Hence the dissatisfaction expressed by some respondents regarding the term 'survivor'. It implied a finality or resolution that they did not recognise. On the positive side, it was this fluctuating nature of mental ill-health that allowed many users (or former users) to play a major role in running organisations, and also provided the basis for a critique of medical labelling which saw people as always ill. From the perspective of identity politics, however, this lack of permanence plus the very real stigma associated with mental -ill-health, means that few are likely to wish to 'come out' as service users, let alone be identified as permanent 'users', committed to the building of a users' movement. To do so would be to risk job, house, family and friendships.

Social construct or immanent condition?

A recent text on identity politics has suggested a polarisation in current social theory between those who see identities as socially constructed and those who see them as rooted in biology (Woodward, 1997). The current discussion would suggest that, as far as making sense of mental ill-health goes neither of these polarities is adequate, that as Barham and Hayward argue in their discussion of the issues facing mental health users in the community, 'neither biological reductionism nor an exclusive social constructivism constitute viable intellectual positions' (Barham and Hayward, 1995: 167). As the discussion around the term 'survivor', indicates, for example, being a 'person with a mental health problem' involves *both* social construct *and* individual experience with profound implications for social functioning, some of which are socially constructed, others of which flow from the experience itself. The issue for the respondents in this study was not *whether* help was needed when people were experiencing mental distress but rather the *type* of help that was on offer and the power relations within which it was offered. As we shall see in subsequent chapters, and as the discussion around the term 'patient' suggests, the clash identified by service users is often between the personal experience of distress and the professional construction of that distress, a distinction which Barham and Hayward correctly describe as 'enormously important'.

An implication of this is that it may not be possible for users of mental health services simply to 'take over' the social model of disability which has been central in the development of the disability movement, since for example, the issue of the type of services on offer and the user's relationship with them is likely to be of greater importance for a user of mental health services than for a disabled person.

A shared identity?

For Woodward, identity politics

involves claiming one's identity as a member of ...[a]... marginalised group as a political point of departure and thus identity becomes a major factor in political mobilization (Ibid.:p. 24).

In essence, this approach involves singling out one aspect of one's experience , such as gender or sexual orientation, and making that the basis of a shared identity. In respect of mental ill-health, the above discussion highlights the difficulties in agreeing on what constitutes a 'shared identity' for people with mental health problems. Who, in other words, is a 'user'? On the one hand, one could adopt a *broadly*-based definition of a mental health identity, based purely on the *experience* of mental ill-health and/or using 'services', however defined; on the other, 'user' could be defined far more exclusively, on the basis of having being hospitalised, for example, of having a psychotic condition. If one adopts the first definition, one would include between a seventh and a quarter of the population of Britain; if the latter, one risks excluding millions of people who are by any criterion experiencing mental distress, while at the same time basing the movement on the most disabled people.

In addition, as noted in chapter three, this approach has been criticised by a number of writers on the grounds that the structural divisions that shape most people's lives , such as class, race and gender are *objective*, not subjective. Without a clear analysis of the social and economic roots of the stigma and oppression experienced by people with mental health problems, of the sort that I have attempted to provide in chapter three, then there is danger that discussions around issues of stigma and oppression will become hopelessly subjective and relativist.

THE USER CHALLENGE

In the preceding section, I have suggested some of the limitations of attempting to develop a 'mental health' identity. This should not be taken to imply, however, that the debates around terminology or the critique of the biomedical model are either unimportant or without significance and in this final section, I wish to look more positively at the *challenge* posed by these debates.

If, as Foucault has argued, the rise of the asylum meant the end of any dialogue between 'Reason' and 'Unreason', and the treatment of the 'madperson' as 'the Other', then by contrast, the dominant discourse in these interviews and discussions is a *normalising* discourse (Barham and Hayward, 1995). Respondents main objection to the medical model, as reflected around the discussion of the term 'patient', was precisely that it defined them as 'other' than normal people, when in fact, they were simply 'people with mental health problems'. The challenge here is two-fold. On the one hand, it poses a challenge to dominant media representations and popular perceptions of mental ill-health as being a source of shame or danger (Philo, 1996). A willingness on the part of service users or former service users to 'come out' begins to create the conditions for a public debate not only about the type of services that should be developed but also about the factors that lead to mental ill-health in the first place. Given the current critique of mental health community care and the growing dominance of the 'dangerousness' discourse, the user discourse becomes particularly important as a counter to (quite literally) reactionary trends in mental health care (Observer, 19/4/98).

On the other hand, it poses a challenge to the medical dominance of mental health services, since the needs of the 'person' with the mental health problem are likely to be far more holistic than is normally acknowledged by psychiatric interventions. That said, as Barham and Hayward have noted, a danger of the 'person with mental health problems' discourse is that it can fit well with the current critique of 'welfarism', leading to a removal of specialist services for the most disabled people on the grounds that these create dependency, or the 'encouragement' of service users to work (through the removal of Disability Living Allowance, for example), in a way which ignores the reality of their mental health problems and the implications, both personal and financial, of relapse.

What service users want from mental health services, and the kind of relationships they wish to have with mental health professionals, are issues explored more fully in the next chapter. From the above discussion of terminology, however, objections to

the dominant medical model included: the tendency on the part of professionals to see people primarily in the context of their illness - the 'clinical gaze'; the power imbalance within the professional/user relationship; a tendency on the part of professionals to discount not only the views but also the abilities of service users; and finally, the failure to see mental ill-health as above all a *process*, involving different needs at different stages as well as being something from which most people emerge. The notion of process is a central one in mental ill-health: part of the debate around terminology, for example, stems from a failure to recognise that people may be at different stages in their ill-health (from 'patient' to 'survivor'), something that is frequently not reflected either in the services that are provided or in the power imbalances within professional/user relationships.

LANGUAGE IN CONTEXT

As noted in chapter three, and again at the beginning of this chapter, language has been given a central role in recent years both within social theory and also within new social movements. An issue specifically addressed, therefore, in the focus groups was the extent to which respondents in this study saw the issue of terminology as an important one. This was done both directly, by posing this question to focus group members, and also indirectly, by asking members to identify what they saw as the major problems faced by service users living in the community. While respondents' comments will be considered in greater detail in chapter ten in the context of a discussion of collective responses to the problems experienced by users, some preliminary discussion of their assessment of the relative significance of issues of language and terminology seems appropriate at this point.

In at least two of the groups, the issue of language was seen as an important one, in terms of reflecting 'internalised' stigma. The use of particular terms was seen (negatively) as reflecting a 'mental health identity'.

I think this is an important issue because it's a case of how people feel about themselves as to the terminology that's used and I sometimes cringe because in

one of the day centres... I've heard a number of them saying 'Are you a patient?' and you know, I cringe at that, that people see themselves as patients even outwith the hospital and it's fairly common.

(Fife Mental Health Survivors' Group)

In the same discussion, another service user commented:

John (to Eric): You told me a story once about somebody who was being introduced to somebody else and apparently he said, 'I'm so and so and I'm a manic depressive' and this guy must be stamped as, you know, 'I am a manic depressive'.

Mary: And we have so and so coming here and saying, 'I'm so and so and I'm a community care patient' - almost as if that goes with their name and it doesn't. If someone's been in hospital a long time, I mean they're hospital patients, then they become them and if no-one challenges that attitude, you lose sort of self respect. And how then how do you get somebody to integrate and feel that they are just a normal member of society? And then there's the stigma because they're feeling the stigma very much...

Iain F.: It's an ongoing debate

Mary: It is but it's worth debating it

Eric: I think it's important.

(Fife Mental Health Survivors' Group)

A worker with Edinburgh Users' Forum highlighted what he saw as the *political* importance of the discussion:

Well, for me as a worker when I hear people describe themselves as survivors I see this as being a very political statement. You know some of us were down at Scarborough at the MIND Conference the week before last and there was a little bit of debate flying around about should the word survivor be differentiated from user? As a worker I

find it important that people begin having that debate to try to unpack some issues but I think survivor/user, to look at what the words represents, for me it's means more than just semantics - it carries a political, social weight as well as just simple language issue.

A service user from that group, however, expressed a more qualified view:

I think I think it important to have discussions about terminology but not to let them dominate if there's more pressing things to talk about. At the end of the day there's always going to be its always going to be a term that someone doesn't like.

Similar views were expressed in the individual discussions. The issue was seen as important insofar as it reflected stigma but could also be a diversion:

Users. We all use, have used, will use mental health services. We could spend all day arguing about names - it's an issue for some people. (SUN)

Significantly, where focus group members were asked to identify what they saw as the major problems facing users in the community, language or terminology was never mentioned directly. 'Other people's attitudes', however, were mentioned as a major problem in every group, which fed into every aspect of people's lives, including employment .

By contrast, *material* problems such as poverty, lack of appropriate services such as crisis centres, lack of information and loneliness were high on people's lists of problems in daily living. Finally, a number of respondents suggested that the problems users faced varied depending on the state of their health:

It is very difficult for me to do it [comment on a list of suggested problems-IF] because such has been the extent of my recovery that a lot of these things are not a problem to me personally. (Fife Mental Health Survivors)

For others, the problems fed into each other and what was the major problem varied depending on among other things their stage in the life cycle:

It's funny - I mean they all feed on one another...it is a vicious circle. I suppose right at the top it is inappropriate services and lack of information which then fuels other people's attitudes which then fuels the loneliness, poverty and hence lack of employment. It's funny, I'm seeing that as the end of a cycle but not less important.... I think it very much depends what stage people were at in their lives at which point in the cycle people come into it at. I think that all the factors do have an effect on people at some point in time - it's just a matter of when. (Eastwood Action Group)

Thus, issues of stigma; material problems of lack of services and poverty; and the need for services which addressed people's needs at different stages of their ill-health and their social position were all seen as central and, by some users at least, as far more important than issues of language and terminology.

Conclusions

Two related issues emerge from the discussion of identity and language in this chapter. On the one hand, a common thread running through many comments is the critique, both implicit and explicit, of the dominant biomedical model of mental ill-health, reflected for example in attitudes towards the term 'patient'. At the heart of that critique is the perceived tendency of that model to define individuals primarily in terms of their mental health problem.

Paradoxically, it is that same reluctance to be defined in this way that gives rise to the second issue to emerge from the discussion, viz., the limits of an identity politics paradigm. In the words of the member of Survivors' Poetry quoted above:

As someone with a mental illness, I tend to feel I've been labelled a patient for ever. I'm so against labelling - I'm just someone with an illness.

What appears to be emerging then is a paradigm which in some of its aspects can be described as *oppositional* in respect of biomedical models of mental health but which at the same time does not sit easily within a framework of identity politics. To that extent, the discussion in this chapter appears to confirm some of the limitations of 'new social movement' perspectives in general and their emphasis on identity in particular in respect of mental health service users already noted in chapter three.

The next chapter will continue the exploration of this emerging paradigm by focusing on the relationships between users of mental health services and the professional mental health workers who provide - and have traditionally controlled - these services.

Redefining Professionalism.

Within the disability movement, supporters of the social model of disability have tended to be hostile to medical professionals and professional interventions on the grounds that disability is primarily a problem of social organisation, not of individual impairment, a fact that is often obscured or denied by medical or paramedical professionals whose main concern is to restore the person to 'normality':

...the medical profession, because of its power and dominance, has spawned a whole range of pseudo-professions in its own image: occupational therapy, speech therapy, clinical psychology; each one geared to the same aim: the restoration of normality. And each one of these pseudo-professions develops its own knowledge base and set of skills to facilitate this. They organise their interventions and intrusions on the basis of discreet and limited knowledge and skills (Oliver, 1996: 37).

This chapter will explore the attitudes of mental health service users towards professional mental health workers. Activists within the mental health users movement in Britain have noted the positive role played by some professional workers in building the movement over the last decade (Lawson, 1991), in contrast to the more negative experience of the US movement (Chamberlin, 1988). To what extent, however, did this more positive attitude extend towards the role played by such workers in the provision of services? How did respondents in this study view their relationship with such workers? To what extent, for example, should mental health services be controlled by them? What skills or qualities should they possess? And how important is it that they themselves should have experienced mental ill-health? Each of these areas will be considered in turn.

PROFESSIONAL DOMINATION OF MENTAL HEALTH SERVICES

The issue of *power* in mental health services is one that has tended to be obscured or denied by liberal evolutionist accounts of psychiatry which see psychiatric interventions as essentially benign and therapeutic and which view the history of psychiatry as a history of more or less steady progress (see e.g. Jones, 1972). Sedgewick characterises such views as tending to

treat the social past as a slope tending towards the medical present, which becomes the apex of all previous endeavours: an incomplete and provisional peak, to be sure, but one whose incompleteness does not mar the grand conception of the long ascent itself (Sedgewick, 1982: 129).

An example of the way in which such a view can lead to the denial of the patient or user experience be found in a recent historical study of a Glasgow psychiatric hospital. After detailing the ways in which patients' complaints over the past one hundred and fifty years were often dismissed and ignored by medical and nursing staff, these writers conclude, with no supporting evidence whatsoever, that

Clearly, of course, many patients' complaints were delusional, overblown and symptomatic. Some made a career of making demands, whether for changes in their circumstances or removal, which could neither reasonably or safely be met (Andrews and Smith, 1993: 108-109).

Such Whiggish perspectives of psychiatric progress and benign intervention were challenged initially by the anti-psychiatry movement of the 1960s and 1970s and more recently by the development of the mental health users' movement. The focus of the current chapter is on the nature and extent of this current challenge to professional (and especially psychiatric) domination of mental health services.

As a first step towards exploring this issue, respondents in the present study were asked to rate and respond to the following statement:

'Professionally-trained mental health workers are the best people to decide the kind of services that users of mental health services should receive.'

TABLE 2 - PROFESSIONAL DOMINATION OF SERVICES

Count Column Percent in brackets	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	8 (19%)	7 (38.9%)
Disagree	19 (45.2%)	11 (61.1%)
Can't decide	7 (16.7%)	0
Agree	6 (14.3%)	0
Strongly Agree	2 (4.8%)	0
Column Total	42	18

As the table shows, the majority of both user and worker respondents either disagreed or strongly disagreed with this statement. Interestingly, however, of that minority of respondents who were either unable to decide or who agreed with this statement, *all* were service users, with all worker respondents disagreeing or strongly disagreeing. In general, the responses of those who disagreed with the statement can be grouped into two main categories: i) *negative* responses which were primarily critical of medical interventions and/or the medical model ii) *positive* responses which

emphasised the centrality of experience of mental ill-health and the mental health system. User responses will be considered first, followed by worker responses.

Service user responses

i) The critique of the medical model.

While many respondents rejected the statement on the basis that it neglected the experience of users, others did so on the basis that it painted far too positive a picture of professional knowledge and expertise. Occasionally, such criticisms were based on individuals' personal experience:

Professionals in day hospitals, they get their say, they decide what's going to happen to you. I think the person himself should have much more say about medication, etc. I've been through the system and the professionals all got it wrong till I came to Fife and the Core Club. Now I can have my say. (Core Club)

My experience of the mental health system is that patient's interests often come last. There are so many things staff have to take account of that they can't always see what patients need or would be best for them. The person who has the problem is the one who knows what's best for them but before I encountered Survivors' Poetry, I wouldn't have known that ! (SPS)

Education is great, training, etc. but just because they're educated doesn't mean they're real people....I see them making very many mistakes, blowing it. I would love to think that somewhere, they're doing something right. (Charlie Reid Centre)

The failure of professionals to take account of cultural issues was particularly highlighted by users from the Saheliya project:

Professionals can miss out. They can be biased in their attitude because of their background and culture, they can be patronising. If they understand the background culture, that helps a lot.

At a more general level, criticisms focused both on the disempowering aspects of the model suggested by the statement and also on the failure of professionals to respond to people's needs in a holistic way:

That's the model that the users movement was formed to oppose. That's what creates mental illness. Losing sight of personal worth, taking away personal autonomy - that makes mental health problems worse. That model belittles and infantilises. (SUN)

The doctors think they know everything but they don't know everything. Doctors try to cure by chemical means alone and chemical means don't always work. I don't condemn them - they're a necessary evil - but they need to work together with services like GAMH [Glasgow Association for Mental Health - IF]. (SPS)

ii) The centrality of experience .

In their study of the mental health users movement, Rogers and Pilgrim note that

The most salient unifying principle articulated in the interviews was the *experience* of being a patient (Rogers and Pilgrim, 1991: 135).

That point also applies in respect of this study. Numerous respondents disagreed with the statement on the basis that it devalued or denied the knowledge of service users themselves.

People who use services have much more knowledge about the services they want and need to use (SUN)

At the end of the day the people who are receiving or have received treatment can look back at it from the perspective of experience and are allowed within some framework to arrive at a consensus as to how services should structure themselves. (Charlie Reid Centre)

They haven't been there. They have a lot of knowledge but they don't really know anything. You need to have been there to know what you're talking about. (Stepping Stones)

It's like who's best to counsel someone who has gone through a divorce is another person who's been through a divorce. Similarly, the person with mental health problems is best. (AdvoCard)

Worker responses

As noted above, workers were even more emphatic than service users in rejecting the notion that services should be professionally controlled, with the theme of *partnership* running through several responses:

Disagree. One of my favourite books is 'To Kill a Mockingbird' by Harper Lee. There's one character says ' You never really know how someone feels till you step inside their shoes' and that's exactly how I feel about mental health. The only people who really know about mental health problems are those who have had them. (Worker, Charlie Reid Centre)

People who have experienced psychiatric services have so much insight into which bits have worked and which bits haven't worked. I don't see how you could learn that as an outsider. (Worker, AdvoCard)

The one who is in the situation knows what is best for the situation. That's why here, the user has a say in everything that happens. It depends on how severely

ill the person is. If he can't decide, then of course you have to take steps yourself. (Worker, Saheliya)

They have a role to play but they are not the best people. There is no one 'best' group. There should be a consensus approach. (Worker, Stepping Stones)

Disagree. It must be in consultation with users, who should have power in decision-making. Other people - such as carers - should also be involved in the process. Mental health shouldn't be a specialism - it overlaps boundaries. (Worker, SPS).

Challenging professional knowledge and expertise.

How should the challenge to professional knowledge and expertise evident in these respondents' comments be understood? Some writers have seen such a challenge as characteristic of 'the postmodern', in which

knowledge is no longer limited to a rational system defining laws and certainties and constructing overarching ideologies and interpretations of history and culture. Instead, knowledge is seen as highly relative, more democratic, local and individualized...Professionals, as part of elite culture and as guardians of the types of knowledge which are now being revalued, may either feel threatened or they may welcome a more equal partnership with users (Wilson, 1995:4).

While superficially attractive, in fact the challenge to medical and psychiatric expertise in recent years has come from a much wider range of sources - material, ideological, scientific and professional - than is suggested by portraying that challenge as the working-out of some underlying postmodern *zeitgeist* (Gabe, Kelleher and Williams, 1994; Bentall, 1990). Similarly, in respect of social work, as I argued in chapter two, notions of citizen involvement have a long history, dating back at least to the Seeborn Report of the mid-1960s while once again the critique of professional power and

expertise has come from several different directions (Clarke, 1993). As against such reductionism and oversimplification, what is necessary is to look at what is *specific* about the critique of professional power and expertise contained in the respondents' comments above. Two main points stand out.

First, in contrast to the dominant view of mental ill-health as a wholly negative experience, for these respondents, the experience of having had mental health problems is seen as something that can be reflected upon, learned from and drawn on in the development of services. Thus the experience can be a valuable one, not in the sense sometimes (and wrongly) attributed to R.D. Laing that mental illness is a desirable experience in itself (Kotowicz, 1997), but rather that the experience can be put to good use.

Second, the capacity for such reflection assumes that if there are periods when people will be unable due to poor mental health to reflect on their experiences in this way, there are also periods when they can. Thus, unlike physical impairment which will often (though not always) be a relatively stable condition, mental ill-health is seen as a *process*, with people going through periods of being 'well' and 'unwell', however these terms are defined. When they are well, not only can they reflect on their own experience but they are also able to contribute to the management and development of services. Sedgewick's comments in chapter five regarding the 'lucid periods' experienced by the vast majority of people with mental health problems are relevant here. (This is not to suggest, of course, that people should not also be listened to when they are unwell, although in some cases, as Rogers, Pilgrim and Lacey note, 'the meaning of distressed behaviour may remain permanently elusive' (1993: 20). Nor should it be taken to mean that respondents were necessarily happy with current mental services and interventions in periods when they *are* unwell).

The implications of constructing mental ill-health as a process are twofold. On the one hand, it challenges the tendency, referred to again and again by respondents in this study, on the part of mental health professionals to treat people as if they are unwell *all*

the time, and to discount their views and experience on this basis. It is the fact that mental ill-health is *not* like this that makes user involvement possible.

On the other hand, it involves the acknowledgement, implicit in some of the above statements, that there are periods when, as a result of mental ill-health, people's judgement *is* impaired and that that impairment has implications for their ability to make decisions (as well as, incidentally, pointing to the need for a *range* of services, including acute psychiatric and also crisis services - a point to which I shall return in the final chapter).

Chapter nine will explore some of the issues and dilemmas which such impairment gives rise to in user-led projects and the ways in which such dilemmas are managed. In the context of the current discussion, many respondents felt that particularly during periods of mental impairment, there was an important role for mental health professionals, although not necessarily the role that they play at present. Thus, one Core Club member disagreed with the statement on professional control of services but added

It might apply to the hospital setting where staff need to be clinically trained. Sometimes you are so ill when you go into hospital, they have to work around you. They decide what's best for you. I found hospital good. The nurses' main job is to listen to you in a psychiatric hospital.

The notion of mental health ill-health as a process with different supports and services required at different stages was also evident in comments of other respondents:

They tend to be the best at deciding your care when you are ill, but once you're not ill, they are not the best people. In hospital, as regards knowing what is the appropriate medication, for example, I'd rather have a psychiatrist doing that.
(Core Club)

I agree to some extent in that while you're really ill, you do need professional help, but you also need groups like ours when people are getting better. we can stop them getting worse, stop them going into hospital. (Stepping Stones)

The recognition that mental ill-health, however defined, impaired social functioning was also important for workers and volunteer advocates in the community setting:

The best person is the user himself but in some cases that isn't possible. For example, a guy here had been hearing voices but the psychiatrists and the social workers weren't listening. He had asked for his medication to be put up. The representative went along with the cardholder to the psychiatrist and he agreed to put up the medication. (AdvoCard)

While many of the above respondents were critical both of the medical model in general and of the actions of specific professionals in particular, none argued that there was no role whatsoever for professionals within mental health services. What qualities and skills, however, did service users value in professionals? How important was professional training? And how important was it that professionals had themselves experienced mental health problems? It is these three areas that will be explored for the remainder of this chapter.

QUALITIES AND SKILLS OF PROFESSIONALS

Respondents were asked the question '**What are the most important skills and knowledge that paid workers in a project like this should have ?**' It is important to note that the question directed respondents towards community-based projects, or even towards their own project, rather than towards mental health services in general, including psychiatric services. Thus, the fact that, as we shall see, very few respondents made any reference to medical or nursing skills and knowledge, such as diagnostic ability, knowledge of symptoms, or skills in administering medication, needs therefore to be treated with some caution.

Responses will be grouped under the headings of knowledge; specific skills; people skills; and worker values, with users' responses once again being considered first, followed by workers' responses.

User responses

i) Knowledge.

Very few users made reference to 'knowledge', in the sense of expertise in a specific knowledge base. In the small number of cases where knowledge was referred to, it generally meant a broad knowledge of mental health issues, including management of particular behaviours:

Ability to cope with circumstances regarding the situation of users - if somebody became ill, for example. They've got to be trained and have a grasp of what's going on, of psychological and mental welfare. If someone's depressed, or hearing voices, for example, they have to be able to make decisions. (Core Club)

How to deal with mental health people having panic attacks. A friend takes quite a few and nobody else in the group knew what to do. I knew but workers have to know what to look out for...Also, knowledge of the services that are available. (Stepping Stones)

In terms of the source of that knowledge, personal experience tended to be valued more highly than 'book-learning' which was often looked down on and occasionally seen as a positive disadvantage:

You need people who can relate and who know when there's something wrong. It's not about books. Books should go out the window. You don't have to be a brainy person. You need to be able to interact with members. (Charlie Reid Centre)

Not to have read too many books and not experienced mental illness themselves ... Workers need re-educating, social workers in particular. The training of social workers doesn't teach them to listen to people. (AdvoCard)

Self-knowledge, by contrast, was highly valued by one respondent:

I would look for someone who had dealt with their own stuff, who was able to see themselves as real and having some ability to be conversant with people and hear what they're saying. To be able to listen to people, to be able to separate themselves from what the other person is saying and maybe that's where their worth would come out. I would look for creativity in these people. (Charlie Reid Centre)

Once again, there is an emphasis on experience, coupled with what on the surface appears to be almost an anti-intellectualism. The strengths and weaknesses of this reliance on experience will be discussed later in this chapter, but given the ways in which many of these users have experienced psychiatric and other knowledges being used in an *oppressive* fashion, as a way of *not* listening, it is perhaps not so surprising that they should be so hostile towards it. (Whether, of course, knowledge *has* to have this oppressive quality is a question I have already addressed in chapter four).

ii) Specific Skills.

A range of specific skills, some of a general nature, others uniquely relevant to particular projects, were mentioned by several respondents. One respondent who was also a worker in another project suggested

Organisational ability; knowledge of working structures; creation of effective information networks. They won't have the same knowledge of the service as users but they can bring organisational strengths. They can form the backbone of the service. (SUN)

Management skills; communication skills; people skills; finance skills; computing skills; journalistic skills; and networking skills.(MDFS)

For a member of SPS

A spectrum of skills and knowledge is required to establish a new charity, especially one in the area of mental health and the arts. What's required are skills in organisation, PR, fund-raising, teaching writing and performing, together with liaison, communication, organisation and planning skills.

iii) 'Peopleskills'.

If user respondents had little to say in respect of the knowledge base required by workers, by contrast, what one worker described as 'peopleskills', such as listening, empathy, communication skills and the need for a holistic approach, were high on the agenda of most respondents. Lindow's comments regarding the perceived failure of professionals to listen to service users were noted in chapter three (Lindow, 1995) and in fact this negative characteristic of mental health professionals was a constant refrain from service users in this part of the discussion. Not surprisingly then, listening in particular and good communication skills in general, alongside qualities such as empathy, were the skills most frequently referred to by users:.

A good ear for listening. Being able to pick up on points quite quickly and use them to help the user overcome problems whatever they may be. Getting the facts correct - accuracy is a big thing. Not just putting your view of what you think the user is saying. (GANET)

Compassionate and good listeners. CPNs on the whole are very good listeners. In psychiatric wards, nurses were good listeners who knew when to talk and when not to talk. (Core Club)

Social skills, such as being able to understand people and motivate people; to be understanding and listen; and to have time for the people who come to the

club. To accept that members have an opinion and to stand by that opinion - it's a 2-way street. Some workers might find that uncomfortable, that they have to listen and take on board what the members are saying. (Core Club)

Qualities such as *competence* and *stability* were also referred to, especially in the context of workers who are also users:

They should be able in a condition of good health to perform duties to a high standard. If they are users, they should have a reasonable or even generous consideration in matters of sick leave but while well enough to come to work, they should be able to perform their duties to a high standard. (SUN)

Reliability - and that includes people who have mental health problems. It doesn't mean that all the paid workers have to be the healthy ones but if all the workers go down at the same time, you don't have an organisation. They should bring professional training and qualifications and also their experience of other organisations or institutions. (MDFS)

iv) Values. Several respondents saw the worker's value base, rather than his/her specific knowledge and skills as being central., with a commitment to empowerment and respect for users being frequently mentioned.

Empowerment; an understanding of mental health issues; how to work on behalf of an oppressed group; respect and effectiveness. Beyond that it depends on the specific role - for example, a good understanding of problems of funding, of structures, of service provision, empathy. (SUN)

Someone who had worked in the field and who knew where we were coming from. Also someone who could work with us as a group. She would have to understand that although she had the general running of the place, it's our ideas she would have to put forward. That might be hard for some people. We want someone who can work for someone who a couple of years ago was in hospital

and can take orders from people whom they feel might not be right, someone who won't put their ideas first but who will be ready to advise us if things don't go right. We might make mistakes but so might she. (Stepping Stones)

An ability to respect the opinions of users, to understand that they can't always give a total commitment to things. To appreciate that users themselves have life and work experience that can be utilised. To really believe in the cause of people in the community being responsible for themselves. (SPS)

Worker responses.

Like user respondents, workers tended to emphasise sound 'peopleskills', skills relevant to a particular post or project and a commitment to empowerment rather than 'knowledge' per se, though some did stress a knowledge of mental health services and mental health law. Some forms of knowledge moreover, notably an adherence to the medical model of mental health, were mentioned as being positively unhelpful.

You have to believe in the current buzzword - 'empowerment'. You have to be the type of person who is relatively non-judgemental. As regards skills, counselling skills are helpful. Regarding knowledge of mental health issues, it's almost a bonus not having extensive knowledge of the medical model and diseases because that perpetuates labelling and not seeing the person but the condition. In this project, you don't need in-depth knowledge of mental health, partly because many people who use the project don't have severe mental health problems.

Similar comments were made by another worker from the same project.

Above all, communication skills. You can buy in people to do specific things. Communication skills, empathy, and a willingness to work in a way that encourages people to find their own power. All the 'people' stuff. My

background is not in the psychiatric services and that's been a strength, not a difficulty.

In general, personal qualities were seen as more important than either professional knowledge or skills:

Empathy, congruence, unconditional positive regard, objectivity. That includes so many issues - personal qualities. They can be translated into professional qualities but they're essentially personal qualities.

Human relations skills - empathy, positive outlook, willingness for project to succeed, highly motivated, sense of humour.

Finally, a worker from Core Club neatly summed up her role in an imaginative and thought-provoking way:

Facilitation skills; communication skills; motivation. It helps if you have a definite skill like art. Planning skills - but the main one is motivation skills. I see my role as a sort of talent scout - bringing out what's already there and building up on that. The main issue is low self-esteem and low self-worth. It's about breaking down these barriers. It also involves being 'real' with that - being genuine.

Redefining professionalism ?

A number of points arise from the above comments. First, there are the close similarities between much of what has been said above by both users and workers in respect of 'peopleskills' and the long-established findings of a range of researchers and therapists in the counselling tradition regarding the centrality of qualities/skills such as empathy, non-judgemental acceptance and non-possessive warmth (Rogers, 1951; Truax and Carkhuff, 1967; Howe, 1987). In this respect, this study tends to lend support to the view that it is these qualities that are often most valued by service users.

Second, there is the striking resemblance between many of the skills and values referred to above, particularly the emphasis on participation and empowerment, and the skills required within community development approaches. Mayo has recently defined community work as being generally associated with

holistic, collective, preventative and anti-discriminatory approaches to meeting social needs, based on value commitments to participation and empowerment (Mayo, 1998: 160).

Significantly, one respondent (from SUN) did comment, in response to the above question that 'if anything, the community education approach is the closest to what we need'.

Finally, there is the issue of what is meant by 'professionalism'. In the face of similar feedback from service users, some writers have begun rethink exactly what professionalism involves (Brandon, 1996; Heller, 1996). Traditionally, a core element of professionalism has been the assertion of the value of a period of specialised training. The next section will consider the extent to which service users saw such training as important or essential for workers in their projects.

THE VALUE OF PROFESSIONAL TRAINING

Respondents were asked to rate and comment on the statement '**Paid workers in mental health projects should always have a professional training in social work, nursing, or a related discipline**'.

TABLE 3 - EVALUATING PROFESSIONAL TRAINING

Count Column percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	7 (17%)	4 (23.5%)
Disagree	19 (46.3%)	8 (47%)
Can't decide	6 (24.6%)	0
Agree	8 (19.5%)	2 (11.76%)
Strongly agree	1 (2.4%)	3 (17.6%)
Column Total	41	17

As the table indicates', only nine (22%) of user respondents agreed with this statement, with just under two thirds of the user group and more than two thirds of the worker group disagreeing . As with the previous statement, the focus is on 'mental health projects' and it is clear from a number of responses that a different answer might apply in respect of hospital-based professionals. As in the previous section, user and worker views will be considered separately.

User Views

At one end of the spectrum of user responses were those who saw professional training as positively damaging. Some of the strongest views in this respect came from SUN respondents:

That just leads to a rigidity of attitude. The experience people have of coming through different kinds of therapy can be equally valuable. The empathic response potential of the non-professional is often vastly superior to the blockages of the professional. The user element can transcend these barriers or limitations. (SUN)

None of these disciplines are helpful. Most are based on oppressive categorisations. Nearest to being useful is community education - at least they deal with a lot of stuff around empowerment. The expertise involved in the other disciplines can be damaging but could also be turned around and used in alliance with users. (SUN)

Traditionally a lot of these qualifications have involved developing a set of attitudes not really in keeping with the ethos of SUN. (SUN)

A lot of the time, they come with so many preconceived ideas and ethical values they're used to working with and a lot of the time, that doesn't fit with community projects. (AdvoCard)

A major criticism of professional training was that it encouraged workers to view service users as 'the other' and provided them with a justification for disregarding users' views. One respondent who placed himself in the 'can't decide' category, provided a succinct critique of 'the clinical gaze', the Foucauldian concept to which I made reference in the previous chapter:

It would depend on the context of their training. Previously training was based on the distance from person to person, and seeing them as a set of symptoms and engaging with them on that basis. Even where there is altruism, they're still wearing that professional persona, which creates problems for people who need emotional reassurance. (SPS)

Other respondents provided examples of such distancing:

Sometimes nurses or ex-nurses treat you like a patient. They look down on you - 'he's mentally ill.' (Core Club)

I've seen good and bad. Often some of the best people to work with are carers. I've seen one person with psychiatric nurse training who was great for a year then we were back into the health board mode with users not being allowed to drink tea or coffee in the front room of their own premises in case they spilled it on the carpet. I've also seen professional workers who were excellent. (SUN)

Social workers were singled out for particular criticism. One AdvoCard respondent who strongly disagreed with the statement felt that

Sometimes it helps but it's not necessary. Particularly social work. I have a lot of experience of social workers. They're the 'glue' in society. They're there to hold society together, not with the patients' best interests at heart - these are poles apart. For example, the social worker in hospital made sure my bills were paid which left me with very little money but never informed me of additional DSS money that was available and that I could have had - and especially as a smoker it would have helped.

Another respondent agreed with the statement but again qualified it in respect of social workers:

I've got a thing about social workers - we just don't agree. I had social workers attending my family. One was a wee lassie straight out of college. Workers need to be good organisers and trained in mental health. (Stepping Stones)

Others disagreed with the statement in general but accepted that particular skills and training were necessary for particular posts, or in particular contexts:

It depends on the capacity you're involving the person in but generally, I'd disagree. However, in other areas, medication for example, I have limited knowledge and wouldn't want to comment on that. There's other areas that psychiatrists would deal with more effectively than I could. (MDFS)

Definitely there should be management and communication training that are specific to mental health projects and even a crash course in mental health but you want to get away from both the medical model and the social work model. (AdvoCard)

Here, you're dealing with people who are going through the 'well' phase. Hospital and Core Club have distinct roles. (Core Club)

The single most common response to this statement, however, was to emphasise again the primacy of experience and 'peopleskills' over formal training. Professional training could be a useful supplement, especially where the person's experience of mental health issues was limited, but it was certainly not the main priority. One SUN Executive member, referring to the project where she was employed as a worker, commented:

We have three nurses working in here. The fact that they are nurses is totally irrelevant. What matters is an individual's personal experience - not the fact that they are nurses. That's just a coincidence.(SUN)

Others commented that

If they have the right nature, then they'll learn. Hands-on experience is better than six or seven degrees. (Stepping Stones)

Some awareness but if it comes through their own life experience, that's good enough. (Charlie Reid Centre)

Life experience and who you are as a person can say a lot more for you than the qualifications that you hold. (Charlie Reid Centre)

As in the previous section, the only areas of professional training to which any respondents referred positively were counselling and community education:

There's a need for understanding but not necessarily qualifications. Community development skills and counselling skills are useful but not essential. (Stepping Stones)

While only two respondents in this section specifically mentioned community development, others also laid stress on the importance of values and skills which would normally be associated with this approach:

Just being understanding, being a good listener is as good as anything. CPNs, for example, have their place but we're trying to stop the revolving door syndrome and in a lot of cases, professionals can't get used to the idea that they have to share power with members. They have to have an understanding of what Clubhouse is about - it's participation. Instead of them doing all the work, they have to encourage others to do the work. (Core Club)

Finally, of those who agreed with the statement that professional training *was* important, the most common reason given was the complexity of mental ill-health:

They have to have some knowledge of where users are coming from, and if they haven't experienced the problems themselves, then they need some knowledge of them. (GANET)

They need some training. I don't think anybody off the street could just come in and do it. (Core Club)

Worker views

In this instance, the views of workers tended to closely mirror those of users. Thus, several workers from different projects (which for reasons of confidentiality will not be named) expressed the view that professional training could be a handicap in working in community-based projects:

When I first started the job, I was very anxious because I didn't have a social work or a nursing qualification. I felt people wouldn't rate me but the management committee thought it was an advantage. Now I think it is, because I haven't come with the baggage of nursing or social work training.

Strongly disagree. More than strongly disagree. People need training but not necessarily professional qualifications. In this context it can be a decided negative. I trained as a nurse and worked for thirteen years as a nurse. When I came over to this side of the fence, I had to lose a lot of concepts e.g. that people are dependent and vulnerable. A great proportion of the training is about how to work within professional structures, not about how to work with people. The essential thing is an understanding of people. Looking for qualifications means putting us into the same conceptual field as other services - we're complementary to these services.

Professional training can be useful but the perspective of coming from a user perspective can come from lots of experience and professional training won't necessarily give you that. In some situations, professional training can block and filter out the user perspective so it could be detrimental.

As with the user responses, an emphasis on experience and human skills was seen as more important than 'paper qualifications':

Experience counts for a lot, and also, if people have had a mental illness, it gives them a better understanding. It depends on the post and the project but just because you have a piece of paper doesn't mean you can do the job.

Not always. You should have a knowledge of mental health issues but if you only go for people with paper qualifications, you can miss out on the human skills.

For some workers, the growing emphasis on qualifications went against the ethos of the voluntary sector and had little to do with the needs of users:

You're looking for the skills that individual people bring. By specifying qualifications, you're ruling out good people. An emphasis on qualifications in the voluntary sector is being pushed on groups by funders.

Finally, as with the users, a minority of workers *did* feel that professional training was important. Two workers from the same project, both of whom were themselves professionally qualified, commented:

A qualification is very important because you know how to deal with people, what are their needs, what kind of services are necessary to meet those needs.

It depends on the role. In some places if you don't have training, you can damage someone. Even among the paid workers, we wouldn't let someone without training do counselling, for example. They [professional qualifications - IF] do help if you have them but I would go more for maturity AND some form of training.

'Streetwise grannies'?

If the critique of professional knowledge evident in the first section of this chapter is capable of postmodern interpretation, then the views contained in the above section on

the limited value of professional skills and training can equally appear to lend themselves to a neo-conservative rejection of professionalism, in the form, for example, of the call by Virginia Bottomley, while Health Secretary in the last Major Government, for 'streetwise grannies' to replace highly trained and 'politically correct' social workers (*Guardian*, 11/1/94). Again, however, such a conclusion would involve a misreading of what these service users and workers are actually saying. For given that the supposed main attribute of these 'grannies' (in what is frankly a sexist and patronising metaphor, not least when it came from a qualified social worker) was their 'common sense' - code for a rejection of notions of anti-discriminatory and anti-racist practice - it is difficult to see how such untrained helpers could assist and empower one of the most stigmatised groups in society.

An alternative interpretation of the comments of these respondents is that they are calling for a different kind of training for professionals, based on what one writer has called 'doing being human' on the one hand (Heller, 1996) and a rejection of the disciplinary power exercised through the 'professional gaze' on the other. Discussing service users' resistance to this gaze, Leonard writes:

What is it that is being resisted? Self-reflection alone might tell us that what is being resisted is the domination over our bodies (physical and social) which is legitimated by reference to professional knowledge. The gaze of power is the gaze of he or she 'who knows'. What we, the subjects know, is what 'lay people' know, knowledge which must be discounted except when the subject's self-disclosure may be used to confirm or particularize the expert's knowledge (Leonard, 1997: 55).

As several of the above comments suggest, this 'gaze' was a core element of what a number of respondents referred to as the 'baggage' acquired through professional training and is at the heart of what Lindow is referring to when she writes of professionals being trained *not* to listen to what service users are saying. The possibilities of developing a professional training which does not rest on such a distancing is a theme to which I shall return in the final chapter.

'WOUNDED HEALERS' - SERVICE USERS AS WORKERS.

While there were differences in respondents' view as to the value or otherwise of professional training, *all* were in agreement regarding the importance of human skills such as compassion and empathy on the one hand, and experience on the other. But what form should that experience take? To what extent, for example, did users and workers accept the view discussed in chapter three and influential within the 'new social movements' that only former users can really understand the user experience and that therefore experience as a service user should be a job requirement? In this case, respondents were asked to rate and comment on the statement '**Paid workers in mental health projects should themselves have had personal experience of mental health problems**'.

TABLE 4 - WORKER EXPERIENCE OF MENTAL HEALTH PROBLEMS

Count Column Percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	1 (2.4%)	0
Disagree	21 (50%)	9 (52.9%)
Can't decide	7 (16.7%)	5 (29.4%)
Agree	9 (21.4%)	3 (17.6%)
Strongly agree	4 (9.5%)	0
Column Total	42	17

As the table shows , while only one respondent strongly disagreed with this view, a majority of both users *and* workers disagreed with this statement, although a large minority of service users - just under a third - either agreed or strongly agreed that personal experience of mental health problems was a relevant requirement for project workers. Again, user and worker responses will be considered separately.

User responses

Of those users disagreeing with this statement, the majority felt that while such experience would be helpful, it was not essential and empathy could develop either on the basis of wider personal experience and/or training:

They have to have an understanding of mental health problems but not necessarily to have had it themselves. For example, if they have had someone in the family who has had problems, then they're likely to be more understanding.
(Core Club)

Not necessarily. It can help in certain circumstances. My counselling training suggests that everyone has a range of emotions so that even if you haven't been mugged, for example, you can understand the feelings involved. In some situations, it probably would help - in cases of addiction, for example
(Stepping Stones)

It just depends on the life experience that a member of staff has had. That's what enables them to be a sponge to us. (Core Club)

A basic understanding of mental health issues, if not as users, then at least they should have empathy.... If there's a basic empathy and they can treat people openly, rather than talking about them behind their backs, then they don't have to be users - decent human beings would do. (SUN)

For others, the central issue was *competence* - whether or not the person could do the job:

I don't think you have to be mentally ill to help people who have been mentally ill. In some jobs that would be really bad. It would depend on the illness but if you had depression, for example, and got stressed out at work, it could bring back your depression. It would depend on where you are now. It doesn't rule you in and it doesn't rule you out - you have to be able to do the job.

(Stepping Stones)

It helps if they have it, either as a user or carer, but it's not absolutely necessary as long as they have training. It's an asset but it's more important that they can do the job. (AdvoCard)

Disagree, although I do think some positive discrimination is very useful, because it's so hard to get a job when you've had a mental health problem. But again it's too inflexible - it should be the best person for the job. (SPS)

A similar tension between valuing the experience of service users on the one hand and recognising the limits of that experience on the other was also evident in the responses of those who were unable to decide:

Experience can often add to people's abilities to do a job but in itself doesn't qualify someone to do a job. (SUN)

It would help but it's not essential. It depends, among other things, on how good the organisation's training is, in telephone skills for example. The volunteer I mentioned earlier didn't get the job because he couldn't be trusted on the phone. (MDFS)

Finally, there were those who agreed or strongly agreed with this statement. Even here, however, while there some respondents who saw such experience as essential, for

others, it was preferable, but no more than that, that workers were themselves users or former users:

It would help. There's no use them just coming in here and giving their version. They have to have been there. (Core Club)

I think it's good. I visited a place last week where the worker spoke from her own heart - she had had depression. (Saheliya)

It helps. However, that experience has to be there for the use of users, not to meet their own needs. It's preferable but not absolutely necessary. It can be useful in advocacy or in drop-in projects - it leads to a more level playing field. (SUN)

Worker responses

A similar divide occurred amongst the worker respondents (several of whom identified themselves as users or former users), though with a slightly higher number unable to decide and a smaller number agreeing with the statement. Once again, those who disagreed with the statement recognised that experience of mental ill-health *could* be an asset but that other life experience could also form a basis for empathy:

It can be an advantage. Also, we might not all have had schizophrenia but we've all had stressful times where we have been borderline with mild mental health problems. We've all panicked or been paranoid at some stage.

Not necessarily. That's where the empathy bit comes in. If you're willing to learn from other people, that's what counts. Even if I had experience of mental health problems, it would be different from someone else's.

One worker who had had recent personal experience of severe mental health problems felt that

The personality factor comes in here. It depends on the person. I tend to find psychiatrists, CPNs and so on tend to have some kind of link with mental health. Some people are just very good at relating to others and don't need to have had mental health problems.

Another worker who disagreed with the statement went further in seeing possible disadvantages in having previous mental ill-health experience:

It can help to a degree but it's like being part of a user-led organisation - people have their own biases and can bring personal baggage with them. Again it's a double-edged sword - the experience is good on the one hand but quite dodgy on the other hand.

Of those workers unable to decide, there was a sense of a tension between what they felt to be the 'politically correct position' - that workers *should* be users or former users - and their own experience as workers in the different projects, with some emphasising what they saw as the limitations of experience of mental ill-health:

I know there are people in the movement who think that but I think you can turn that round and say that just because you've had a mental health problem, doesn't make you more suitable. It depends on the personality. I wouldn't class myself as a user though I was in hospital twenty years ago. But I have experienced depression off and on since then - not clinical depression but it still helps me with the work. With someone who had no awareness of mental health problems, it would be more difficult.

Theoretically, yes, but in practice it's very stressful. I'm the one who's still here! In this organisation we don't have support mechanisms to enable someone to be supported when they're vulnerable. I've seen too many people become ill when working with mental health organisations.

While very few other respondents addressed here the issue of the difficulties which users employed as workers might experience, this issue was explored in depth within the individual interviews and will be discussed in the next chapter in the context of a discussion of the dilemmas of user-led organisations.

Of the minority of workers who agreed or strongly agreed with the statement, there was a clear assumption that service users were more likely to have an understanding of the problems which other user-workers experienced:

You know the pressures that you're under. You accept the fact that they're not going to be well all the time - you don't dock wages, for example.

For our project, it's an essential part of the job. It would be helpful in all mental health projects (which I take to mean community-based, voluntary organisations). In certain projects, they strongly discriminate in favour of people with mental health problems.

CONCLUSION

Valuing the *experience* of mental health service users has been a central theme of this chapter. Given that historically, that experience has been discounted by psychiatry and public alike, that 'reclaiming' of the experience both of mental ill-health and of mental health services and its assertion as a basis for the future development of services is a crucial first step in shaking off the stigma of mental ill-health.

At the same time, however, as respondents recognised, there are limits to the uses of experience, in at least two respects. On the one hand, given the extent of mental ill-health, making it in effect part of 'the human condition', a narrow politics of identity which required, for example, that all those who work with service users must themselves have suffered from severe mental ill-health, was seen by most respondents as inappropriate and unnecessary. Instead, there was a 'politics of empathy', based on

the (universalist) belief that it is possible, given a willingness to listen, for one human being to enter into the experience of another.

A second limitation of experience, perhaps less recognised by respondents, is that unless that experience of mental ill-health and of mental health services is informed by a wider *theoretical* and *political* understanding of the nature of mental health oppression; of the limits and potential of user-led services; and of the issues involved in building a users' movement, then that experience may on the one hand be hi-jacked into endless 'consultations' or on the other used as a pretext for 'dumping' services onto users which should properly belong with the State. In this connection, the anti-intellectualism expressed by some respondents, while understandable, is potentially unhelpful. It is to a consideration of these and other issues arising out of the experience of user involvement in the management and development of services that we shall now turn.

The experience of user involvement.

The previous two chapters have focused on some of the ideas dominant amongst service users and project workers in the nine projects. In this chapter and the next, the focus will shift from ideas *about* involvement to the actual experience *of* involvement. The previous chapter suggested that the overwhelming majority of respondents - users *and* workers - believed that service users *should* be involved in the planning, development and management of services. But what forms does such user involvement actually take? What factors promote such involvement and conversely, what factors constrain it? These are the issues which will be addressed in this chapter, while chapter nine will consider the issues or dilemmas that involvement has thrown up in these projects.

Before looking at the ways in which service users were involved in the running of these projects, a preliminary comment is necessary. As noted in chapter four, all of the projects in this study were invited to participate on the basis of professing a genuine and substantial commitment to the involvement of service users in the running of the project. In contrast to other studies, however, where the main concern has been to establish the extent to which the 'rhetoric' of user involvement is matched by the 'reality', the present study is primarily concerned with exploring the issues to which such involvement gives rise and therefore *assumes* a high level of user involvement (cf. Shemmings and Shemmings, 1995). The study, in other words, is exploratory in nature rather than evaluative or comparative. That said, inevitably there were differences between projects in the forms and degrees of user involvement, as well as degrees of satisfaction or dissatisfaction within particular projects regarding the quality or extent of involvement, and where such issues arose, I shall comment on them.

FORMS OF INVOLVEMENT

The first part of this chapter will look at the ways in which users are involved in the management and development of services and, drawing on Arnstein's Ladder of Citizen Participation referred to in chapter two, will focus on user involvement in the four areas of *information provision, planning, financial matters and the hiring and firing of staff*. As previously, figures drawn from SPSS analysis will be used to illustrate perceptions of involvement in respect of each of the four areas covered, with the qualification that the small numbers involved mean that these figures need to be treated with great caution. Nor should they necessarily be treated as indicators of satisfaction or dissatisfaction; in several cases, it was clear that if people were not involved in a particular area, such as finance, it was because they chose not to be.

Information provision

As noted in chapter one, the provision of information about a service is seen by most commentators as the 'bottom line' of user involvement. As Beresford and Croft note

Without information we cannot make rational choices. ..We need information to know:

- what our services and neighbourhoods offer and how they could be improved
 - how agencies and organisations work and how we can gain a say in them
- (Beresford and Croft, 1993: 63).

While the critique of consumerism contained in chapter one suggested that by itself, the provision of information endows consumers with only limited power, nevertheless, *without* relevant information, service users are extremely limited in the role they can play within services. To explore the issue of information provision within these projects, user respondents were asked firstly to respond to the statements that **'In this project, I am kept fully informed about day to day activities'**, while project

workers were presented with the statement 'In this project, project users are kept fully informed about day-to-day project activities'.

TABLE 5 - INFORMATION

Count Column percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	1 (2.3%)	0
Disagree	12 (27.9%)	3 (16.7%)
Can't decide	2 (4.7%)	1 (5.6%)
Agree	15 (34.9%)	10 (55.6%)
Strongly Agree	13 (30.2%)	4 (22.2%)
Total	43	18

As the table shows, almost two thirds of service users agreed or strongly agreed with this statement, while a higher percentage of project workers agreed. A variety of different approaches were used by different projects to ensure that their members were kept informed. The main factors affecting the degree and form of information received appeared to be, firstly, the purpose of the project and secondly, the particular role played by the individual within the organisation, with committee members, for example, receiving far more information than non-committee members.

The most comprehensive information provision appeared to take place within the Core Club, in part because most members attended on a daily basis:

There is a formal meeting every morning but you can walk into the office at any time. There's also an informal chat after lunch as well as a weekly newsletter.
(Core Club)

At the morning meeting, what went on the day before is talked about and the diary for the day, as well as any visitors who are coming, discussed. (Core Club)

By contrast, where members were only involved in a particular activities group, as with Stepping Stones or the Charlie Rid Centre, or on an occasional basis, as with AdvoCard, GANET, SUN or MDFS, information tended to be provided through an occasional newsletter or monthly forums:

We have a quarterly newspaper, written by the workers, and sent out to everyone in their own homes. (Worker, Stepping Stones)

They're informed via the quarterly magazine, the annual conference, the groups, by the packs we produce, by correspondence and by telephone.
(Worker, MDFS)

There was a perception that Board or Executive members tended to be better informed than ordinary members:

Strongly agree, as a Board member. If I wasn't a board member, I'd have to disagree. (MDFS)

Can't Decide. Maybe because I'm not on the management committee but now that I'm trained as an advocate, it might become more accessible to me.
(AdvoCard)

While a relatively large minority of users (just over 30%) disagreed with the statement, this did not necessarily indicate that they were unhappy with the amount of

information they received. Often, it was through choice or affected by factors such as illness:

It's not my job as an Executive member to be informed of day to day activities.

(SUN)

I try to keep out of that sort of stuff - I choose not to receive certain stuff.

(SUN)

I get as much information as I want. (AdvoCard)

It's not because I don't need it. I get the information that I need to know.

(Core Club)

There was also, however, a minority of respondents, located mainly in two projects, who expressed some unhappiness about the amount of information they received. One respondent who strongly disagreed with the statement commented that

Sometimes when I ask for information, the response is 'oh, haven't you been told about that or 'why do you need to know?' It's very disempowering.

while from another project

They are good at sending out quarterly or half-yearly programmes but sometimes notice of meetings is too late. Communications can sometimes be poor and misunderstanding can and does arise, due to reliance on word of mouth.

In respect of more general information, such as policy development or the financial situation within the project, there appeared to be higher satisfaction with only 16% of users disagreeing with the statement that '**Within the project, I am kept fully informed about all project activities**'. Once again, the most developed forms of communication appeared to take place within the Core Club:

Strongly agree. Everything is brought to the Friday meeting and everything is discussed for the coming week. There's a weekly newsletter and a quarterly gazette. Anybody can put anything into the newsletter.

In addition, a quarterly meeting outwith the premises gave members an opportunity to discuss wider policy issues, while in other projects, newsletters, community meetings or patients' forums seemed to be the main mechanisms for disseminating information.

In general, the provision of information did not appear to be a major source of discontent in all but two of these projects. This did not, however, mean that the issue of information provision was entirely unproblematic. Two issues arose in connection with information provision, both raised by workers from different projects. Firstly, there was the issue of what service users were able to *do* with the information they received

There's the newsletter, plus poster upon poster upon poster. The community meetings are also supposed to be once a month. They can be frustrating. People tend to raise things like 'There's no chalk for the pool cues', when, for example, we're facing a major funding crisis.

An issue of a quite different sort was raised by two workers from the same project and concerned situations in which it was appropriate to *withhold* information from users:

There is one current issue to do with premises and those involved didn't want members to know about it but it's a case of having to do that for the money. That's the only exception that I know of.

There's a situation cropped up about which I don't know what will happen. I don't want to inform the members at present because it would be a downer.

What the first example suggests is that involving users on committees or providing them with information does not necessarily empower them in itself. There is clearly a

wider issue here about the skills required by workers to make such information or committee involvement meaningful and I shall return to this point in the concluding comments in this chapter. The second example raises the issue of when it is appropriate to withhold information and poses the question of when, if ever, what might be construed as paternalism is justified.

Involvement in project planning

'Involvement' and 'consultation' are the rather amorphous terms employed by Arnstein to denote the rungs immediately above 'keeping fully informed' on her Ladder. Within this study, these areas were explored through a focus on involvement in *planning* services. User respondents were asked firstly to respond to the statement that **'I am involved in planning day to day project activities'** and secondly, **'I am involved in planning long-term project strategy'** (with statements to project workers being amended in the same way as the information statements above).

TABLE 6 - INVOLVEMENT IN PLANNING

Count Column percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	1 (2.4%)	0
Disagree	16 (38.1%)	1 (5.6%)
Can't decide	3 (7.1%)	5 (27.8%)
Agree	12 (28.6%)	9 (50%)
Strongly agree	10 (23.8%)	3 (16.7%)
Total	42	18

The table shows responses to the statement regarding involvement in day to day planning. In response to this statement, just over half (52%) of all users agreed , with more than a third disagreeing or strongly disagreeing. Once again, project workers tended to have a more positive view of the extent to which this happened, with two thirds agreeing with the first statement and only one respondent disagreeing. Once again also, Core Club respondents were most positive in agreeing with the statement:

Strongly agree. On a Friday, we have an activity planning meeting - whatever activities people want to do, and the financial side of that, is discussed and we decide whether we can afford to do it or not. On a Friday morning, there's an open agenda. I'm also part of the group for the building, trying to get larger premises.

Similarly a Core Club worker commented:

Strongly agree. Morning meetings, the unit meetings - in food services, for example, we'd look at the menu, then make up a list of activities. People can choose what they want to do.

Another Core Club member disagreed with the statement but made clear it was through choice:

The Club as a whole plans but I prefer to come along and see what's coming up.

If the prevailing model in Core Club was one of *direct* democracy, with all members involved in the decision-making process, then in other projects, a more *representative* model operated, with involvement in day to day planning taking place through the presence of users on committees. Some issues relating to 'representation' and 'representativeness' have already been touched on in chapter five and the dilemmas to which contested understandings of representation gave rise in these projects will be

explored in chapter nine. In practice, such representation varied from 100% user involvement to a presence alongside workers and other professionals. In this connection, SUN members made the distinction between *user-controlled* organisations where the leading bodies were made up entirely of users and *user-led* where non-users were also involved) At the user-controlled end of the spectrum were organisations such as Stepping Stones and SUN. A Stepping Stones Worker explained that users were involved in day to day planning

firstly, through the management committee and the development group who would look at the overall situation; secondly, within each group where activities are planned, deciding what they will be doing in the coming month, for example

- a positive view that was also shared by Stepping Stones respondents.

In other projects, such as the Charlie Reid Centre, staff felt that they were committed to involving members in planning but in practice this proved difficult. A worker who was unable to decide commented that

On numerous occasions, we've set up social activities and social committees but they just don't happen. For example, the members wanted a singles night. They wanted to do it themselves but it just didn't happen. I end up being the biggest culprit here by organising the Balloch barbecue or the Xmas night or the Burns night. But at the end of the day people really enjoy it. The Halloween night for example was a fantastic night.

In similar vein, an AdvoCard worker felt that *more* user involvement in planning would help her as a worker:

We would like *more* involvement from the management committee. They only meet every two months. The Executive meets once a month. In lots of ways, what the project does is what the people coming through the door want. That's

why there's been the 'Flying Advocates' development - that's what people were requesting.

What both of the above comments suggest is that involving and supporting users in decision-making processes is a highly skilled process, skills which workers in community-based mental health projects, whose backgrounds may be in nursing or who may be untrained, may not possess. In this context, Mayo's comments on her study of community work with long-standing community organisations, the major finding of which was the high level of support which these organisations required, seem apposite:

If they needed so much support, how much more support might less-established community organisations require if they were to take on such tasks of community management effectively? (Mayo, 1994: 192).

The issues of skills and the type of training that workers in such projects require is one that we shall return to in the final chapter.

The importance of informal involvement was also emphasised by respondents from other projects. In only one project was there strong feeling that all planning decisions were made by the paid staff, with no opportunity for involvement. Comments from members of this group included:

Disagree - the planning is done by the development officers.

Disagree - but I take part in the planning after it's been planned.

Can't decide - I am involved in the planning but I still feel at the end of the day that the powers that be are making the decisions.

Another member of this group also disagreed with the statement but added

I would want to stress, though, that this is a young growing organisation and this could change in the future.

By contrast, the worker in this project felt that service users *were* involved in day to day planning, perhaps another example of the common research finding of 'a lack of congruence between the words used by workers to *describe* their actions and what they did in practice' (Shemmings and Shemmings, 1995: 51).

In respect of long-term or strategic planning, a slightly higher number of service users felt they were involved (56%) , though again a sizeable minority dissented (30%). Once again, workers took a more positive view, with 78% of workers agreeing or strongly agreeing with the statement and only two respondents dissenting.

Respondents from Core Club were extremely positive about the quality of their involvement in long-term planning:

Because of the budget being financed on a yearly basis, we can't plan further than a year at a time. However, regarding things like holidays, it's all discussed in advance, we do fund-raising and so on. Also members as well as staff interviewed both members and staff to see who would go to Sweden [International Conference on Clubhouse Development] , who would represent the club and bring back information. We've also planned to go to the US for Clubhouse training - we'll interview for that and get the best candidate. (Core Club)

Strongly agree. We have meetings all the time and agree on things but it's always the members who have the say. (Core Club).

Stepping Stones had a separate, user-dominated Development Group which had primary responsibility for long-term planning. A worker, who strongly agreed with the statement, commented that

Not all members - just members of the Management Committee who are on the Development sub-group - but all members have the opportunity to come to the bi-monthly members forum

- a view shared by Stepping Stones user respondents. Within Saheliya, a worker explained that

Some of our members are attached to the advisory group attached to each area of activity. Recently we've been putting together a business plan and the advisory groups have gone through the business of evaluating the activities.

In several projects, however, it was clear that users felt excluded from long-term planning, even though workers invariably felt they *were* included. The following comments - all from different projects - were not untypical.

Things are not as fully discussed at the moment as they should be. It's not happening at the moment with myself. However, both myself and my depute convenor have been out of things recently due to ill-health.

I used to go along to the community meetings but they haven't been having them lately. The staff have staff meetings. It's partly because I'm dealing with stuff that I haven't gone. There's no advisory committee or management committee.

There seems to have been a shift from being a volunteer with few staff members to a lot of staff members, though that may be because I've just come back from a period of illness. I'm not asked to come in to staff meetings and am given very short notice as to what I'm participating in - there's no forward planning.

Strongly disagree. That's left to the management committee. Nobody gets asked if they have particular skills. I'm all in favour of user involvement but you need the skills to do it.

I have had some input but the average member is not invited to contribute to that - it's not offered. There's not a sufficient structure for users to put forward ideas.

One user from the same project as the previous speaker felt that

these issues are raised but often presented as a *fait accompli*. It wouldn't feel safe to say that. I've been working up the courage to say that for 2 months. I'm getting quite tormented by this - I've tried before but got an easy answer, a response which was quite patronising.

A rather different perspective on some of these issues came from the worker who agreed with the statement and added

But the members might disagree. That's predominantly what the centre advisory group is for - for users who have been elected by the membership. That's their platform. To make sure that things are being followed through. That's where we're accountable. It's a very important platform but it's whether they are asking the right things or not, like 'Where are we moving the pool table to?' If only they could learn to use it to their own advantage. This is where they do have the professionals sitting next to them. For example, we're discussing changes to the mental health act, or the funding deficit, and we go to the pool table for example. If only they could get themselves to draw up a list of priorities. It's getting the balance between what's right for them and these wider issues.

Again, the need for skills which can help respondents move on to address the 'big picture' is evident here.

Involvement in financial decision-making.

Control over spending is generally seen as a key indicator of the extent to which power has devolved from one group to another. To what extent, then, were service users in this study involved in financial decision-making within their own projects?

TABLE 7 - INVOLVEMENT IN FINANCIAL DECISION -MAKING

Count Column Percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	4 (9.3%)	1 (5.6%)
Disagree	14 (32.6%)	5 (27.8%)
Can't decide	2 (4.7%)	2 (11.1%)
Agree	16 (37.2%)	8 (44.4%)
Strongly agree	7 (16.3%)	2 (11.1%)
Total	43	18

Once again, just over half of user respondents (54%) agreed or strongly agreed that they *were* involved in financial decision-making , with 42% disagreeing. In this area, the highest degree of user involvement was shown by Stepping Stones, where the finance committee was entirely made up of users - something which the workers experienced as problematic:

There is a finance group who make recommendations to the management committee. That's been an issue for me. Where we put money has major development implications but it's not seen as appropriate for me to be on that group.

Within Core Club, there was a degree of financial involvement, though some areas were clearly off-limits:

Agree to a point. Members are not involved in salary issues or management fees to SAMH but are involved in everything else affecting the Core Club. Basically, anything that I can change, Core Club members can also change. (Worker, Core Club)

More commonly, involvement in financial decision-making was indirect, with user representatives on the Management Committee considering financial issues in their capacity as Committee members. Saheliya users, for example, agreed with the statement and commented

Through the financial advisory group. Some of the committee members are on that and also, the accounts are available in the annual report.

The limits of such 'indirect' representation and the scope for tokenism were particularly evident in one project where the worker agreed with the statement and added

A majority of both the management committee and the Steering Committee are users.

By contrast, user respondents from the same project *all* disagreed - some strongly - and commented:

That's the weakest part of all as far as user involvement goes. The management committee are not even asked about this.

Strongly disagree. The workers would do that.

Similarly, in another project, this was perceived to be a management task.

Clearly, financial matters often require a degree of expertise that makes this area less accessible to both service users *and* most workers, and several respondents made it clear that they were happy *not* to be involved in this area. Nevertheless, there were wide variations between projects in the extent to which users were involved in this area. In some cases, the impact of particular mental illnesses, such as manic depression, was a relevant consideration:

We're very wary about the financial side because if people become ill, the first thing they do is go on a spending spree, hence the treasurer does not have the illness. (MDFS)

What was particularly impressive about the way that this particular organisation - MDFS - handled this issue (and in fact, a whole range of issues regarding the impact of ill-health on user involvement) was its openness in tackling the issue head-on, with the matter clearly having been talked through within the user-controlled executive.

Finally, the 'content' as opposed to the 'form' of user involvement in financial matters was succinctly expressed by a respondent who was a member of the Advisory Committee of the Charlie Reid Centre:

If we're needing things, I'm the one who would put it forward to the advisory committee. Myself and two other members would input into what we need but nine times out of ten, we don't have money for what we need.

As well as pointing to the issue of tokenism, this comment also highlights the wider economic context in which user involvement is taking place and the danger that poorly funded services are 'dumped' on users, who are then seen as responsible for their development.

Involvement in hiring and firing staff.

While the scope for tokenism is at least as great in this area as in any other , user involvement in the hiring and firing of project staff potentially gives service users a degree of control that goes beyond simple 'participation' and locates them on the upper rungs of Arnstein's ladder. To what extent then were service users in this study involved in hiring and firing ?

TABLE 8 - INVOLVEMENT IN HIRING AND FIRING STAFF

Count Column percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	2 (4.7%)	1 (5.6%)
Disagree	17 (39.5%)	2 (11.1%)
Can't decide	3 (7.0%)	2 (11.1%)
Agree	13 (30.2%)	10 (55.6%)
Strongly agree	8 (18.6%)	3 (16.7%)
Total	43	18

Just under half (49%) agreed that they were involved in the process of hiring and (less commonly) firing , with a slightly smaller number (44%) disagreeing. As before, worker respondents were much more positive, with over 70% believing that service users were involved.

In most cases where there was involvement, appointment of staff appeared to be a delegated responsibility, involving users who were either on the management committee or on a sub-group set up to oversee staffing issues. Within Stepping Stones, users appeared to play an equal, if not a majority part, in the selection of staff:

Strongly agree. The project has just appointed a new development worker, for example, and there were three members of the management committee and the Social Work Department rep involved. (Worker, Stepping Stones)

Strongly agree. I'm on the staffing committee so I do get a say. (Stepping Stones)

Agree. I've just hired K. (Stepping Stones)

Within Core Club, users felt that they were involved at every stage of the process, at least in the hiring of staff:

Agree. We're involved in hiring. We'd have the SAMH manager, the project manager, and two members interviewing as well as an informal meeting of the candidate with members, then we'd all make the decision.

Within AdvoCard, both workers and users who were also committee members strongly agreed with the statement:

Agree. Again, through the management committee. All our interview panels have had users on them and there have always been people on the committee. Even with the recruitment of volunteers, someone from the committee would be involved in helping out with that. (Worker, AdvoCard)

Agree. They're intimately involved in the hiring of staff but we've had no staff changes in three years. The management committee members are aware that that's a responsibility for them. (Worker, AdvoCard)

Strongly agree - we did it for J.'s post. (AdvoCard)

Agree. The management committee are closely involved with the management of staff. (AdvoCard)

Some users who were *not* management committee members, dissented from the statement ,however, implying that the basis for involvement was too narrow.

Finally in some projects, there was little evidence of user involvement in hiring and firing. One project worker who strongly disagreed with the statement commented that

We used to have. For my interview, I had to sit in a room with five professionals and three users. But we had an interview a couple of months ago and didn't have a user on the panel. It's not an issue if the users have trust but otherwise it can be an issue if the users don't have trust and confidence. If the group had said they'd wanted someone on the panel, I'd have had no qualms, but you must stress confidentiality.

Within this project, there had been user involvement in the firing of a member of staff - an issue which clearly caused considerable trauma within the project and will be discussed in the next chapter. Another worker from this project spelled out what he saw as the issues in involving members in this area:

We *have* included the members in an interview panel but the members did not want to be involved. There's also the issue of confidentiality and the equal rights of centre members to get jobs on his or her own merits. These have to be professional decisions because of the intimidation of members. It has to be a professional operation with total confidentiality.

In another project, there was once again a marked discrepancy between the view of the project worker who felt that users *were* involved in the process of hiring and firing and the views of project users who dissented strongly from this statement.

As we have seen, in each of the four areas covered, a minimum of around half of user respondents (and in some projects far more) agreed that they *were* involved in these areas. The examples cited above suggest that in many cases that involvement was more than a token one. Given traditional assumptions about the limited capacities of people with mental health problems, the fact that users within these projects were clearly playing an important role, both individually and collectively, in the development and management of these projects is of considerable significance. That said, there were clearly variations between projects in the role that users played, with some organisations clearly achieving a higher level of involvement than others. What then were the *constraints* on user involvement, and conversely, what factors *promoted* it? It is these questions that the next two sections will attempt to answer.

CONSTRAINTS ON USER INVOLVEMENT

When respondents were asked to identify the major constraints on involvement, six main factors were identified. These were: lack of confidence; professional power and culture; structures and resources; mental ill-health; stigma; and the history and culture of the user movement. Each of these will be considered in turn.

Lack of confidence

By far the most commonly mentioned barrier to involvement, referred to by respondents in all projects, was lack of confidence on the part of service users. Three major factors were seen as contributing to this lack of confidence: firstly, the experience of mental ill-health in itself, secondly, the experience of the mental health system - 'the system' - which was often seen as disempowering and undermining individuals' capacity for decision-making; thirdly, the sense of stigma associated with

mental ill-health which in many cases had had very practical and material consequences:

Lack of confidence, lack of self-esteem. They've been knocked down a lot and are frightened to come. That stems from being ill in the first place but thereafter you need people to pick you up and some people might not have that. People lose jobs through the illness, for example. That might be put down to a lack of skills and it may have nothing to do with that. (MDFS)

You need confidence. Lack of confidence comes from the illness. At meetings, I'm quite happy to speak out but other members sit quietly...If I'm ill, I drop out completely because I'm useless but that's quite acceptable.
(Stepping Stones)

The tendency on the part of the psychiatric system to undermine individuals' decision-making capacity was emphasised by several respondents:

When you first come, it's lack of confidence. You think it's another day hospital with them making the decisions for you but after about a week your confidence builds up. It's not just the staff helping you, it's other members too.
(Core Club)

A lot of people feel too cowed to get involved, as a result of having had mental illness and been through a system which is extremely abusive and deprives you of any confidence or self-esteem. A lot of people are used to having decisions made for them or taken away from them and are probably a bit afraid of having to take the process on themselves. (SPS)

The similarities between this respondent's experience and the view expressed by another respondent in the previous chapter that professional domination of services 'is what *creates* mental illness' should be noted. A similar point was made by a user from another project:

People's lack of confidence in themselves, low self-esteem. They're so used to being a patient. In a ward, nobody asks your view. It's just a case of 'Fuck you, take your medication'. There's also stigma. (GANET)

Professional power and culture.

Reference was made in the first section of this chapter to the ways in which project workers and other professionals were experienced by some users as consciously or unconsciously hindering user involvement. In this section, examples of such perceived 'blocking' were cited, ranging from the direct use of professional power through to the more diffuse impact of a 'professional culture' which users experienced as inaccessible and disempowering.

At one end of the spectrum was the perception that, given the power imbalance in professional/user relationships, challenging professionals, particularly psychiatric professionals, could be dangerous. This fear concerned both professionals from whom respondents were receiving treatment and also workers within the project. The issue of professional power was particularly mentioned by workers and users from advocacy projects, as well as in the focus group discussions. A worker with an advocacy project noted in respect of its members, for example, that

The experience of mental health services may also have affected their self-esteem so much that they find it hard to confront power. It's not true of everyone but there's a good section who still feel vulnerable to make criticisms. People are too scared because it could affect their treatment.

That fear was also highlighted by members of the People Need People discussion group, as the following exchange highlights:

M: We do have a Forth users network but we are frightened to tackle such issues because of the fear of being taken ill and being at the mercy of

nurses or psychiatrists, you know, if we have to go back into the hospital so we're really not taking on board what's happening.

IF: So if I could just clarify what you're saying there, M., it's that people are a bit wary of challenging the lack of involvement because you're then going to have to deal with these professionals. Is that what you're saying?

M: Yes, these people do have the control. At the end of the day, they control if you're taken into hospital ill again, they have that power over you

IF: So that's quite interesting because a lot of people tend to say there's now much more user involvement than there used to be but basically your feeling is that there's still a real lack of involvement. Is that right?

M: Well there are users' groups, don't get me wrong, there are users' groups but they are there and that's it that's as far as they'll go, they'll never tip the balance with the professionals you know....

IF: So the whole thing's still very much dominated by the professionals?

M: Very much.

As well as these concerns about professional power in general, there were also issues about the behaviour of particular workers - including workers who were themselves users or former users - within projects. Members from one project, for example, felt that

X [project worker] wants to make all the decisions, have all the ideas, and it has to be done in his time, what he wants when he wants it. Y [another project worker] is heading in the same direction.

There's a sort of hard-core group - it all revolves around X who periodically I feel is overworked. He takes too much on and is difficult to influence, to make an impact.

One user who worked as a volunteer with a project saw the main constraint on involvement as being

the imbalance of power between management, workers and volunteers. The only reason I've stayed with this project is because I believe in what it stands for - other volunteers have walked away. I'm holding on for a more positive outcome and trying to change things. There's an imbalance of power.

As well as users experiencing the exercise of worker power as a block, professional 'culture', in the sense of familiarity with committee structures and processes, as well as the use of professional language, often left users feeling excluded and intimidated:

Lack of a common language. The context of meetings is very contrived in terms of professionals - it's their territory, it's their home ground. Users have common experiences, gut level responses. There is a sense of a need to be right, a fear of being in the way. Meetings are a challenging environment and there's little room for anything which doesn't pertain to the issues of the day.
(SPS)

A similar point was made by a user from another project who did, however, end on a more positive note:

A lot of the time they see it as very official and there'll be a lot of terminology they don't understand and they'll be asked to make decisions they don't feel qualified to make but it's not like that. (AdvoCard)

Structures and resources.

The challenge of creating democratic and accessible structures which permit a high degree of user involvement was a major one for several of these projects, particularly those like SUN and MDFS which operate at a national level. One MDFS Board member identified the major constraints as

Firstly, geography. The membership is very dispersed and the West Coast orientation is an aspect of this. In fact, the membership are not really involved in the decision-making process other than through the AGM - there are no elections to the Board, for example. It's by invitation and recommendation. My own view is that that should be transitional. The Board is elected at the AGM but people are co-opted in the interim. On the surface it's democratic but I don't think it really is.

Similar points were made both by SUN Executive members and workers:

The AGM is the only time when SUN's policies are discussed. People find it difficult to use the election procedure. People think they can turn up and be elected - there's a lack of awareness of procedures.

Apart from coming on to the Executive, there's no way to be involved in financial or management issues and not everyone wants to be on the Executive. What we're missing is another tier of regional representation which would be talking about the main areas of development.

A range of resource issues such as unsuitable premises, inadequate funding and lack of childcare were also felt to militate against involvement.

The impact of mental ill-health.

'Common sense' assumptions about mental health service user involvement would suggest that the major barrier to involvement would be the mental health problems of users. Conversely, some of the user literature tends to deny that such problems have any bearing whatsoever on user involvement. Responses from users and workers in this study suggests that the reality lies somewhere in the middle. On the one hand, 'poor mental health' as a constraining factor on user involvement came a very poor second or third in the list of constraints, well below lack of confidence, for example; on the

other hand, it *was* mentioned by user and worker respondents from almost every project as something which did affect the extent to which users became involved:

Sometimes members are ill - they make a commitment when they're feeling good, then when the time comes, can't make it. Members' health goes up and down. (SPS)

It depends how you're feeling. If you're fine, you gladly get into it but if you're unwell, you have a blindfold on - you don't see past your own tunnel. (Core Club)

Simply because of the type of illness they have. If someone's unwell, it can show itself in many different ways. You can't always rely or depend upon someone to do what they've said they'll do. Also, if they're unwell, they're not thinking as well as they could for decision-making. (MDFS)

The very fact that we are mental health patients. Sometimes we all do have relapses. You might think you're OK, so you go to this meeting, then another, then another, then you find you're inundated with things to do. It's finding a happy medium. (Stepping Stones)

The last comment highlights a major issue for mental health users who wish to play an active role within their projects or organisations, viz., the levels of stress involved and the danger that such stress may in itself damage their mental health:

There's also the stress of running a service on people's mental health. The stress can be too great at particular times. They may be keen to be involved but the illness restricts them. That can be difficult at times. (Worker, AdvoCard)

Stigma.

The stigma and labelling associated with mental ill-health was suggested by some respondents as a factor in preventing users from associating in too public a way with mental health projects, particularly those involved in campaigning activities:

There's a huge amount of stigma attached to the diagnosis so that while people are happy to seek information, they wouldn't want to be involved in a way that might lead to publicity in the newspapers, for example. (MDFS)

Another aspect of labelling was that when people became well, they wished to move *away* from the world of mental ill-health. I have noted above the comment of the SPS member who felt that

As someone with a mental illness, I tend to feel I've been labelled a patient for ever. I'm so against labelling - I'm just someone with an illness.

In similar vein, an MDFS member spoke of

one guy I met in hospital who said 'I don't want to be labelled - I want to get on with my life'. The fact you're manic depressive shouldn't rule your life.

The history and culture of the user movement.

The history and nature of the mental health users' movement will be more fully explored in the next two chapters, but within the context of a discussion of constraints on involvement, some comment is necessary at this stage. Most histories that have been written to date have been understandably concerned with defending the users' movement in the face of an often hostile psychiatric establishment and have therefore been reluctant to voice any criticisms of a still fragile and developing movement. For some respondents in this study, however, the negative role played by some personalities and what one respondent referred to as 'a culture of backstabbing' ,

particularly within SUN, was often problematic and was seen as one factor in making users reluctant to become more involved:

SUN has been dominated in the past by one or two key people whose personalities put people off. It's also well-known that SUN has had other difficulties. (SUN)

The very nature of the organisation has been troubled historically with in-fighting and politicking on the Executive, which is very detrimental to health. It's sometimes more of a battleground than a helping organisation. It's about a lack of a decent standard of ethics, it's about ego and personal agenda issues. It's always been a conglomerate of individuals and not a representative body. It's changing, but it's proving hard work to change the internal culture. (SUN)

While the problem of culture and personalities was referred to more frequently by SUN respondents than by others, the problem was by no means confined to SUN. A user-worker from GANET commented that

Certain individuals who may be leading the project may have certain ideas about where the project is going and there may be friction about how the project should be led. There may be personality conflicts. That can make it difficult for volunteers or other people working in the project.

Again while 'common sense' might suggest that such difficulties are primarily due to the mental health problems of those involved, such negative characteristics are by no means uncommon in movements of the oppressed. The experience of in-fighting within the American women's' movement, for example, led one activist to quip ' Sisterhood is powerful - it kills sisters!' (cited in German, 1996). Some of the factors contributing to this culture within the mental health users' movement will be explored more fully in the next chapter.

FACTORS PROMOTING USER INVOLVEMENT

Not surprisingly, suggestions for *promoting* user involvement tended to mirror the areas identified as constraints and fell into the categories of confidence-building; improved structures; additional resources; and challenging stigma.

Confidence building.

At the most basic level, user involvement means *attending* a group or project. For some users, however, even this was too threatening and one project - Survivors Poetry Scotland - , therefore, was exploring ways of contacting users in their homes:

We need a more specific project that works with individuals. That's a new idea - a one-to-one writing programme, with volunteers going to people's houses - there's a clear need for a project like that. A lot of potential members need that initial contact. (Worker, SPS)

Even where respondents *did* make it along to projects, their lack of confidence often remained profound. Such a lack of confidence is, of course, by no means unique to users of mental health services. In respect of social work clients, for example, Barber, has emphasised the importance of helping clients achieve small goals as a means of building confidence and overcoming 'learned helplessness' (Barber, 1991). In similar vein, a member of the Charlie Reid Centre emphasised the need

For staff to be more supportive in the right sense, not forcing them but almost encouraging them when they are moving towards something. For things to be acknowledged to people when they do something, that's what's needed. Recognition, acknowledgement, for the least little thing. In my own life I'm finding out that's what was missing. People's esteem needs to be helped. The issue is often not low self-esteem - it's no self-esteem.

Once users had made that initial step of visiting the project, then the ethos of the project and the response of workers and members were crucial in overcoming an initial lack of confidence. Respondents from several projects felt that their projects often were successful in building confidence:

The way things are working at the moment is the best way. When people come in at first, they're just out of hospital and they use it as a drop-in. Gradually, they realise it's like a family, that everyone had had an illness. They learn to voice their opinion and that builds up self-esteem. (Core Club)

This is the first organisation I have come across where people will listen and take things on board. I have depression and seasonal affective disorder and they didn't hold that against me being a volunteer. They let me try it and that does empower a person and gives them self-confidence. (AdvoCard)

You have to have an aptitude for it. Some people prefer just to come along and sit. But if you do want to get involved, you get an awful lot of support. People are encouraged through the newsletter to become involved. (Stepping Stones)

Particularly for those users who were taking on positions of responsibility, however, the need for training and support was identified by both users and workers,

Some sort of training. God knows how you'd do it or who would do it. Not confidence-building but us saying 'we want you to be more involved'. Now if you want to get involved at that level, there's training that would help, to explain to people how committees work for example. I've been employed by the NSF for six years and it's taken me that time to understand the structures. (Worker, Charlie Reid Centre)

More support for users who get into positions of responsibility. There should be external support for workers - external professional support or consultancy and more training for those who want it. (SUN)

Improved structures.

In several of the projects, more accessible structures were seen as important in increasing levels of user involvement:

'The management committee is run in a very traditional way is there a more radical alternative way of running an organisation that doesn't place so many demands on members, especially the business aspects? The members' forum is a struggling group. (Worker, Stepping Stones)

A more direct link between local user groups and the Board. We're gradually becoming more conscious of the fact that the users are there and trying to consult - the current user/carer consultation is part of that. (MDFS)

A regional structure. Also, if local groups could be developed and people saw the results locally, then they would participate nationally.

Resources.

For several of these projects, both the nature of their funding, which often came from several sources and had to be re-applied for annually and also the amount of their funding, severely limited their ability to involve users. Hence, more money was seen as a prerequisite for increasing involvement:

More money, then we wouldn't have to fundraise so much. Like being able to have your own mini-bus. (Core Club)

More funds would mean we could pay for baby-sitting. There's one woman here with two kids, for example, who has to leave meetings at three o'clock to be back home for them. (Stepping Stones)

The wider issue of the funding of mental health projects is one that will be addressed more fully in the final chapter.

Challenging stigma

Finally, there was a recognition that the extent to which users felt able to be involved was not simply an 'internal' matter for these projects but concerned the much wider issue of stigma. Given the risks involved in 'coming out' as a mental health service user, it is not surprising that many preferred to remain 'in the closet':

If there was an overall destigmatisation, members would be involved in all levels of society. Via the newsletter, we have encouraged people to write in but there's been a poor response, mainly due to the illness. They can't do it when they're ill and when they're not ill, they don't want to surround themselves with the illness.... You really need a general shift in attitudes before people would come out and nail their colours to the mast. (Worker, MDFS)

The importance of the need for such an 'overall destigmatisation' of mental ill-health as a precondition for the majority of users to 'come out' can scarcely be overemphasised. There is a danger in the mental health users' movement, as in the gay movement, of a moralism developing which is critical of service users who choose not to come out. Yet for reasons already mentioned in chapter three, the costs of coming out as a mental health service user may simply be far too great for individuals to contemplate.

CONCLUSION

Such research as has been undertaken suggests that in general, the involvement of users in service provision is more advanced within the voluntary sector than within the statutory sector. In a national survey of user involvement carried out in 1990, for example, Croft and Beresford found that just under a third of social services departments, as compared to nearly half of voluntary organisations surveyed, reported

that they had formal policies to include service users in the provision of their services (Croft and Beresford, 1990). Reviewing that study four years later, they noted that

in mid-1994, a year on from the full implementation of the community care reforms, the situation does not appear to have improved greatly (Croft and Beresford, 1995).

Against a background of such a low level of user involvement, it is reasonable to assume that the levels of user involvement within the projects in this study are likely to be in advance of most of the statutory sector and also, given that a commitment to user-led services was a criterion for participating in the study, much of the voluntary sector too.

The findings of this chapter suggest that the scope for involving service users in the running and management of mental health projects is far greater than is generally recognised. That said, it is also evident that there were very considerable variations amongst the projects in terms of the degree of user involvement, variations which are not attributable to the types of mental ill-health experienced by project members. How are such variations to be explained?

In part, they sometimes simply reflected the nature of the particular project. Thus, the scope and rationale for involving service users in the Core Club, for example, is different from AdvoCard or SUN, where involvement is of a more instrumental nature. In the latter cases, a regular newsletter and occasional meetings might be perfectly adequate ways of letting members know what is going on whereas there is scope for more intense involvement within the Clubhouse model.

Alternatively, the variations reflected the quality of procedures within the organisation which varied considerably from project to project depending on a range of diverse factors including the level of funding and the skill of the personalities involved. MDFS, for example, impressed as particularly professional in this respect, partly because it is well-funded, partly because many of its leading members are from a professional

background and bring a range of skills - in accountancy, or public relations, for example - to the organisation.

Negatively, there was no evidence that the degree of involvement was necessarily higher where users or former users were employed as workers. In fact, some of the most critical comments came from members of such projects, while some of the most positive comments about involvement were by members of projects where none of the workers professed any history of mental ill-health

As well as these particular factors, three more general factors seem relevant in explaining the high level of involvement in some projects. Firstly, a commitment to participation and empowerment as values in themselves. As noted in chapter two, the value of participation is most frequently stressed within the community development literature (as well as in Marxist theories of political change). In this respect, there was a profound difference between those projects which, at best, included a small number of users on a management committee and those for whom the participation of the members was the *raison d'être* of the project.

Secondly, a willingness to acknowledge that the involvement of users in service provision will inevitably give rise to dilemmas and a willingness to explore and attempt to resolve such dilemmas in an open manner. The type of dilemmas that arose in these projects and the way they were addressed will form much of the subject matter of the next chapter.

Thirdly, the employment by workers of what are best described as community development skills, ranging from an understanding of *how* to involve people and the need to go at the members' pace through to a grasp of committee structures and the politics of organisations. Even where workers had not received a formal community work training, it was evident in several cases that they were employing such an approach. Conversely, as is evident in a number of the comments above, some workers clearly lacked such skills and were at a loss as to how to increase levels of involvement, despite their wish to do so.

The project which most effectively encapsulated all three of these qualities was the Core Club. By involving its members in decision-making at every level, the Club was able to address what has been identified above as the major constraint on involvement - lack of confidence - in an effective way. Numerous comments from Core Club respondents attested to the ways in which their confidence had grown since they became involved. While the particular characteristics of staff and members within the Dunfermline project clearly play a large part in this, such a growth in confidence appears to be a common outcome of Clubhouse projects generally. In the words of one Clubhouse director:

It never ceases to amaze me as I witness the literal transformation that takes place as members discover their roles in the clubhouse and begin to use their own ideas, talents and abilities to enhance part of the clubhouse for the benefit of the members. It is as if you can watch the layers of armour shielding them from ignorance, contempt and indifference gradually drop off to expose feelings of power, mastery confidence and self-esteem (cited in Oliver, Huxley, Bridges and Mohamad, 1996: 210-11).

Not surprisingly, then, the Clubhouse model is an increasingly popular one amongst both service users and purchasers of services. That said, the model is not without its critics. There is, for example, a rather evangelical ring to the above statement and a recent critique of the Clubhouse model has argued that a narrow, dogmatic and evangelical approach is in fact a common feature of the International Clubhouse movement (Perkins, 1998). Again, despite its undoubted strengths, there is a danger that the model could contribute to the 'ghettoisation' of people with mental health problems. Despite these possible limitations, in respect of the projects within this study, the Core Club appeared to have gone further than most in developing user involvement and in addressing the dilemmas which such involvement throws up. It is such dilemmas and the ways in which projects have attempted to deal with them that will form the subject matter of the next chapter.

‘On Our Own’? The Limits of User Involvement

The rejection by a majority of respondents in this study of the view that professional mental health workers are best placed to decide on the form and content of mental health services was noted and explored in chapter seven. Not only did respondents feel that such a view overestimated the knowledge and skills of professionals but crucially, neglected the experience of service users themselves. To what extent, however, did this imply an acceptance of the directly opposing view put forward by some sections of the American users’ movement (Chamberlin, 1988) (and at least suggested by a politics of identity) that mental health services should be user-controlled?

The second half of this chapter will explore the responses of users and workers to this separatist view, neatly summed up in the title of Chamberlin’s seminal text which heads up this chapter. Before then, however, as a means of contextualising that discussion, some consideration of the issues and dilemmas arising out of the forms of user involvement referred to in the previous chapter is necessary. The tendency within the academic and professional literature to regard user involvement rather uncritically, as self-evidently a ‘good thing’, was noted in chapter one. A consequence of that tendency is that relatively little has been written about the dilemmas which such involvement raises. Yet it is clear from these interviews and group discussions that within most of these projects, a wide range issues *had* arisen, sometimes related to ill-health on the part of users or user-workers, sometimes not.

In the first part of this chapter, these dilemmas, which may point to some of the *limits* of user involvement will be explored, through examining the three issues most frequently raised by respondents. These were: the impact of ill-health on user involvement; issues of representativeness and accountability; and user/worker relations.

ISSUES AND DILEMMAS IN USER INVOLVEMENT

Not all respondents felt that user involvement had raised major issues or dilemmas within their projects. For some, this absence was a measure of their project's success. In response to the question

'Has user involvement created any issues or dilemmas within this project', a Core Club member replied:

Not really . If anything , it's made us stronger. For example, our drink policy - that there's no drink on the premises - was made by the members, not by the staff. We have a set of rules but they can be changed - we're flexible. On holidays, we're adults and we've agreed that we can drink on holidays. We've only ever had one member who was barred. The staff initially barred her, her behaviour was discussed at a Friday meeting and the decision to bar her was taken jointly with members and staff.

Similarly, a member of Stepping Stones commented:

There's the odd fallout between members but that's usually sorted out. The staff are brilliant. We're usually quite successful.

It should be noted that both these comments came from service users. Workers from these projects made reference to issues which *they* had seen as dilemmas and these will be considered below.

A second group of respondents also identified a lack of dilemmas arising from user involvement but saw this absence in rather a different light:

No, but that isn't necessarily a good thing, because user involvement isn't that high just now.

No - I wish it had. I wish users were more in control of the project rather than staff. I feel it is very much staff-led.

More frequently, dilemmas *were* identified by users and staff and these will now be considered.

The impact of mental ill-health on user involvement.

A wide range of issues were mentioned which related in one way or another to the mental health of users and/or workers. Firstly, reference was made to the ways in which ill-health impacted on the functioning of the organisation - a particular issue for MDFS, given the nature of manic depression:

The health of one person, or actually a few people, is a limiting factor and their judgement is not as clear as it could be. But because we're specialists, it's something we can take account of. People do go high or low - that's a problem. (MDFS)

Because of the nature of the illness, especially the highs, where people become incredibly creative, there's a flow of ideas but the ideas are sometimes fantasies. If you are speaking to someone who is a board member and they're asking you to do something bizarre, you have to decide 'is this person well or unwell'? You play it by ear. To a degree there are mechanisms for dealing with this but each person is an individual. There are different options open to you. Previous experience dictates how we react. (Worker, MDFS)

I think you're aware that due to the type of illness, strong personalities can clash and behaviour can be difficult. People can behave in ways they wouldn't do if they were well. If someone's a bit high, a Board meeting can be disastrous. (MDFS)

Workers from other projects also identified some of the difficulties that can arise where a user in a management position becomes unwell:

Sometimes there's a feeling that if someone's not well, you don't want to tell them that. You handle it differently from other situations. You're scared of being too forceful because you don't want to upset them. It's very difficult with some people. It's not too bad with our committee. People can be very manipulative and if they become unwell, then it's something you've said or done to them, or conversely their bad behaviour can be excused because they weren't well.

When people are going downhill, you don't want to talk about it in front of them. When someone's not taking their medication, for example, staff would advise the CPN and advise the member of this, especially when there's a risk of self-harm.

Sometimes the stresses of managing, or working in, a mental health project in itself could be damaging to mental health. A worker who was himself a user felt that

The work is stressful. There have been some stresses within the organisation and some workers and some volunteers have been off with stress-related illnesses. It's quite intense work, quite stressful.

The extent to which such ill-health impacted on a particular organisation seemed to depend not only on the degree of illness but also on the mechanisms which were in place to address such occurrences. Several of these projects had developed a 'practice wisdom' for dealing with these problems, reflected in the form of agreed procedures, for example, or different types of support and back-up. Perhaps in an example of necessity being the mother of invention, MDFS seemed to have thought these issues through most fully. A worker who was also a user noted that

We had problems last year when I was off ill for three months. Nobody knew what my job was and it created a void that put a lot of strain on other workers. ... I went off but was still giving instructions which should not have been given. Now, if anyone's off ill in the slightest way - including flu, for example, - we will not take instructions from them. That can be difficult, if it's Board members, for example, and you think they're a bit high and are not going to carry out their instructions.

We've had problems because of illness. Someone came into a Board meeting and said 'I've brought Jesus Christ with me today'. The Chair replied, 'I'm sorry - Jesus Christ isn't a Board member - he can't come in'. It's about dealing with delusions. We're all very aware of each others illnesses. We watch for differences and for certain behaviours. We know what to look out for. (MDFS)

When people get ill, if there's no back-up for the rest of the committee, it's a problem. I was off ill for a while and nobody could do my job. We're trying to set up something outwith the Social Work Department to help the committee as they no longer have the people to help us. (Stepping Stones)

As these examples show, mental health problems on the part of workers or management committee members clearly did create specific difficulties from time to time for these projects. It would be wrong, however, to exaggerate the significance of these difficulties. In the first place, where support and back up was available, or as we have seen, where projects had worked out ways of dealing with these issues, they did not need to impact on the overall running of the organisation:

People sometimes experience mental health problems. That leads to problems of continuity of management of the project and creates problems for you as a worker. I'd emphasise that in terms of competency, there is no problem, regarding accountancy and overall management, for example. (Worker, Stepping Stones)

Further, as an MDFS member pointed out, other voluntary organisations also experienced 'deficits' from time to time, albeit of a different type:

In other organisations, you get deficits - not enough skills, for example. But because of our funding, we can buy in skills we've bought some training from the Scottish Institute for Human Relations, for example. We'll also get someone in if there's a need for troubleshooting or analysis, for example. It works mainly because we have a lot of very committed people. (MDFS)

Implicit in this comment, however, is the recognition, noted also by the Stepping Stones committee member above, that effective user involvement is dependent on adequate resources being made available, in the form both of finances and support staff, if the stress created in managing and developing services is not to actually worsen the mental health of those involved.

Representativeness and accountability

Reference was made in the previous chapter to what one respondent described as the 'backstabbing' that went on within sections of the users' movement. It should be emphasised that such behaviour was not evident in all, or even most, of the projects visited. In several, the dominant culture was one of solidarity and mutual support. Nevertheless, there were sufficient references to the damaging role played by particular individuals within projects or within the wider movement to make this an issue worthy of consideration. The strongest statement of this view came from a worker who was not a user, referring to meetings of the Executive of the organisation:

I've never come across such a volatile group - tears, swearing, stomping out. There's an incredible amount of behind-the-scenes backstabbing and politicking.

Such behaviour appeared to be linked to a lack of representativeness and accountability, with some individuals acting in what seemed to be an thoroughly individualistic, or even maverick, fashion. A worker from another project commented:

Because confidence has been shattered, you will always get some people who are able to express themselves and they will dominate, particularly in mental health. You go round the committees and you find these people cropping up. That's fine but you don't want these people expressing the feelings of the whole user movement. Some personalities dominate the whole scene. There's an issue of representativeness.

A respondent from another organisation summed up the problem as

terrible individualism, often based on people's own needs, rather than the need to create a user movement. Crass individualism - decisions made at one Executive meeting were frequently reversed at the next.

One organisation which had experienced particular difficulties of this nature over the years was SUN. These difficulties centred on a small number of powerful individuals playing what was perceived by other members to be a damaging role within the organisation and contributing to the development of a rather malign internal culture which was felt by some members to be inimical both to the growth of the organisation and also to the health of members. Due to SUN's position as a national organisation, these difficulties were fairly well-known, both inside and outside the organisation, and reference was made to them by several respondents:

SUN has been dominated in the past by one or two key people whose personalities put people off. It's also well-known that SUN has had other difficulties. (SUN)

Some flavour of the difficulties experienced is evident in the following comment from a SUN respondent:

..the history of SUN has been chequered to say the least. There was the AB affair. A former secretary, he was totally autocratic, off the wall. AB *was* SUN. He was finally expelled last year. The next secretary stole money. so he went. Then C., the development worker, left under a cloud...it was very difficult until AB finally went at the AGM at the end of June - until then, he kept turning up.

Several factors seemed to contribute to these difficulties. Firstly, the poor mental health of particular individuals, particularly if unacknowledged, may impair their judgement and contribute to the sort of problems described above.

Secondly, the experience of suddenly being given a degree of power and responsibility, perhaps after a lifetime of feeling disempowered and being the object of other people's decision-making, was something which some users struggled to manage.

For several respondents, however, more important than either of these factors, was the lack of clear democratic structures within particular projects and within the wider users' movement. The complex interrelationship between structures and individuals with mental health problems was well summarised by a SUN Executive member, who felt that the main issue for SUN was

Its history. We have spent the past 2 years dealing with the consequences of it being formed in the wrong way. It was a users' network but didn't really represent users. We're still having to create a 2-way flow. The users' movement is still forming. That relates to the lack of funding for collective advocacy. Users forums only exist in some areas. We face all the usual pressures that apply to any organisation but with an extra layer - our own mental health problems. The pressures mean that feelings can be more difficult to handle - that can create instability. Sometimes people take on the power for themselves and they have to be challenged. For some people, it's their first experience of power. That means there have to be clear structures and ground

rules, though based on our needs, not imported from outside. There's a need for clear standards, accountability.

While in part, the lack of such structures relates to the stage of development of the users' movement, it can also be seen to relate to the ideas which inform the 'new social movements' more generally. The creation of democratic and accountable structures is something which not only the users' movement but several of the other 'new social movements' including the women's' movement, have often failed to achieve.

Occasionally the absence of such structures is justified on the grounds that structures intimidate people or reflect 'male' ways of organising (Rowbotham, Segal and Wainwright, 1980). Yet often it is the absence of such structures which creates a space for the rise of 'charismatic' leaders who are accountable to no one. In a discussion of the US womens' movement, for example, Smith argues that

Although set up as 'non-hierarchical', the picture was hardly one of mutual support. Instead the atmosphere tended to be extremely moralistic and extremely judgemental towards lifestyle. {One participant} described ' In the name of anti-elitism, they were trying to pull off the most elite thing possible. The meeting ended in charges and counter-charges and a distinct lack of a feeling of sisterhood' (Smith, 1994: 10).

In similar vein, after a particularly acrimonious conference of the British Womens' Liberation Movement in 1978, one participant wrote to the the feminist journal *Spare Rib*

the threatening stances, arrogant posturings and self-indulgent introspection I am my friends witnessed at conference have ensured that none of us will ever try to establish contact with the movement again (cited in German, 1989: 193).

A second factor contributing to some of the difficulties discussed above is the idea, common within the new social movements, of the *authority of experience* , the view already discussed in chapter seven that personal experience of mental ill-health

overrides any other considerations, such as competence, skill or ability. Several respondents were clearly bitter about the way in which they felt some individuals had used their personal experience in a manipulative and self-serving way:

SUN was re-created just over a year ago. Before that, it was the worst sort of patronising tokenism you've ever come across. People were pulled together by the Edinburgh Association for Mental Health. There were a lot of people on it but they didn't do anything. Just because you're a user doesn't mean you can be a nuclear physicist, for example. So being a user is important but you can't have someone as a treasurer who can't count. It sickens me when I think of it - it was very damaging to the cause of user involvement.

Nor, it was felt, was such experience a substitute for democratic debate. While the experience of being a user may provide one basis for commonality, the notion that there is a 'user view' ignores the wide range of other factors which also shape the ideas in the heads of service users. As one worker commented:

Users are not a uniform monolith. As in any organised thing, there can be conflicts of ideas. Also, people's experiences are so varied. For example, most people are opposed to ECT but some stand by it. You have to take account of that and that can cause tension.

Similar comments are provided by a respondent in Beresford and Croft's study of user involvement:

We aren't all the same. The only thing we may have in common is the mistreatment we may share through use of some service or the attachment of some stigmatic label. All of us aren't equal as service users. The wider discriminations still apply.... There isn't a 'user view' (Beresford and Croft, 1993: 149).

The fact that, as Beresford and Croft argue, the allegation of lack of 'representativeness' has often been used by statutory agencies and service providers as a basis for not dealing with users groups is not in itself sufficient reason for failing to address the real problems which a lack of proper democratic structures creates.

User/worker relations

A characteristic feature of the experience of mental health service users has been the lack of power they enjoy relative to the mental health professionals who provide their care. It is perhaps not surprising, then, that the relationship between members of projects and project workers should have been identified as an area which produced a range of dilemmas. Such dilemmas fell into two broad categories - role issues on the one hand and power and control issues on the other. Each of these will be considered in turn.

Role confusion.

A diverse range of issues arose relating to the role of workers in relation to members; in relation to other workers; and also to the role of management committee members in relation to both workers and other members. Interestingly, such issues were raised most often by project workers. One issue raised by a service user concerned the role of a worker who was also a service user and reflects the points made in the previous section about the need for clear accountability:

X is a user, as are some other staff members, so user involvement crosses the line. That's a different question from volunteer user involvement. The edges tend to get blurred. It is the management committee who should decide policy.

The need for clear lines of role accountability was also stressed by Saheliya users (Saheliya currently operates as a workers' collective):

We need a top person, a manager. You need a manager to resolve issues, someone to complain to. It would be helpful if there was someone to manage

the staff and the users. Maybe even a suggestion box where the workers could discuss the suggestions.

It was not simply the lack of clarity regarding *workers'* roles that caused confusion, however,. At least as many issues arose in respect of management committees made up of service users, with a major one being confidentiality. One AdvoCard member identified the issues in her project as

boundary issues, change of roles, conflict of interest. On the management committee, people tend to forget they're in different roles. there's issues about confidentiality. You say something to an office-bearer and it's repeated elsewhere. It causes a lot of problems.

This issue of people wearing different hats was also identified as problematic by a worker from another project:

It's sometimes exasperating as a worker because people are attending groups as members who are also on the management committee and are wearing two hats - that's difficult for that person and for the worker. For example, if there is someone in the group who is also a member of the management committee, people will approach them with a problem and that's not their role. It can be exasperating but it keeps you on your toes and stops you being complacent.

A further issue, identified in two projects, was the issue of non-user workers working alongside workers who were also users. In part this related to what I have described as the 'authority of experience'. A worker who was not a service user saw the problem as follows:

It's difficult to tell if the problems are due to user involvement per se. The employment of myself as a non-user created conflict between myself and the user/worker. ...I had a problem with my co-worker, though not with the Executive. She saw herself as having the authority.

An Executive member from the same project identified the same issue but from a different perspective:

There has been conflict. There is the dilemma of a user being the paid worker. Where users and non-users are working together, there's a greater danger of patronising attitudes and lack of understanding - the mix is more difficult to manage. There's a respect issue. Where other workers might go through a bad patch and be supported, if it's a user, people will say 'It's the disability again'. A lot of blaming goes on that tends to escalate into more serious problems for workers.

Issues of power and control.

In some projects, the challenge to professional power which user involvement implies was perceived as having created real dilemmas for these projects - for one project manager, 'huge, enormous, cataclysmic dilemmas'.

In one project, the issue was summarised by a project worker as being about

Where does the power and control lie. Before the workers were appointed, the management ran [the project] independently. There's a difficulty in adjusting to a culture where they employ staff. It's difficult for me coming from the voluntary sector - here, there's a 'hands-off' culture, especially around finance. Initially, workers were not allowed to make even tiny decisions - that's changed. Sometimes it felt like 'why do they bother to employ a development worker'? There's a big issue about trust.

Again, given the history of relations between psychiatric patients and psychiatric professionals, such a lack of trust is perhaps unsurprising. In the case of one project, however - the Charlie Reid Centre - this lack of trust had exploded in what staff felt was a potentially destructive manner. The issue - which was identified as a major

dilemma by both staff and user respondents - was outlined as follows by a Centre member:

There is a member who had a run-in with staff at a time when we thought people were going to be made redundant. This person started a campaign against the other staff - he got up a petition. That split the camp at one time. They got up a letter to send to Edinburgh. People felt intimidated by this member. Again, it was all financial - because staff were going to be made redundant, though in fact they weren't. The good thing was that the members thought so much of that member of staff that they were prepared to go to great lengths. It shows the bond between members and staff.

From the staff side, a worker who also identified this issue as a major dilemma described it in the following way:

Yes. There was a specific issue. A user had too much power and was using it in a destructive way. Other members were being intimidated. The only way to deal with it was by not practising what we preach and say at the end of the day 'We're in charge'. It was as if you had to drag the project back to you. It was as if we were all on equal terms then this member sprouted up. The staff felt disempowered but the members were also frightened. This member was saying 'Back me or else'. At that point, the staff group said, 'If no one else is going to do anything, then the staff group will'. We had to make members feel safe and let them know that nobody had unlimited power in the centre.

For another worker respondent, the issue had highlighted the dangers of 'unrepresentative' user involvement:

It wasn't just about user involvement but about lack of trust and tokenism. If you have two people every week, for example, and that's your community meeting, then you have problems.

For another user respondent, it raised issues about

how much can someone who is recovering be involved in decision-making. It also raised the question: what's the difference between *campaigning* and *harassing*? On the whole, it revealed personality clashes and how ignorant people were of the way the Charlie Reid Centre was run, and the funding. It involved one member being expelled, although he is now reinstated.

There appeared to be consensus, then, amongst both staff and user respondents that, in this specific instance, there *was* intimidation of users by a particular user and that staff were right to act as they did. The example also highlights, however, some of the complexities surrounding mental health service user involvement. On the one hand, it shows the dangers of a simplistic view of users as simply passive victims with professional workers as their oppressors. On the other, there is the danger that *legitimate* user protest might also be construed as 'irrational' or 'manipulative'. Similarly, the charge of 'intimidation' is one that is routinely thrown at those who try to involve their peers in collective resistance to the decisions of managers or policy-makers.

TOWARDS A USER-CONTROLLED MENTAL HEALTH SERVICE?

As the discussion on constraints on involvement in the previous chapter and the discussion on dilemmas in this chapter have shown, user involvement in the management and development of mental health services is not without its difficulties. How then did users and workers respond to the statement that 'All mental health services should be run only by users or former users'?

TABLE 9 - USER-LED SERVICES

Count Column Percent	USER RESPONDENTS	WORKER RESPONDENTS
Strongly disagree	6 14.3	2 11.8
Disagree	23 54.8	13 76.5
Can't decide	6 14.3	2 11.8
Agree	6 14.3	0
Strongly agree	1 2.4	0
Total	42	17

As this table indicates, while some service user respondents were more positive than worker respondents about the notion of all services being user-led, nevertheless the overwhelming majority of both workers *and* users rejected this statement. Three main reasons were offered for this rejection: the need for *partnership* between workers and users; the need for a *range* of services; rejection of separatism.

Partnership

The most common single response was that a 'mix' of service users and professional workers - a 'partnership' - was necessary. Some of the difficulties surrounding the notion of partnership were alluded to in chapter one (for a fuller discussion, see Braye and Preston-Shoot, 1995) and many of the points made regarding 'participation' in chapter two could also be applied to the notion of partnership.

Writing from a separatist perspective, Chamberlin is scathing about models of mental health services based on a partnership model:

In the *partnership model*, professionals and nonprofessionals work together to provide services. The recipients of the service are told that they, too, are partners in the service. However, the distinction between those who give help and those who receive it remains clearly defined. I consider services based on these models to be alternatives in name only...Mental health professionals are used to taking a controlling role and they continue to do so even in 'alternatives' based on the partnership model (Chamberlin, 1988: 93-94).

Others are more pragmatic. In a recent discussion of the issue, for example, Thompson has suggested that working in partnership involves

moving away from a medical model in which the worker presents him- or herself as an 'expert', with the expertise to define what the problem is and what needs to be done...Partnership entails reducing the power differential between professionals and users of services (Thompson, 1998:212).

What did the term mean to respondents in this study?

You need a mix. I personally think you have to have some people who have had experience of psychiatric services but also others who don't. That mix has to be prepared to respect each others' experience but that has to be meaningful - not just lip-service. (Worker, AdvoCard)

It should be 50-50. We do need professional knowledge but you also need to have the other side of it too, to have been there. If we could get what we want plus professional knowledge, that would be brilliant. (Stepping Stones)

It depends on the mix, on the respect issue being worked out, so that there's not an automatic subordination of users by others. There's a need for cultural clarity, for equality and respect - mutual respect. (SUN)

Whereas responses to the earlier statement about professional domination of services tended to emphasise the limits of professional input and the significance of the user contribution, here by contrast, respondents emphasised what they saw as positive in professional input as well as some of the limitations of user involvement. As well as bringing professional knowledge and skills, professional workers were seen as bringing a degree of *objectivity* and *stability* to a project:

That's far too simplistic. We have to recognise the importance of professional expertise. What is true is that users should be involved and consulted in the running of all mental health services and should certainly run some of them.
(MDFS)

You need a balance. User input is vital but we must remember carers and dispassionate professionals. You need balance and by the nature of the issue, you need someone who can look clearly at both sides. (Worker, MDFS)

A worker who was also a service user commented:

There's a need for a stabilising element in there. It's also good to have someone who can stand back. I have a CPN who is more emotionally detached, who can stand back and say, for example, 'You're not ill'. Sometimes working in the mental health area can be very bad for your own mental health - you can make yourself ill.

There have to be staff - a figure of hope and positivity leading somewhere.
(Charlie Reid Centre)

Whereas these respondents tended to stress the positive input of professionals, others focused on what they saw as the limits of the user contribution. One respondent who answered 'can't decide' to this statement went on to provide an effective critique of approaches which elevate user experience above all other consideration:

The bottom line is that services should be controlled by users. It doesn't mean that workers have to be users but policy should be determined by users. Just being a user isn't a qualification to run a drop-in centre for example.

Sometimes it's dangerous. If you have a user who's a worker, they can sometimes substitute themselves, as in 'I must be doing it right because I'm a user'. I've seen that happen a lot with users who are workers. The only people who really know about a service are those who use that particular service, so if you're being that pure about it, then they should really come from that particular project. (SUN)

Other comments tended to emphasise the impact of mental ill-health as a limiting factor:

There is a place for professionally qualified people, because with people who have had mental illness, there will always be relapses and setbacks. There have to be people with a professional knowledge of mental illness. (SPS)

It's limited if all the people involved have mental health problems. We've got to have the steadfastness of people who don't have mental health problems. (MDFS)

It's very useful for users to be there but there should be a balance. There are times when individuals can feel under a lot of pressure. The climate we are in is very stressful. Women with depression *have* come on to the staff team but have needed a lot of support. There should be a mixture. (Worker, Saheliya)

In term of the *type* of professional input that is required, one respondent again specified the need for community work skills:

At this point in time, a lot of support is needed. Community development workers should provide support, not CPNs. The motivational force, however,

should come from users. The nature of mental health is such that a lot of support is needed. But in an ideal world, I would agree. (Stepping Stones)

The need for a range of services.

The notion of mental ill-health as a process has already been explored in chapter Seven. Here, that notion was evident again in the views of a number of respondents that a *range* of services was necessary, reflecting the health needs of particular individuals:

It depends what the service is. They should have user input and consult users but not necessarily run by users. (AdvoCard)

The recognition, for example, that at certain stage of the cycle of ill-health or of the life-cycle, people may need to be more dependent and may be less able to take on the role of the 'empowered user' was implicit in the comments of the following respondent :

I wouldn't want to make a blanket decision because I can see that Clubhouse is ideal for our situation but might not suit, for example, older people who just want to sit down and have a cup of tea. The Clubhouse ethos is to work and participate and that might not suit them. (Core Club)

Another respondent emphasised a theme that has been referred to earlier, viz., that the role of user-led, community-based services is primarily *preventative* and *rehabilitative*:

I agree that this sort of group should be [user-led] but there's a need for Goldenhill too [local mental health centre]. When you're in hospital, you need that sort of support, but when people are ready to move on from that, you need services like this. It should be user-led at this level. We have more idea of how you can move people back into the community. We're on the border - we can stop people going back into Goldenhill. (Stepping Stones)

Finally, a project worker and a user respondent addressed the dilemmas associated with all workers being users:

For some mental health services, that's fine but if you have user-only projects, you will have leaders who have mental health problems - what happens when they become ill ? If there were no staff to provide continuity, what would happen? In a way, we're also supposed to be positive role models. (Worker, Core Club)

It depends on their level of recovery. I see people struggling, unwilling to admit that they're not coping. Everybody wants to work for a living - if you're working, you're OK. The danger is that a person is interviewed when in remission from the illness, and can be seen as very capable, but they then find the job difficult and can't talk about the difficulties. The issue has to be looked at very carefully. There's a huge difference between doing voluntary work and a paid job. As a volunteer, if I don't feel well enough, I phone in and that's accepted. There must be a balance. (GANET)

Rejection of separatism.

For a third group of respondents, the statement that all mental health services should be user-led smacked of an anti-psychiatric politics (or in the context of the 1990s, a politics of identity) which they rejected:

You do need some staff. The autonomy sounds good but you do need staff. It's a partnership, not a militant group, that you're creating. I have really strong views about that kind of thing. (GANET)

There are good and bad professionals, as there are good and bad users, and a damned sight more good than bad. There are decent people who are committed to caring. We have had a lot of disaffected users who have perhaps had a bad

experience of the psychiatric system. I have a major problem with users who are strongly anti-psychiatry. Regarding ECT, for example, as long as there are proper safeguards and controls, then it is all right that it is there. People have a right to different treatments. Overall, I would prefer to see a more holistic approach, but I have major problems with users who see professionals as the opposition. We can't deny people the right to particular treatments. I think to be anti-medication is wholly inappropriate. We have to work in partnership. At SUN, we try to get that ethos right. (SUN)

Taken in isolation, such statements might imply a continuing acceptance of professional authority, almost a deference towards psychiatric knowledge and expertise, including physical treatments. Such deference towards medical authority runs deep within society as a whole and undoubtedly a very small number of respondents *did* continue to adhere to the view that 'doctor knows best'. Taken in the context of responses to the earlier statement about professional domination of services, however, a more accurate reading is that they reflect an impatience with what was sometimes felt to be a preoccupation with what, given the current economic and political climate, were seen to be secondary issues. In response to the earlier question about terminology, for example, this last respondent had commented that 'We could spend all day arguing about names - it's an issue for some people' and to his statement above, he added:

The major issue is about community care. There's a lack of resources but also a lack of community preparedness.

It was this recognition of the climate in which user-led services are being developed, and the dangers inherent in that climate, which led two other respondents to reject the statement:

Unless there are safeguards, that gives a huge amount of responsibility, although I suppose it also depends on how you define a user. It feels like society's saying 'Right, you lot, you do it. It's nothing to do with us. ' There's

a need for safeguards against exploitation and abuse, a need for personal protection. There's a need for partnership, for financial resources to be put in, for training and education, for real supports that are built in. (Worker, Stepping Stones)

I don't want to see apartheid between those who have mental health problems and those who don't. Users want a role but not just because they're users.
(SUN)

In chapter one, I noted the ideological roots of consumerist models of user involvement in a New Right agenda whose main preoccupations are the withdrawal of the State from the provision of welfare and its replacement by market forces. There was real concern, particularly amongst project workers, that the emphasis on user-led services located in the voluntary sector could provide a convenient cover for just such a withdrawal. In response to a question regarding the advantages and disadvantages of the voluntary sector as a service provider, while recognising advantages of flexibility and independence, such concerns were nevertheless to the fore:

It doesn't seem right that the statutory sector tries to hive more things off to the voluntary sector. More should be done in the statutory sector. It's the contract culture - it's such a waste of time. All these little projects working separately from each other with little contact. (Worker, AdvoCard)

The disadvantages are that they take away the responsibility of the State to provide decent health services. They're seen by central government as a way of doing things on the cheap. They're patchy - but then so is the statutory sector. On the one hand, as someone who works in the voluntary sector, I see advantages but in another way we're going backwards to charities, not rights, where we're expected to raise funds. It would be fine if it was properly funded but it's not. (Worker, SUN)

It would worry me that voluntary mental health organisations would replace the NHS. From our point of view as a young charity, there are certain things we can't do. Care in the community doesn't have the back-up and support to make it function. There's a general concern that the NHS will disappear.

(Worker, MDFS)

CONCLUSION

If there is a single dominant theme emerging from the above discussion, it is the desire on the part of both service users and workers for *partnership* in mental health services and the struggle involved to achieve such partnership. Thus, on the one hand, in both this chapter and in previous chapters, there is an overwhelming rejection of the paternalism and professional domination that has characterised mental services in the past. On the other hand, there is also a rejection of separatism, grounded in a recognition of the contribution that professional workers can make and also in an acknowledgement of the debilitating effects of mental ill-health.

Some of the factors that can contribute towards the creation of such partnership were mentioned at the end of the last chapter, viz., a willingness to confront issues and dilemmas openly; a grasp of a community development approach; and a commitment to the values of participation and empowerment. From this chapter two more factors can be added. Firstly, proper funding of projects which, among other things, allows for the provision of a range of supports, both administrative and consultative, for the provision of crèche and transport facilities, for training in committee and other procedures, and above all, allows staff and users to concentrate on the development of the service, rather than being continually preoccupied with securing next year's grant. The second requirement for partnership is the creation of democratic structures and support for service users in employing these structures effectively.

However, while such factors are the basic prerequisites of genuine user involvement in mental health services, they by no means tell the whole story. The focus in this chapter and in the previous chapter has been on user involvement in the management and

development of services. The progress of such user-led services, however, cannot be viewed in isolation from the wider social context, and as several respondents noted above, the current context is one in which community-based mental health services are often inadequately funded while the dominant discourse is increasingly one of the 'dangerousness' of people with mental health problems.

By their nature, such issues cannot be addressed at a local level and hence the role to be played by a national users' movement takes on a greater significance. The extent to which mental health service users are capable of organising collectively to build a movement capable of addressing stigma, structural oppression and the limitations of current mental health services will form the subject of the next chapter.

Mental Health Service Users - a 'new social movement'?

It is now customary to identify 1985 as the year in which the British mental health users' movement really began (see, for example, Barker and Peck, 1987; Rogers and Pilgrim, 1991). As noted in chapter one, an indication of the growth in its influence since then is that while few, if any, service users were consulted in the preparation of the 1983 Mental Health Act, service users and their organisations are now routinely consulted by both national and local government over mental health issues (Campbell, 1996), albeit that, as I have argued in chapter two, such consultation is often tokenistic and its findings disregarded.

This chapter will explore the nature of this movement and in particular its characterisation by some writers in the critical social policy tradition as a 'new social movement' (Rogers and Pilgrim, 1991; Rogers and Pilgrim, 1996; Barnes and Shardlow, 1996; Barnes, 1997). Drawing mainly on focus group discussions and, where appropriate, individual interviews, the chapter will consider the extent to which mental health service users espouse a social model of health; their capacity to engage in collective campaigning activity and the content of such activity; attitudes towards a mental health users' movement; and the scope for class-based alliances.

A SOCIAL MODEL OF HEALTH?

The social model of disability has been a crucial element in the development of the disability movement (Campbell and Oliver, 1996). According to an early and still influential definition of that model

In our view it is society which disables people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. disabled people are therefore an oppressed group in society (UPIAS, 1976).

The extent to which a social model of health, in the sense of seeing mental health service users problems as primarily social or structural, similarly underpins the mental health users' movement, is less clear (Lindow and Morris, 1995; Barnes and Shardlow, 1996). While the social model is by no means universally or uncritically accepted within the disability movement itself (see the discussion in Oliver, 1996), nevertheless an acknowledgement that the roots of the problems of disabled people or mental health service users are primarily social would seem to be an essential precondition for addressing these problems through collective action.

As a basis for exploring the extent to which respondents in this study adhered to a social model, focus group members were asked to identify what they saw as the three of four major problems facing people with mental health problems living in the community. As a 'trigger', they were each given a sheet of paper with suggested problems including: lack of community care services; mental health professionals (such as GPs and psychiatrists) not listening; side- effects of medication or ECT; poverty; feeling bad as a result of mental ill-health; lack of user involvement in services; lack of employment; loneliness; inappropriate community care services (e.g. not open at the right times); other people's attitudes to mental illness; other problems not mentioned above. Three main areas of problems were identified.

Stigma.

Stigma, in the form of 'other people's attitudes', was identified by several respondents in every group as perhaps *the* major issue facing service users, feeding into almost every other problem which users identified. It was seen, for example, as the major contributory factor to the loneliness experienced by many people with mental health problems:

Of course, other people's attitudes to mental health, that's responsible for a lot of the loneliness of members you know, that's why places like this are set up...it's a refuge for people. (Ayr)

Loneliness is another [problem] and again I think it's because of the stigma. I'm one of the lucky folk who can go out and go quite a lot of places on my own but there's a huge amount of folk that can't. I mean I don't find it so terrible walking into a strange group but there's thousands of people who wouldn't. (Fife)

Stigma was also seen as the major barrier to obtaining employment:

I fill in application forms and if it says, 'are you suffering from depression?', I lie, I mean, I wouldn't admit to that because I feel I would be put right down the bottom of the heap. It's just there, you know, it still has the stigma. I don't care what anybody says, there is a certain amount of stigma attached to mental illness. (People Need People)

Deficiencies of existing services.

As with other studies, a range of issues relating to the provision of mental health services, such as professionals not listening; lack of information about services; and the side-effects of medication were high on the agenda of several individuals and groups:

Personally I would say that for me, the main things were the mental health professionals such as GPs and psychiatrists not listening...I don't feel I got the help I needed at the right time. I don't feel that I was sort of taken seriously at an early stage and I think I could have been helped a lot better in more ways and medication wasn't necessarily one. It was sort of the prescription pads was the first thing that comes out of the GP. (Fife)

To me the major problems are lack of community care services, mental health professionals not listening, and other people's attitude to mental illness. For me I feel that the other problems could possibly be minimised or even resolved if those three were in place and properly addressed. (Edinburgh)

At the height of my problems, like when I was discharged after a really acute spell of illness the side effects of medication were a huge issue for me and I was fortunate enough to be able to get my medication reduced and an understanding GP who was able to - able and willing to - let me work on the balance of tablets to deal with the side effects which were both hugely important in terms of my recovery and being able to lead a normal and fairly full life. (Fife)

I think one of the big problems is lack of community care services. There is so little money in mental health services in the community that you're lucky to have got, say, one day centre in each area and if that day centre doesn't suit, you know, I mean obviously all services don't suit everybody so if one day centre, the only one in the area, doesn't suit a large number of people, then they've no place to go. (Fife)

Material issues.

Lack of employment was the first problem identified by several respondents:

Lack of employment and the lack of help getting it. There should be people there helping you, you know, finding the job, helping you get into the job. You have to look at people on medication. People can't get up at times. (People Need People)

A lack of employment - I would widen that to say a lack of meaningful things to do, lack of structure in my life...The key bit for me was actually getting

involved in voluntary work initially as a charity shop worker and then gradually became involved in volunteer work through mental health. (Fife)

Relative poverty was also identified as a major issue in the Ayr, Eastwood and Edinburgh groups:

Although I'm not on the breadline, I would still say that I am on benefits and I get what I'm entitled to but I can't afford to buy the foods that I would like to buy in order to help me...If you can't afford to buy the foods or exercise...these are all things that keep you well and help keep you well, if you haven't got money to do these things, that's where the loneliness comes in, it's a very lonely existence. (Edinburgh)

Three main points emerge from the above discussion. Firstly, the problems experienced by service users were overwhelmingly seen as being 'social' in character, as opposed to having a naturalistic origin in some pre-existing mental health condition. The *least* mentioned category, for example, was 'feeling bad as a result of mental ill-health', with few respondents making reference to the difficulties involved in coping with voices or depression, for example. One respondent who addressed this issue directly commented that

You've got a thing here which we've been looking at which is feeling bad as a result of ill-health and we've been having talks before and what we've come down to is that the results of the stigma of mental ill-health is actually a larger problem than actually having mental ill-health. (Edinburgh)

In this respect, then, these users did seem to be espousing elements of a social model of health.

That said, a second issue emerging from the discussion is respondents' emphasis on the adequacy and appropriateness of *services*. At the very least, such an emphasis involves an implicit recognition of the disabling effects of mental ill-health itself and the need for

responsive services, and to that extent implies a rejection of the view that the problems experienced by service users are wholly socially constructed. While there is a growing debate within the disability movement regarding the relationship between illness and disability (Barnes and Mercer, 1996), this emphasis on services implies that the concerns of mental health service users in respect of the treatments they would like to see, for example, or regarding relationships with professionals, may not always be identical to those of people with physical impairments.

Thirdly, a range of *material* issues, including lack of employment, poverty and lack of resources were mentioned as major issues in every group. Given the discussion of class and mental ill-health in chapter three, this should not come as a surprise. In the context of considering collective responses to the problems which users experience, however, what is perhaps surprising is the common research finding that users' groups or of the wider users' movement frequently fail to collectively address these material issues. Thus, Rogers and Pilgrim note the apparent paradox that a movement based in large part on the rejection of a narrow biomedical model of mental ill-health and the labelling associated with that continues to define itself in terms of mental ill-health, as a *users'* movement and continues to focus on *services*:

The user movement has defined itself in terms of the services it has had contact with, and the diagnostic labels which are considered stigmatising. This has the effect of focusing their remit of demands on the narrow agenda of clinical services and diverting energy from wider social and material provision which is recognised in principle as being important (e.g. jobs, inadequate housing, non-medicalised support networks). Indeed one of the respondents identified this as a vulnerability within the movement (Rogers and Pilgrim, 1991: 147).

Similarly, Barnes and Shardlow for example, while noting the poverty experienced by many people with mental health problems, nevertheless conclude that

none of the three groups we looked at were involved in broad ranging campaigns in this area. They may perhaps be better understood as examples of

'new social movements' whose objectives are cultural and ideological rather than material (Barnes and Shardlow, 1996: 127).

Thus, along with an emphasis on identity, the apparent failure of service users to address material issues is suggested by these writers as a second factor which justifies their characterisation of mental health service users as a 'new social movement'. If, however, that failure to address such issues could be shown to be a temporary or contingent feature of the users' movement, then this characterisation would seem less valid. The issue will be explored in the next section by looking at the extent to which the groups in this study had been involved in collective, campaigning activities and the content of these activities.

CAMPAIGNING

The capacity to address problems through collective action is perhaps the most basic characteristic of social movements, new *and* old (Tilly, 1985). To what extent, then, had focus group members in this study participated in such collective action? What had been the focus of such activity? What barriers or constraints had they encountered?

Members in four out of five of the focus groups, as well as several of the projects, had been involved in some form of campaigning activity over the past year, though the form of this activity varied widely and it sometimes appeared to be at a fairly low level. Drawing attention to gaps in mental health services, often through some form of consultation procedure, appeared to be the most common form of group activity. According to members of Fife Survivors Group:

George: It depends on what we're talking about or what our parameters are on what campaigning is, because we did do a joint submission to Fife Health Select Committee with the local Association for Mental Health on the pressures on acute beds...there wasn't much in the actual report but they did recognise the point we made and actually put it within the report, it said that we commend Fife Mental Health Survivors Group for their submission..

Anne: ...the follow-up is we just got a letter in from the Select Committee saying that their next submission's going to be on mental health...maybe the fact that we did that has opened it up - I'm not saying they weren't going to do that but there was no mention of it before.

Similarly, members of the Eastwood Mental Health Forum had been involved, with some success, in highlighting the shortfall in mental health services in their area:

The thing we did right at the beginning when the Forum formed was Sainsbury's Mental Health Trust gave us a small grant to conduct a survey of needs of users and carers so that from that survey of needs we assessed the needs of the area. To that end we tried to fund raise for what seemed to be the top ten things, including a drop-in centre, but actually both the health care trust and also social work must have taken that survey into account because they went and funded a drop-in centre for us to the tune of £186, 000 for six workers, so that can't be bad.

Although members of People Need People felt that their involvement in campaigning activities had been limited, the local community education worker who supported the group felt that to some extent the group's very existence and their current use of community education premises was to some extent the product of a campaign:

...in some ways the group arose out of a campaign with dissatisfaction with the existing mental health services. A number of people approached myself to try and work out alternative provision or service development and the group really did start from that, from five or six people and then it snowballed and there's quite a few people got involved campaigning to get a different mental health service in Falkirk as opposed to the typical medical or social work or charities model of provision that existed.

After involvement in consultation activities to highlight shortfalls in mental health service provision, letter-writing was the next most common activity, either to the press

or to elected officials or council officers. This varied from the occasional letter to what appeared to be highly-organised campaigns:

I think there's been a debate among members as to whether we're a campaigning organisation and I think on the odd occasion, perhaps when one of the bigger newspapers has carried a controversial article, they have written to the editor giving probably a much fairer perspective on the situation, you know. Maybe the article's been about schizophrenia being harmful and dangerous - that's just such a gross exaggeration and misrepresentation of the illness and these are issues that we as a group feel strongly about. But to be fair, we probably aren't as diligent about representing ourselves on matters like that, just for the workload that is involved for members of the group.

(Eastwood)

By contrast, Fife Survivors Group had organised letter-writing campaigns around a wide variety of issues, even if the results were not always what they hoped:

George: We've written several letters to MPs in Fife about various issues such as psychosurgery, the loss of the mobility component in DLA where people are in hospital so they haven't been in care

Anne: We did write to all the councillors this time last year on the service cuts to the voluntary sector...all councillors got a letter and we wrote to the Scotsman, the Courier and various papers...the local papers printed it, the Scotsman and the Courier didn't...of course the response from the council was very poor. There was maybe two replied eventually and the leader of the council replied.

We involve users in consultations and surveys. We also involve them in campaigning around issues such as ECT, around the removal of the mobility component from Disability Living Allowance, around exemption from prescription charges. (SUN)

In one sense, the above comments appear to reinforce the 'new social movement' analysis in that most of the activities described are concerned with obtaining or providing services on the one hand, or challenging media portrayals of mental-ill health on the other. To that extent, they might be seen as *cultural* or *ideological*, rather than material, in content. Other factors would challenge such a conclusion, however.

Firstly, several of the groups had also been involved in campaigns in defence of Disability Living Allowance which was under threat from the then Conservative government. Given that the majority of these respondents were dependent on this and other benefits, by any criterion this was a *material* issue which affected their most basic living standards.

Secondly, several groups, including SUN, Saheliya and Edinburgh Users Forum had been very actively involved in the Scottish trade union-led campaign against local authority cutbacks to statutory and voluntary services in early 1997. A very well-attended workshop during the Scottish Users' Conference in February of that year, for example, was on the theme 'How Do We Fight the Cuts?'. Again, while the issue here was the defence of services, it would be misleading in the extreme to portray such a campaign as primarily 'cultural' or 'ideological'. The dependence of most of these users on public services meant that the loss of such services would have had serious 'material' consequences in terms of the quality of their lives, consequences which wealthier service users would have experienced much less. In that sense, then, there was clearly a strong *class* dimension to this campaign:

On the one hand, what such examples suggest is that users' organisations *are* capable of moving beyond a narrow clinical agenda and addressing wider social and economic issues - even if the starting-point for that movement is often the defence of user-led services. It is the *dynamic* nature of this process and the factors that enable oppressed groups to move beyond their immediate issues that NSM analyses often fail to grasp.

On the other hand, once they do move beyond these narrow issues, what may matter is not so much *difference* - what distinguishes them from other oppressed groups, trade unionists and so on - but rather *commonality*. In particular, the unifying factor in the example cited seemed to be material or class issues, such as the defence of welfare benefits and the defence of publicly-provided services, with the initiative for this campaign coming from the official trade union movement. I shall return to this point later in the chapter when the issue of class-based alliances is considered.

CONSTRAINTS ON COLLECTIVE ACTION

If the above discussion suggests that users' groups have the *potential* to engage in collective campaigning activity, it was also evident from these group discussions that there were clear constraints on their capacity to do so, constraints which have implications for the development of a mental health users' movement. These included: the impact of stigma; resource constraints; stress and burnout; and fear of professional power. Each of these will be considered in turn.

Stigma

The basis for any movement of oppressed people is a willingness on the part of individuals who belong to that group to 'come out' and challenge the stigma associated with their particular status, be it linked to gender, ethnicity or sexual orientation. As noted in chapter three, however, the stigma associated with mental ill-health is often of such a profound and all-embracing nature that the costs of coming out may seem too great, especially when the stigma is mirrored by the lack of confidence that can result from hospitalisation and mental ill-health itself:

I'm here because I've no confidence. You see other people, they say G. was a union man. But when you're in the hospital, you depend on the staff to help you, you look up to them. So when it comes to shouting the odds, you've no self-confidence. You can't go out into the street and walk up and down with a

placard and shout 'I'm daft - what are you going to do about it?' You've had no self-confidence in the first place - you hide away. (Ayr)

Stigma was seen as a factor which not only affected people's willingness to participate in public protest but more generally their willingness to be associated with a users' movement. Sometimes it was the term 'users' which was seen as off-putting:

You know, it doesn't bother me personally but I've had people said to me, I would join but I don't want to be called a user and they stay away, a lot of articulate people, a lot of people who'd put a lot into the movement, I think deliberately stay away because they feel a stigma attached to the name.

The fact that this comment came from a member of Fife *Survivors'* Group suggests that, while particular terms may indeed be off-putting, it may be it is their association with mental ill-health, rather than simply the term itself, that is problematic.

Resource constraints

Groups identified a number of resource issues which affected their capacity to be involved in campaigning activity. The first of these - the small numbers involved in each group - may be seen in part to be a consequence of the stigma discussed above.

That said, stigma is unlikely to be the only factor affecting the numbers involved. Studies of the women's' movement or the gay movement, for example, suggest that outside of high profile events such as Gay Pride, ongoing involvement in a women's' 'movement' or a gay 'movement' may for much of the time be limited to a relatively small number of individuals (Field, 1995; German, 1996). In general, it could be argued that outside of periods where there is a high level of political struggle, the numbers of individuals involved in oppositional political activities is likely to be small and in this respect, people with mental health problems are no different from the rest of the population. In a comment likely to be familiar to anyone who has ever been involved in such activities, a member of the Edinburgh Users' Forum commented

One of the problems is enthusiasm amongst ourselves because sometimes it takes quite a bit of effort to get people's enthusiasm up and people say, oh yes we're interested and then we arrange a meeting and nobody turns up and sometimes it can be quite difficult to build up that enthusiasm...with service users, not everybody's an activist, not everybody's a natural activist and for some people it can be quite hard for them to bring themselves out and be active about things that are important to them.

A consequence of the small numbers involved on the one hand and the very limited resources available to groups on the other meant that they were often forced to make choices between involvement in campaigning activities on the one hand and involvement in more mundane consultations or service-providing activities on the other:

There are really only so many hours in one week because there's a limited amount of numbers and with the amount of sub-committee meetings and link-up meetings and committee meetings and community care this and that, your week does become chokker so it potentially can take the fun out of why you originally came because you're doing so many tasks. Ultimately you know if you campaigned, you probably could recruit...so maybe to that end it may actually pay us some good service to go out and campaign and do a bit of good PR because we might have more members to help us do so. (Eastwood)

This tension between trying to provide a service for people with mental health problems and be involved in campaigning activity was also evident in comments from members of the Fife group:

If we'd had a social support group, it wouldn't have been a problem. We tried to do that but because we had so much to do, we've concentrated more on trying to do campaigning with fewer people so it's sort of self-defeating...The problem is that people don't want to do the work and don't want to be

involved in the campaigning. They want this standing on the sidelines cheering us on but the problem is getting enough people that will actually do the campaigning. will take part in the consultations.

A key issue arising out of these comments concerns the nature and future of community care consultation. It was evident that such consultation formed a large part of what groups saw as campaigning activity. Whatever the value or limits of such consultation, however, as Beresford and Croft have pointed out, it needs to be supported, in the form of both financial resources and staffing (Beresford and Croft, 1993). Yet from these group discussions, it was clear that not only did service providers frequently expect groups to be involved in community care consultations without providing additional support but several of the projects and groups had in fact experienced cuts in their budgets during the previous twelve months. Not surprisingly, this led to some serious questioning regarding the value of such consultation and the motives of those who instigated it. As one leading activist put it at the Scottish Users' Conference in 1997:

There's been a sea-change in attitudes in the past few years. People have been going overboard to involve us in consultation - the Scottish Office, the Health Board and so on. My cynicism may be proved wrong but while we're talking about making improvements, the powers that be have been making cuts... Without money to back up services, it's just a talking shop. We will not sit passively by and watch our lives being destroyed by intolerable funding cuts. Don't give us something and then take it away again. To take funds away from a project that is working is obscene. (Scottish Users Conference, 1997)

At the same time, as the above comments make clear, involvement in these activities was often at the expense of potentially more effective campaigning activity, a danger which Mayo has noted is inherent in the extension of the 'mixed economy of care' to the voluntary sector (Mayo, 1994).

Stress and burnout

A consequence of the lack of active members, on the one hand, and the lack of resources on the other was to place considerable stress on those who were involved. One issue here, as with user involvement more generally, was the mental health problems of those involved, which were seen as an occasional impediment to activity. A member of the Eastwood Forum felt that the extent to which the group was involved in campaigning activity was

influenced by the resources we have as a group and the numbers and people's own mental health problems. There's the downfall of being a user-led organisation - you have your own mental health problems and you've got to cope with that, bearing people's ups and downs, and you don't get enough people to fill in for people.

More frequently, however, it was the stresses of involvement which were seen as damaging to mental health. In an earlier chapter, reference was made to the issue of stress and burnout in relation to involvement in the management and development of services. Similar comments were made in relation to campaigning activity:

It affects your mental health, it's too much of a strain. It's because people care so much and they realise how much is wrong in mental health, really wrong, criminal - I couldn't put it more strongly than that - that people are burning themselves out because they don't want to give in. (Fife)

The issue was not simply the amount of time and energy involved but also the struggle to change what was experienced as an enormously powerful psychiatric establishment. In one of the individual interviews, a SUN Executive member had identified a weakness of SUN as being

The possible burnout of the people who have given commitment, and whether they can change a psychiatric system that has been around for hundreds of years and whether in the short-term, effective changes can be brought about.

In similar vein, a Fife member listed the reasons for people not becoming involved as being

Other than the nature of the illness, it's confidence, self-esteem, the same things you know, and I think a lot of people think you know, we won't alter anything anyway, it doesn't matter what I say and what I do.

Another member of the same group added:

Disillusionment. A lot of people that have joined in the movement to try and change things just think ' what's the point of going to all these consultations and doing everything?'

While, then, mental health problems may predispose people to burnout and relapses may obviously occur independently of group activity, there is also a wider issue here of the power and capacity of service users and of a service user movement to address the issues of stigma, discrimination and inequality, of the mismatch between the enormity of the task and the resources - in the widest sense - available to service users. The next section will begin to address this question, by looking at the extent to which group members saw a mental health users' movement as a vehicle for addressing these issues.

Fear of professional power

One group - Ayr Action - felt that they had had little or no involvement in campaigning activity. The group had a members' forum but the main purpose of this seemed to be the organisation of social events. The leading activist within the forum felt that the rest

of the members often lacked the confidence to put forward their demands, especially if this involved challenging local mental health professionals:

It's me that speaks on behalf of the forum. What you find is that when we have a meeting of the forum, members speak when a point comes up, they'll all have their say but the minute a member of staff comes on the scene, they tend to go with the staff member, they tend to change sides, and it makes things very difficult...I think it's because of some stupid fear within them. They seem to be afraid of authority, they seem to treat the staff as some authority figure, you know, and that's what I'm finding.

Similar issues emerged from Barnes and Shardlow's exploration of identity issues within English users' groups:

Because people in distress are scared of losing any sort of help, or because they themselves are confused by or scared of what is happening to them they may go along with the explanation they are given of what is wrong with them. If later they come to question professional authority to define their problems, either individually or collectively, they may find themselves patronised, or worse, treated as unreasonable upstarts (Barnes and Shardlow, 1996: 121).

The risk of being treated as an 'unreasonable upstart' was also recognised by members of the Fife group:

Member A: I think there's another thing that might prevent some people [from getting involved] - for want of a better word - fear. I think that maybe they think they'll be noticed by certain psychiatrists or doctors or nurses and they'll go 'Watch him, he's a troublemaker'.

Member B: It does happen...it's the power thing.

Member C: It makes it very difficult. It depends on the scenario. A lot of people are scared that they may be sitting next to the psychiatrists at a consultation or a workshop or whatever.

The existence of such professional power clearly has implications for the development of a users' movement. Under existing legislation the rights of service users living in the community continue to be far more precarious than those of, say, people with physical impairments, and given the trend in recent years towards greater professional control of their behaviour, fuelled by the discourse of 'dangerousness' as exemplified in the 1995 Mental Health (Patients in the Community) Act, the risks involved in challenging that authority are not simply imaginary and could be one factor which inhibits the growth of the users' movement. While there were variations in the extent to which this fear of professional authority was seen as a problem, it was clearly one factor which affected people's willingness to be publicly involved in campaigning or movement activities.

ATTITUDES TOWARDS A MENTAL HEALTH USERS' MOVEMENT.

As the earlier discussion indicated, most of the groups and several of the projects in this study had been involved to a greater or lesser degree in some form of campaigning activity. To what extent, however, did that local campaigning lead respondents to generalise and conclude that there was a need for a users' *movement*, analogous to the gay or disability movement and operating at a national level to challenge the stigma, discrimination and disadvantage that people with mental health problems experience? Views on this issue varied considerably from group to group.

The strongest negative response came from members of the Eastwood group:

J. Personally, I don't. I think it has its place but my view is that these groups can tend to go a bit extreme. I think they end up isolating themselves by doing so.

C. I go along with that 100%. I mean I think we should be there to influence how things should be but not to this degree alone in our quest for services or whatever. We need to have other people on our side who will manoeuvre with them and seek the services.

L. Yes. it's a co-operation thing, it's a liaising system where if people are going to put in services, whether they be social work or health board, if they're polite and nice enough to come to a user organisation...we can give them something which, as a depute director of social work said, they can't buy, they can't buy that experience...so it's actually something they can harness off us and we give positive input into the services within the community. It's a worthwhile exercise all round - they get effective services first time round rather than putting something in that doesn't work hopefully we get what we need.

One respondent from this group located the issue both within as the historical context of the users' movement as well as within the experience of this group

Historically the problem with the user movement is that it has tended in the past to be very aggressive and seeing the professionals in inverted commas as the enemy and we want to go in and modify that attitude because what we've done over the last two and a half years is to co-operate and liaise. We do have allies. We have allies that are in the local council.

By contrast, other groups were more responsive to the statement.

I would say that it would be great if the mental health groups worked together. What I would like to see is all disabled groups working together, even if they met so many times a year, because it would be a stronger voice. But I think it is going that way. (Fife)

I think it's something that's really necessary ...people with mental health problems need to be heard and a movement like that would allow them to be heard. They do need somebody to speak up for them, to give them confidence

to speak for themselves and they know they would belong to, to be able to get somewhere. (Ayr)

Yes, it's something they need to be doing. The question is whether they would be able to, it depends what mix of people you've got, whether they have the wherewithal to do it, that's a different matter. But yea, it's certainly something they need to be doing. (Edinburgh)

These statements nicely illustrate some of the complexities of the politics of mental health. On the one hand, Eastwood group members appear to espouse a fairly straightforward liberal-reformist position which disdains radical tactics in favour of an emphasis on co-operation and partnership with sympathetic professionals. The rejection here is not simply a rejection of an approach based on identity politics but of any form of militancy. The other groups, by contrast, were much more positive about the need for a movement. Even they felt, however, that there were a large number of obstacles to the development of such a movement, most of which have already been referred to in the earlier discussion on campaigning activities. One respondent, for example, felt that the problems of people with poor mental health were such that any movement would inevitably tend to be professional-led:

Again you get back to this confidence. How many people with mental illness - and I don't think there's any such thing as having HAD a mental illness, it's always somewhere in the background...- are there people within the mental health client group who are actually up to taking this to national level when it's obviously so difficult at grass roots level?

This speaker went on to make what he saw as an important distinction between the experience of mental health service users and people with physical disabilities:

Physically disabled groups, there are plenty of people with very good mental faculties but just stuck in a wheelchair or housebound or whatever but they're perfectly articulate and confident but it's a different problem. It's difficult to

get it to a county level and then to a national level without, as I said, ending up being taken over. (Ayr)

The small numbers involved, and the workload on individual groups, were also seen as factors militating against groups coming together:

I think part of the difficulty, as we talked about earlier, is that there's very few people involved and it's the same sort of people coming up all the time, so it's left to four or five individuals from each group to get on with the work of that group which leaves very little time to come together as a whole as a users' movement in Fife. (Fife)

Several other respondents made reference to the fragmentation of the users' movement in Scotland, both geographical and social:

I think Scotland has got a major problem in user involvement because it is so lacking in cohesion. We have very little association with for example Glasgow which has got to be one of the other major areas and there is quite a lot of divide and rule applied to us where you get two users of services saying that we've been allowed to set up a user group and the person who's allowing them to set up the group is the psychiatrist. Now that's not a user group, it's not something you are allowed or not allowed to do. (Edinburgh)

At present, SAMH (the Scottish Association for Mental Health) does not appear to play the unifying role played by a body such as MIND south of the border and respondents varied in their assessment of the role played by Scottish Users Network in bringing groups together, with some more positive than others:

The one group that we do have which is the Scottish Users Network is losing funding and is constantly being undermined by other groups. (Edinburgh)

M. SUN's been around for a while and there's been a lot of money put into SUN

L. ...and you're not getting anything out of it really. They're ploughing the money into SUN but then you're not getting anything.

M. Well, you're keeping them in work, you're keeping them in jobs, just by being a user.

L. Just by being in membership, you just fill in a form and they send out a membership card but at the end of the day, they're not doing anything.

(People Need People)

Where there did seem to be agreement amongst respondents was that the development of collective user organisation at any level - local or national - required practical and financial support. Where such support was available, however, then the prognosis for the development of such collective organisation was felt to be more hopeful:

Where I come from in Blackpool, they've been trying to set up a user movement for years and it hasn't happened and when I came up to Edinburgh I think that sort of thing that was pointed out to me quite quickly was the fact that you know you need some sort of support, for instance where you have agencies like CAPS which have given us the premises in which to do it, we've got the premises, we've got the admin. support, we've got stamps and use of the photocopying machine so you're not paying for it so I think you need something like that an organisation like CAPS in order to help to support a user movement to be set up. (Edinburgh)

CLASS-BASED ALLIANCES?

Given the difficulties involved in building and sustaining users' organisations, the need on the one hand for support of the sort outlined by the respondent's comment above and on the other, for the users' movement to cultivate allies and develop alliances, was a common refrain from several groups and projects. Most frequently, such allies tended

to be local mental health professionals and occasionally local politicians. Such allies were seen as important even where groups did not share the Eastwood group's rather negative attitude towards the objective of a user movement. Most groups could cite examples of sympathetic local professionals who had played an important role in helping to give service users a voice. The following comment from a member of the Fife group was not untypical:

There are individuals in different agencies who have a vastly different philosophy on service user involvement and there are some encouraging places where we're getting people that are wanting to work together like QM [a local psychiatric hospital]. The Director of Mental Health there is JS who as far as I'm concerned is almost a service user himself, he's that much of an ally. Other places, we've got the health board where they've got a couple of folk that are on the ball that are willing to talk to you and willing to listen to you and they've got a couple of folk that just patronise you and say right, we'll take that on board and they don't, so I think it's changing, I think more and more people are coming intoI mean I'm fairly optimistic at the moment that more and more people gradually are beginning to say, yes, there is this is worthwhile and the service users say, yes, you know service users can work with professionals. A lot of it is fear.

The importance of such 'allies' in the development of the users' movement in Britain was noted in chapter seven. The converse of this is the absence within the British movement of any strong separatist current, of the sort advocated by the American activist Judi Chamberlin (Chamberlin, 1988). The above discussion on the need for a users' movement suggests that while there were different views on the desirability or otherwise of such a movement, there was little evidence of sympathy for the view that users should 'go it alone', or that professionals are 'the enemy'. Put slightly differently, there was limited support for a 'politics of identity' of the sort discussed in chapter three. That said, however, was there any evidence of the 'class-based' alliances which Rogers and Pilgrim on the one hand and Barnes and Shardlow on the other failed to find in their studies of users groups? It will be recalled that the finding that ' there is

little evidence of groups allying themselves with class based movements' (Barnes and Shardlow, 1996: 127) was one factor which led them to characterise the users' movement as a 'new social movement'.

In fact, the campaign against local authority cutbacks in early 1997, initiated by the Scottish Trades Union Congress, might be seen as providing evidence of such alliances. As noted earlier, several of the groups and projects has been actively involved in that campaign. Some sense of the nature of that involvement is provided by a respondent from the Edinburgh Users' Forum:

Kate: In the past year, we've been involved in quite a few campaigns, some small, some big. I think the biggest one we did was the cuts, the campaign against the local council cuts in services. That was actually quite a big campaign as it involved other agencies and we were all quite exhausted at the end of it, the workers as well.

Jack: ...We were in contact with old age pensioners, UNISON, and all sorts of other groups...

Kate: ...who were also being threatened by the cuts basically. That was the joint march on the 1st of March through Edinburgh and then some of them went off to a rally but then we organised and chaired a meeting at the South Side Community Centre to which those other people were invited but we did a lot of work before that on our own, writing to MPs, local councillors, a deputation to the council - that was sort of the biggest thing we did. We did a lot of smaller things. (Edinburgh)

Similarly a worker from Saheliya noted:

Last year when we did a lot of campaigning against the cuts, they went on the march and were very much involved. That was a very big thing. (Saheliya)

The fact that it is possible to point to such examples suggests that the lack of involvement to date by user groups in 'class-based' campaigns identified by Rogers

and Pilgrim may be a *contingent*, rather than an *essential*, feature of the development of the users' movement, related, for example, to the generally low level of trade union struggle in Britain during the late 1980s and 1990s. The wider argument that characterising movements such as the users' movement as 'new social movements' is based on an over-estimation of what may prove to be temporary or contingent features of such movements is one that I shall develop in the next and final chapter.

That said, the mere *existence* of such alliances of course does not in itself provide a theoretical justification for them nor does it answer the wider rejection of class-based analysis which underpins NSM theory. In the last section of the final chapter, an attempt will be made, however, to provide the bones of such a theoretical response by drawing on the concepts and categories of classical Marxism.

Issues, Prospects, Conclusions.

As previous chapters have shown, both the development of mental health service user involvement and the emergence of the mental health service users' movement pose, at least potentially, a serious challenge to the way that mental ill-health is constructed, both by the psychiatric profession and by the wider public; to the relationships between service users and professional mental health workers; and to the stigma and discrimination which has historically been the lot of people with mental health problems. Pulling together the findings of previous chapters, this final chapter will attempt to evaluate the nature and extent of that user challenge in each of these three areas: to assess, in other words, the potential and limits of mental health service user involvement.

Much of the thesis has also involved an argument, both explicit and implicit, with those who characterise the users' movement as a 'new social movement'. The recent willingness on the part of some of those who characterise the movement in this way to see a new Labour Government as perhaps offering the best hope for service users (Rogers and Pilgrim, 1996), will, in the middle part of the chapter, provide a basis for discussing the changing policy context of the late 1990s and the extent to which such expectations may or may not be justified.

Finally, the rejection of class-based analysis in general, and Marxism in particular, has historically provided the starting point for NSM theory, as well as for its Marcusean antecedents (Scott, 1990; Foweraker, 1995). By contrast, Marxist concepts of both class and totality have informed much of the present thesis. In the final part of the chapter, the extent to which classical Marxism is capable of making sense of the oppression experienced by users of mental health problems and of suggesting strategies for overcoming that oppression will be assessed.

THE IDEOLOGICAL CHALLENGE

In chapter six, I argued, on the basis of a discussion of language and identity, that the search for a single 'user view' or ideology is often misguided and futile. The notion that someone's world-view is determined exclusively or even primarily by their experience of mental ill-health or mental health services ignores the infinite range of personal experience on the one hand and structural factors on the other which shape which shape the ideas in the heads of service users no less than the rest of the population. In that sense, as I have argued earlier, a politics of identity which defines individuals in terms of their mental ill-health can be seen as the mirror image of labelling that individual as a 'patient'. That said, it is possible to identify some ideas or beliefs that were espoused either implicitly or explicitly by the overwhelming majority of respondents - users *and* workers - in this study. Three in particular seem especially significant: the rejection of patienthood as a permanent status; an emphasis on the role of social and structural factors in contributing to the problems experienced by people with mental health service users; and a recognition of the disabling effects of mental ill-health. Each of these will be considered in turn, as the basis for a discussion of the extent to which respondents could be said to espouse a social model of mental ill-health, comparable to the social model of disability.

1) The rejection of patienthood

The rejection of the 'patient' label was explored in chapter six, where it was also noted that what respondents frequently valued about their projects was that they weren't treated 'like a patient'. The stance of many respondents could be summed up by the comment of a mental health worker cited by Barham and Hayward that 'chronic illness doesn't have to mean chronic patienthood' (Barham and Hayward, 1995). As the discussion in chapter six suggested, part of being treated 'like a patient' meant being the object of the 'clinical gaze' - in other words, being seen by mental health workers as 'the other', as 'alien', as well as the tendency on the part of these workers to disempower service users by treating them as if they are unwell all the time, as

opposed to seeing mental ill-health as a process in which people have periods of being well and unwell.

As noted in chapter three, it is the neglect of patients' narratives by mental health professionals, of the *meaning* which they give to their lives and their ill-health, that is the single most commonly voiced criticism of psychiatric professionals. Noting that only a tenth of the users in their study of 516 service users framed their mental health problems in terms of seeing them as an illness, for example, Rogers and Pilgrim comment that

Given that most of these users would have been labelled by psychiatrists as having suffered from some form of mental illness, this indicates at the outset that a substantial discrepancy exists in the basic way that professionals and users of services construe their mental health problems (Rogers and Pilgrim, 1995: 208).

Not surprisingly then, an emphasis on *experience*, in the face of the disregard and denial of that experience by mental health workers, is a common theme in the current study as it has been in earlier studies. While I have suggested in chapter seven some of the limits of such a 'politics of experience' (cf. Laing, 1967), it clearly provides a powerful starting point for the elucidation of an alternative to the dominant biomedical paradigm.

ii) Emphasis on structural issues.

Alongside an unwillingness on the part of respondents to be to be defined primarily in terms of mental ill-health was an emphasis, discussed in chapter ten, on a range of structural factors such as stigma (in the form of other people's attitudes), poverty, and a lack of community care services as the major contributory factors to the problems in living which they experienced. To that extent, respondents could be said to adhere to a social model of mental health, in seeing such factors rather than their mental health problems *per se* as contributing to their problems in living (though, as I

shall argue in the next section, their acceptance of such a model was qualified by a recognition of the disabling effects of mental ill-health). Furthermore, as was also noted in chapter ten, at least some of these groups and projects had been involved in collective campaigning around these issues, in contrast to the experience of Barnes and Shardlow who, in their study of users' groups, found that 'there is little evidence that the mental health user movement bases its strategies on a social model of mental illness' comparable with the social model of disability' (Barnes and Shardlow, 1996: 122).

iii) Disabling effects of mental ill-health.

Both of the above two points imply a rejection by respondents of dominant biomedical approaches to mental ill-health. That rejection was partly qualified, however, by an evaluation on the part of most respondents of mental ill-health as a *disabling* experience, in terms of its impact on social functioning. Not only did several respondents explicitly refer to this, sometimes using the language of 'illness', but also, as we have seen, mental health problems on the part of both workers and service users often had severe implications for the running of the projects discussed. Even where respondents did claim to be 'glad to be mad', this often seemed to imply a rejection of the stigma associated with mental ill-health rather than a positive celebration of mental ill-health as such.

Acknowledging the disabling effects of mental ill-health does not, of course, commit one to uncritically espousing a biomedical paradigm. The underestimation of the disabling impact of severe mental health problems was an important element of the 'left' critique of anti-psychiatry put forward by Marxist writers such as Sedgewick (1982) and Warner (1995). Discussing Laing's description of the 'schizophrenic career' for example, Sedgewick argued that

The course of the illness and its recovery is presented as a two-stage process beginning with disintegration and culminating, after the climax of the first, regressive phase, in a restitutive journey towards an authentic self and a non-

repressive relatedness towards others...But the majority of patients with a schizophrenic diagnosis do not display this one-and-for-all remission of symptoms. They continue, at various intervals, to become disabled in their personal and work relationships and highly eligible for the mental-patient role. For the counsellor or befriender of the schizophrenic with a recurring state of illness, Laing's work appears as either misleading or irrelevant (Sedgewick, 1982: 121-122).

The acceptance that mental ill-health *in itself* is disabling has both ideological and practical implications. *Ideologically*, it means that 'pure' versions of the social model of disability, as well as some of the more specific notions that have gained currency within the disability movement in recent years - that people with disabilities are *differently*-bodied, rather than disabled, for example - may not be automatically applicable to mental health service users.

Practically, it means that the issue of available and appropriate services, as well as the relationship of workers and service users which I shall explore in more detail below, may be a central one for mental health service users in a way that it is not for many people with disabilities.

The relationship between illness and disability is also, of course, a live debate within the disability movement (Barnes and Mercer, 1996). One activist cited by Campbell and Oliver, for example, has argued that 'the issue of illness needs to be considered and that, for many disabled people, high- quality medical services are just as important as the removal of social barriers' (Campbell and Oliver, 1996). Similarly, in a polemic against the tendency referred to above to see disabled people as simply 'differently-abled', thus effectively seeing disability as *wholly* socially constructed, Stack has argued:

Some people say you're not disabled, you're 'differently abled'. It's rubbish. I would have loved to have been able to dance, play the guitar and play for Ireland in the World Cup. None of these things were available to me because of my

disability. We should recognise what we face in society. We don't bend to it, don't bow to it, don't cringe before it and fight against it. We aim to lead as full but normal a life as possible. We want to overcome every obstacle that can be physically overcome without playing word games that pretends that something is what it isn't (Stack, 1995).

Here again the dangers of seeking a single 'disabled' perspective are evident. That said, the intermittent, unpredictable and subjectively distressing nature of mental ill-health may make the issue of available and accessible services even more of an issue for these service users than for people with physical impairments.

A new paradigm of mental ill-health?

Insofar as there can be said to be a developing user ideology, then these three elements - the rejection of patienthood as a basis for mental health services; an emphasis on the role of structural factors in the problems experienced by people with mental health service users; and a recognition of the disabling effects of mental ill-health - would appear to be central to it. What issues does such an ideology raise?

Firstly, as I argued in chapter six, it cannot be captured exclusively in the categories of biomedical essentialism on the one hand or in those of social constructivism on the other. Once again, Barham and Hayward's comment on the approach which they adopted in their study of service users seems apposite:

If...there is a form of medical reductionism which quickly disposes of the whole struggle to get to grips with the other person, then there is also an opposing form of normalising discourse in which difference comes to be glossed over or denied, as though a benign regard or the force of good intentions could prose away the stubborn reality of chronic mental illness. We have tried as best we can to avoid these oppositions and to recognise the complications that are involved (Barham and Hayward, 1995:5).

The issue of difference is a complex one, since it could be argued that an acceptance of difference *per se* underpins the clinical 'gaze', rejected by so many service users. Nevertheless, most respondents in this study *were* prepared to acknowledge the 'realities' of mental ill-health to which Barham and Hayward refer and the point has been made in chapter nine that where such realities were discussed openly in projects, such as the Manic Depression Fellowship Scotland, then the chances of finding an acceptable solution which was not experienced as disempowering by service users were greatly increased.

Secondly, insofar as these elements constitute an emerging paradigm of mental health, then this paradigm is at an embryonic stage and cannot yet be said to provide the 'coherent overall philosophy that can integrate a clearer range of discrete focuses', the development of which Campbell in his history of the British users' movement has identified as a major challenge (Campbell, 1996: 224). Interestingly, Oliver makes a similar point about the theoretical underpinning of the disability movement when he writes that

For me the social model of disability is about personal experience and professional practice but it is not a substitute for social theory, a materialist history of disability nor an explanation of the welfare state (Oliver, 1996: 41).

That said, despite the limitations of user experience as a basis for the development of a user movement, the current study suggests that the experiences of these user and worker respondents has led them to arrive at some tentative theoretical conclusions which are sufficiently coherent and commonly shared to be distinguishable from biomedical models on the one hand and social models of health and disability on the other.

What are the implications of this user discourse for workers and services? Is it, in fact, possible for mental health workers to overcome 'difference' between themselves and service users and at the same time recognise what Barham and Hayward refer to as the 'realities' of mental ill-health (including, in a very small number of cases, the risk of

violence to self or others) (Barham and Hayward, 1995)? Is such 'partnership' between workers and service users possible? And what kind of professional training, if any, does it imply? It is to a consideration of these issues that I shall now turn.

THE CHALLENGE TO RELATIONSHIPS BETWEEN SERVICE USERS AND PROFESSIONAL WORKERS

The *desire* on the part of both service users and workers for partnership in the planning and running of health and social services, noted in chapter nine, is a finding not only of the present research but one which emerges consistently from the research literature on user involvement (Lindow and Morris, 1995). To what extent, however, is it possible for workers and organisations to move beyond 'good intentions' to make such partnership a reality?

The most pessimistic response to this question comes from those within the users' movement who take a separatist stance and regard the idea of partnership between workers and users as a chimera. Chamberlin's critique of services such as the International Clubhouse movement which purport to be based on a partnership model, for example, was noted in chapter nine.

By contrast, in research commissioned by the Social Services Policy Forum to look at the key features of user-controlled services and the extent to which these features could be taken on by the statutory sector and large-scale voluntary organisations, Morris concluded that many social service workers saw themselves as allies of service users, while their organisations often had a real commitment to involving service users in the decision-making processes (Morris, 1994).

What the present study suggests is that while there was considerable unevenness between projects in the degree of partnership achieved, in at least some of the projects there was a sense of users and workers working together, if not as equals, then at least with considerably reduced power differentials. Some of the factors contributing to a successful 'mix' were noted in chapters eight and nine and included: a willingness to

confront issues and dilemmas openly; the adoption of a community development approach; a commitment to the values of participation and empowerment; adequate funding; and democratic and accountable structures.

The argument about the possibility of partnership is an important one. As we saw in chapter nine, given the difficulties and dilemmas to which user involvement gives rise, to conclude that professional workers, by virtue of being professional workers, will *inevitably* seek to control and oppress users and therefore have no role to play in helping people with mental health problems is to paint a rather bleak future for user involvement in mental health services. Again, however, respondents in this study overwhelmingly rejected such a separatist position and both implicitly and explicitly espoused the universalist position that workers *are* capable of developing genuine empathy with service users and of behaving in non-oppressive ways towards them.

Neither did the experience of at least some respondents and projects support the corollary of this separatist attitude towards professionals, viz., that users themselves cannot behave in oppressive ways towards other users. Several examples were given by respondents of users in positions of power behaving in abusive or manipulative ways which were often more concerned with addressing their own needs than the needs of the project. Again, in this respect, the experience of people with mental health problems is no different from that of other oppressed groups. Discussing the elite of black politicians who now control many American cities, for example, the radical black theorist Manning Marable has confessed that

Most of us had not anticipated an ideological shift among many African-American or Latino politicians, using racial solidarity to ensure minority voter loyalty, but gradually embracing more moderate to conservative public policy positions, especially on economic issues (quoted in Smith, 1992).

A rejection of separatism, however, should not lead to an underestimation of the difficulties involved in achieving partnership between workers and service users. In part, such difficulties stem from specific ideologies, whether biomedical or populist,

which emphasise *difference* and which can be reinforced (or challenged) by professional training on the one hand and by 'moral panics' concerning 'dangerousness' on the other. The role of such ideologies in constructing people with mental health problems as 'alien' or 'other' should not be underestimated. At the same time, their influence is not static and, as the SAMH study referred to in chapter three suggested, popular ideas about mental ill-health, as well as the ideas held by many mental health workers, have changed enormously in recent years. The same is true of the 'clinical gaze': there were a sufficient number of positive statements about project workers to suggest that it *is* possible for workers to get beyond such professional distancing.

That said, an overemphasis on the ideological or cultural factors which prevent partnership can lead to an underestimation of the *statutory* and *organisational* barriers to partnership, something which the present study with its focus on projects located in the voluntary sector has only touched on. Yet while social work theorists such as Barber (1991) and Thompson (1998) are surely right to emphasise that a degree of partnership is possible even within involuntary worker-client relationships, the fact that a range of mental health workers in both the psychiatric services and local authority social services have very considerable statutory powers in relation to service users gives rise to real power differentials which will not be eliminated by 'good intentions' on the part of these workers. *Pace* proponents of separatism, however, who see mental health workers as committed to retaining such powers, it is significant that a wide range of professional organisations, including the British Association of Social Workers, have been at the forefront of campaigns in recent years opposing government attempts to extend such powers to include 'patients in the community', on the basis that such an extension of powers would undermine trust between workers and clients.

No less significant than statutory barriers to partnership are organisational barriers. Reference was made in chapter one to the impact of managerialism on health and social services. If, as was argued in that chapter, reconstructing service users as 'customers' does not necessarily lead to increased choice, nor is there any guarantee that the

fragmentation of services to which managerialism contributes will necessarily enhance partnership, either between service providers and service users or between different providers (Clarke, 1996; Newman and Clarke, 1997). As Langan and Clarke have noted

'Care management' is driven by two competing injunctions. One is to use the competition inherent in the mixed economy of welfare to obtain 'value for money' services...The second is concerned with the 'enabling' and 'partnership' visions of service delivery...It is not clear that these two versions of the local authority role sit comfortably together (Langan and Clarke, 1994: 88).

While there is some recent evidence that care programme and care management approaches which are based on a personalised relationship between care manager and service user - the 'clinical' model of care management (Huxley, 1994) - can achieve a degree of partnership (Carpenter and Sbaraini, 1997; Lewis, 1997), this is not the dominant model and both of these studies emphasise the point made a decade ago by critics such as McLean (1989) and Biggs (1989) that in the absence of adequate resources, care management can simply become a mechanism for rationing scarce services.

IMPLICATIONS FOR PROFESSIONAL TRAINING

The domain of social work is compelling, important and contested. It demands and requires integrity, enquiry, debate and research. Above all, it demands new partnerships in the formation of its knowledge base and curricula which involve the users of these services and those social constituencies which have hitherto been considered as not counting (Jones, 1996: 210).

Users of mental health services are a prime example of a constituency whose views have 'hitherto have been considered as not counting' in the development of social work training and whom Jones argues must now be involved as partners. What lessons

can be drawn from the current research regarding the type of education and training that users believe social workers and other mental health professionals require?

As the discussion in chapter seven indicated, a majority of respondents in this study - both users and workers - viewed the current training of mental health workers in a very negative light. The term 'baggage' was occasionally used to describe such training and where project workers had received a professional training, particularly nursing training, this was often felt by them to be a positive disadvantage rather than an advantage. The main reason for such a negative appraisal of professional mental health training has been neatly summarised by Johnstone, a clinical psychologist, in words not dissimilar from those employed by respondents in the present study:

The medically-based training of doctors and nurses in particular encourages them to override their natural common-sense reactions and see their charges as patients with illnesses, rather than people with problems. Not only are most mental health professionals not trained to see people in a whole-person, whole-system way, they are actually trained not to do so. All of this means that although each member of staff may be doing the best job they can within the limitations imposed by their own training and the institution itself, the results can still be disastrous (Johnstone, 1989: 163).

The fact that social workers, whose training often involves an emphasis on a social rather than medical model of health, did not seem to be viewed in a more positive light than other mental health professionals suggests once more that, whatever the 'good intentions' of individual practitioners, it is often the controlling, rather than the caring, aspects of social work practice of which users are most conscious. It may also reflect the weaker professional status of social vis-à-vis psychiatry and the tendency of social workers, particularly in the hospital setting, to adapt to the more powerful biomedical ideology.

The danger of this essentially libertarian critique of professional training being hijacked by the neo-conservative discourse were noted in chapter seven where it was also

suggested that a different form of training, rather than no training, was implied by respondents' comments. What, however, should be the elements of such a training? A useful framework for exploring this question, based around five core themes, is suggested by Brandon in a discussion of 'normalising professional skills' (Brandon, 1996). The themes are: good relationships; maximising choices; effective participation; personal development and greater mixing.

1) Good relationships.

As so many of the statements in chapter seven indicate, 'people skills', rather than technical knowledge, was viewed as the most important attribute of the mental health worker. This appeared to incorporate but go beyond the 'core conditions' of empathy, non-possessive warmth and non-judgemental acceptance identified by Rogers (1951), Truax and Carkhuff (1967) and others. It also implied a willingness not to see users as the 'other' but to address issues - including problematic behaviour stemming from mental health problems - openly and directly. In the words of a SUN member quoted earlier:

If there's a basic empathy and they can treat people openly, rather than talking about them behind their backs, then they don't have to be users - decent human beings would do.

Once again there is a rejection of the element of surveillance implicit in the professional 'gaze' and its place a normalising or equalising discourse. As noted in chapter nine, the most successful projects, including MDFS and Core Club appeared to be those in which such an openness between workers and users had been achieved. As Brandon comments:

The implications for training are immense. We need to explore and share our vulnerability - to move away from the macho traditions of our professions... That must include more appreciation of users' attainments and more diffusive relationships which allow consumers to make a greater

contribution to the quality of services. That involves a 180 degree turn in the existing training (Brandon, 1996: 298)

ii) Maximising choices

There are two aspects to this. Given the lack of choices which service users have often experienced, particularly in hospital settings, it involves workers who are able to use every opportunity to help people make choices and help them gain some degree of control over their lives. Brandon describes such people as 'practical dreamers' who are able to provide service users with 'realistic optimism'. A good example is the worker in the current study who described herself as

a sort of talent scout - bringing out what's already there and building up on that. The main issue is low self-esteem and low self-worth. It's about breaking down these barriers. It also involves being 'real' with that - being genuine.

Secondly, maximising choices means recognising that different clients have different needs and responding appropriately. In the words of a Core Club member

I can see that Clubhouse is ideal for our situation but not suit, for example, older people who just want to sit down and have a cup of tea. The Clubhouse ethos is to work and participate and that might not suit them.

This implies the need for workers to have skills in service brokerage - helping to link users up to the kind of services that meet their individual needs.

iii) Effective participation.

As was evident in chapters eight and nine, not all projects were equally successful in involving service users. While the *desire* for participation was almost invariably there, the same cannot be said of the skills required to achieve it. As Brandon notes

Professionals are often fearful of power-sharing. They came in to social work, nursing or medicine to take up quasi-parental positions. They may not know how to cope with greater equality, more brotherly-sisterly relations (Ibid.).

It is significant that perhaps the only type of professional training to which users referred positively was training in community education or community development. Where workers had experience of such training (as for example in the case of the worker who described her role as being 'a sort of talent scout'), the difference in the way they worked with users was often almost tangible while workers who lacked such training sometimes appeared to be floundering. Occasionally, this was linked to a fear of users 'getting it wrong', yet as one user commented

We want someone who can work for someone who a couple of years ago was in hospital and can take orders from people whom they feel might not be right, someone who won't put their ideas first but who will be ready to advise us if things don't go right. We might make mistakes but so might she.

iv) Personal development.

By this Brandon is referring to the personal development of both worker and service user. In respect of workers, this means feeling valued by the organisation and given opportunities to develop both personally and professionally. In this study, a majority of both users and workers saw it as essential that workers were supported to do what was recognised to be a stressful job, both for their own sakes and also for the sake of service users. A SUN Executive member who was also an advocacy worker in another project commented:

It's very important for people themselves in their professional development to have good supervision but it's also one way to strive towards providing good quality services to users.

Within Core Club, opportunities for such support and development were seen to come not only from the supervising organisation, SAMH, but also from members. A worker commented:

SAMH has a support system and counselling. There's also good line management. However, in the Club, our support starts with the members. The majority of staff in here are open about problems - if you're coming in having had only a few hours sleep and feeling rotten, you'd mention it at the morning meeting.

In respect of the personal development of service users, Brandon highlights the importance of workers having counselling skills and again, counselling skills was one of the only two areas of professional skills specifically identified by service users in this study (the other being community education).

v) Greater mixing.

Here Brandon is referring to the need to help service users move out of the 'ghetto' of mental health services and into 'normal' services, be it housing, further education or recreational services. Despite its strengths, a criticism that has been made of the Clubhouse model is that it tends to encourage such 'ghettoisation' (Perkins, 1997). While acknowledging the role played by projects as havens in the face of stigma and social isolation, many service users nevertheless saw the need to move beyond such havens:

the goal...is to reintroduce the client or the patient back to a, for want of a better word, a normal type of life. Reintegrate them into the community within employment, not specific employment or special employment for someone with mental health problems, but into a bank into a shop into an appropriate setting for that person and get them back rehabilitated, not standing up on crutches basically with all this big pyramid of social network support. (Eastwood Forum)

The problem is somebody says I want to do creative writing or art, that's popular things to do, but if you do, you do it with mental health people, but you want to go into an art group with normal people in inverted commas. instead you come out and you end up in an environment where you're with all these people with mental health problems and to a certain extent you do become a mental health problem. (People Need People)

The skills required to help service users move out of the ghetto are *networking* and *linking* skills (Trevillion, 1992). As Brandon comments

Staff must learn skills to help access. They learn to be effective bridges into wider neighbourhood and community facilities. They are less central to the support of the devalued person and more facilitating of other relationships, which are more important over the long term (1996: 302).

These, then are some of the skills that could form the core of a new and different kind of professionalism, based on a much closer partnership with service users. Given the shift, however, in recent years (in social work training at least) *away* from an emphasis on anti-discriminatory practice on the one hand (Dominelli, 1998) and *towards* more employer-led, competence based approaches on the other (Jones, 1996), the scope for developing such a new professionalism may be rather limited.

THE POTENTIAL AND LIMITS OF COLLECTIVE ACTION

While consumerist and professional-led models of user involvement - both forms of what I have called 'user involvement from above' - have undoubtedly played a role in putting user involvement onto the wider social policy agenda over the last decade, as I have argued in chapters one and two, they also share certain characteristics which severely limit the challenge which they pose to the stigma, discrimination and disadvantage experienced by many service users: both, for example, are *top-down* approaches, often dictated by organisational or policy priorities which do not necessarily coincide with the needs of users themselves; the forms of involvement

which they envisage, in the NHS and Community Care Act for example, are fairly *minimalist*; they are concerned primarily with *procedural* rights rather than *substantive* rights; and their focus, particularly in consumerist models, is on the user as *individual customer*, a construction which I have argued in chapter one often bears little resemblance to the reality of life for many users (Ferguson, 1997).

By contrast, as I argued in chapters three and ten, the growth of 'user involvement from below' in the shape of user-led activities and the development of collective organisation in the users' movement potentially poses a far greater challenge. Implicitly, and sometimes explicitly, the very emergence of the movement involves a recognition by service users that they, like other oppressed groups before them (Oliver, 1990), can no longer rely on well-meaning politicians, professionals or charities to bring about an improvement in their situation but rather that they themselves must fight to secure social and civil rights, an awareness that, as David Harvey has argued, 'true empowerment must be won by struggle from below and not given out of largesse from above' (cited in Mayo, 1994: 54).

It is this growing *political* awareness of service users as an *oppressed* group on the one hand and the organisational forms and campaigning strategies which accompany it which has led a number of writers to characterise service users as a 'new social movement', similar to the women's movement or the gay movement. At various points throughout the thesis, I have argued against such an analysis, whether it is offered as description or prescription, on the grounds that an emphasis on *identity* is not especially helpful either as a tool of analysis or as a basis for organising users; that the emphasis on *cultural/ideological* issues which some researchers have identified can be seen as a contingent, rather than an essential, characteristic of the movement; and that similarly, lack of evidence of *class-based alliances* may often stem less from a deep ideological distaste for such alliances than from the opportunities provided by the wider class struggle.

These limitations of NSM theory are also evident in its treatment of two other issues which have considerable significance for mental health service users viz., the issues of

power and *agency*. Following Foucault, it is now common in much social theorising to see power as dispersed and localised, as located in multiple sites rather than in particular institutions or classes (Smart, 1985: 76). While such an analysis can be helpful in drawing attention to the exercise of power within particular micro-relationships, including worker-user relationships, it can also lead to losing sight of the *structural* sources of power discussed in chapter three, whose roots are precisely in class inequality, medical power and the State.

The difficulties experienced by groups of service users in challenging these structural inequalities were noted in chapters nine and ten, particularly in relation to the high level of stress and burnout amongst movement activists:

It affects your mental health, it's too much of a strain. It's because people care so much and they realise how much is wrong in mental health, really wrong, criminal - I couldn't put it more strongly than that - that people are burning themselves out because they don't want to give in. (Fife Survivors' Group)

while as noted earlier, a SUN Executive member had identified a weakness of SUN as being

The possible burnout of the people who have given commitment, and whether they can change a psychiatric system that has been around for hundreds of years and whether in the short-term, effective changes can be brought about.

It may be this awareness of the relative lack of power of users to challenge such powerful structures which has led to the tendency noted by Rogers and Pilgrim (1991) and also Barnes and Shardlow (1996) of some user groups to focus on more immediate - and what may seem more achievable - issues relating to their clinical care, rather than on wider structural issues of poverty or unemployment. The apparent disinterest in these areas, in other words, may stem from a not unrealistic assessment of their ability to bring about change in these areas rather than from any deeper ideological motive.

That lack of power directs us to the issue of *agency* (Callinicos, 1989), of the need to identify a social force that is capable of overcoming these inequalities. While this issue is not addressed directly by the adherents of NSM theory, it is possible to discern in the writings of Rogers and Pilgrim in particular an implicit recognition of the limits of the users' movement in respect of challenging structural inequalities and the need to search for other, more powerful, actors to who *are* capable of bringing about change. Writing in 1996, that search leads them in a not unfamiliar direction, in terms of the experience of previous social movements :

If user campaigning has had an influence on Labour policy, it raises some interesting conceptual questions about making a neat separation between old and new social movements....With the collapse of Leninism in much of the East and the political diversification of much of the aims of Western social democratic parties beyond the demands of labour it may be that old and new social movements are being brought together rather than being separated. What is currently missing in regard to the influence of the mental health service users' movement is the opportunity of a Labour government to be tested in its commitment to a new pluralistic health and welfare agenda (Rogers and Pilgrim, 1996: 171).

The future of the users' movement, in other words, may lie with a Labour government sympathetic to the needs and aspirations of service users. Given that the opportunity to which Rogers and Pilgrim refer was presented in 1997 with the election of a New Labour government, it is already possible to make some tentative comments regarding the prospects for such a strategy. Before doing so, however, two other points can be made in respect of Rogers and Pilgrim's argument.

Firstly, a theoretical point. The apparent ease with which Rogers and Pilgrim seem prepared to abandon the 'neat' distinction between 'old' and 'new' social movements highlights what might be viewed as the *superficiality* of much NSM theorising, in that what was previously seen as an essential difference between different types of social

movement now turns out to be in fact temporary or contingent features of these movements. In similar vein Scott has argued that other supposedly core characteristics of new social movements, such as the non-negotiable nature of their demands, stem from their newness (in a chronological sense) rather than from their essential nature, while their supposedly different organisational forms have many parallels in the 'old' social movements (Scott, 1990).

Secondly, the performance of previous Labour governments gives few grounds for optimism regarding the prospects for the success of this particular strategy. Goodwin's observation regarding the willingness of every previous Labour government to accept unquestioningly the legitimacy of psychiatry was noted in chapter three (Goodwin, 1990). While there has sometimes been evidence of the 'good intentions' of Labour governments, as reflected for example in the 1975 White Paper *Better Services for the Mentally Ill*, in practice the overriding commitment of every Labour government to 'sound economic management' (involving for example, cuts of £6 billion from public sector spending in 1976 at the behest of the IMF) means that there has often been little difference in real terms between Labour and Conservative policies towards people with mental health problems (Rogers and Pilgrim, 1996: 74-75).

Could it be, however, that the influence of the mental health users' movement on the one hand and the apparent commitment to consumerism of the current New Labour government on the other will mean that the experience this time round may be a different one? Government policy and practice in relation to key issues affecting people with mental health problems the two years since the 1997 election suggest otherwise.

Firstly, the discourse of 'dangerousness', far from having lessened under the current government, has if anything become more pronounced. It is this discourse, for example, which appeared to underpin the statement by Health Secretary Frank Dobson in July 1998 that 'community care has failed' and that a 'root and branch' review of the 1983 Mental Health Act is required in which the issue of 'security' will be to the fore (*OpenMind*, Nov/Dec, 1998); of the statement of junior minister Paul Boateng in September 1998 that 'non-compliance with agreed treatment programmes is not an

option' in what he described as a 'safety-plus' approach to mental health (ibid.): and to the statements of Home Secretary Jack Straw in February, 1999, regarding the indefinite detention of some people diagnosed as having personality disorders and regarded as dangerous - even where no crime has been committed and despite the fact that, as the National Schizophrenia Fellowship has pointed out, more than half of those initially diagnosed as having a personality disorder subsequently have that diagnosis revised.

Significantly, from the perspective of user involvement, and in direct contradiction of the statement by Peter Campbell which introduced chapter ten of this thesis, *no* service users, nor any representatives of user organisations, are to be included on the Mental Health Act 1983 Review Panel which instead is made up of lawyers, clinicians, a police officer, a social service representative and the Chief Executive of the Mental Health Act Commission (though interestingly, service users *have* been included in the Panel reviewing the parallel Scottish legislation). The committee have been further advised that 'it will be particularly important to consider defining the rights of carers and advising on how these might be taken into account in preparing the new legislation' (*OpenMind*, Oct/Nov, 1998).

Against this, it could be argued that the government's announcement of its intention to create a national service framework for mental health, covering both health and social care, including more acute beds, assertive outreach, and 24-hour crisis services shows a more user-friendly approach (*OpenMind*, September/October, 1998) and in some ways contradicts the more punitive approach suggested in other statements. While such an extension of services is likely to be welcomed by service users, however, given the relatively small amount of extra spending involved (*Community Care*, 17 December, 1998), it could also be seen as little more than a 'sweetener' for the essentially authoritarian thrust of its other policies in this area, especially as such extra spending could still be withdrawn in the event of the British economy moving more deeply into recession. As Means and Smith have argued, given the government's overriding commitment to financial prudence and responsibility

In terms of community care policy and practice, such financial restrictions are likely to mean that the policy agenda will continue to be dominated by rationing rather than rights, and that guaranteed standards of service will only apply to those who are deemed most at risk and thus qualifying for a care package (Means and Smith, 1998: 240).

Thirdly, as noted in chapter three, at the heart of the current government's welfare strategy is an emphasis on work (DSS, 1998), an emphasis which is likely to have considerable implications for people with mental health problems. Recent pronouncements have made clear that *all* claimants, including those with severe mental health problems, will be required to attend job interviews. Underpinning this policy is the government's stated determination to reduce spending on disability benefits. The potential of such a policy to significantly increase the level not only of fear and anxiety but also of poverty amongst people with mental health is considerable. Locating such 'welfare to work' strategies with the government's wider economic strategy, Ellison comments

Lacking any formal control over the corporate sector and with a wary eye to the international economy, social policy may be used progressively more 'coercively' to ensure compliance with designated economic goals. Individuals could incur increased penalties for specific performance failures, for example, even as the opportunities on offer become less appealing. With the potentially contradictory commitments to flexible labour markets *and* low unemployment levels it is difficult to see how any government could continue to offer high-quality employment opportunities during periods of negative growth. Indeed those most dependent upon increasingly meagre state services would stand to lose most, being forced to take the lowest-paid job or training opportunities which by implication will yield low benefit entitlements, adding to their vulnerability in sickness and old age (Ellison, 1998: 43-44).

Given that, as we have seen in chapter three, people with mental health problems figure prominently amongst those 'most dependent on increasingly meagre state benefits', it

is difficult to see how they can benefit, either financially or in mental health terms, from a policy which seems designed to coerce them into jobs which they may find great difficulty in holding down.

MARXISM AND OPPRESSION

The last section suggested that on the basis of its performance to date, the current Labour government may prove no better than its predecessors in improving the situation of people with mental health problems and, that, given its emphasis on 'dangerousness' on the one hand and the current potential for severe economic recession leading to cuts in services on the other, may even in some respects be worse. Rogers and Pilgrim's tentative optimism in this regard may prove therefore to be misplaced. That said, where then *can* service users look for allies to help them challenge the stigma and oppression they experience?

In this section, I wish to return to the question of class-based alliances discussed in chapter ten and more specifically, to consider what contribution Marxism might make both to analysing and challenging this oppression.

The notion that Marxism is incapable of accounting for oppression and the movements that arise to challenge that oppression is at the heart of new social movement theory:

NSM theory developed partly in response to what was considered an outmoded style of class analysis...the theory presumes that class analysis can no longer trace the main contours of social reality (Foweraker, 1995: 36).

The marginalisation of class within social theory was noted in chapter three and rests, *inter alia*, on a particular sociological interpretation of structural changes within the working class on the one hand (the 'end of the working class' thesis') and a philosophical critique of historical materialism on the other, based on post-structuralism and postmodernism on the other. Space does not permit a full exploration

of this critique, though the limits of postmodern theorising in particular have been comprehensively addressed elsewhere (e.g. Callinicos, 1989; Harvey, 1990; Smith and White, 1997; Ferguson and Lavalette, 1999).

The goal in this final section is the much more modest one of pointing to some ways in which Marxist analysis might be of relevance to mental health service users wishing to challenge their oppression. In that context, four elements of the classical Marxist tradition seem to be of particular significance. Firstly, there is the central role accorded by Marxism to the working class as the agent of a socialist transformation of society (Draper, 1978). Again, space does not allow for a full discussion of the thesis that the working-class has disappeared or is no longer capable of acting as an agent of socialist change (Gorz, 1982). Against this, however, it has been argued that on a *world* scale, the working- class - including the industrial working-class- has grown enormously over the past twenty five years (Callinicos and Harman, 1987), while within Britain and the rest of Europe, as a result of what Braverman has referred to as 'the industrialisation of white-collar work' (Braverman, 1974) there are now large numbers of workers, including teachers, nurses, social workers and even lecturers in further and higher education who two decades ago would not have seen themselves as working -class but whose conditions of work bear more and more resemblance to those of traditional industrial workers.

Secondly, there is the Marxist theory of oppression. Since, for Marx, that working class is the only class in society capable of overthrowing the ruling class and beginning to build a society based on need and not profit, anything which weakens or creates divisions within that class must be opposed. Discussing anti-Irish racism in Victorian England, for example, Marx noted that 'every industrial and commercial centre in England possesses a working class divided into two hostile camps, English proletarians and Irish proletarians' and argued that:

This antagonism is artificially kept alive and intensified by the press, the pulpit, the comic papers, in short by all the means at the disposal of the ruling classes.

This antagonism is the secret of the impotence of the English working

class, despite its organisation. It is the secret by which the ruling class maintains its power. And that class is fully aware of it (cited in Callinicos, 1992: 18-19).

What this analysis suggests is that given that many varieties of oppression are employed to divide workers - straight against gay, white against black, or in this case, 'normal' versus 'mad' or 'loony' - combating that oppression is in the interests of *all* workers and not just (as identity politics would have it) those who experience the particular form of oppression.

In the case of the oppression of people with mental health problems, it could be argued that such a response would not be based purely on altruism but rather on a recognition that the majority of ordinary people directly or indirectly suffer from such oppression. With one in seven people likely to experience mental health problems at some time in their lives (Melzer et al, 1994) and stress identified by 6, 000 health and safety representatives in a recent TUC survey as the single major health and safety issue experienced by workers (TUC, 1998), it could be argued that stigmatising people with mental health problems creates a climate in which people are afraid to acknowledge or seek help, while their structural roots of these problems within the capitalist family and work process is obscured and unchallenged, removing the possibility of a collective response.

The third strand of the Marxist analysis of oppression is that not only does the working-class have an *interest* in challenging all forms of oppression but it is also the only social force that has the *power* to do so. This power stems from its position within the process of production and the collective organisation to which that gives rise. Members of oppressed groups by contrast tend to be more fragmented and isolated. It is that lack of power which can lead them to seek more powerful allies, which in the British context has often meant looking towards a Labour government. Some of the limitations of such a strategy were explored in the previous section.

Finally, the argument that it is not only people with mental health problems who suffer from the stigmatising of mental ill-health and that there is therefore a wider interest in challenging that stigma, points to a different kind of relationship between service users and their 'allies'. On the one hand, it suggests that rather than the task of 'allies' of the users' movement being to give uncritical support to whatever initiatives or activities users are involved in, a relationship of mutual respect needs to be developed, based on debate and discussion of the best way forward for all those involved in challenging the oppression associated with mental ill-health. On the other, it suggests a need within the wider trade union and Labour movement to challenge the stigma surrounding mental ill-health, in the same way as other forms of discrimination and oppression such as racism, sexism and homophobia have been challenged in recent years (Field, 1995). Given the continued scapegoating by both media and government of people with mental health problems as 'dangerous', the possibility exists of an increase in the influence of an identity politics within the users' movement which sees 'non-users' as 'the enemy', leading to greater internalisation. Yet the experience of the 1997 campaign in Scotland against cuts in community-based services, discussed in chapter ten, suggests that it is when service users make common cause with public sector trade unionists and other groups in defence of services that they are most effective. Pagel arrives at similar conclusions in his history of the disability movement:

In Britain the major changes which have assisted the self-organisation of disabled people have been inextricably linked to the formation and subsequent development of the Labour and Trade Union movement...Disabled people, and every other group of oppressed people need to continue to build alongside the Labour and Trade Union movement to ensure that the political commitment for radical change is found (Pagel, 1988).

CONCLUSION

Until very recently, users of mental health services, along with disabled people and elderly people, have tended to be the objects rather than the subjects of social policies. The growth of mental health service user involvement, and more especially of the

mental health users' movement over the past decade has begun to challenge that situation, as far as people with mental health problems are concerned. In this study I have suggested that if that challenge is to succeed, it will need to address and overcome a number of difficulties and dilemmas, some of which relate to the impact of mental ill-health on the people involved but which more frequently concern issues of support, resources, alliances and the contradictory agendas involved in the practice of user involvement. While the enormity of the task should not be underestimated, what this study also suggests is that the user challenge over the past ten or fifteen years has resulted in the growth of significant, if still fragile, roots in the areas of mental health ideology, involvement in services and the collective challenge to stigma and discrimination. For many respondents in this study, the journey 'from the patient to the person' is now well underway; on the evidence presented here, they will not easily be turned back.

Appendix A

Individual Interview Schedule

The Limits and Potential of Mental Health Service User Involvement

Date of Interview :

Project :

Respondent :

Gender :

Age band :

1. Personal Introduction.

2. Purpose of the Study.

In recent years, there has been a growing acceptance of the idea that users of mental health services should have a greater say regarding the services they receive. The purpose of the study is to explore the *potential* of user involvement - how much control can or should users have over services - and the *limits* of user involvement - what factors prevent user involvement , as well as any disadvantages user involvement may have .

3. Tape recording, note-taking and confidentiality.

I would like to tape record this interview. This will allow me to 'capture' your words and ideas. [**And/or**] I would also like to take some notes while I am conducting the interview, so I can keep track of the interview as it progresses. Do you have any objection to this ?

Nothing that you say will ever be identified with you personally and you will not be identified by name as a study participant.

4. Statement informing interviewee why he/she is being interviewed.

You are being interviewed as someone who has experience of using mental health services and who is presently actively involved in the [**name of project**] .

1. Traditional Medical and Psychiatric Services.

To start with, I'd like to ask you about your experience of traditional medical and psychiatric services.

A1. When people are experiencing mental health problems, often the first person they contact is their GP. In your experience, what are the things that your GP does or did that you find most helpful?

A2. In your experience, are there things that your GP does or did that you find less helpful?

A3. To what extent do you feel that you have (or had) a say over the kind of help you receive from your GP?

B1. Many people with mental health problems will have contact with a psychiatrist. In your experience, what are the things that psychiatrists do that are most helpful?

B2. In your experience, are there things that psychiatrists do that are less helpful?

B3. To what extent do you feel that you have (or had) a say over the kind of help you receive from your psychiatrist?

C1. Sometimes people with mental health problems will also have contact with other psychiatric staff such as community psychiatric nurses or psychologists. In your experience, what are the things that these other staff do that are most helpful?

C2. Are there things that these other staff do that are less helpful?

C3. To what extent do you feel that you have (or had) a say over the kind of help you receive from other psychiatric staff, such as community psychiatric nurses or psychologists?

D1. Are there any other comments you would like to make about your experience of the psychiatric services?

2. The experience of user involvement.

A1. Can you tell me a little bit about how you first became involved with this project/organisation?

A2. In what ways do you feel that this project differs from the psychiatric services?

A3. What things about this project/organisation do you like most?

A4. Are there any things about this project/organisation that you do not like?

A5. In what ways are you involved with the Project at present ?

A6 . To what extent do you feel that users have a say over the things that happen in this project/organisation ?

A7. What are the things that project staff do that you find most helpful ?

A8. Are there things that project staff do that are less helpful ?

A9. To what extent do you feel that you have a say over the activities of project staff ?

A10. In your opinion, how if at all could users be more involved in the development and management of this project ?

A11. What kind of things make it hard for users to become involved in developing services ?

A12. What kind of things help users to become involved in developing services ?

A13. What do you think are the benefits of involving users in managing and developing services ?

A14. Are there any drawbacks or dangers ?

A15. What have you personally gained from your involvement in this project ?

B1. Are there any other comments you would like to make about your experience of this project/organisation ?

APPENDIX B

Group Discussion - A Mental Health Users' Movement ?

- Q. Some people think that users of mental health services need to organise themselves collectively into a mental health movement , like the womens' movement, to campaign for improvements to their situation. Do you agree ?
- Q. What experience, if any, have users in this project had of acting collectively around common issues ? What was the focus of this collective activity ?
- Q. What links, if any, do users in this project have at present with other groups of users ?
- Q. What are the main issues that a mental health movement should be addressing ?
- Q. What do you see as the main obstacles, if any, to users organising collectively ?
- Q. Who would you see as the main allies, if any, of a mental health movement ?
- Q. What role, if any, do professional mental health workers have in building a mental health movement ?

APPENDIX C

User Interview Schedule

The Limits and Potential of Mental Health Service User Involvement

Date of Interview :

Project :

Respondent :

1. Personal Introduction.

2. Purpose of the Study.

In recent years, there has been a growing acceptance of the idea that users of mental health services should have a greater say regarding the services they receive. The purpose of the study is to explore the *potential* of user involvement - how much control can or should users have over services - and the *limits* of user involvement - what factors prevent user involvement , as well as any disadvantages user involvement may have .

3. Note-taking and confidentiality.

I would like to take some notes while I am conducting the interview, so I can keep track of the interview as it progresses. Do you have any objection to this ?

Nothing that you say will ever be identified with you personally and you will not be identified by name as a study participant.

4. Statement informing interviewee why he/she is being interviewed.

You are being interviewed as someone who has experience of using mental health services and who is presently actively involved in the [**name of project**] . If for any reason you would prefer not to answer a particular question, then please do not feel under any pressure to do so.

A. User Identity

1. Throughout this interview, I'll be referring to people with mental health problems as 'users'. However, terms such as patient or client or survivor or customer are also commonly used to describe people with mental health problems. Which, if any, of these terms do you think best describes people with mental health problems and why?

[Provide respondent with cards listing options, including 'other'].

B. Aims , Content and Focus of Project Activities.

1. Can you tell me what you see as the purpose of [name of organisation/project] ?
2. On a typical day here, what kind of activities might you be involved in ?
- 3 . What do you see as the main strengths of this project ?
4. What do you see as its main limitations ?
5. In your experience, how if at all does this project differ from other mental health services you have had contact with, such as those provided by an psychiatrist, a GP or a psychiatric nurse ? [For example, less reliance on drugs/less emphasis on professional power] .

C. User Involvement within the Project.

In this section, I want to ask about your views on user involvement and then to look at the ways in which users are involved in this project. I will read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

[Provide respondent with card listing options].

1. 'Professionally-trained mental health workers are the best people to decide the kind of services that users of mental health services should receive.'

Strongly agree agree can't decide disagree strongly disagree

Comment:

2. 'In this project, I am kept fully informed about day-to-day project activities'

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

3. 1. 'I am kept fully informed about *all* project activities'

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

4. ' I am involved in planning day to day project activities'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

5. ' I am involved in planning long-term project strategy'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

6. ' I am involved in financial decision making within the project'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

7. ' I am involved in the hiring and firing of project staff'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

8. Are there any other ways in which users are involved in this project ?

Comment/give examples.

Thank you. Now some more questions about user involvement.

9. What things make it hard for users to get involved in making decisions about what happens in this project ? (For example, lack of confidence).

10. Are there particular things that would help users to be more involved ? (For example, training).

11. What are the main benefits of user involvement in this project ?

12. Has user involvement created any dilemmas or conflicts within this project ? If yes, can you give me an example ?

13. I will once again read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

'All mental health services should be run only by users or former users'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

D. Role of Paid Workers.

In this section, I want to ask you about the role of paid workers within mental health projects.

1. What are the main areas that paid workers in this project need to know about ?
For example, welfare benefits ; psychiatric conditions.

2. What attitudes or values is it important for paid workers in this project to hold ?
For example, being non-judgemental.

3. What are the most important skills that paid workers in this project should have ?
For example, good communication skills.

In the next few questions, I will once again read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

4. 'Paid workers in mental health projects should always have a professional training in social work, nursing, or a related discipline'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

5. 'Paid workers in mental health projects should themselves have had personal experience of mental health problems'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

6. 'Paid workers in mental health projects need to have their own support systems within projects'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

7. 'Paid workers in mental health projects should belong to a trade union'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

8 . 'Mental health workers can only empower users if they themselves have power within their organisations'

Strongly agree agree can't decide disagree strongly disagree

Comment:

E. Biographical Information.

1. Male/Female :

2. Age :

3. Ethnic origin

4. Present or previous occupation (if any).

5. What kind of contact have you had with mental services in the past ?

6. Have you ever been given a name for your mental health problem ?

7. Do you hold any particular post within the project/organisation e.g. secretary ?

8. Prior to your involvement in this project, have you been involved in any other organisations - for example, a trade union or community group ?

Thank you for your co-operation with this interview.

APPENDIX D

Paid Worker Interview Schedule

The Limits and Potential of Mental Health Service User Involvement

Date of Interview :

Respondent :

Project :

Post :

In recent years, there has been a growing acceptance of the idea that users of mental health services should have a greater say regarding the services they receive. The purpose of the study is to explore the *potential* of user involvement - how much control can or should users have over services - and the *limits* of user involvement - what factors prevent user involvement , as well as any disadvantages user involvement may have .

3. Note-taking and confidentiality.

I would like to take some notes while I am conducting the interview, so I can keep track of the interview as it progresses. Do you have any objection to this ?

Nothing that you say will ever be identified with you personally and you will not be identified by name as a study participant.

4. Statement informing interviewee why he/she is being interviewed.

You are being interviewed as someone who currently works in a paid capacity with people with mental health problems in a project which has a commitment to user involvement. If for any reason you would prefer not to answer a particular question, then please do not feel under any pressure to do so.

A. User Identity

1. Throughout this interview, I'll be referring to people with mental health problems as 'users'. However, terms such as patient or client or survivor or customer are also commonly used to describe people with mental health problems. Which, if any, of these terms do you think best describes people with mental health problems and why?

[Provide respondent with card listing options].

B. Aims ,Content and Focus of Project Activities.

1. Can you tell me what you see as the main purpose or purposes of [name of organisation/project] ?

2. On a typical day here, what kind of activities might you as a worker be involved in ?

3 . What do you see as the main strengths of this project ?

4. What do you see as its main limitations ?

5. In your experience, how if at all does this project differ from other mental health services you have had contact with, such as those provided by an psychiatrist, a GP or a psychiatric nurse ? [For example, less reliance on drugs/less emphasis on professional power] .

C. User Involvement within the Project.

In this section, I want to ask about your views on user involvement and then look at the ways in which users are involved in this project. I will read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

[Provide respondent with card listing options]

1. 'Professionally-trained mental health workers are the best people to decide the kind of services that users of mental health services should receive.'

Strongly agree agree can't decide disagree strongly disagree

Comment:

2. ' In this project, project users are kept fully informed about day-to-day project activities'

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

3. 'Project users are kept fully informed about *all* project activities'

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

4. ' Users are involved in planning day to day project activities'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

5. ' Users are involved in planning long-term project strategy'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

6. ' Users are involved in financial decision making within the project'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

7. ' Users are involved in the hiring and firing of project staff'.

Strongly agree agree can't decide disagree strongly disagree

Comment/give example.

8. Are there any other ways in which service users are involved in this project ?
Please comment/give examples.

Thank you. Now some more questions about user involvement.

9. What things make it hard for users to get involved in making decisions over what happens in this project ? (For example, lack of confidence).

10. Are there particular things that would help users to be more involved ? (For example, training).

11. Has user involvement created any dilemmas or conflicts within this project ? If yes, can you give me an example ?

12 . I will once again read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

‘All mental health services should be run only by users or former users’.

Strongly agree agree can't decide disagree strongly disagree

Comment:

D. Role of Paid Workers.

In this section, I want to ask you about the role of paid workers within mental health projects.

1. What are the most important skills and knowledge that paid workers in a project like this should have ? For example, knowledge of psychiatric conditions; good communication skills.

In the next few questions, I will once again read out a statement and then ask you to say whether you strongly agree with the statement ; agree; can't decide; disagree; or strongly disagree. I will then ask you to comment on your choice, if you wish, perhaps by giving an example.

2. ‘Paid workers in mental health projects should always have a professional training in social work, nursing, or a related discipline’.

Strongly agree agree can't decide disagree strongly disagree

Comment:

Do you yourself have a professional training ? In what area ?

3. ‘Paid workers in mental health projects should themselves have had personal experience of mental health problems’.

Strongly agree agree can't decide disagree strongly disagree

Comment:

Do you yourself have experience as a user or former user of mental health services ?

4. ‘Paid workers in mental health projects need to have their own support systems within projects’.

Strongly agree agree can't decide disagree strongly disagree

Comment:

What support systems are there,if any, for workers in this project ?

5. 'Paid workers in mental health projects should belong to a trade union'.

Strongly agree agree can't decide disagree strongly disagree

Comment:

Are you a member of a trade union ?

6 . 'Mental health workers can only empower users if they themselves have power within their organisations'

Strongly agree agree can't decide disagree strongly disagree

Comment:

E. The Future of Mental Health Services.

1. Mental health services seem to be increasingly located within the voluntary sector. What do you see as the advantages of this ? Are there any disadvantages ?

2. What are your main concerns,if any, about the future development of mental health services ?

Thank you for your co-operation with this interview.

APPENDIX E

Dear ,

Further to my recent telephone call, I am writing to ask if the [name of project] would wish to participate in PhD research which I am currently undertaking into mental health service user involvement in Scotland. As you are no doubt aware, there has in recent years been a growing acceptance of the idea that users of mental health services should have a much greater say regarding the services they receive. The purpose of the study is to explore the *potential* of user involvement - how much control can or should users have over services - and the *limits* of user involvement - what factors prevent or limit user involvement .

The research would be based mainly on individual interviews lasting one to one and a half hours with between six and eight members who are actively involved in decision-making in the organisation and with two or three project workers, but access to relevant documents such as annual reports or minutes of meetings would also be helpful and I would hope to observe one or two meetings within the project. Should you require more information, I would be happy to provide it by phone, in writing or by attending an Executive meeting.

I have managed to 'ring-fence' Wednesdays as the day when I normally conduct my research and if your organisation does wish to be involved, I would like to commence the interviews in December or January. My hope would be to conduct an average of three/four interviews on Wednesdays, over a period of several weeks, with additional visits to observe other relevant meetings.

As regards myself, my professional background is in social work and community work and before coming to work at Paisley University in 1990, I was employed as a social worker at Gartnavel Royal Hospital where I trained as a mental health officer and co-led a relatives group for 2 years. More recently, as well as co-ordinating the teaching on mental health on the social work course at Paisley, I have until recently been actively involved in the Renfrewshire Association for Mental Health, both as an Executive member and as a member of a working group on user involvement. I am not currently a user of psychiatric services but, like most people (including many mental health professionals, if they are honest), have certainly experienced periods where my own mental health was far from perfect and was made aware of the difficulties of finding appropriate help.

More generally, while this research is for Ph.D. purposes, I would hope that it would also play a part, albeit a small one, in challenging the stigma associated with mental ill-health and contributing to the empowerment of service users in Scotland.

I hope to hear from you in the near future,

Yours sincerely

Iain Ferguson
Lecturer in Social Work

Appendix F

The Limits and Potential of Mental Health User Involvement.

Focus Group Schedule

Introduction.

Thanks for participation. Introduce self. Outline of Research Project. Format of group discussion. Aim of group discussion - views and experiences, not right and wrong. Examples helpful. Confidential. Will ask for completion of short form at end.

Ask people to give their first name and note. Test out equipment.

Section A - Problems of Community Care (15 minutes)

Q1. Community care policy means that most users of mental health services now live not in hospital but in the community. As users of services, I would like to know what are the main problems you experience living in the community ? Here are some issues that other users have identified as problems but there may be others you feel are more important. [Supply card] Which *three* issues do you see as most important ? Take a few moments to consider.

Probe: There seems to be a lot of debate within the users' movement about which term best describes users e.g. user, survivor client. How important do you see this debate as being ?

Section B - Involvement in campaigning activity. (30 minutes)

Q2. Have users in this area been involved in campaigning around any mental health issues, local or national, over the past year ? If yes, what form did these campaigns take ? Tell me about them. If no involvement in campaigns, why might that have been ?

Q3 . What do you think are the main difficulties users face in building campaigns ?

Probes: mental health problems, lack of resources, lack of confidence. Concrete examples of this group's experience of organising users. What links, if any, do they have with other groups of users ?

Q4. Some people believe that there is a need to build a mental health users' movement, like the women's' movement or the gay movement, to campaign against the discrimination and disadvantage experienced by users of mental health services. Do you share this view ?

Probe: What would be the advantages of having such a movement ? Any dangers e.g. ghettoisation .

Section C. Mental Health Services (30 minutes)

Q5. If you were designing your ideal mental health service, what would it look like ?
What would be its main components ?

Probe A. What role would users play in this service ?

Probe B. How important would psychiatric treatments such as medication
be in this ideal service ?

Some problems experienced by people with mental health problems living in the community

Poverty

Lack of community care services

Mental health professionals (such as GPs and psychiatrists) not listening

Side- effects of medication or ECT

Lack of employment services

Lack of user involvement in

Feeling bad as a result of mental ill-health

Loneliness

Inappropriate community care services (e.g. not open at the right times)

Other people's attitudes to mental illness

Other problems not mentioned above

Group Discussion

Venue:

Date:

Biographical Information - Name:.....

1. Male/Female :
2. Age :
3. Ethnic origin
4. Present or previous occupation (if any).
5. What kind of contact have you had with mental services in the past ?
6. Have you ever been given a name for your mental health problem ?
7. Do you hold any particular post within the project/organisation e.g. secretary ?
8. Prior to your involvement in this project, have you been involved in any other organisations - for example, a trade union or community group ?

Thank you for your co-operation with this interview.

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