User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature

prepared by

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Contents

Acknowledgements

Executive Summary
Key themes and messages

Origins and context of the review

This review examines the literature on user and carer involvement in change management in organisations in a mental health context. It was funded by the NHS Service Delivery and Organisation R & D Programme. The review team included user and professional researchers. User and carer involvement in health and social services has been a theme of government policy for over two decades. During this period users and carers have become increasingly active in the development and delivery of services.

Methods

This review examines literature about user and/or carer involvement in managing organisational change within mental health services. It examines how users and/or carers have been consulted about or involved in creating or implementing changes at the level of procedures, organisational structures, service design or delivery.

Such changes include:

- issues of democracy, representation and consultatio n
- changes in the mission or profile of organisations
- changes in organisational culture
- restructuring of organisations
- new policy initiatives
- changes in service provision or delivery.

Literature was accessed from a range of electronic and archival sources. Following advice from a reference group formed of users and carers, a coding frame was devised. Over 850 abstracts or papers were considered for the review; 112 papers were included in the final corpus. These papers were coded in relation to the central research themes:

- tracking modes of user/carer involvement
- types of organisational change
- factors facilitating or impeding involvement.

Coding sheets were entered into an SPSS data file to analyse the frequency counts for different categories. An archive of articles appearing in two journals in 1989 and 2001 was compiled and reviewed. These two exercises give a basic map of the terrain.

In the main body of the report three clusters of types of organisational and service change are considered, forming a continuum from a 'soft' approach to change management to more 'step' or 'hard' changes in organisations that entail user or carer involvement. The three clusters are:

1   promoting democracy and representation and/or cultural change

2   strategic planning, restructuring and policy initiatives

3   new service provision and the employment of service users in organisations.

Mapping the terrain

Analysis of frequency counts for coding frame categories

- The literature is dominated by discussion of user involvement. Only one-quarter of the literature mentions carers. There were a small number of papers that dealt with carers only. Collective consumerism is the dominant type of user involvement activity.

- A facilitative organisational culture is the most important single factor identified in the literature for involving users in change management, closely followed by a strategy for providing information and the provision of resources. Training of staff, especially by users, and the training of users are also important.

- A resistant organisational culture is the single most important factor impeding user involvement in change management. Factors pertaining to mental distress and lack of autonomy are also important.

- The outcomes identified in the literature are hardly ever measurable ones, indicating the difficulty of measuring cultural and organisational change, and its sustainability. The majority of papers indicated that the outcomes of user involvement in change management are unclear or unknown.

Analysis of articles on user involvement in change appearing in *Health Service Journal* and *Openmind* (1989 and 2001)

In this part of the study, we reviewed 15 articles, news stories or book reviews in *Health Service Journal* (*HSJ*) and 31 in *Openmind* (*OM*) in the years 1989 and 2001. The aim here was to consider both quantitative and qualitative changes over time in the coverage of user involvement issues in a professional journal and a user-oriented journal.

Comparing the two sample years, there was an increase in items reviewed. In *HSJ* there was a modest increase (from 6 to 9) and in *OM* a more significant increase (from 8 to 23). It was notable that the authorship of items differed between the two magazines. None of the items in *HSJ* was written by service users whereas at least 11 of the 23 items appearing in *OM* during 2001 were written by service users.

The material considered in this comparative review suggests that service user involvement has extended into areas not foreseen or intended by the consumerism advocated in 1989. The material from 2001, particularly from *OM*, provides evidence of the energy and enterprise of those service users who are involved. At the same time it is clear that involvement in change is problematic, both because there are differences in goals among the parties involved and because the processes themselves are not of sufficient quality.

Promoting democracy, representation and cultural change

Although papers in this sub-sample focus on issues of democracy in organisations, formal representative structures do not appear as sufficient in themselves for effective user/carer involvement in change management. In this literature, resistant organisational or professional cultures and embedded power differentials are seen as primary obstacles to user involvement in formal representative structures. Lack of resources is also important.

Strategies of user and carer representation need to be embedded in more broadly supportive organisational cultures, or risk becoming tokenistic measures to demonstrate that agencies have user involvement 'covered'.

This sub-sample of the literature can be seen to constitute a relatively weak evidence base for the impact of user involvement on organisational change: few papers refer to specific outcomes of user/carer involvement. This finding is indicative of the way that, while representative and supportive organisational cultures are seen in the

literature as critical for effective change management, it can be difficult to research cultural change and its outcomes in an empirical manner.

This section focuses on papers that identify the promotion of democracy and representation, or cultural change, as distinct or 'stand-alone' types of organisational change. Our larger review suggests change tends to be most successful when 'soft' change at the level of organisational culture (which often is gradual and hard to measure) occurs together with 'hard' changes in organisational structure, systems and services. In this respect, the literature goes beyond approaches that see representation or a supportive culture as organisational ends in themselves, to consider if and how representative structures and cultural factors shape the management of other types of organisational change.

Strategic planning, restructuring and new policy initiatives

Strategic planning in the UK took a 'consumerist' turn with the advent of the purchaser/provider split in 1990 in health and social care. The practical literature reviewed here generally describes mechanisms for consumer feedback into the planning process and less often representation on planning committees. It is not clear if the former ever has a meaningful influence on planning even to the extent of increasing the range of options from which consumers may choose. Writers from a professional perspective express concern that users, particularly mental health service users, will be over-zealous in their demands while writers from a user perspective express concern that their efforts are not appreciated.

Much has been written about the transition from institutional to community care but the literature reviewed here specifically concerns the place of user involvement within this transition. The more over-arching reports emphasise material, organisational and cultural obstacles to the possibility of users and user groups having a real influence on the shape of the new community services. Papers which describe more local initiatives are more mixed in their views about what is necessary to successfully manage change at the levels of restructuring and/or the implementation of new policies influenced by a user perspective.

Change management, new service provision and user involvement

The provision of a new service or the delivery of an existing service in a new way is usually a radical form of organi sational change requiring new ways of working from managers. It is particularly radical if it involves service users themselves as the providers of the new service rather than simply as groups that are consulted about a new service. If the new service exis ts within mainstream services then it will only be successful if other forms of organisational change – including cultural, attitudinal and structural change – are also brought about. If the new service exists as a user-controlled organisation in parallel to mainstream services there may still be involvement of the mainstream management in the form of grant aid, contracts and monitoring. Many papers reviewed in this section make mention of resources and secure funding – rather than rolling one -year contracts – as vital to the success of new services.

The papers reviewed in this chapter represent probably the 'hardest' form of user involvement in change management encountered in the literature. The examples often involve the employment of service users as staff and/or the setting up of user-led services. These projects arguably pose a greater challenge to managers than initiatives which aim to promote democracy and representation or cultural change. This is because the employment of service users or the develo pment of user-controlled services can represent a fundamental shift in service patterns. However 'softer' changes such as widening representation or engaging in cultural change may be a prerequisite for the successful execution of more far-reaching developments.

Theoretical frameworks

Models of user involvement

There are several models of public participation that are often conceptualised as 'ladders'. The best -known of these is Arnstein's ladder of citizen participation (Arnstein, 1969). Our model of user involvement, developed in our coding frame, draws on Arnstein's ladder but has been modified in light of developments in user and carer involvement in mental health, and recent critiques in the academic literature. The typology marks a break between concep ts of consumerism and citizenship. Consumerist thinking maintains that users of public services can exercise choices through the health care

'market'. Approaches to citizenship position users and carers as citizens to whom public bodies are accountable and who have a role in determining wider social and political processes.

Stakeholding, consumerism and citizenship

The language of stakeholding is increasingly evident in the literature on user and carer involvement. It is important to ask what constitutes a 'stake' in this context, as well as to recognise the very differently weighted 'stakes' that various actors have within organisations.

A central framework for analysing the stakeholder relation in mental health services turns on the distinction between users and carers as *consumers* and as *citizens.* Consumerist approaches to user involvement are most often concerned with the detail of service provision, rather than with strategic, service and organisational planning. The aims of user movements, however, a re not always consonant with or limited to consumerist interests. Service users may have a dual identity as consumers of services, and as citizens to whom such services are accountable. The limited rights of 'exit' or 'choice' available to many mental health users mean that they cannot be understood simply as consumers of services, however empowered. The user movement calls for a more robust range of citizenship rights than those found in the customer relation. Such a conception of users as citizens both challenges a view which positions users as 'passive recipients' of services, and equally challenges models of the 'active citizen' based on the figure of an independent volunteer. User movements are not concerned only with pursuing service needs nor simply with articulating citizen rights, but also can represent a social movement that seeks to re-define the marginalised identities of mental health service users.

User involvement as a technology of legitimation

Strategies of user involvement can work to reinf orce the power of professionals and managers. This is especially the case where the 'user card' is played strategically so as to bolster certain professional interests against other organisational interests. Furthermore, in a 'pluralistic' or network model of public service stakeholding, users become one of many different interests. Their demands must be offset against those of other (including more powerful) stakeholders. Managers retain power at the centre of a network mediating the competing interests of professionals, users, carers, the public, and political actors. A shift from top-down hierarchies to more inclusive networks or markets in the organisation of public services in these ways can produce new techniques for legitimising managerial and professional power.

Discussion

A number of issues arise from the review of the literature that have specific relevance to change management in a mental health context. In particular, these are issues where users/carers and professionals/managers have different interpretations of events, processes and outcomes.

Reference group categories

The members of the reference group all have many years' experience of user or carer involvement in mental health and in change management in mental health organisations. In contrast, the change management literature in mental health is largely authored by professionals and targeted at a professional audience. The question then arises as to why there is a discrepancy between the views of these user and carer activists, and those who write about their activities. This review addresses three categories in turn, where the study's reference group highlighted key themes that were absent from or rarely evident in the literature:

- Change not sustained
- Champion absent or leaving
- Risk and risk assessment.

Change not sustained

The virtual absence of this issue in the literature by professional authors obscures the importance of sustainability as a problem for user and carer groups. There is little if any research focus on initiatives tha t fail or groups that collapse. In this context, longitudinal research would be valuable in analysing ongoing processes of change and issues of sustainability over time.

Champion absent or leaving

A key concern of our reference group was the importance of professional allies or 'champions'. These are managers and professionals who personally maintain the momentum for user involvement within organisations. Rather than being embedded in organisational practices, user involvement is understood here as a margin al activity that largely depends on the commitment of individual managers. It is notable that a mainly professionally authored literature appears to ignore the important role of professional user involvement 'champions'.

Risk and risk assessment

Members of the reference group pointed out that there can be a tension between two recent emphases in mental health policy: requirements for user involvement, and the priority given to managing risk. Whereas user involvement in principle implies a transfer of power from professionals to users, issues of risk often reinforce professional power and control vis-à-vis users. Explicit discussion of this issue is largely absent from the literature reviewed on organisational change, even where factors pertaining to mental distress are seen to make user involvement a 'risky' organisational strategy.

Ambivalence regarding user involvement in mental health

I'm a feather in their cap and a thorn in their side.

(Service user activist (Parkes, 2002)

User involvement is pervaded by ambivalence. On the one hand, the experience of services is seen as a direct and authentic expression of what is acceptable and what is not. On the other, being mentally ill is itself seen to disrupt the possibility of rational action.

Such ambivalence is not surprising when a group of people who have been defined socially as not competent start to take on roles defined by this very competence. At one pole, psychopathology is seen to preclude an extensive degree of user involvement, and at the other it is argued that positive steps need to be taken to support users or ex-users to effectively involve them in developing new services. It is also recognised that references to mental distress may be used to dismiss the contribution of service users.

User workers in case management roles, for example, are recognised as better able to empathise with their clients than professionals who have not themselves experienced mental health problems. However, at the same time this very ability can be seen as problematic because user workers may have different ideas from their colleagues about what constitutes appropriate professional 'boundaries'.

It appears to be a particular problem that users and carers are asked to be more 'representative' than any other group of stakeholders in the change management process. Articulate users may be criticised as unrepresentative because 'ordinary' users are often not seen as articulate. Other stakeholder groups, in contrast, will not be subject to such challenges – articulate and assertive professionals or managers, for instance, as not likely to be questioned as 'unrepresentative'.

Power differentials

Much of the literature reviewed makes reference to power differentials and these are perceived as an important obstacle to user and carer involvement in change management. At one level, such a finding seems quite simple to interpret, since it is obviously the case that most professionals have more power and status than do users and carers. However, issues of power operate on a number of dif ferent levels.

There may be conflict, for example, between users who wish to establish more equitable ways of working and hierarchical and structural obstacles in mainstream services that militate against this. Power may also operate in mental health in qu ite subtle ways – as in the pathologisation of complaints where users attempt to exercise a right of 'voice'.

Structural inequalities in society are magnified in the power differentials that exist in a mental health context. Those groups disadvantaged in society as a whole – poor people, those from ethnic minorities and women – are over- represented in psychiatric facilities. Those who make the final decisions about their treatment – psychiatrists and psychologists – tend to reflect the opposite pole of the social strata.

Conversely nurses and other social care workers occupy a lower professional (and by extension social) status. Of the groups with whom they come into close contact, only patients are coded as lower status. So, community and hospital nursing and support staff may have a vested interest in maintaining the power differentials between themselves and their clients.

The experiential knowledge of users may be valued for its authenticity but when set beside forms of knowledge which can claim the stat us of 'evidence', that authenticity occupies second place. In addition, the direct experience of users and the way it is expressed may sometimes be dismissed as too distressing or disturbing.

Processes in change management

The processes of user and carer involvement in change management can be as important as the outcomes. It is a mistake to assert that conflicts should or can be resolved before a process of change is begun. Power differentials between users and professionals and differences in perceptions of satisfactory outcomes mean that conflict is to be expected. The tension between professional and user/carer discourses is a central justification for user and carer involvement. If all the actors in the change management process agreed, user and care involvement would become largely redundant. The management and resolution of conflict is an ongoing function of change management.

User involvement as 'therapy'

A citizenship or rights-based approach challenges professional assumptions that the purpose of user involvement is largely 'therapeutic'. If resistant professional and organisational cultures emerge in our review as the chief factor constraining user involvement in mental health, there is also an argument to be made that some 'supportive' professional attitudes can limit the impact and effectiveness of user participation by reducing this to individual therapeutic outcomes. That is, user involvement may be endorsed by professionals as performing a therapeutic or rehabilitative function in enhancing individuals' skills, competence and self-esteem. In contrast, understanding user involvement in a social movement or citizenship framework emphasises larger objectives of organisational change, of transforming social attitudes, and of gaining political recognition. Some parts of the 'user movement' may be engaged in a form of 'identity politics' similar to feminism and movements promoting gay rights.

Conclusions

The literature assembled presents a complex picture of user and carer involvement in change management. It is very diverse and of variable quality.

Our review suggests that the role of organisational culture is key in both facilitating or impeding user/carer involvement in change management. Change tends to be most successful when 'soft' change at the level of organisational culture occurs together with 'hard' changes in organisational structure, systems and services.

There is a danger that government demands for agencies to demonstrate user involvement may mean that user activities become a

formal procedure to be ticked off, rather than an embedded and powerful organisational practice.

The threat posed by user involvement means that changes often have remained very much at the level of tokenism.

Mental health users have a stake in how organisations op erate internally, as well as in service quality. Models of change management generally position service users as *external* stakeholders. Mental health users, however, tend to be more involved or 'embedded' in organisations: the structures and processes thro ugh which services are delivered are therefore a legitimate interest on the part of users and carers.

There can be tension between workers and users/carers. Managers and other staff may see user involvement as both of value and a threat. One way of underst anding this is as a conflict between staff and managers' desire to implement a rather limited consumerist agenda and the hunger of many users to reclaim their spoiled identity and reassert themselves as citizens. User involvement in change management will work best when frontline staff and other stakeholders are also meaningfully engaged in organisational processes. However conflicts will inevitably arise between the various actors.

The literature suggests that the employment of service users as practitioners and the development of user-controlled services are more prevalent in USA and Canada. These practices are at the cutting edge of user/carer involvement in change management and present the greatest potential challenges and rewards. UK services are devel oping in this direction and it would be prudent to learn as much as possible from the American and Canadian experience.

Further user-led research is required to establish reliable outcome measures for user and carer involvement in change management. Such measures must incorporate the important role of processes and the difficulty of measuring cultural changes, and acknowledge that different stakeholders will have different perceptions of what represents a positive outcome.

Good practice points

Tables 1 and 2 show factors which facilitate and hinder user and carer involvement in change management. (The factors are not ranked and many individual factors are interlinked).

Table 1

Factors which facilitate user/carer involvement in change management

- Adequate resources present
- Facilitative organisational culture
- Good-quality organisational information strategy
- Autonomous user groups
- Professional champion present
- Staff training by users
- Training of users
- Payment and/or employment of users
- Representative structures
- Recognition and understanding of power differentials
- Acknowledgement of and sensitivity to factors pertaining to mental distress and practical measures in place to minimise these (for example advocacy)
- High-quality, meaningful and measurable involvement processes

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Table 2

Factors which hinder user/carer involvement in change management

- Lack of resources
- Resistant organisational culture
- Poor information strategy
- Lack of autonomous user group
- Professional champion absent
- Power differentials not understood
- Factors pertaining to mental distress not acknowledged
- Involvement for the purposes of display only

Table notes

Information

Information and communication are an important factor in promotin g user involvement in change in mental health services. In the mental health literature, effective information strategy is cited as facilitating involvement twice as often as are formal representative structures. The timing and quality of information are t herefore key issues for effective and inclusive change management.

Professional champions – autonomous user groups

It is clear that user and carer involvement in change management requires proactive professional managerial input. However, there is a delicate balance to be struck by managers. On one hand they need to be supportive of involvement both practically and by helping to create a facilitative organisational culture. On the other hand managers need to ensure that they do not compromise the autonomy o f users and carer groupings by attempting to manage and control them. Independent user groups are a prerequisite for the development of user-controlled services.

Power differentials

Power differentials are an inevitable consequence of both the mental health system and wider structural inequalities. They can be managed and to some extent mitigated only if they are made explicit. Training, various forms of support, advocacy and ability for structures to be flexible all contribute increasing the possibilities for more equal partnerships.

Factors pertaining to mental distress

Several factors linked to the experience of mental distress can impair people's ability to participate in standard change management processes. Therefore structures need to be flexible and responsive to individual needs. For example, minutes and papers may need to be put onto audiotape, meetings timed around public transport constraints and jargon minimised. The nature of some mental health problems is episodic; therefore systems need to ac commodate this, perhaps by ensuring that participation involves as many people as possible. A challenge exists for change managers in viewing user needs and demands as drivers for, rather than constraints on, change – as opportunities rather than as threat s.

Recommendations

1 User and carer involvement should be adequately and sustainably resourced. This includes supporting autonomous groups and paying individual users properly for their time.

2 Organisations need to strike the right balance between support ing user and carer involvement and allowing user and carer groups to remain autonomous.

3 Training of staff by users is an important factor to facilitate user involvement; training of users is also important. Research is required to determine how such training can be delivered most effectively.

4 User involvement in change management should begin at the earliest possible stage of a project and should be maintained at every subsequent stage. Users should be engaged not only in consultations prior to change programmes, and in evaluations of change outcomes, but in organisational processes of change management.

5 A high-quality information strategy is essential to user and carer involvement. Organisational governance and decision making should be as transparent as possible.

6 Power differentials need to be acknowledged, understood and sensitively managed.

7 Change management processes need to be adapted to ensure they are accessible to service users, including making all reasonable accommodations for the partic ipation of people experiencing mental distress.

The Report

Chapter 1 Introduction

1.1 Origins of the review

This review examines the literature on user and carer involvement in change management in organisations in a mental health context. It was commissioned under the NHS Service Delivery and Organisation Research and Development Programme. The review team includes three individuals (Diana Rose, Peter Fleischmann and Peter Campbell) who have been active in user involvement since the 1980s. The team also includes Til Wykes, Director of SURE, who brings to the team a professional perspective of user/carer involvement in managing change, particularly in the area of mental health research. The SDO specifically requested that the theoretical literature also be examined and a sociological expert (Fran Tonkiss) was brought in for this part of the work.

It became apparent at an early stage that there was no pre-existing or coherent body of work in this area and so a corpus of literature had to be built up from various sources. This corpus is extremely varied, ranging from one-page articles to entire books. It also became evident that the review could not in any way approximate a 'meta-analysis' as the literature is in the main discursive and the research it does contain very rarely includes measurable outcomes (cf. Rutter *et al.*, 2001). The way in which the literature was compiled is described in Chapter 2.

The discussion in this introductory chapter comprises three sections. First, we review the policy context for change in mental health services, concentrating on the UK but considering also North America and Europe. Second, we briefly describe existing overviews of user and carer involvement that are relevant to this work. We have identified three such overviews. Finally, the structure of the review is described.

1.2 The policy context

The *National Service Framework* (NSF) *for Mental Health* (Department of Health, 1999a) states that one of its core values is 'user and carer involvement'. Subsequently Local Implementation Teams were set up to take forward the plans of the NSF and guidance stated that user involvement in these teams should be encouraged.

Chapter 10 of the *NHS Plan* (Department of Health, 2000) is devoted to how user involvement in the NHS can bring about a 'patient‑centred service'. It proposes Patient Advice and Liaison Services (PALS) and many trusts now have these in place. It also proposes Patients' Forums which would have an inspection role and hear complaints. Finally, there is a proposal for a user to sit on each trust board as a non‑executive director. This is already in place in some mental health trusts.

However, this focus on user involvement in health and social care is not specific to the present administration. The 1990 NHS and Community Care Act (Department of Health, 1990) introduced a market‑based approach to health and social care by separating purchasing and provider functions. The patient or client was re‑conceptualised as a 'consumer' and it was assumed that greater choice would be brought about both through market mechanisms (e.g. fund‑holding GPs, case managers) and through consumer feedback which would direct the kind of services that purchasers would demand of providers. However, because providers were usually monopolies, this 'market' came to be known as a 'quasi‑market'.

Developments in mental health included a Mental Health Task Force which included a user sub‑group. This produced a Charter and a Code of Practice for Advocacy and held a user-only conference in Derbyshire in 1992. Following *The Griffiths Report* (1989), local authorities were obliged to consult users and carers in relation to their Annual Community Care Plans. The health and social care 'quasi-market' also placed an emphasis on the 'end user' of services and this was strengthened in 1995 with *Building Bridges* (Department of Health, 1995) which stated that all health and social care providers must implement the Care Programme Approach without delay and that users should be involved in their CPAs. The current administration has continued this focus on individual user involvement in care.

It should be said that policy makers are not always consistent in their approach to mental health. *Modernising Mental Health Services* (Department of Health, 1999b) both promotes social inclusion and at the same time argues that 'community care has failed', citing homicides by people with a mental illness as evidence. Recent proposals for new mental health legislation (Department of Health, 2002) was seen as draconian by nearly all stakeholders.

The legislative and policy situation in North America is quite different because there is no equivalent to the NHS, health care is managed largely through insurance companies or the public 'safety nets' of Medicaid and Medicare, and many policy and legislative decisions are taken at state and not federal level. However, through a complex process of lobbying, many states in the 1970s and 1980s agreed that at least one mental health facility in each county should be user-run.

It might also be argued that user involvement in the UK and the USA was driven by the policy of de-institutionalisation. Individuals who previously would have spent their lives in institutions, and perhaps had spent some time there, were galvanised into campaigning for better rights and treatment for people with mental health problems. In the USA, de-institutionalisation was explicitly driven by a rights-based agenda and so it is not surprising that ex-users should have continued along these lines. However, the rise of user groups in the UK may have been an unintended consequence of de-institutionalisation rather than following directly from it.

In other European countries, only Italy has had a full programme of de-institutionalisation. Countries such as Germany, Austria and the Netherlands have not gone down this route although the latter has a wide network of Patients' Councils in its psychiatric hospitals, which are funded by central government.

1.3 Previous work

Three pieces of work were identified as overviews relevant to the current literature review: a previous literature review (Rutter *et al.*, 2001); a 'health technology' approach to user and carer involvement (Simpson *et al.*, 2002); and a survey of the user movement in England (Wallcraft *et al.*, 2002) to which we were given pre-publication access via our reference group. An additional unpublished thesis was accessed via our reference group (Parkes, 2000) and this will be used on occasion in the review but not discussed here.

The three overviews take very different approaches and come to very different conclusions. Rutter *et al.* (2001) rely heavily for a conceptual framework on Arnstein's (1969) 'ladder of citizen participation'. This 'ladder' itself rests on the conclusion that much of what is called participation is in fact 'tokenism' or 'for purposes of display only'. Rutter *et al.* (2001) are concerned with user involvement in the planning and delivery of health care across all patient groups but point out that the literature base they compiled is heavily biased towards mental health. Their conclusion is that most user involvement, at least in the UK, belongs on the 'tokenism' rungs of Arnstein's ladder. Two points in particular are worth drawing out. First, especially in relation to mental health, they consider that much user involvement is conceived, at least by professionals, as 'therapy'. This is one of Arnstein's categories of 'tokenism'. However, there is a question concerning whether a ladder

of participation constructed to understand community regeneration is immediately transferable into the health field. Second, Rutter *et al.* (2001) consider that most user consultation works to an agenda pre-formed by purchasers and providers and is essentially a rubber-stamping exercise with no real influence on the planning and delivery of services. Any changes that take place would have taken place anyway.

Simpson *et al.* (2002) take a quite different approach. They argue that all user involvement activity should be tightly structured with clear aims and objectives set in advance, processes well defined, outcomes clear and measurable, and with evaluation procedures in place to make sure that outcomes are monitored. They also counsel that any potential conflicts should be resolved in advance of the change process. As the authors are well aware, hardly any of the literature in the field takes this form and so their manuscript is a recommendation for 'how to do it'. Much of the report takes the form of check-lists to be completed before a change agent embarks on user or carer involvement in mental health service planning, delivery or research. The chief problem identified by these authors lies with characteristics of the client group to be involved. The strict organisational clarity which they argue is necessary for change may be threatened by lack of 'coherence' among some service users. The authors are of the view that not all service users will be able to become involved, or not all of the time, and that some will require advocates to speak on their behalf. So, while Rutter *et al.* (2001) may be cynical about the motives of change agents, Simpson *et al.* (2002) are doubtful about the capacities of some service users. This is a tension or ambivalence that will reappear frequently throughout this review.

Wallcraft *et al.* (2002) report on a survey of the user movement in England. This survey was designed and carried out by service users themselves. It contains the results of a postal questionnaire returned by 318 groups. These are largely quantitative, but the main part of the report is qualitative. There are abundant direct quotations from 'leading figures' in the user movement, groups, officers and workers and user group members who are less active than the others interviewed. All the interviews and focus groups were carried out by service user researchers. This report is of significance for the present review because the bulk of the literature we accessed was written by professionals for a professional audience. So, for example, many of the users interviewed by Wallcraft and her colleagues (2002) give a much more positive picture of what they have achieved and are achieving than the picture which would be drawn from the conclusions of Rutter *et al.* (2001).

1.4 Structure of the review

The next chapter, Chapter 2, is the Methods chapter. It describes how the literature was assembled and also how a coding frame was put together. Particular attention is paid to how a 'ladder of participation' was constructed, drawing on previous work but at the same time modifying it. A reference group, assembled to assist with the work, was particularly helpful in generating some of the coding categories. More details of the work of the reference group can be found in Appendices B and C.

For each piece of literature, the coding sheets were entered into an SPSS file. The aim here was to 'map the terrain' of the literature and to generate a framework for exploring the substantive material in more detail. The results of the mapping exercise make up Chapter 3.

There are three substantive chapters, which comprise another 'ladder of participation' in terms of the type of change described in the paper, report or book. Chapter 4 looks at material which only mentions either the 'promotion of democracy and representation' or 'cultural change'. It is considered that such change, while important, represents the 'soft' end of organisational change. Particularly in terms of promoting democracy and representation, the material can be almost tautologous. It reports on measures to set up representative structures and which thereby are seen to achieve greater democracy and representation.

A more substantive type of change is considered in Chapter 5. Here we take together changes in strategic planning, restructuring and policy initiatives. Often, material coded under one of these headings was also coded under a second, and sometimes all three were rated. There is a clear conceptual affinity between strategic planning and restructuring. When the papers were read in detail, it was often difficult to distinguish substantively between those rated as describing a new policy initiative and those rated under strategic planning or restructuring.

Chapter 6 focuses on new service delivery or the delivery of existing services in new ways. On close inspection, this category frequently involved the employment of users as staff or volunteers. This appears as a specific, substantive and measurable organisational change, and one that can be seen to represent a significant challenge for change management.

Chapters 4, 5 and 6 do not attempt to review each and every paper relevant to their substantive content. In the mapping exercise (Chapter 3), we examine the distribution of papers and reports across each coding category. We then take a *sample* of these to examine in the substantive chapters. These are purposive samples, since we have aimed to include the higher-quality reports at the expense of weaker ones. Higher-quality papers are those rated on our coding frame for inclusion in the review as 1 (Recommend inclusion) and 2 (Consider

inclusion). Approximately one-third of the total literature is discussed in the substantive chapters.

Chapter 7 considers the theoretical literature. The chapter looks at both the change management literature and at the growing body of writing on the distinction between 'consumer' and 'citizen'. This was thought to be relevant because the conceptualisation of patients and clients as 'consumers' with the introduction of the purchaser/provider split is now subject to increasing criticism in the theoretical literature. The chapter considers how the theoretical literature links to the research papers and practical discussions that make up the rest of the work reviewed here. Some papers also appear both in the theoretical chapter and elsewhere in the report, because they are relevant both theoretically and substantively.

Chapter 8 is a short discussion chapter in which three main issues are addressed. The first concerns the distinction between 'partners' and 'stakeholders' and which of these concepts best describes user and carer involvement in change management today and why. The second question to be addressed is the ambivalence that runs through much of this literature and which focuses particularly on issues surrounding the involvement of users of mental health services in change management. Finally, we consider the argument that user involvement is of benefit to the mental health of the users who are involved and ask whether this means that many professional writers see user involvement in mental health as 'therapy'. A different way of looking at this issue is proposed.

There are 3 Appendices: 'A' detailing the coding frame the research team used to categorise the literature; 'B' describing the reference group convened to assist with research design and analysis; and 'C' discussing the analytic themes that emerged from the reference group.

Chapter 2 Methods

2.1 Definition of user/carer involvement in change management

This review examines literature about user and/or carer involvement in managing organisational change within mental health services. It examines how users and/or carers have been consulted about or involved in planning or implementing changes at the level of procedures, organisational structures, service design or delivery.

Such changes include:

• issues of democracy, representation and consultation

• changes in the mission or profile of organisations

• changes in organisational culture

• restructuring of organisations

• new policy initiatives

• changes in service provision or delivery.

2.2 Literature sources

The literature reviewed for this report was assembled from five sources:

1   electronic databases

2   an existing research archive

3   recommendation by expert members of a project reference group

4   a comparative sub-sample of articles in two key journals

5   snowball searching.

2.2.1 Electronic databases

Medline

PsycINFO

Embase

HMIC

Social Sciences Citation Index

King's Fund Library

2.2.2 Existing research archive

Purposeful searching of an archive assembled for a literature review entitled *User Involvement in the Planning and Delivery of Healthcare* (Rutter *et al.*, 2001) at the Department of Public Mental Health, Imperial College School of Medicine at St Mary's, London.

2.2.3 Reference group

Literature recommended by the reference group convened for the project, comprising individuals with expe riences of user/carer involvement in mental health (see Appendix B).

2.2.4 Comparative review: *Health Service Journal* and *Openmind*

Alongside the main literature review, we undertook a smaller comparative review of a sample of articles appearing in two key journals across the time -frame of the study. The aim here was to consider both quantitative and qualitative changes over time in the coverage of user involvement issues in a professional journal and a user-oriented journal. In this part of the study, we r eviewed 15 articles, news stories or book reviews in *Health Service Journal* (*HSJ*) and 31 in *Openmind* (*OM*) during the years 1989 and 2001. We discuss the findings from this comparative review in Chapter 3, Section 3.11.

2.2.5 Snowball searching

Bibliographies of relevant literature identified were in turn searched so as to generate further references.

2.3 Search terms

The following search terms were used:

- user, client, consumer, patient, caregiver, carer, family
- involvement, participation, empowerment, representation
- mental health, psychology applied, mental disorders
- health delivery, health care planning, health care services, health care delivery, health care development, health care provision, health care reform, health planning
- service delivery, service development, service planning
- decision making – organisational, organisational change, organisational development, organisational merger
- health services administration, organisation and administration, patient care management, delivery of health care, integrated health care reform, health services accessibility, quality of health care, health care quality, access, and evaluation
- health services administration, organisation and administration, annual reports, constitution and bylaws, decisio n making, organisational efficiency or efficiency, organisational, governing board, hospital administration, institutional management teams, models, organisational, organisational culture, organisational innovation, organisational objectives, ownership, pl anning techniques, referral and consultation

2.4 Exclusion criteria

The following exclusion criteria were used to refine the search:

- literature published before 1987
- literature in languages other than English
- literature concerning people aged under 18 years or over 65 years
- literature concerning user or carer involvement in auditing or evaluating services, where changes following the audit or evaluation are not described

The review surveys literature in English published over a 15 -year period, 1987–2002. This time -frame was selected so as to cover the reforms in mental services in Britain that followed the Griffiths Report (1989) and the Community Care Act 1990. Literature published prior to this period describes services structured markedly differently from the current system. In practice, electronic searches using an extended

range of search terms yielded very few references prior to 1989, and only two texts published in 1988 were included in the final analysis. Other exclusion criteria were determined by the SDO's research specification: firstly, services for children and older people fell outside the remit of the review; secondly, literature dealing simply with user/carer involvement in audit or evaluation was to be excluded from the study, given that the research brief was to focus on more substantive involvement in *processes* of change management.

2.5 Initial search results

2.5.1 Electronic databases

Research into user/carer involvement in processes of change management represents a new agenda for enquiry. In initial searches, entering the search terms 'user involvement' or cognates together with 'change management' resulted in no 'hits' in any electronic database. This suggests that there is no pre-existing coherent body of literature on this subject, or that the literature has not been indexed in this way in the database catalogues. For this reason, a large number of proxy terms were used in searches. This in turn meant that the initial database searches generated a large number of references. After the removal of duplicates, approximately 850 abstracts were read by two readers and 150 papers were identified as relevant. Copies of these were obtained and read as the basis for the review.

2.5.2 King's Fund Library

This provides a source of 'grey' literature appearing in unrefereed journals, organisational reports, occasional papers and so on. Again, a search combining the terms 'user involvement' and 'change management' yielded no results. The abstracts of all references to user involvement were then inspected online and 20 identified as potentially relevant to the study. Later cross-referencing established that 8 were duplicates of results from the other electronic databases.

2.5.3 Existing archive

An existing archive compiled for the review by Rutter *et al.* (2001) on user involvement in the planning and delivery of health care was searched for suitable references. The Rutter study was concerned with health services in general, and a sub-sample of 27 papers was identified as specifically relevant to the subject of change management in mental health services.

2.5.4 Literature pertaining to carers

Despite a specific search for literature about carer involvement in change management, only one-quarter of the literature included in the study made me ntion of carers. There were a small number of papers that dealt with carers only.

2.5.5 Reference group

A reference group was convened to guide the project. Users and carers who are active in user/carer involvement and academic researchers with an interest in user/carer involvement were invited to join the group. The main input of the group was in the development of the coding frame used to analyse the literature, helping to specify different types of change; and factors tending to facilitate or impede eff ective change. Additionally, through the reference group we were also able to access pre-publication material (Wallcraft *et al.*, 2002) and an unpublished thesis (Parkes, 2002).

2.6 Refining the searches

Two readers read approximately 850 abstracts yielded by electronic and purposive searches. Full papers were then accessed where abstracts met the following inclusion criteria:

1   Date: 1987–2002
2   Language: English
3   User and/or carer involvement
4   Mental health
5   Change.

While an extensive literature exists on user/carer involvement in mental health services, the greater part of this literature has not focused on *processes* of change or on issues of *change management*. Having met the five criteria, 156 papers were read in full and coded for inclusion on a four-point scale:

1   Recommend inclusion
2   Consider inclusion
3   Marginal – some insights
4   Reject.

Inclusion at this stage was assessed by readers in terms of the paper's empirical and/or theoretical relevance to the three key research concepts: user/carer involvement; mental health services; change and change management. A sub-set of papers was read by two readers and inter-rater agreement was 80%. Our aim was to be as broadly inclusive as possible, given that only a relatively small literature has explicitly

brought together user/carer involvement with issues of change management. At this reading stage 44 papers were rejected, mainly because the paper concerned audit or evaluation only, or were not sufficiently focused on questions of change; 25 papers were rat ed 'marginal' to the key research themes, but were included in the final database and fully coded. As explained in Chapter 1, these papers were less likely to be selected for the substantive analyses in Chapters 5, 6 and 7, unless they offered specific ins ights into given themes. The final number of papers included for analysis was 112.

2.7 The coding frame

A coding frame was used to rate all the literature in terms of its relevance to the key research concepts, and as the basis for preliminary analysis of the literature. The coding frame was designed to incorporate for analysis the main themes of the review: as well as recording the type and source of the paper, coding categories covered modes of user/carer involvement, forms and drivers of organisational change, and factors facilitating or impeding involvement. The reference group made substantial input into the categories used in the coding frame, and the draft coding frame was revised following trial coding of a sub-set of 25 papers by two readers. In Ch apter 8, Section 8.2, we discuss the differences between the categories that were elicited from a reference group active in user involvement activities, and those that appeared most frequently in what emerged as a largely professionally authored literature.

A copy of the coding frame is included as Appendix A. At this stage, the categories relating to 'models of user involvement' warrant specific explanation.

2.7.1 Models of user involvement

1   Consumerism (individual)

2   Consumerism (collective)
    (a) Consultation
    (b) Representation
    (c) Partnership
    (d) Evaluation
    (e) Involvement in staff recruitment

3   Citizenship
    (a) Campaigning
    (b) User control

There are several models of public participation that are often conceptualised as 'ladders'. The best-known of these is Arnstein's ladder of citizen participation (Arnstein, 1969). Our typology of user involvement above draws on Arnstein's ladder but has been modified in light of developments in user and carer involvement in mental health and recent critiques in the academic literature. In particular, the typology makes a distinction between concepts of consumerism and citizenship as models for involvement.

> *Consumerist philosophies claim that individual users of public services can be empowered through the market.*

> (Barnes and Shardlow, 1997).

While consumerism was a dominant concept in health reforms and debates in the early and mid-1990s, the concept has been subject to critiques more recently, as in the writings of authors such as Barnes (1999), Barnes and Shardlow (1997) and Bowl (1996a, 1996b). Our ladder of involvement considers consumerism on a number of levels.

2.7.1.1 Consumerism (individual)

The ladder starts with what is considered to be the most basic level of user/carer involvement, consumerism at the level of the individual. By this we mean the user's or carer's involvement in their own day-to-day care. This could range from a resident of a care home being consulted about the decoration of their bedroom to users and carers being involved in the development of an individualised care plan.

2.7.1.2 Consumerism (collective)

The second level of involvement is concerned with collective consumerist activities. This concerns groups of users and/or carers being involved in the planning, development, implementation and monitoring of the services they use. The sub-categories here range from groups of users being consulted about services to involvement in staff selection.

(a) Consultation occurs where users or carers are asked about their preferences about services or types of change. However, there is no compunction for managers to act on these preferences nor necessarily any structures whereby users can influence the outcomes that result from the consultation.

(b) Representation is where user and/or carer representatives are involved to some extent in decision-making bodies. This may include users or carers sitting on a planning group, and extends to user/carer places on NHS trust boards or the management committees of voluntary organisations.

(c) Partnership implies a more equal relationship between users and carers and professionals. Here users or carers are equal partners with other local or national stakeholders.

(d) Although evaluation was to some extent outside the remit of this review, it appeared as a very common theme within the literature and therefore it was important to record its frequency. Moreover, we were concerned to include literature that described changes following user/carer involvement in evaluation, or instances where evaluation formed part of an extended process of user and/or carer involvement.

(e) Involvement in staff recruitment is a clear example of user/carer involvement in the management of services. While such involvement can be tokenistic, where effective it is regarded, for example by Brandon (1991, 2001; see also Bowl 1996a, 1996b), as the peak of user involvement at an organisational level.

There are occasions in the literature where the distinction between individual and collective consumerism is less than satisfactory. This is particularly the case where individual users may be the focus of the literature but where their position is quite an empowered one. An example is the literature on users as workers in the provision of services where the service itself is not user-controlled.

2.7.1.3 Citizenship

From users and choosers to makers and shapers.

(Cornwall and Gaventa, 2000)

The term citizenship is used to refer to user and carer activities considered to pertain not only to users and carers as consumers of particular services but as linked to their status as citizens of democratic societies with an important function in determining wider social processes. Citizenship is subdivided into two categories.

(a) **Campaigning** denotes activities that involve users or carers taking social action to exercise their rights as citizens. Such activities are commonly public campaigns to challenge the stigma of mental illness and lessen societal discrimination, campaigning for and against legislative changes or on other issues such as cuts in service funding. They could also be activities that seek to hold public bodies to account.

(b) **User control** denotes a further degree of control over decision-making processes, such as having control of organisations delivering services. A user-controlled service is defined as either having a majority of service users on a governing body or as having a majority of employees who are users or ex-users of mental health services. A parallel situation would be the case for a carer-controlled organisation.

2.8 Inter-rater reliability

The inter-rater reliability of the coding of papers was assessed with a sub-set of 30 papers. Two raters coded the material independently. Agreement was high at 79.9% when every coding category was included. Additionally, every paper or re port was assessed by at least two readers to check for any inconsistencies or oversights in rating.

2.9 Selecting papers for substantive review

The following chapter outlines a broad 'map' of the literature used in the review, based on frequency counts of categories in the coding frame. In the three subsequent chapters, we consider three clusters of types of change management, forming a continuum from a 'soft' systems approach to change management to more 'step' or 'hard' organisational changes. The three clusters are:

1   Promoting democracy and representation and/or cultural change

2   Strategic planning, restructuring and policy initiatives

3   New service provision and the employment of service users in organisations.

For each cluster, we discuss in substan tive detail approximately one-third of the literature selected for review. Papers were selected for this more detailed analysis on the basis of readers' assessment of quality and research relevance. The most important category of literature here is those papers coded 'Recommend inclusion' due to their clear coverage of key research themes (user/carer involvement, mental health, organisational change), with an emphasis on papers with an empirical, evidential or practical orientation. Papers coded 'Consider inclusion' or 'Marginal – some insights' were included where they involved empirical or practical insights, or reported on specific issues of critical relevance – for example, papers that reflected issues of equality and diversity.

Chapter 3 Mapping the terrain

3.1 Introduction

In this chapter, we look in broad terms at the nature of the literature compiled for this review. The aim is to give an overall picture of the literature as a basis for the more detailed study in the following three chapters. In order to 'map the terrain' of the literature, the coding sheets for each paper, report or book were entered into an SPSS data file. This chapter reports frequency counts for the different categories (see Appendix A) and some cross-tabulations. Commonly, the frequencies add up to more than the total number of papers because more than one category was relevant under each sub-heading. Cross-tabulations were tested with chi-square to assess the significance of co-occurrence of categories. A significance level of $p < 0.05$ was used. Lack of a relationship between two factors does not mean that they never appear together. The test is simply one for random effects.

3.2 Type of paper, year, country and target audience

The final corpus of literature included 112 papers, reports and books. It includes a wide diversity of material ranging from one-page articles to entire books.

Discussion papers dominate the literature – 61 discussing practice and 43 discussing concepts. Some papers discuss both. There were 34 qualitative research papers and 16 quantitative research papers. Only 6 papers were purely quantitative and this includes 4 trials. Research papers were sometimes situated in the context of discussion of concepts or practice. There were 7 organisational reports and 2 unpublished dissertations.

With regard to date, 10 papers were published in or before 1991, 25 between 1992 and 1995, 36 between 1996 and 1998 and 41 between 1999 and the end of the period of data collection (October, 2002). The rate of publication of material in relation to user involvement in change management has therefore increased with time and this is most probably linked to policy changes.

71 papers and reports were from the UK and 42 from the USA or Canada. 1 was from Europe, perhaps reflecting our criterion of English-language material only, and 3 from Australia or New Zealand. 9 papers or reports discussed user involvement in change management in more than one country.

Overwhelmingly, the papers targeted a professional audience, with 92 of the 112 being focused in this way; 44 papers addressed an academic audience but many of these overlapped with the professional audience; 26 papers were rated as addressing a user audience but only 8 of these were aimed solely at users.

3.3 What drives organisational change?

There were 23 papers which did not state who or what was responsible for driving organisational change; 46 papers mentioned users or carers, 47 organisations and 45 policy and funding considerations. However, these were interrelated. Policy or funding was identified as the sole source of change in 10 papers, 20 focused solely on organisations as the drivers of change, and 11 on users and carers.

3.4 Types of user involvement

Figure 1 shows the frequencies for types of user involvement that were the focus of the literature.

Figure 1 Frequencies of different forms of user involvement
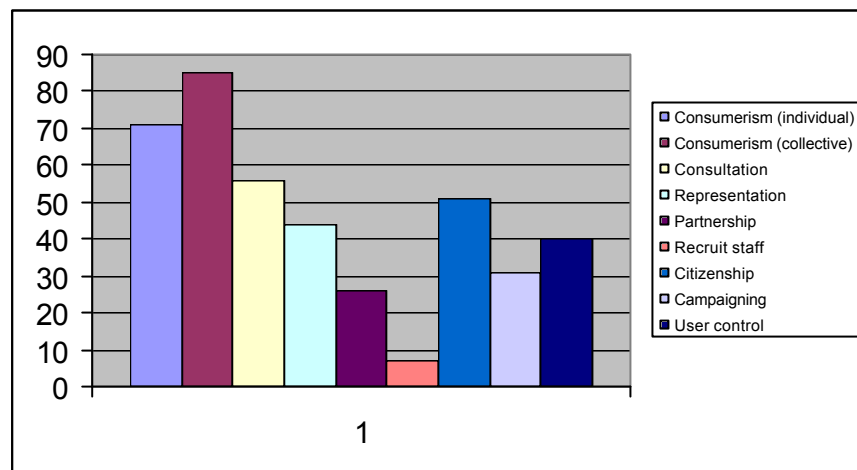
Collective consumerism is the dominant category of user involvement found in the literature. Consultation, representation, partnership and involvement in staff recruitment represent a 'ladder' of participation and it is clear that as the level of participation increases fewer papers take it as their focus. Individual consumerism is much more frequent in the North American literature. This partly refers to the employment of individual users as health care providers (a stronger form of involvement than individual consumerism in respect of care plans, for instance), and may also reflect a cultural emphasis on individual human rights. At the same time, there is a tendency for user control to be more common in the USA and Canada. The citizenship categories, especially user control, tend not to relate to the consumerism categories, implying that this is a different activity and one that may stand outside mainstream organisational change in mental health services.

3.5 Types of change management

Figure 2 shows the frequencies for types of change management

Figure 2 Frequencies of types of change management
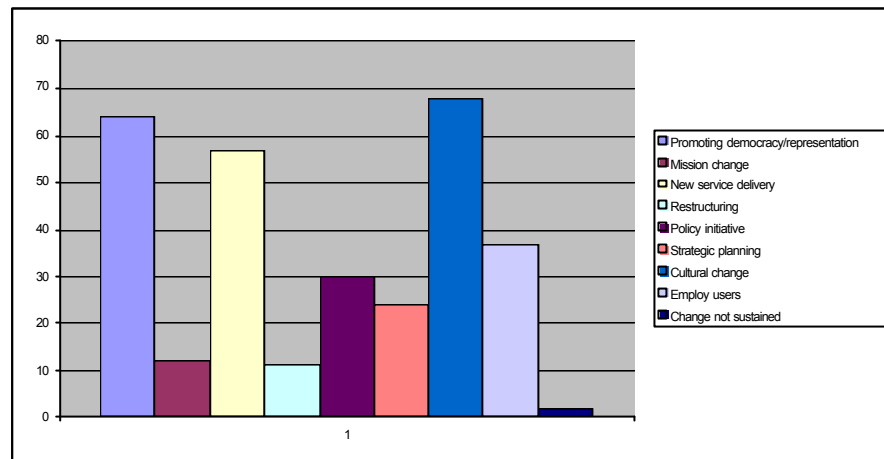
Promoting democracy or representation and organisational change at the level of culture are both the focus of over 50 per cent of the literature. New services or changes in the ways that services are delivered are also important, as are policy initiative s. The different types of organisational change appear to be independent activities except for two instances. In the case of strategic planning, all but one of the papers has the additional focus of promoting democracy and representation. This may imply that promoting democracy and representation can be a *means* to the end of strategic planning – especially through involving users in formal consultation procedures as part of a strategic planning process. There is also a relationship between new service provision and the employment of service users and this relationship is particularly marked in the North American literature.

3.5.1 Relationship between type of user involvement and type of change

In this section, relationships between forms of user involvemen t and types of organisational change are considered, using chi -square tests. Due to the large number of tests run, the results should be treated with caution. The category 'change not sustained' has been omitted because only two papers were rated in this w ay.

Individual consumerism is associated with strategic planning, because this form of organisational change often seeks the views of populations or samples of consumers. Many of these papers were published soon after the purchaser/provider split was introduced and they discuss the

canvassing of consumer opinion as part of the strategic planning process (for example, in relation to the development of community care plans). Many of these papers are also coded under 'evaluation'. Individual consumerism is also strongly associated with new service provision and the employment of service users, as has already been discussed.

When collective consumerism is mentioned there tends also to be mention of the promotion of democracy and representation, change of mission, restructuring, strategic planning and cultural change. The latter is particularly important. Collective consumerism can be seen as the means by which attempts are made to bring these forms of organisational change about at the level of *groups* of users and/or carers. Collective consumerism is also associated with the category 'for purposes of display only' implying that some authors judge that exercises in change management are not taken seriously by managers and other professionals and exist only at a 't oken' level.

Consultation is strongly associated with the promotion of democracy and representation and in this way the two form a virtuous circle. Consultation is also associated with strategic planning – as in the case of individual consumerism, above; c onsultation with user/carer groups is an increasingly standard element of planning processes. It is notable in this connection that the category 'for purposes of display only' is also associated with consultation; this is congruent with the arguments of Ru tter *et al.* (2001). User involvement that takes the form of representation shows exactly the same pattern as for consultation although we know from Figure 2 that the absolute numbers of papers taking representation as their focus is smaller than for consul tation. The category of 'partnership', which represents one of the higher rungs on our ladder of participation, shows no systematic relationships with any form of organisational change. However, the absolute number of papers here is small. This is even tru er for the category of 'involvement in staff recruitment'.

Citizenship categories, like many of the other forms of user involvement, are associated with the promotion of democracy and representation. It is not clear, however, whether the form of democracy at stake here is the same as that for the consumer categories, or whether the consumer/citizen distinction involves a distinction between representative and participatory democracy. Citizenship is associated with change of mission, whereas none of the consumerism categories showed this relation. A change in the mission or profile of an organisation represents a fairly radical form of organisational change. Similarly, citizenship is associated with new policy initiatives, and also is related to cultural chan ge. Campaigning as a user involvement activity shows the same relationships to types of organisational change as citizenship in general. User control is related to new service provision and weakly to the employment of service users. This tends to refer to services that are run or managed by

service users, and which may lie outside mainstream services or have only a weak relation to them.

3.6 Which groups do the papers take as their main focus?

Figure 3 shows the number of papers which took as their main fo cus or foci the categories of individuals and groups shown in the coding frame in Appendix A.

Figure 3 Frequencies with which specific groups are taken as a focus in the literature
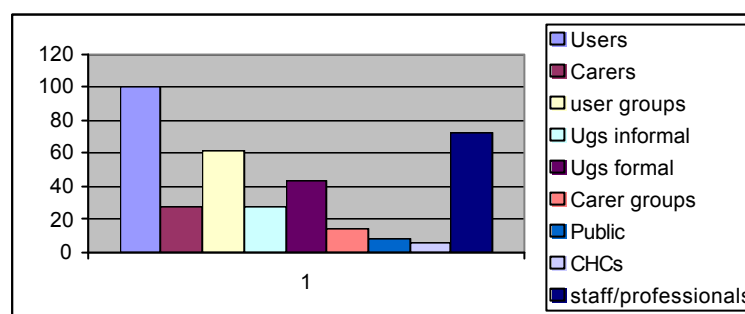
The dominant categories are service users, us er groups and staff or professionals. Despite the fact that a specific search was done for carers, carers and carer groups figure far less frequently. Carers are rarely the sole focus of a paper (for exceptions, see Briggs and Koroloff, 1995; Mullen *et al.*, 1992). Staff appear as a focus in the literature, not only because organisational changes require changes by staff as well as users, but because they are often implemented or administered by staff. This focus might also result from the bias in the literature towards professional authorship and audiences.

Under the 'special constituencies' section of the coding frame, 13 papers have a focus on or include reference to ethnic minority communities, 10 on women, 4 on people who use substances, 6 on homeless people, 3 on acute care and 3 on older people. The papers referring to substance misuse and homelessness are all from North America.

3.7 What facilitates user and carer involvement in organisational change?

Figure 4 shows the frequencies with which various categories assumed to facilitate user and carer involvement in organisational change appear in the literature.

Figure 4 Facilitation of user involvement in change management
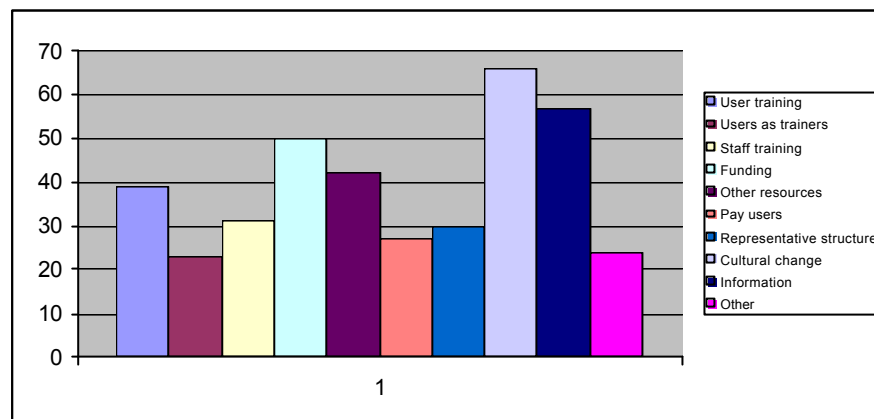
Among the 'other' factors promoting user involvemen t in organisational change were technical assistance, mentoring and advocacy, peer support and legislative changes.

The most important factor for involving users in change management is, according to this literature, a facilitative organisational culture. Information provision or a strategy for providing information is almost as important. Resources are mentioned by almost half the papers and the resource categories cluster together. The training categories form a distinct cluster and refer to users trainin g staff, although training users themselves also is important.

When representative structures are mentioned as a factor facilitating user involvement in change management, a welcoming organisational culture also tends to be mentioned. However, the absolute numbers show that a facilitative organisational culture can be a positive source for change on its own. As we will argue below (see Chapters 4 and 7), formal representative structures in themselves appear as an insufficient condition for user involvement – they are most effective when embedded in a more broadly supportive organisational culture.

3.7.1 Relationship between facilitative factors and types of organisational change

User training is important in new service provision and the employment of users. It is perhaps obvious that to fulfil a role as employees, users will need to be trained.

Users acting as trainers appears as important for cultural change, implying that to bring about change in the culture of an organisation it is useful for users to have a training role vis‑à‑vis staff. There were no systematic relationships between staff training and any form of organisational change.

Funding is important to all types of organisational change except new service delivery and the employment of service users. (This maybe because in these cases the requirement for funding is so obvious that it does not warrant explicit mention). Other resources – for example for office equipment – are important for the promotion of democracy and representation, specifically in facilitating the work of user/carer groups. Payment of users is important for change of mission, new service provision and the employment of users.

Representative structures are important for promoting democracy and representation and restructuring and these are predictable relationships. Representative structures are also related to cultural change. Again, such structures may be seen as the *means* for bringing about other forms of change. Perhaps surprisingly, representative structures are also related to the category of 'for purposes of display only' indicating that some authors judge them to be tokenistic or ineffectual.

A facilitative culture is most important for promoting democracy and representation, restructuring and cultural change. With this last type of change management we again find a virtuous circle. Information provision is particularly important in the promotion of democracy and representation and new service provision.

3.8 What are the obstacles to user involvement in organisational change?

Figure 5 shows how often various factors that impede organisational change are mentioned in the literature.

Figure 5 Factors impeding user involvement in organisational change
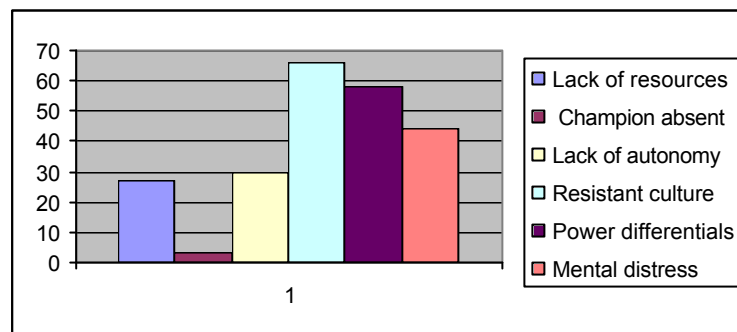
Equal numbers of papers or reports mention a resistant organisational culture as impeding user involvement and a facilitative organisational culture as helping it. It is notable these are not necessarily the same papers. Power differentials are mentioned as an obstacle to user involvement in over half the papers. Later in this review we will consider in more detail how these power differentials operate.

Factors pertaining to mental distress are mentioned quite frequently but this is a rather heterogeneous category – as we suggested in Chapter 1, it appears both as an argument for the support users may need in order to become involved, and as a professional rationale for limiting user involvement. Lack of resources is perhaps mentioned less often than would be expected, especially given the findings rep orted in Section 3.7. Again, this might be due to the fact that this literature is largely professionally authored. The category 'champion absent' was suggested as an obstacle to user involvement by members of the project reference group, but hardly appears in this literature (this mismatch between reference group categories and literature categories is discussed in Chapter 8).

3.8.1 Relationships between obstacles to user involvement and type of organisational change

Lack of resources proved a particular obstacle to the promotion of democracy and representation and change in the mission of an organisation. New service provision was *negatively* related to lack of resources – that is, there was a systematic tendency for papers which took new service provision as their focus *not* to mention lack of resources. This mirrors the situation described in relation to facilitative

factors. The pattern is particularly marked in the North American literature. The cross-tabulations showed that lack of autonomy hampers the promotion of democracy and representation, change of mission, strategic planning and restructuring.

A resistant organisational culture is important in the literature but is only systematically related to two types of organisational change. The first is cultural change and so this time the circle is vicious and not virtuous. Secondly, all but one of the papers coded as 'for purposes of display only' also mentioned a resistant organisational culture. Perhaps this means that where organisational cultures are resistant to user involvement, change will only be tokenistic. The same pattern applies to power differentials and later there will be some discussion of the forms these take and how they operate.

Factors pertaining to mental distress can mean that users re quire special support to engage in user involvement activities or it can take the form of the 'coherence' arguments of Simpson *et al.* (2002). Alternatively, a paper coded under this category may be concerned with the way references to mental distress are used to undermine the contributions of service users. This category was related to cultural change and the employment of service users. It also was related to the category 'for purposes of display only' and in these cases may mean that managers do not serio usly believe that users of mental health services have the 'coherence' necessary for proper involvement in change management.

3.9 Outcomes

The 'outcomes' in these papers and reports are hardly ever measurable ones. They are the writer's opinion of what ha s worked and what has not. Given this, the majority of papers – 58 in total – indicated that the outcomes of user involvement in change management in organisations were unclear or not yet known; 52 papers mentioned positive outcomes and 14 negative ones. However, in all but one case, the negative outcomes were in the context of there being positive outcomes as well. This may be the result of publication bias. The type of outcome was not related to the type of paper.

3.10 Facilitation of and resistance to organisational change in relation to types of user involvement

There was variation in how factors facilitating or impeding user involvement in organisational change related to different types of involvement on our 'ladder of participation'.

- **Individual consumerism** appears in the literature as hampered by factors pertaining to mental distress. This is consonant with the relation found above between mental distress and the employment of service users, as we know that a number of references to individual consumerism are to users working as providers. It also reflects the possibility that mental distress may inhibit individual users' involvement in their own care.

- **Collective consumerism**, across all sub-categories, is hampered by lack of resources, lack of autonomy and a resistant organisational culture. Collective consumerism is enhanced when users act as trainers, when staff receive training, and when both material and non-material resources are in place. It is also helped by a facilitative organisational culture and representative structures.

- **Consultation** is enhanced when staff receive training and resources are in place. It is strongly enhanced by representative structures and also by a facilitative organisational culture and a strategy for the provision of information. Consultation is hampered by lack of resources and lack of autonomy and relates weakly to power differentials.

- **Representation** – the whole resource cluster is important for strategies of representation, including lack of resources as an obstacle. Representative structures are also highly important, which is not surprising because the meanings of the two factors overlap. The same factors inhibit representation as inhibit consultation, although here the relation with power differentials is stronger. Representation is not related to a facilitative organisational culture or to information provision and this is perhaps surprising.

- **Partnership** is related to users as trainers and staff training implying that where partnership exists users are training staff. Partnership also relates to representative structures. Partnership is not related to any of the obstacles to user involvement. The factors that impede partnership have not been captured by the way we have coded our data. This may be because such a small proportion of papers focused on partnership.

- **Citizenship** – factors that promote citizenship include the whole resource cluster, representative structures and a facilitative

organisational culture. The factors that inhibit the exercise of citizenship are lack of resources and lack of autonomy. Power differentials show a weak relationship.

- **Campaigning** requires resources, both material and non‑material. It is also enhanced, but only weakly, by a facilitative organisational culture. Campaigning is impeded by lack of resources and lack of autonomy. There is a tendency for papers focusing on campaigning to make mention of factors pertaining to mental distress which will be discussed more substantively later.

- **User control** is strongly related to material resources and payment, for users. It is also enhanced by a facilitative organisational culture and by representative structures. In some papers, these may be representative structures within user‑controlled organisations themselves. User control is impeded by lack of autonomy and, given the importance of resources, this may imply a dependency relationship on funders. There is a weak relation between user control and factors pertaining to mental distress. This will be discussed in Chapter 6.

3.11 Comparative literature review

Alongside the main literature review, we undertook a smaller comparative review of a sample of articles appearing in two key journals across the time‑frame of the study. The aim here was to consider both quantitative and qualitative changes over time in the coverage of user involvement issues in a professional journal and a user‑oriented journal. In this part of the study, we reviewed 15 articles, news stories or book reviews in *Health Service Journal* (*HSJ*) and 31 in *Openmind* (*OM*) in the years 1989 and 2001.

Comparing the two sample years, there was an increase in items reviewed. In *HSJ* there was a modest increase (from 6 to 9) and in *OM* a more significant increase (from 8 to 23). It was notable that the authorship of items differed between the two magazines. None of the items in *HSJ* was written by service users, whereas at least 11 of the 23 items appearing in *OM* during 2001 were written by service users. At this point *OM* could be seen to be reflecting significantly the viewpoint s of a service user constituency. All the items in *OM* concerned change in mental health services, while a number in *HSJ* looked at health services as a whole.

All the items reviewed were in favour of the involvement of service users in changing mental health services. Nevertheless there was evidence that different articles expressed different ideas about what service user involvement really meant. Thus, on a conceptual level, material from 1989 included one article in the *HSJ* (Pollitt, 1989) that talks about consumerism, while another, in the *OM* (Parker *et al.*, 1989) talks in terms of empowerment and self‑advocacy. In a third article, in the *HSJ* (May, 1989), a service user is quoted as saying 'People who

use mental health services don't have the power or choice to be consumers.'

These conceptual differences are reflected on a practical level in the articles from *OM* in 2001. Here it becomes clear that some service user authors see involvement as being concerned more with the creation of alternatives to mainstream psychiatry than with modifying existing mental health services. One article (Rose, 2001) calls for 'emancipatory discourses' to set against the medical discourses of psychiatry and looks for radical alternatives rather than 'improvementism'. Another article (Nicholls, 2001) describes the Strategies for Living project where service users are researching and creating alternatives to mainstream mental health care. Such material is in contrast to that contained in *HSJ* at the same time, which tends to consider service user involvement as involvement within services.

Running through the material reviewed is scepticism about government intentions regarding service user involvement. One author (Pollitt, 1989) examines in the *HSJ* the White Paper *Working for Patients* and questions government intentions about widening participation. An article from 2001 in the *OM* (Read, 2001) looks at the NSF for Mental Health and sees service users at the bottom of the pile once again, as well as contradictions between a government desire to involve service users and numerous references to their dangerousness. This, the author suggests, gives the impression that service users are seen 'at best, as people with problems and, at worst, a problem.' In these circumstances, it is difficult to see how service user involvement can be empowering.

These doubts are more notable in the *OM* material from 2001 because it is also clear that service user involvement has made significant progress since 1989. A number of articles look at the development of independent mental health advocacy where service user initiatives have been crucial. Other articles are testimony to service user involvement in other areas: involvement in staff recruitment (Newnes *et al.*, 2001; Wolf, 2001); the work of a user development worker on Bradford's Home Treatment Team (James, 2001); and service user-led research (Nicholls, 2001). It is clear from the material that, by 2001, service users in the UK were extensively involved.

But the involvement of service users remains problematic. Two articles from the 2001 material raise questions about the quantity and quality of involvement. One, in the *HSJ*, examines the Sainsbury Centre's *Capable Practitioner* report (Warner, 2001). The report reveals that service users feel uninvolved in the most basic aspects of their care and treatment: assessment, care planning, the delivery of therapeutic programmes. 'Though there were some positive examples of involvement, users felt that many staff were not yet committed to or skilled at it in a meaningful way.' At the same time an article in *OM* (Trivedi, 2001) looks at consultation about the development of the NSF

for Mental Health and is severely critical of the process. There was no support for the service users involved, who were accused of being unrepresentative without having the time or resources to consult other service users. Issues of race and culture were not addressed and the two black service users involved were subject to institutionalised and personal racism. The author states 'I am very clear that I would never again be involved in such a disempowering and damaging consultation process.' (For these issues of representativeness, and the involvement of black users, see the discussion in Chapter 4.)

Other articles from 2001 raise additional issues: the sustainability of service user involvement and its ability to deliver change. In *OM* (Newnes, 2001) the author describes the difficulty of keeping service user groups in Shropshire going over a period of years and suggests that the lack of activists may affect service user organisations nationally and thus curtail the long-term growth of involvement. Two *OM* articles (Shaw, 2001 and Linnett, 2001) show that little has changed in acute services and supported housing. In the same journal, one author (Smith, 2001) suggests that change has only occurred for an elite of service users.

The material considered in this comparative review suggests that service user involvement has extended into areas not foreseen or intended by the consumerism advocated in 1989. The material from 2001, particularly from *OM*, provides evidence of the energy and enterprise of those service users who are involved. At the same time it is clear that involvement in change is problematic, both because there are differences in goals among the parties involved and because the processes themselves are not of sufficient quality. While some service users seek change beyond mental health services, the ability of involvement to secure real change within services remains uncertain.

3.12 Conclusion

This chapter has provided an overall picture of the change management literature analysed according to our coding categories. In the next three chapters, we take clusters of types of change management and review them in more detail, based on a se lected sub-sample of the literature. The clusters move from the 'soft' end of change to the more challenging end. The first cluster comprises papers which focus on promoting democracy and representation and/or cultural change, and forms the subject of Chap ter 4. The second cluster focuses on strategic planning, restructuring and policy initiatives, discussed in Chapter 5. The final cluster concerns the provision of new services or new modes of service delivery, including the employment of service users as p roviders: these types of change are discussed in Chapter 6.

Chapter 4 Promoting democracy, representation, and cultural change

4.1 Introduction

Over 50 per cent of the literature we surveyed focused o n organisational change in terms of the promotion of democracy and representation, and changes in organisational culture. In this chapter we discuss these modes of change in relation to a sub -sample of the literature surveyed. There is an important distinc tion to be made here between democratic or cultural change as an end in itself, and as a factor which facilitates other types of organisational change – especially new forms of service delivery or strategic planning. In the majority of cases, democratic or cultural change represented 'stand-alone' changes; the significant exception was the case of strategic planning, which was correlated with the promotion of democracy and representation – partly due to the way that user consultation and representation is built into planning processes.

Our coding frame considered issues of user representation at a number of levels: as a mode of user and carer involvement, as a type of organisational change, and as a factor facilitating user and carer involvement. Enhanced representation might in this sense be seen as a form of 'transactive change' (Lord *et al.*, 1998), that is, an intervention at the level of organisational processes that itself can promote change in a wider sense. Similarly, organisational culture appeared a s the most important factor in promoting user and carer involvement in change management, as well as the most prevalent site of change. The promotion of democracy and representation and cultural change both form part of a 'soft systems' approach to change management that stresses the role of organisational values and norms in fostering or impeding effective change (see Chapter 7, Section 7.1.4).

The discussion in this chapter is based on a sub -sample of 15 papers. The bulk of these are discussions of existing practice, with just 5 reporting on original research (2 of these – Bowl, 1996a and 1996b –

comment on the same research). We focus on the research findings in greatest detail here, drawing on discussion papers to introduce or emphasise key conceptual themes. This relative lack of research evidence might be indicative of the difficulty researchers have in operationalising such categories as 'promoting democracy' or 'cultural change' in empirical contexts. There were 11 papers published in the UK, 3 in North America, and 1 in New Zealand; 3 papers deal specifically with carer involvement in mental health services, while 2 (one UK and one US) are concerned with ethnic minority users. The papers tend to replicate the larger patterns we found in the study, including a descending 'ladder of participation' which sees consultation occurring with greater frequency (11 papers) than representation (9 papers), partnership (2 papers), evaluation (2 papers), or involvement in staff recruitment (4 papers). Collective consumerism (13 papers) appears as the primary mode of user/carer involvement in this sub-sample, with citizenship models featuring in 5 papers. As in the overall sample, a supportive organisational culture (8 papers) and a strategy for information provision (12 papers) emerge as the chief factors in facilitating user involvement, although funding and other resources (taken together, 8 papers) are also important.

In the discussion that follows, the literature on democracy, representation and cultural change is examined in terms of several sub-themes:

- strategies of representation
- the impact of professional cultures
- organisational management
- cultural diversity and cultural competence.

4.2 Strategies of representation

In an account of the difficulties he experienced as a user employment development worker for a large English mental health charity, Linnett (1999: 1) asserts that the 'purpose of user involvement is to change the balance of power in an organisation', with a shift in power away from professionals and towards users. The strategies by which such a shift might occur are both cultural and practical (see also Philpot, 1994; Strong, 1995). At the level of organisational cultures, user involvement entails a critical questioning of professional–client boundaries, role and relations, such that users are no longer understood as passively 'receiving' those services 'delivered' by professionals. The practical structures through which such a cultural shift become embedded – procedures for consultation, representation, planning and decision making – have been an important focus for changes in mental health organisations since the late 1980s, but their implementation has been variable and their effects open to question.

This relationship between the transfer of organisational power and practical structures of user representation informs Bowl's study (1996a, 1996b) of user involvement in the UK in the light of the 1990 NHS and Community Care Act. Bowl employs a multi-method approach to analyse attitudes towards and experiences of user involvement on the part of professionals and users. The project was based on:

1   a telephone survey of principal officers with responsibility for mental health services in 31 local social service departments

2   observations, group and individual interviews with 135 users and carers in three authorities in the West Midlands, either in day centres or via independent user and user/carer forums.

The research aimed to examine existing practice in relation to user involvement and to explore attitudes of professionals and users/carers. Bowl also had a broader analytic aim in terms of user representation: to assess 'the interests represented; the form of representation and the extent to which power is transferred' (1996b: 171).

Bowl found a high degree of stated commitment to user involvement in the survey with principal officers. Only 3 of the 31 authorities surveyed reported having no policy on user involvement. Such 'policies' for user involvement were diverse and frequently patchy, including brief statements of principle, sections of the Community Care Plan, individual service plans, and complaints procedures. In only a minority of cases was there any explicit policy for more extensive consultation or participation (1996a: 290). The latter included one authority with a detailed user involvement strategy covering access to information, involvement in assessment, and user participation in service planning, design and evaluation. The strategy was based on a commitment to 'participation' or 'power sharing', rather than simply consultation, and recognised the importance of staff training in facilitating user involvement. It also contained a commitment to the review of established time scales and structures in the department's management and planning processes. The examples of staff training and review of fixed planning structures and timetables represent two practical measures that tie specific changes in working practices to wider changes in organisational culture. In one other local authority, Bowl notes, a comprehensive strategy for user and carer involvement was developed by user and carer representatives, and was designed to complement the authority's Mental Health Services Plan. In addition to a statement of principle about user involvement , this strategy included costed and timetabled implementation plans for user participation in service design, planning and delivery, training of professional and volunteer staff, and service evaluation. It also involved a strategy for widening representation among service users and carers.

These variable policy positions on user involvement and representation were matched by variability in practice. Bowl considers three key areas for user and carer representation:

1   staff recruitment

2   involvement in service planning and strategy at authority level

3   user committees within specific agencies.

4.2.1 User involvement in staff recruitment

Taking up the argument that participation in staff recruitment represents the real test of user involvement within organisa tions (see Brandon, 1991; 2001), Bowl notes that over half of the 31 authorities surveyed had no role for users in staff selection. Moreover, he encountered resistance to the idea of such involvement, either because it was seen as difficult to implement, o r because users were viewed as likely to behave in inappropriate ways or to choose unsuitable candidates. While 8 authorities had procedures where users met informally with candidates, only 6 had formal user representation on selection panels. Even in these cases the issue was seen as problematic, because users asked 'inappropriate questions' or favoured inappropriate candidates (Bowl, 1996a: 291; 1996b: 171) These reservations are reflected more widely in professional concerns over the 'coherence' of user representatives in organisational decision making (see the discussion in Chapter 5).

A number of the users in the interview study had experience of staff selection, but Bowl also found mixed attitudes here. While users supported involvement in principle, their experience at times had been confusing or disappointing. In this context, Bowl notes that only one authority had an established programme for training users in staff recruitment and equal opportunities procedures, and that this initiative had wider positive effects in enhancing users' confidence and promoting further participation in other areas. Alongside this positive example, he questions the widespread practice wherein user and carer representatives do not receive the same training and preparation that would routinely be required for paid staff participating in recruitment processes.

4.2.2 Involvement in service planning and strategy

The second context for Bowl's analyses of user and carer involvement was in service planning and strategy at a loc al authority level – most commonly through representation on departmental committees, working parties and planning groups. Bowl notes that the precise form and extent of representation varied between different authorities, but makes a more general argument that user and carer representatives generally have to fit into existing structures and procedures. Departmental committees tended to be dominated by councillors and officers, who had greater experience of such structures and greater facility with the lang uage and procedures of meetings than did most user or carer representatives. These differentials in power and confidence were compounded by the way that mental distress could affect user participation. Individuals could not always be sure of attending meet ings, and user perspectives and feedback would therefore be erratic. Users also reported that the absence of representatives was rarely followed up, indicating a weak commitment on the part of committee chairs to ensure sustained user involvement (Bowl, 1996a: 296). A number of user representatives interviewed by Bowl were aware of the limits of their 'representative' status – expressing reservations as to their ability to speak for a wider constituency (all users of a specific service, for example), and recognising that their claims as a representative could be questioned by other committee members (ibid.). One strategy for addressing this issue was for key staff (for example, in day centres) to support the work of user representatives by providing time for preparation and discussion in advance of meetings (going through previous minutes, agenda and related papers, gathering information and canvassing views), and for feedback to other users afterwards.

4.2.3 User committees

The third area for user represen tation examined by Bowl was the involvement of user committees in local service agencies, specifically day centres and residential establishments. This appeared as the most common form of user involvement in the study, and was established practice in over 80 per cent of the authorities that took part in the telephone survey. The principal officers surveyed, however, frequently saw such committees as tokenistic, with advisory power at best. The users who participated in the interview study also were ambivale nt about the value of user committees. The decision -making remit of user committees tended to be fairly limited, and budgetary powers even more modest. Often user committees worked to channel information from staff to users, rather than vice-versa (Bowl, 1996b: 170). Service users could be discouraged from participating by the perception that committees had little power, achieved nothing, and were not listened

to. Many respondents voiced a desire for more direct involvement on staff and management teams.

Bowl's study suggests that these formal strategies of representation – in staff recruitment, in departmental committees, and in local user committees – not only vary significantly between different UK authorities, but do not in themselves ensure a meaningful transfer of power from managers or staff to users. Users and carers often are obliged to respond to existing agenda, while providing a rubber stamp for policy and service decisions. A similar argument was made by Brotherton (1988), who contends that representation on committees does not simply translate into decision-making power, especially when users are in a minority on committees where others are seen to have greater authority or expertise. The concept of representation appears in Bowl's study as highly ambivalent. In a number of cases, principal officers expressed the view that authorities were content to meet legislative requirements for consultation, without enquiring too closely into the representativeness of the user or carer voice. In the officers' views, this failed to address the problem that carer interests could dominate independent user/carer groups, or the need for specific representation of particular user interests, for example those of women or ethnic minority users (Bowl, 1996b).

Bowl's findings indicate that representative structures need to be supported by both practical measures and a facilitative organisational and professional culture. He emphasises the importance of staff and user training in order to promote user involvement, covering such matters as awareness issues, information-sharing, recruitment and equal opportunities, facilitating group discussions, confidence and assertiveness training, public speaking, budgetary and committee structures and procedures. While users and carers can be supported in developing skills for committee work and other forms of representation, Bowl also points to a need to adapt committee procedures to promote user participation. This includes reviewing the location, timing, format and pacing of meetings; taking into consideration the variety of disability or support needs users might require; and ensuring continuous user representation that does not over-burden certain highly involved individuals – including by making sure that there is a high number of user members in the first place.

Mullen *et al.* (1992), in the USA, suggest similar practical strategies for involving and representing carers and carer groups in mental health organisations and networks (see also Briggs and Koroloff, 1995). Mullen and his colleagues report on a series of workshops with carers of clients of the Maudsley Hospital in London, designed to better inform and consult carers. These annual or biannual meetings brought hospital staff from multidisciplinary teams (including nurses, occupational therapists, psychiatrists, psychologists and social workers) together with carers, and were led by carers' concerns and questions. Following small group discussions to generate issues and frame questions, a

series of emergent concerns – from requests for recreational facilities at the hospital to information on particular health conditions, and the effects of health service finances – were outlined for discussion and feedback. The meetings facilitated relationships between carers and professionals, improved information to carers, and allowed space for both groups to recognise and value the role of carers. The authors argue that this local initiative carries a larger lesson for mental health professionals: given the increasing responsibility for care assumed by family and other carers, it is important that staff establish good working relationships with those 'at the forefront of the delivery of care' (Mullen *et al.*, 1992: 207).

4.3 The impact of professional cultures

The findings of Bowl and Mullen *et al.* stress the importance of organisational and professional cultures in facilitating effective user and carer involvement. The potential impact of professional cultures on the representation of users is examined in Kent and Read's (1998) study of consumer involvement in the planning, management and evaluation of mental health services in New Zealand. Their study is based on a survey of 72 professionals across the mental health field, including registrars, psychiatric nurses, psychologists, community workers, occupational therapists and social workers. The survey instrument was designed in consultation with selected mental health users (mainly from a local Psychiatric Survivors group), mental health managers and medical school staff, and covered issues of user involvement in treatment, evaluation, service planning and management. Survey items covered both professionals' awareness of what forms of user involvement (from complaints procedures to involvement in staff recruitment) were currently in place in their agencies, and their opinions as to the likely positive or negative outcomes of greater user involvement. The research aimed both to measure current levels of consumer involvement from the perspective of professionals, and to assess the relationship (if any) between professionals' orientation to the aetiology of mental health problems and their attitudes towards user involvement. The measurement of professional attitudes replicated earlier work by Wyatt and Livson (1994) which measured attitudes on a continuum from 'psychosocial' to 'medical' using a 53-item Likert scale (p. 299). While Kent and Read's study is focused on mental health professionals, it is informed by research which suggests that users' involvement has a positive impact on mental health outcomes (Nelson and Borkovec, 1989) and that the cooperation of professionals might have a beneficial effect on the course of mental illness (Lefley, 1990). The authors therefore are concerned to examine the relationship between professionals' knowledge of and attitudes to existing user involvement, their opinions as to the likely outcomes of greater user involvement in service planning and delivery, and the possible impact of

professional cultures on the extent and effectiveness of user involvement.

The study is interesting not only in examining the spread of user involvement as an organisational change in itself, but in assessing different professionals' attitudes to the likely outcomes of further change – especially as to whether greater user involveme nt in the planning and delivery of services would have a positive or negative impact on the quality of services. While their findings show a significant degree of stated professional support for the principle of user involvement, the authors argue that suc h involvement appears to have developed more rapidly in respect of individual consumerism (users' involvement in their own treatment), rather than in terms of more comprehensive organisational change. Moreover, Kent and Read found some statistically signif icant differences between 'medical' and 'non - medical' professionals. Medically oriented respondents were more likely to 'take greater responsibility for deciding the goals of treatment' than were professionals of a more psychosocial disposition, and were m ore likely to agree that clients should 'occasionally' (rather than 'usually' or 'always') be involved in the evaluation or diagnosis of their presenting problems (Kent and Read, 1998: 303). Psychiatrists and psychiatric registrars were less likely to know about the extent and kind of user involvement in their own agencies (from complaints procedures to involvement in staff recruitment or training) than were other professional groups combined (p. 305). In respect of the predicted outcomes of user involveme nt, those professionals with a more medical orientation to mental health were less likely to agree that services would improve if users were involved either in service planning or in service provision, than were those professionals with a more psychosocial orientation.

In discussing their findings, Kent and Read consider the possibility that a medical orientation might not only shape professionals' perceptions (and basic awareness) of user involvement, but might itself act as a barrier to effective consumer participation – particularly given this professional group's degree of institutional power. It is notable that a relatively high proportion of medical professionals saw users' lack of 'ability or knowledge' (40 per cent, as compared to 18 per cent of 'non - medicals') as a constraint on user involvement. This leads the authors to consider whether the specialised nature of medical training might make it more difficult for this group of professionals to recognise alternative (including experiential) types of 'ability or knowledge'. They argue for a more collaborative approach to professional education and training, which integrates different professional perspectives and expertise. (In Chapter 6 of this review we discuss related arguments for the role of users as providers of training and education to mental health professionals.) In a wider cultural sense, Kent and Read advocate the promotion of a shared vision on the part of mental health agencies, endorsed and articulated by senior management, and

informed by the perspectives of users, and those of different staff and professional 'players' (for a qualitative approach to assessing the impact of managerial attitudes on user involvement, see Milewa, 1997).

A more 'creative engagement' between professionals and users is advocated from a psychiatric standpoint by Cohen (1998). Writing in a British context, the author suggests that psychiatrists often have been viewed as resistant to user demands, and outlines key challenges the user movement poses to psychiatric power and practice. Cohen speculates (p. 157) that the 'heated and polarised' nature of anti-psychiatry debates may have constrained the development of sensitive and co-operative treatment models, and delayed many psychiatrists' recognition of the value of communication and consultation with patients. Cohen's short paper is interesting in that it highlights certain advantages that increased user involvement might have for psychiatric practice. Firstly, a cultural shift away from perceiving users as passive recipients of treatment to engaging with them as active and informed participants may result in more realistic expectations on the part of users and carers as to what mental health services can provide, and what treatment outcomes will be possible. Secondly, a more explicit public debate over the ethical features of psychiatric practice might help to clarify issues of competence and responsibility on the part of mental health users, and therefore promote understanding of psychiatrists' decisions regarding intervention and non-intervention. Thirdly, more co-operative work with users might require that psychiatrists relinquish a degree of professional power, but will also help to clarify the limits of medical understanding of mental illness, and to admit alternative definitions of mental distress (Cohen, 1998: 156 – 7).

4.4 Organisational management

The attitudes of mental health professionals form part of a wider organisational culture for user involvement and change management. Rea and Rea (2002) draw on theori es of change management to emphasise the importance of information and communication strategies in shaping a participatory and responsive organisational culture in mental health services. They argue that a potential tension exists between two core aspects of recent government policy on public and social services: improved public leadership, and increased user involvement. Leadership strategies that are highly directive or top -down fail to address the dispersed structure of many public services, including me ntal health services, and can work to impose a management culture rather than recognising diverse organisational cultures and competing interests. This point is 'particularly important if working across organisational boundaries … and where users are involved' (p. 83). Furthermore, the authors make a distinction between the requirements of performance management based on post -hoc evaluation, output targets and comparative measures such as government league tables, and the 'management of performance' understood at the level of organisational processes and inter -organisation working. Echoing attitudes expressed in Bowl's study, described above, Rea and Rea identify a danger that government demands for agencies to demonstrate user involvement may mean that user consultation or evaluation becomes a formal procedure to be ticked off, rather than an embedded organisational routine that actually informs planning and decision making.

These arguments are based on research undertaken over a four -year period (1998–2002) in Swansea, Wales. A series of questionnaires was conducted with service users, covering such issues as attitudes to services, service needs, the value of care management, need for and availability of information, and how information should be provided. Information issues included diagnosis; effects of users' condition on other aspects of their lives; available and alternative medical treatments; local services and self -help groups; and user rights and service standards. A further research aim was to initi ate a dialogue between service users and service providers, so that the views of users might feed into planning and delivery processes. The research began as a local initiative on one Community Mental Health Team, but by 2001 extended to cover all Swansea CMHTs. This larger survey also involved users in questionnaire design (Rea and Rea, 2002: 86 –7). The authors found that the quality of information available to users was variable, and that care management (through written care plans) was not consistent. They suggest that some professionals may be resistant to the culture of care management because they see it as a basis for rationing services, while others view it as a clear commitment to meeting user needs (pp. 87–8). The survey evidence indicates,

however, that users who are familiar with care management value it (p. 88). Rea and Rea suggest that this brings a user perspective to bear on debates over the purpose and usefulness of care management. Similarly, the research found that the majority of users sur veyed would value more and better information about diagnosis, although the views of professionals at the research design stage were divided as to the utility of such information to users (p. 89).

Rea and Rea assert that these user perspectives shed light on contentious and under-researched topics: the value of care management, and the benefit of greater information on diagnosis to mental health users. More broadly, they argue that this local initiative for accessing user views can feed into a larger inform ation and service strategy. This will involve managers working to ensure that systems are in place for professionals and providers to offer clear and useful information to users about their care, their rights, and their options. It also requires a culture of information sharing that works across agency boundaries, and gives priority to user views. User perspectives on services are not simply a matter of post -hoc evaluation within formal requirements of performance management, but represent a resource for the ongoing and responsive management of organisational performance, facilitating user involvement 'in assessment, analysis, and planning service developments' (p. 90).

4.5 Cultural diversity and cultural competence

In addition to promoting organisational c ultures that are conducive to user involvement in general, arguments also arise in this field about the need for cultural sensitivity on the part of professionals and organisations in relation to different user needs. Gibbs and Fuery (1994) in a US context , and Sassoon and Lindow (1995) in the UK, consider the culture of mental health organisations from the standpoint of black users. Gibbs and Fuery review perspectives on black women's mental health and well-being in the USA. They identify the prevalence of either a 'needs-prevention' or a 'rights-advocacy' approach to mental health services, which tend to reinforce the expertise of professionals as either 'teachers of competencies' or 'providers of treatments' (Gibbs and Fuery, 1994: 564). Both involve a mo del of user involvement based on individual consumerism in relation to professionals. In contrast, the authors argue for an empowerment perspective that stresses the resources and competencies of black women in respect of both their psychological well -being and their wider social environment. User and carer involvement is understood in terms of active citizenship, and is addressed on a community as well as on an individual level – particularly in relation to prevention and early intervention. Different local agencies – Afrocentric schools and centres, social and recreational programs for senior citizens and for youth,

neighbourhood security measures, parenting and grandparenting groups, self-help groups for stress management and related issues – all might form part of a community psychology approach to black women's mental health. The authors argue that such local and community-based agencies may be more responsive to black women's mental health issues than centralised agencies; they tend to foster women's competencies and control in relation to their social environment, and promote social and economic self-sufficiency.

Alongside community interventions that seek to promote mental well-being through enhancing black women's control over structural and environmental stress factors, Gibbs and Fuery argue for the importance of culturally sensitive research, education and training, and modes of service delivery. Integrating issues of diversity into the mainstream of professional training programmes should help to promote 'culturally competent' mental health professionals; the authors also argue in the US context that efforts to recruit women and minority students need to be reinforced. Culturally-sensitive services, further, will include outreach programmes, flexibility in respect of schedules to take in women's caring and economic roles, more diverse staffing, better community relations (particularly via community gatekeepers) in order to 'legitimise' services, and enhanced continuity of care through the co-ordination of mental health and other social services.

Writing in a British context, Sassoon and Lindow (1995) argue that racism is both a factor contributing to mental distress, and is reproduced within mental health services. They outline the development of the UK user movement as a predominantly white movement, but also point to efforts within the 'mainstream' user movement to highlight issues of race and racism, through anti-racism training and support for specific campaigns on the needs or concerns of black users (including, for example, deaths in custody). The authors identify two strands to empowerment models for black and Asian users: 'reactive' measures that respond to existing problems in service provision (this includes advocacy and legal representation, and training for black users); and 'innovative' measures that focus on forms of self-organisation as well as campaigning for reforms within the mental health system.

The Black Carers and Citizens Project in Brixton, South London, and the Awaaz support group for Asian users in North Manchester are cited as examples of innovative involvement, providing information, advice, advocacy and casework for users, as well as (in the Brixton case) providing awareness and anti-racism training and consultancy to mental health agencies and educational institutions. As with Gibbs and Fuery's account in the USA, Sassoon and Lindow argue that innovative approaches to black and Asian user empowerment will tend to target the wider social environment for mental health, for example through black history seminars, information provision in community languages, advice and support on wider issues (such as benefit entitlements), and

liaison with other community groups and leaders. They report that the expansion of such self-advocacy groups, and the 'mainstreaming' of minority issues in wider mental health services, will be constrained by lack of resources unless a commitment to minority ethnic needs can be built into the contract culture in health and social services (p. 104).

4.6 Conclusion

It is interesting to note that although we have been concerned here with changes associated with the promotion of democracy and representation, only 4 papers in the sub-sample cite formal representative structures as facilitating user involvement in this context. A resistant organisational or professional culture (10 papers) and power differentials (9 papers) are seen as the primary obstacles to user involvement, although lack of resources (7 papers) also figures as important. Strategies of user and carer representation need to be embedded in more broadly supportive organisational cultures, or risk becoming tokenistic measures to demonstrate that agencies have user involvement 'covered'. This point is particularly acute given Rea and Rea's argument that a policy emphasis on user involvement exists in tension with a policy emphasis on robust public management.

This sub-sample of the literature might be seen to constitute a relatively weak evidence base for the impact of user involvement on organisational change: only 5 papers refer to positive outcomes of user/carer involvement (one also discusses negative outcomes), while in the other 10 papers outcomes are unclear or as yet unknown. This spread is indicative of the way that, while representative and supportive organisational cultures are seen in the organisational literature as critical for effective change management (see Chapter 7, Section 7.1.4), it can be difficult to research cultural change and its outcomes in an empirical manner.

In this chapter, we have focused on papers that identify the promotion of democracy and representation, or cultural change, as distinct or 'stand-alone' types of organisational change. Our larger review suggests that change tends to be most successful when 'soft' change at the level of organisational culture (which often is gradual and hard to measure) occurs together with 'hard' changes in organisational structure, systems and services. In this respect, the literature goes beyond approaches which see representation or a supportive culture as organisational ends in themselves, to consider if and how representative structures and cultural factors shape the management of other types of organisational change. The discussions that follow, concerning change in respect of strategic planning and in service delivery and provision, will therefore consider the literature that correlates these types of change with representative and cultural factors.

Chapter 5 Strategic planning, restructuring, and new policy initiatives

5.1 Introduction

This chapter looks at papers, reports an d books which considered the interrelated topics of strategic planning, restructuring and new policy initiatives. It is considered that in terms of any 'ladder' of participation, the literature discussed in this chapter falls between the promotion of democracy or cultural change (previous chapter) and the provision of new services, particularly where these are user-controlled or led (the subject of the next chapter).

The literature ranged in nature between one -page articles and full-length books. Some of it was rated under two or more categories of organisational change. It also became evident on close examination of the material that very similar papers and reports might be rated under different headings within this sub -category of change management. This indicates that it may be difficult to distinguish conceptually in some cases between strategic planning, restructuring and new policy initiatives and this provides an additional reason for treating these three categories together.

5.2 Strategic planning

Of the 19 papers which took strategic planning as their focus, 7 were selected for closer analysis; 5 of these were from the UK and 3 appeared in the volume *Counting for Something in Mental Health Services*, edited by Leiper and Field (1993). This was conside red a seminal text as one of the first to be produced after the purchaser/provider split was introduced in health and social services in the UK. Two papers were from North America and one of these, by McLean (2000), could arguably also have been taken unde r the heading of restructuring. One of the UK papers was authored by a service user (Lindow, 1993). Most of the papers also focus on the promotion of

democracy and representation, which may be seen as one way in which changes in strategic planning may be brought about.

The form of user involvement most commonly associated with strategic planning in the UK literature was collective consumerism. Consultation was always mentioned and usually evaluation was too. Representation was mentioned twice and partnership once. Collective consumerism in the UK papers usually referred to ascertaining the views of populations of consumers in the form of feedback of views rather than ascertaining the views of consumer groups or their representatives. In the North American papers collective consumerism was also mentioned, with partnership highlighted in both papers. In these cases, it was the activities of groups that were the focus of attention. The two papers also made reference to citizenship in the forms both of campaigning and user control.

5.2.1 UK literature

The UK papers all discussed strategic planning in terms of the purchaser/provider split which was introduced in the NHS, and Community Care Act of 1990. Two of the professional papers from the UK from the Leiper and Field (1993) collection (Rafferty, 1993; Leiper, 1993) come in the second part of a book whose first part discusses ways of eliciting consumer views. The second part of the book discusses how such views may be fed into the strategic planning process in terms of purchasing and contract specification and this was typical of this literature.

Rafferty (1993) gives the example of Wandsworth Health Authority which carried out consumer and household surveys before the purchaser/provider split was introduced and takes the view that its introduction will greatly increase the possibilities for consumer input into the structure and nature of the NHS and Social Services.

Leiper (1993) is one of the few papers in this entire review to refer explicitly to the change management literature. He bases his paper on force field analysis (Lewin, 1951), which will be discussed in the theory chapter. His main argument is that consumers, but especially purchasers, should be clear about the purposes of collecting information on consumer views and about what change it is possible to achieve given current circumstances. He argues that consumers should not be overly judgemental and critical because this will simply be seen as a threat. Instead, he believes there should be a shared vision for change but recognises that this entails changes to organisational culture and staff attitudes and morale as well as sufficient resources, clarity about the problem and an absence of exposure to emotional threat. All these he categorises as 'resisting forces'. 'Driving forces' are the need to obtain contracts, performance demands, cultural change, the desire of staff to provide good services and a moral concern with this. His vision of change is: 'one centred around respectful treatment,

due regard for civil rights, access to resources, partnership and involvement'. However, Leiper is clearly concerned that users will overstep the mark and that conflict will be suppressed in a way that undermines change.

Milewa (1997) describes a set of qualitative int erviews with managers in a local authority where user forums were convened. However, these were not user-only forums and it is clear from the responses of the managers that they placed heavy restrictions on the kind of change that users were permitted to be involved with. For example, only half the managers interviewed said users or carers should be involved with the appointment of staff, nearly all were of the view that they should not 'duplicate' the work of community health councils (CHCs) and all said that users and carers should remain 'apolitical'.

Godfrey (1997), by contrast, argues that purchasing should begin from *user-defined* health outcomes. This research paper demonstrates that users' conceptions of becoming ill, being ill and the process of reco very may differ dramatically from a narrow focus on symptom relief. The paper is also concerned with carers' perceptions and shows how carers' knowledge of their friend or relative's mental health problem is often not given due weight by professionals. The locality where this research was carried out had recently introduced an Intensive Home Treatment Team as an alternative to acute admission or as a route to early discharge and it is demonstrated that users and carers preferred this to the acute ward. Although this paper takes a more 'radical' or user - focused approach to the incorporation of users' views in the purchasing process, it is a research paper and an example of what could be done rather than what is being done.

Beeforth (1993) writes from the pers pective of being active in a user group. She contests the 'top-down' model of user involvement which robs user groups of their autonomy, and argues for cultural change so that meaningful user involvement may be brought about. She is particularly concerned to make the point that true user involvement, especially involvement on planning committees, requires a great deal of work on the part of users, emotional as well as material. Users need to build their confidence in order to participate on equal terms with managers but, at the same time, much of what user groups do goes unresourced. Beeforth expresses frustration at the consequences of rapid turnover of staff, with each new team wishing to construct user involvement from scratch. In this sense, change may n ot be sustained because new staff do not accept the arrangements put in place by their predecessors. On the other hand, Beeforth is grateful to those professionals and managers who have supported the endeavours of her user group.

Resources are seen by all the UK authors as key to bringing about strategic change and representative structures are also vital. Training users in committee work is mentioned by some authors as is the

provision of sufficient information to enable users to participate. For Beeforth, this means that users must learn the 'jargon', but at the same time professionals must listen to the experiences of users because it is these experiences that are so valuable in bringing about organisational change in a direction that is more acceptable t o mental health service users.

Apart from Rafferty, who gives a quite benign account of user involvement in strategic planning, all the UK authors mention lack of autonomy, a resistant organisational culture and power differentials as obstacles to user inv olvement in strategic planning. Most also mention lack of resources. Power differentials appear here to take the form of professionals and managers 'setting the agenda' for organisational change and this clearly links to the presence of a resistant organisational culture. The question of lack of resources particularly concerns Beeforth who argues that, as she has no secretary and has to do all the preparation and paperwork for meetings herself or together with other members of her group, she is effectively 'paying' for her own involvement in organisational change. The workload, she argues, is particularly onerous to a group of people who are, by definition, vulnerable.

Writers such as Rutter *et al.* (2001) and Parkes (2002) are of the view that this form of 'consumer feedback' into strategic planning usually works to an agenda pre -formed by the purchasers, or even legitimates decisions which have already been taken or would have been taken anyway. In this sense, such consultation represents 'tokenism' on Arnstein's ladder of citizen participation. Certainly, there are no specific references to changes that have been brought about as a result of these 'consumer feedback' exercises. Rather there are vague references to 'influence' on the part of writers like Raff erty and, as we have seen, concerns expressed by writers such as Leiper that users will be 'too' critical and destroy the possibility of influence such as it is. Research papers such as Godfrey's (1997) point the way to how users might more fruitfully 'set the agenda' but without giving any practical advice as to how this might be put in place.

5.2.2 North American literature

There is one paper from the USA by McLean (2000) and one from Canada by Pyke *et al.* (1991), which focuses on nurses. They are quite different papers and so will be treated in turn.

Pyke *et al.*, in a short article, describe changes in the mental health system in Canada which were brought about by users or carers, as well as barriers to these changes. They focus not only on strategic pla nning but the promotion of democracy and representation (like the UK papers) as well as restructuring and policy. Pyke *et al.* seek a change in the way in which people with a mental health problem are perceived. As long as they are perceived as not competen t, they will be excluded

from decision making. The task of professionals, according to Pyke *et al.*, is to empower service users so that they may be partners in the decision-making process. This is a rather different view from that of Beeforth, who sees it as essential that users should empower *themselves*. However, Pyke *et al.* give the example of Toronto where users are now members of planning boards. The barriers to 'patients' becoming equal partners on planning boards are seen as resistant professional attitudes and 'role strain' (the difficulty of being both a service user and a service planner). They also argue that users need to be taught committee skills as well as committees becoming more user-friendly in terms of language, information and input into the agenda. 'Mentoring' by experienced users is seen as one solution. Finally, it is suggested that nurses establish a 'consumer reference group' made up of representatives of consumer organisations including self-help groups.

Pyke *et al.* are clear that the interests of users and carers do not always coincide. This is also a major part of McLean's (2000) argument. As well as discussing strategic planning and the promotion of democracy and representation, as all the other papers do, she also discusses change of mission, new service delivery, cultural change and the sustainability or otherwise of change.

McLean's paper discusses the national situation in the USA from the late 1970s to the late 1990s. She charts the development of the user movement in the USA from a radical anti-psychiatry group to a form of 'consumerism' and argues that this change was brought about, first, by changes in national policy around mental health, and second by the emergence of a family organisation with an opposed ideology to the initial anti-psychiatry movement. The policy changes began with the creation of the Community Support Programme (CSP) under the auspices of the National Institute for Mental Health. At that point, radical consumers aligned themselves with the CSP. Thereafter the CSP was separated from the NIMH as the medical model became more dominant and the CSP also lost much of its power and resources. Those consumers who chose to remain aligned with the CSP then adopted a 'consumerist' approach to change management in the form of planning that would maximise choice. Some of the more radical consumers dropped out at this point because they saw the strategy as one of co-optation.

A further development was that states were mandated to make available consumer-run services as one of the range of services that users might choose from. Initially aiming for democratic and egalitarian structures, McLean argues that soon a split opened up between consumer staff and the consumers who used the services. This she argues was a result of consumer staff being 'unrepresentative' in the sense that they tended not to have roots in the user movement and to have credentials and qualifications which 'ordinary' users did not have. Thus power differentials were operative within consumer-run services themselves which, in addition, were never properly resourced.

In parallel to this and entwined with it, McLean charts the way in which the interests of users and carers can openly conflict. In the late 1970s a group of, mainly professional, families forme d the National Alliance for the Mentally Ill (NAMI). In short, NAMI's model of mental illness was biomedical and thus in opposition to the radical anti‑psychiatry model, which NAMI took to be family‑blaming. NAMI then closely allied itself with the National Institute for Mental Health and continued that alliance after the CSP was separated from the Institute. There developed a situation where consumers were involved in the planning of the community‑oriented CSP and families in the biomedically dominated NIMH. Since the NIMH was much the more powerful body, families consequently developed more power in managing change than first‑line consumers of mental health services. McLean argues that some sections of the 'consumer' movement then moved to accept the medical model of mental illness and to press for structures that increased their choice of services as well as promoting individual rights through schemes such as advocacy.

For McLean, resources are key to user involvement in strategic planning. NAMI's advocacy of a biomedical model of mental ill health has led to funding by the pharmaceutical industry. User‑led schemes which contest this model are by contrast under‑funded. Representative structures are also, as reported in the rest of the literature, important for involvement in strategic planning while a facilitative organisational culture promotes that involvement and a resistant one hinders it. The complex nature of the power differentials between professionals, carers and users has been discussed above.

On the whole, the literature reviewed above presents the view that user involvement in change management at the level of strategic planning has had either both positive and negative outcomes or else the outcomes are as yet unclear. If reference is made to more general literature, however (for example, Rutter *et al.*, 2001; Parkes, 2002), particularly in the context of the UK, the analyses presented tend to conclude that there is no evidence of specific user influence in strategic planning and that the claim to involvement by professionals is a form of tokenism masquerading as change.

In conclusion, when users are involved in change management at the level of strategic planning, they are involved as populations or as user groups and there is a 'ladder' where they are most often consulted, less often represented and even less often act as partners. In North America the question of citizenship is more important and user‑led services are both more widespread than in the UK and have a longer history. Strategic planning is linked to the promotion of democracy and representation and the latter may be seen as a means to bring the former about. Resources, representative structures and a facilitative organisational culture promote user involvement in strategic planning. Lack of resources, lack of autonomy, a resistant organisational culture

and power differentials, which may be complex, are factors which hinder user involvement in strategic planning.

5.3 Restructuring and policy initiatives

These two forms of change and their management will be taken together because they tend to overlap in the literature. They also overlap with some papers discussed in the previous section, particularly the two from North America. There are two main types of paper – broad-sweep analyses of historical and policy changes in mental health and the role of user involvement in this and, secondly, papers which describe restructuring and/or policy initiatives at local level. We will take two broad-sweep analyses and four examples of local initiatives. The papers and book come equally from the UK and North America.

5.3.1 Broad-sweep analyses

David Brandon's (1991) book *Innovation Without Change* reads more than 10 years on as both dated and yet resonating in parts with the modern arena. He is concerned with the restructuring of mental health services from hospital to community care and the role, if any, of the user movement in this. The book is dated in two ways. First, the hospital closure programme was by no means complete as Brandon was writing. Secondly, he estimates that there were 35 independent user groups in England in 1990 whereas Wallcraft *et al.* (2002) estimate that in 2001 there were upwards of 700 groups.

Nonetheless, certain of Brandon's arguments may retain some validity. He asserts that de-institutionalisation has simply led to small 'institutions' in the community. These may be actual bricks-and-mortar establishments or they may be 'virtual' institutions in the sense that, particularly because of stigma, people with mental health problems associate only with each other and with staff. The latter, he argues, have vested interests in retaining the distance between themselves and users both actually and symbolically. For Brandon, nurses in particular are themselves disempowered and so they have no wish to increase the status of those who are even more so. This is one of the ways in which 'power' in mental health may operate. As Parkes (2002) points out, such an analysis sees power as a 'zero-sum game' in which if one group assumes more power, another will lose an equal amount. The work of writers such as Foucault (1967) both argues against such an analysis of power, by pointing out that power may be distributed in increasing and varied ways, and by tying power to knowledge systems. As will be seen in the next chapter, there are good reasons in mental health for paying attention to what Foucault calls 'knowledge/power axes'.

Brandon argues that most user organisations, which he describes as 'advocacy' or 'self-advocacy' groups, have very limited decision-making

authority. The decisions they can make are made not by them but by providers (his book only alludes to the purchaser/provider split). In other words, the managers and professionals set the agenda for what may be influenced by users and use r groups. This argument retains some force today although Brandon's examples may be outdated. Still, there is evidence in Wallcraft *et al.* (2002) that some groups are still confined to choosing the colour of the bedspreads rather than appointing the Chief Executive.

On the other hand, and in relation to strategic planning as well as restructuring, there is ample evidence from users and user group officers interviewed by Wallcraft *et al.* (2002) that they see their persistence and 'refusal to go away' as key to the influence they have with local purchasers and providers. They are 'part of the scene' and this has been accepted by many managers. In this context, the argument by Harrison *et al.* (1997) is pertinent. From interviews with managers, they state that user groups have indeed been accepted as stakeholders by managers. However, this acceptance may be qualified, for example, by criticisms of their 'unrepresentativeness' or 'chaotic organisational style'. Harrison *et al.* argue that managers emphasise their acceptance of user groups' positions when the groups are endorsing their decisions and emphasise their qualifications of this acceptance when there are disagreements either between managers and groups or between different managers. This Harrison *et al.* describe as 'playing the user card'. This article will be discussed more fully in Chapters 7 and 8.

Kauffman (1999) describes the development of the consumer movement in the USA. There are certain similarities between her argument and that of McLean (2000) des cribed above. The two main differences are, first, that Kauffman focuses on the question of resources, both local and national, in relation to the consumer movement and brings this up to date by discussing the implications of managed care. Secondly, she di scusses the question of identity, specifically how involvement in user action may shift a 'spoiled' to a valued identity, and relates this to new social movement theory. This discussion has implications for the argument put forward by Rutter *et al.* (2001) that much user involvement is 'therapy' and therefore qualifies only as 'tokenism' on Arnstein's ladder of citizen participation (Arnstein, 1969). We will take up this issue in the discussion.

McLean and Kauffman both make the point that the rise of the consumer movement in USA with de -institutionalisation led to a reliance of some parts of the movement on state, federal and not -for-profit sources of funding and that often these sources were less reliable and powerful than those upon which more mainstream s ervices relied. Kauffman's contribution is to consider what will happen now that the funding of mental health services has been put in the hands of for -profit managed care organisations (HMOs). Her view is that since these organisations pay for (and ration) packages of care for individuals, it

will be much more difficult for group‑led user‑controlled services to fund themselves through 'block purchasing'. This has interesting implications for the NHS and Social Services in the UK.

Kauffman also discusses at length the organisational culture in which user involvement initiatives must operate and it is here that the tension between medical and psychological models of the kind of people users are and users' own definitions of who they wish to be come in conflic t. As stated, this bears on issues of identity and involvement as 'therapy' and will be discussed later.

Brandon and Kauffman (like McLean) give over‑arching analyses of restructuring and new policy initiatives and the place of user involvement in these. Both authors consider 'restructuring', at least in part, in terms of the move from large institutions to community care. The rest of the literature to be discussed in this chapter comprises more local instances of managing change in structures and policy in the direction of user involvement.

5.3.2 Specific analyses

A very clear account of restructuring within an organisation is provided by Lord *et al.* (1998). This paper describes the restructuring and consequent service changes in a housing and support agen cy and does so in the context of a theoretical discussion of change management. This aspect of the paper is discussed in Chapter 7.

The housing and support agency described by Lord *et al.* (1998), which is located in Ontario in Canada, had decided to chang e its philosophy towards greater consumer involvement and community integration. To do this, it set up structures which engaged all stakeholders, including consumers and family members, and engaged an outside facilitator to enable these structures to function. The aim was to achieve 'bottom-up' rather than 'top‑down' change.

The structures set up were a strategic planning committee, an implementation committee and an evaluation committee. Plenary meetings, small meetings and focus groups took place in relat ion to each of these committees. According to the authors, consumers were at first reluctant to take part. Consumers who use residential and housing support services are among the most marginalized; they lacked confidence and were unsure whether their view s would actually be taken seriously. However, consumers did eventually become full members of the strategic planning committee with some adopting the role of leader and 'mentor' to others.

One change decided by the strategic planning committee was the de‑coupling of housing from support services so that care could be tailored more to individual needs. Staff in particular were less happy about how the implementation committee set about putting this change into practice. For some, the pace of change was too s low and for others

too rapid. Staff also tended to express concern about their new roles and new work identities. There were also some examples of conflict between consumers/survivors and family members.

Nonetheless, when the change process within the organisation was evaluated, consumers in particular expressed satisfaction with the new housing and support arrangements. There was also general agreement that the 'ownership base' of the organisation had widened and that consumers now had more control in the management of the organisation. At the time of writing, consumers made up 30 per cent of the management board and were the only group where there were more nominees than places for them. Consumers were active in the evaluation process itself, although there is no consumer author on this paper.

This is one of the few papers to specify not only a clear change process but clear outcomes – a change in service delivery, broadening the ownership base of the organisation and evidence of greater consumer/survivor participation in the management of the organisation itself.

Gummer and Furney (1998) describe the setting up of a Joint Consultation Forum for User Empowerment in a London NHS trust. This had six representatives from user groups and a number of trust managers. The role of the Forum was to enable user input into service development, such as the commissioning of acute services and women-only services, as well as into the strategic planning of the trust. Significantly, users were paid a reasonable fee for their contribution.

Writing as managers, Gummer and Furney are concerned with the effects of involving people experiencing mental illness on this type of structure. They talk about powerful expressions of emotion, people not being well, hidden agendas (between users and user groups) and the effect of enduring mental health problems on effective communication. On the other hand, they are clear about the benefits of hearing the direct, authentic voice of people who have experience of using mental health services. This ambivalence about the role of mental illness in user involvement – the benefits of direct experience and the disruptive effects of distress – occur again and again in the entire literature.

One of the ways in which this trust has attempted to keep user involvement on the agenda and as part of its decision-making structures – to manage this change – is to appoint a senior manager to take responsibility for user empowerment (one of the authors). She takes it as part of that role to be 'upfront' with users about what can and cannot be delivered. So although there are many examples of the Forum having influence, there are other examples where this influence has not been successful or sustained. Arguably these are areas of great importance to users, for example crisis services, over-reliance on medication, and the implementation of the Mental Health Act. The conclusion is that the most important change has been in the 'ethos' of

the organisation – that is what we have called here its culture. It is also claimed that involvement has benefited the users psychologically. We return to both these issues in the discussion section of this review, Chapter 8.

Gummer and Furney conclude that there have been both positive and negative outcomes of the Empowerment Forum. Ross (2000) evaluated user involvement in a day centre in the UK. Users wished to take some control over the running of the day centre and to establish structures to make this possible. However, according to Ross, this initiative was undermined at every turn by staff at the day centre. Like many other writers, she argues that mental health professionals in low -status positions will be particularly resistant to user involvement activities. This is because maintaining status differentials between them and the ir clients is one way in which they can avoid the fact of their own low status. There may also be a perceived threat to job security.

Silva (1990) writes from the USA but part of his argument is also about staff perceiving user involvement as a status and security threat. He assesses the conditions under which clinicians might consider user involvement an opportunity rather than a threat. Two of these are 'boundary maintenance' and enhancing consumers' social engagement skills, the latter being seen as both outcome and condition for successful consumer involvement. Staff who are resistant to consumer involvement are argued to need time and support from staff who have already been persuaded of its benefits. Silva's analysis of these relationships is psychodynamic.

Other parts of Silva's (1990) paper give examples of successful user involvement which initiated or influenced policy. In one, a consumer group succeeded in blocking a contract initially awarded to an agency which the group did not think suitable to run the service in a user-oriented way. This was done by forming alliances with other groups. A second example concerned a transitional housing programme where there was a question of a respite apartment in the programme. This was preferred by users of the programme to respite in traditional facilities and away from home and friends. Eventually an agreement was reached to provide respite within the programme staffed by users on a rotational basis. These successful examples are argued by Silva to have been made possible by good working relationships between consumers, consumer groups, clinical staff and funders.

5.4 Conclusion

Strategic planning in the UK took a 'consumerist' turn with the advent in 1990 of the purchaser/provider split in health and social care. The practical literature reviewed here generally describes mechanisms for consumer feedback into the planning process and less often representation on planning committees. It is not clear if the former ever has a meaningful influence on planning, even to the extent of increasing the range of options from which consumers may choose. Writers from a professional perspective express concern that users, particularly mental health service users, will be over-zealous in their demands while writers from a user perspective express concern that their efforts are not appreciated.

Much has been written about the transition from institutional to community care but the literature reviewed here specifically concerns the place of user involvement within this transition. The more over-arching reports emphasise material, organisational and cultural obstacles to the possibility of users and user groups having a real influence on the shape of the new community services. Papers which describe more local initiatives are more mixed in their views about what is necessary to successfully manage change at the levels of restructuring and/or the implementation of new policies influenced by a user perspective. There is a pervasive ambivalence about the role of factors pertaining to mental distress here. On the one hand, the experience of services is seen as a direct and authentic expression of what is acceptable and what is not. On the other, being mentally ill is itself seen to disrupt the possibility of rational action – what Simpson *et al.* (2002) call the requirement of 'coherence'. When this ambivalence is used by managers in their own interests, Harrison *et al.* (1997) call it 'playing the user card'. A change process that appears to have avoided these problems is that described by Lord *et al.* (1998).

Chapter 6 Change management, new service provision, and user involvement

6.1 Introduction

The provision of a new service or the redevelopment of an existing facility clearly requires organisational change and ways of managing this process. We argued in Chapter 1 that it is this form of organisational change that provides the greatest challenge to change managers. Wallcraft *et al.* (2002) report that 28 per cent of user groups in the UK are involved in the provision of services and it was seen in Chapter 3 that most new service provision in a change management context often involved the employment of service users themselves. The employment of service users as providers to other users clearly means a change in the profile of the workforce in an organisation.

It was also seen that the majority of papers describing this form of change came from the USA or Canada. The establishment of user-led services and the employment of service users as providers have a longer history in North America than in the UK. At the same time, it would appear that those user-led services that do exist in the UK and were identified by Wallcraft *et al.* (2002) have not yet entered the literature. Since this review targets a UK audience, we will concentrate here on UK literature. However, there are two aspects of the North American literature that are notable. First, there are sometimes commentaries on a paper by other writers and so a debate develops around the employment of service users as providers. We shall take one example of this (Dixon *et al.*, 1994). Second, this section of the literature contains three trials with measurable outcomes, two of them including a service described elsewhere in the literature (Nikkel *et al.*, 1992). These are the only trials in the entire corpus and so they will be included. In addition, we include a paper by a British nurse who visited a user-controlled service in New Jersey (Barker, 1994).

Four examples of new service provision involving users providing services to other users in the UK are discussed (Perkins, 2002; Truman and Raine, 2002; Baggini, 2000; Barker *et al.*, 1997). Bhui et al. (1998), also writing in the UK, describe changes in the way professionals provide services to their individual clients.

Two papers (Barnes *et al.*, 2000; Frisby, 2001) and one report (Campbell and Lindow, 1997) are taken as examples of situations where users provide a service to purchasers or providers. One example of such a service would have been clinical audit or monitoring, which is increasingly carried out by user groups. However, as discussed in the Chapter 2, that body of literature was excluded from this review at the outset. The other main example is where user consultants or representatives of groups provide training to health or social care staff. It is this service which is exemplified in the papers discussed here.

The remaining three papers are more general and consider new service provision in the context of a theoretical and/or practical discussion (Barnes and Shardlow, 1997; Smith, 1998; Williams and Lindley, 1996). All these papers are from the UK and the first two are as easily seen as examples of 'strategic planning' where specific services that have changed as a result are described, however briefly. Helen Smith's paper (1998) acts as a counterpoint to the specific service provision papers in that she discusses situations where users are consulted over new service provisions as well as involved in actually providing them. An even more counterpoised example is Hostick's (1998) research which asks users their opinions about existing and 'ideal' services without in any way intending to involve service users in actual service provision.

6.2 Type of user involvement

In terms of the type of user involvement associated with new service provision, Bhui *et al.* (1998) focus on individual care. Some of the papers which focus on users as employees do so at an 'individual' level. Although there is usually more than one user employed in these services, they are not always constituted as a 'user group'. It is this instance that was picked out as problematic for the individual/collective consumerism dichotomy in our coding frame in Chapter 2. Other papers are concerned with involvement by groups of users in new service provision either as groups to be consulted or as actually providing services themselves. User-led services imply a new type of citizenship for mental health service users and this is picked up conceptually by both Smith (1988) and Barnes and Shardlow (1997).

All the papers reviewed in this section, to varying degrees, counsel a move from 'passive patient' to 'active citizen'. The most limited of these is Bhui *et al.* (1998) who describe changes to the ways they involve patients in their care. Writing as clinicians, they do not step very far beyond the traditional boundaries of client care; their strategies for inolvement are limited to the provision of more

information to clients, and they see obstacles to their endeavour chiefly in the psychopathological characteristics of their patients. Although the intention is to make services more responsive to users' needs, there is no user influence over the service described by Bhui *et al.* The authors, in addition, point out that there are legislative constraints upon how much power they can hand over to their clients.

6.3 Users as service providers to other users

At the other end of the spectrum to the approach of Bhui *et al.* (1998) lie descriptions of fully user-controlled services including case management (Nikkel *et al.*, 1992), a user-led service providing the range of services from community housing to self-help groups (Barker, 1994), a trust-wide user employment programme (Perkins, 2002), a social firm (Baggini, 2000), a community gym (Truman and Raine, 2002), and advocacy (Barker *et al.*, 1997). A counterpoint to the user-led case management team described by Nikkel *et al.*, (1992) is the account by Dixon *et al.* (1994) of the employment of users as consumer advocates within an Assertive Community Team (ACT). In this section, we also consider two trials involving the service described by Nikkel *et al.* and one further trial of a demonstration project as well as two commentaries on the paper by Dixon *et al.* (1994).

The consumer-operated case management team described by Nikkel *et al.* was contracted in 1990 by Oregon State to provide services to 30 clients. This was because the State was overwhelmed by demand for its psychiatric services. Called Mind Empowered Inc., the case management team is fully staffed and controlled by service users. Although it operates in a similar way to other case management teams (it uses a keyworker model), the fact that the staff are service users brings certain unique features. Most of all, there is a breaking down of the 'staff/patient' divide. User case managers can identify with their clients and this is seen as a positive way in which they can understand their clients' problems. They can also model coping skills and see the meaning in psychiatric symptoms.

Nikkel *et al.* characterise the programme as 'experimental' with outcomes as yet not clearly defined. Among potential difficulties for the project are stresses for the staff, who may be recovering from stress-related conditions themselves and the support services that need to be put in place to ensure that staff can remain in post. The issue of vulnerability is high on the agenda of all the papers in this review that include the employment of users as staff and new forms of service delivery that meaningfully include users.

6.3.1 Randomised controlled trials

Mind Empowered Inc. was subsequently the subject of two controlled trials. In fact, it becomes clear that the project was a research-supported one and so exempt from many of the financial constraints that usually beset such agencies. A randomised controlled trial was carried out by Solomon and Draine (1996). Clients were randomly assigned either to the consumer-led case management team or a case management team made up purely of professional staff. The main finding was that the consumer-led team had more client–case-manager contacts whereas the other team had more 'collateral' (staff-to-staff) contacts. The consumer case managers, in line with this, were more likely to describe their relationships with their clients in terms of 'friendships'. There was no difference between teams in the number of referrals outside the mental health system. This led Solomon and Draine to speculate that both teams were equally concerned that their clients would experience stigma in the wider community.

The authors state that there were no differences in psychosocial outcomes between the clients of the two teams. This, they conclude, means that a consumer-led team is as well equipped to help clients as a professional one. In addition, the consumer-led team tended to have higher expectations of their clients. This may have been because they themselves had experienced recovery, if only temporarily, or because they were in fact more highly educated than the non-consumer team. According to Solomon and Draine (1996) the most effective case management teams would be those which combined consumer and non-consumer workers.

The second trial involving Mind Empowered Inc. was carried out by Paulson *et al.* (1999). Although not explicitly stated, there must have been organisational changes by this time as Mind Empowered Inc. then operated both a consumer-run and a non-consumer-run ACT. It is these two services that are compared. It is not made clear whether clients were randomly assigned to the teams. The findings of Paulson *et al.* in terms of activities undertaken by the two types of case managers are in contrast to those of Solomon and Draine (1996). They found that the two teams spent similar amounts of time on a range of tasks and both spent most time with other staff. However, the authors found differences in style of working, what they call the 'culture' of the organisations. These were revealed through participant observation corroborated by interviews. First was the much-noted dissolving of boundaries between clients and consumer case managers, which is argued to have both advantages and disadvantage. Second, the consumer case managers made much less use of power and authority in their relations with clients and they were more likely to work co-operatively. The third difference was the 'task orientation' of the non-consumer staff as opposed to the relationship orientation of the consumer staff. Again, there is an emphasis on the empathy which people who have 'been there' can bring to the provider role. Finally, the

non-consumers frequently talked about the burden of their position and the fatigue brought on by the work. The consumer staff, by contrast, tended to see problems at work as due to their own vulnerabilities rather than the 'burden' presented by their clients' problems.

A further feature mentioned by Paulson *et al.*, and by other authors, is that consumer workers may face stigma. It is argued that this stigma is greatest within mental health agencies, for example those to which clients may be referred, rather than in the wider community. The authors argue that other mental health workers are most likely to think that consumers cannot perform their job competently because of their mental health status.

Despite the positive picture painted of the consumer case-management team, the authors do point out that the consumer team experienced far greater absenteeism and staff turnover than the non-consumer team. Another factor with this work, which the authors themselves point out, is that the non-consumer team may not have been typical since it was managed by a consumer-run agency, 80 per cent of whose management board were consumers. But in this case, the differences in culture between the two teams are even more striking.

The final trial in this literature also concerns a 'demonstration' programme, this time for homeless people with a diagnosis of severe mental illness which was implemented in sites across the USA (Chinman, 2000). Many of the sites included consumer staff although they were always in the minority. The trial here is not truly random because it compares clients of consumer staff with clients of non-consumer staff within mixed teams. It is demonstrated that these teams had more disabled clients than teams with no or very few consumer staff and also that the consumer staff were allocated clients who were as severely disabled as the clients allocated to the non-consumer staff. Consumer staff received the same salaries as other staff and were expected to do the same job. Clinical outcomes and the quality of the therapeutic alliance were measured.

Essentially the findings were that there were no differences in outcomes or therapeutic alliance according to the status of the worker. The clients of both groups improved clinically over a two-year period and therapeutic alliance was good for both groups. The authors acknowledge that their measures were not subtle and therefore may have failed to capture the kinds of factors revealed in other studies. Also, the consumer-providers were working in a context where the majority of their team were professional staff. However, since the sample was very large, they conclude that consumer workers are as effective as other staff and provide both an avenue for the employment of people who have themselves experienced severe mental health problems and an additional resource for the benefit of clients who are vulnerable.

6.3.2 Users working in professionally led services

Involvement of users in case management, as distinct from user-controlled case management, is described in the account by Dixon *et al.* (1994) of the employment of users as consumer advocates within an ACT in Maryland, USA. This team works with homeless people with a diagnosis of severe mental illness. In this instance, consumer advocates are working alongside case managers and medical staff so the organisational issues are different from those identified by Nikkel *et al.* (1992). There is, for example, no requirement that the team work in a non-hierarchical fashion as tends to be the case for user-controlled organisations. The ACT did in fact have a clear medical and administrative hierarchy.

Dixon *et al.* identify many of the same strengths which the consumer advocates bring to the ACT identified by Nikkel et al. (1992) including identifying with users, positive role modelling and first-hand experience of drug and alcohol issues. Since the consumer advocates have all themselves been homeless, the authors also argue that something they call being 'street smart' (that is, having acquired through experience the knowledge and skills to survive a marginalised and dangerous existence on the streets) has been vital to keeping users engaged with the team. The authors acknowledge a two-way information flow. Consumer advocates require some training to carry out their role effectively but they have also 'trained' the team, for instance, in explaining the experience of the side effects of neuroleptic medication.

The authors identify five issues which have not been fully solved by the team. Two of them are the opposing side of the strengths which are seen to come from employing people with experience of mental distress and street homelessness. The first is that the role of the consumer advocates tends not to be clearly defined. This has the advantage that consumer advocates may tailor their work to the needs of individuals but the disadvantage that the role is vague both to the consumer advocates and to other staff. The second is identified as 'boundaries' which are seen to be much less clear in the relation of clients to consumer advocates than to staff. Are consumer advocates meant to be 'friends' to clients, implying a two-way relationship? A particular concern for the clinicians and administrator authoring this paper is confidentiality in the sense that consumer advocates may not pass on all the information they are given by users.

There is lack of clarity in the team about who should be providing supervision and support for the consumer advocates. At the time of writing, a clinician carried out this role but it was recognised that peer-support might be more appropriate. Again, as with most of the papers in this section, the issue of the consumer workers' own experience of mental illness exercises the authors and the team they describe. There was greater turnover of consumer than professional staff in the team which 'appeared' to be illness related (but see next paragraph). The

authors make the interesting observation that some clinical staff inappropriately adopted a therapeutic role in relation to consumer staff. At the same time, some consumer staff were uncomfortable about being 'team members', exemplified by their difficulty in calling the medical director by his first name rather than 'Doctor'.

The penultimate paragraph of the paper by Dixon *et al.* (1994) contains some surprising information because it implies that the consumer advocates were not paid (!) or were paid very low salaries. There is reference to the 'inability to bill for the servic es of the CA' (p. 625) which would appear to mean that insurance companies were not prepared to pay for these services. As the authors themselves hint, it may have been deflated salaries and poor job security that were responsible for the high turnover of consumer workers rather than their status as people with a mental illness.

Two papers provide commentaries on Dixon *et al.* (1994): Fox and Hilton (1994) and Solomon (1994). Both are highly critical of the vague role definitions assigned to the consumer adv ocates which they say lay a burden on them to define their own role. This is a burden which the other members of the team do not have to shoulder. They are also critical of the lack of clarity in the supervision arrangements and in the training arrangements. In the view of the commentators, the tasks carried out by the consumer advocates are equivalent to that of the other case managers and they should be assigned a definite role with proper training, supervision and remuneration arrangements.

6.3.3 North America – the view from the UK

We turn now to the last of the papers focusing on North America which this time is authored by a British nurse (Barker, 1994) who visited a community programme in the State of New Jersey run by 'prosumers'. This term is used to describe people who have been patients and now run services. Like Mind Empowered Inc. the programme is underpinned by a culture of positive role modelling and the belief that experiencing mental illness can be a tool to help others. The programme provid es services to nearly 1500 people and includes supported housing, drop -in centres spread across 11 counties, self -help groups and 'buddy systems', and membership of national consumer organisations. For Barker, the most interesting aspect of the New Jersey programme is the leavening of the divide between 'staff' and 'patients' and he counsels UK nurses who have used services to 'come out of the closet' in the interests of their users, while acknowledging that this has been made more difficult by the Clothier Report (Clothier *et al.*, 1994).

The 'prosumers' of the New Jersey programme sometimes work in an exclusively user-controlled way and sometimes work in collaboration with clinicians and managers. A facilitative organisational culture and attitude among these professionals is therefore essential to the success of such collaborations. At the same time, more radical

consumers (cf. McLean, 2000) are wary of collaborating with professionals and the leader of the New Jersey programme informed Phil Barker that these radical consumers referred to him as an 'uncle Tom'. In the USA, then, it seems that ideological differences within the consumer movement may hamper change management in the direction of new services. At the same time, legislative change in the form of de-institutionalisation and the mandating of states to set up consumer-run services enable this.

We have spent some time in this chapter describing the North American literature on new service provision and specifically the employment of service users as providers of services to other users. The reason for this is that such changes are set to happen increasingly in the UK for reasons described in the Section 1.2 in Chapter 1. Although the policy, legislative and funding context is different, particularly in the USA, we believe that there are lessons to be learned for the emerging situation in the UK.

6.4 Users as providers in the UK

Recent developments in the UK, such as the employment of user development workers by NSF, local implementation teams, are too recent to have reached the literature. Therefore, not surprisingly, three of the examples from the UK which we will review here are on a smaller scale that those from North America. The exception to this is the User Employment Project (formerly Pathfinders) at South West London & St Georges Trust which was established in 1995 (Perkins, 2002). By 2002, this project had supported 81 people with long-term mental health problems to work in the trust. Many of these moved on to open employment either within the trust or elsewhere. In contrast to the US experience of higher absenteeism among user workers, in this project the average amount of sick leave is lower among those in the user employment project than among ordinary workers.

The trust developed a Charter for the Employment of People who have Experienced Mental Health Problems. In line with the monitoring established as part of this project, it was calculated that the numbers of people with mental health problems employed in the trust rose from 9 per cent in 1997 to 15 per cent in 2001. The majority of these employees require no support from the programme.

The User Employment Project also runs a volunteer/work experience programme which has developed over time to enhance the possibility of users spending short amounts of time in the programme and then moving on to open employment. By 2002, 114 people had made use of this programme, of whom 29 moved on to open employment within or outside the trust.

Perkins (2002) argues, as do many of the North American authors, that user workers bring special value to their posts. She uses the term

'experts by experience' to describe the way that user workers relate to clients. However, Perkins does not equate this with the kind of ambivalence found in the North American literature and makes reference to levels of disability only to show what can be achieved rather than to identify a problem. The User Employment Project seems itself to have brought about a change of culture within the trust by demonstrating how such a project can work successfully.

The other three examples from the UK are more modest. Baggini (2000) looks at the transformation of an NHS sheltered workshop into two social firms in Northern Scotland, one of them providing printing facilities (the activity of the second is not specified). The social enterprises are now independent of the NHS and the rationale for this transformation is once again to turn 'passive patients' into active employees. Individual benefits from becoming active employees are emphasised in the UK papers and include increased self-confidence and skills. Representative structures are key to the success of these enterprises – users make up 50 per cent of the management committee and it is claimed that this is not tokenism but actually represents 50 per cent of the power. Baggini discusses the social firms as sometimes a challenge to mental health professionals while at the same time arguing that the change was made possible by the presence of 'champions' within health and social services. Thus change management in the context of this new service was both a threat to some professionals and enabled by others.

Truman and Raine (2002) describe the setting up of a community gym for mental health service users which previously had been housed in a hospital. The gym has clear structures where users can move from the position of 'client' to 'staff'. Included in these structures are NVQ qualifications. In fact, it is not clear from this paper whether those users who become 'staff' are paid or are volunteers – the two words are used interchangeably.

Truman and Raine's paper is a report of a piece of qualitative research, including both focus groups and individual interviews with staff at the gym and members. The first condition for the gym to be successful, they argue, is that it should differ from traditional services in being more democratic and less hierarchical, with a greater degree of user involvement. The organisational or cultural context is thus key to success. However, the paper does not say whether there are users on the management committee of the gym. As with Baggini's analysis, emphasis is placed on how individuals benefit from the move from user to volunteer/staff – in self-confidence and in skills. And as with the other papers, the breaking down of the 'patient/staff' distinction is seen as important and this is another facet of the change in organisational culture.

The main barriers identified by Truman and Raine to meaningful user involvement in the gym again relate to characteristics of service users

– not only those who are involved but the reaction to them of professional staff and non-involved users. They identify 'role strain' in crossing the user/staff boundary. This can be uncomfortable for the volunteer user and a threat to professional s taff. Non-involved users also told the research team that they were not sure that people with mental health problems were able to take on the role of staff. This attitude Truman and Raine see as a reflection of society's conception of mentally distressed people which has been internalised by members of the group themselves.

In light of the above, the gym has had to confront the problem of sustainability. Trying to oppose the idea that users are not 'competent' to be workers has been important. Within the pr oject, this has been accomplished through a process of positive role modelling. As non - involved users see others move into the position of volunteer, not only do the volunteers themselves become less socially excluded but other users see them as role models. Another key element has been the constant attention to the contract between volunteers/user staff in relation to their role in the gym.

Ingrid Barker and colleagues (1997) provide a review of advocacy services in the UK based on individual interviews wi th key people in each of ten advocacy projects. Most of these were service users themselves so this is another example of change in the direction of new service delivery where users have some, if not complete, control. The most common type of advocacy iden tified was Patients' Councils, hospital-based groups who try to bring about improvements in NHS facilities. This form of collective advocacy was preferred by the respondents although two projects focused on individual advocacy.

Five of the projects had an independent management committee and four were situated in larger voluntary organisations such as MIND or the National Schizophrenia Fellowship (now Rethink). Although some of these projects were user-led, the main financing arrangement was grant aid from health or local authorities. This means that such authorities had a role in managing the provision of new advocacy services and the main way this was done was through monitoring.

This paper is one of the few to mention specific groups of users. One of the projects had a specific remit for older people. Most reported an equal gender distribution but often commented that it was more difficult to engage women in advocacy than men. Although several of the projects were based in ethnically diverse areas, only on e had even 20 per cent of its projects taken up with black groups. Interviewees stated that black users might be better served by organisations made up of people from their own ethnic group – an issue that is discussed at length by Wallcraft *et al.* (2002).

The most important facilitative factor according to the interviewees was resources. Better resourcing led to quicker development and more positive outcomes. Almost as important was the presence of an

independent and flourishing user group in the locality. Information, training and networking with similar projects were also seen to be important.

Barriers to the success of the advocacy projects included resistance from staff, especially clinical staff, insufficient and insecure funding, finding sufficient users to sustain the project (demand was often very high) and the danger that paid advocates would be seen as 'professionals' and so separate from 'ordinary' users. This last point echoes the conflicts between 'mainstream' consumer-providers and radical users in the USA. Paid user advocates may also be the sole worker in an organisation leading to a sense of isolation in people vulnerable to this in the first place for social reasons.

These papers which provide practical examples of user involvement in new service delivery for other users all emphasise a cultural shift from passive recipient of care to active provider. In most instances, this has meant shifting an organisation from control by statutory services to at least some control by service users. However, all the new projects described were dependent for their funding to some degree on statutory sources and, especially in the USA but to some degree in the UK also, legislative changes were argued to have made this possible. When users become workers, the issue of their mental health is always to the fore although this varies from positive steps to ensure support to doubt about capacity.

6.5 New service provision by users to purchasers or providers

The two papers and one report to be discussed in this section concern either nurse education by service users or service user involvement in teaching post-qualifying interprofessional courses. It should be noted that some authors express cynicism about this ever being anything but token. Hopton (1994), focusing on nurses, argues that the structural contradiction in mental health between care and control, coupled with the subordinate position of nurses in relation to psychiatrists, generates an organisational culture that will forever resist the inclusion of meaningful service user involvement in nurse education. He argues this to be so despite the prevalence of 'consumerism' as an ideology and the focus on users of services in the 1990s.

Consumers themselves are not always so cynical. Peter Campbell and Vivien Lindow are two activists in the user movement who have experience in training mental health staff. They distill their experience in training nurses in a report published for the RCN entitled *Mental Health Nursing and User Empowerment* (Campbell and Lindow, 1997). As the title suggests, the object of users being involved in the training of nurses is to enable nurses to be more empowering in their treatment of service users and in their dealings with service user groups, be they

local groups or service-based groups such as Patients' Councils. A clear objective of user involvement in nurse training is then to bring about cultural change in the NHS. To this extent, an organisational culture open to the contribution of users in nurse training is essential.

Campbell and Lindow are clear about the obstacles. The 'pathologisation' of users' experience is a constant temptation to professionals, and yet it is to the very experience of mentally distressed people that these authors wish to see nurses paying attention. To dismiss a contribution or, more seriously, a complaint as a symptom of mental illness is one way in which power differentials may operate. It may also lead to user involvement in nurse training being a token gesture, something these authors wish to see avoided at all costs and for which they give guidelines in order that it is avoided.

These authors also discuss the specific situations of women, people from ethnic minority communities, disabled people and lesbians and gay men. Honesty and clarity are countenanced again and again in this report. In particular, Campbell and Lindow argue that nurses should be clear and honest with users about what can and cannot be achieved. The situation of detained patients is pertinent here.

Campbell and Lindow provide an interesting discussion of advocacy – both individual and collective. While they accept that nurses may advocate for their patients, there is always the possibility that the patient's 'best interests' will be defined by the nurse and not by the user. It is for this reason that independent advocacy has emerged and that this is often provided by people who have used services themselves. This links this report with the paper by Barker *et al.* (1997), discussed above.

For user involvement in nurse training to be effective it needs proper resourcing, including payment of service users, a clear and full strategy for the provision of information, representative structures for bodies like Patients' Councils and local user groups to contribute to the training and, as already mentioned, a facilitative organisational culture.

Obstacles to effective user involvement in nurse training are a culture which is resistant, power differentials, and the type of pathologisation of experience discussed above. Campbell and Lindow (1997) also mention two other factors. One concerns nurses who have themselves used services and whether there is a culture of openness and empowerment around this. The second is the often mentioned and vexed question of the 'representativeness' of involved users. This will be discussed in Chapter 7.

Diana Barnes and colleagues (2000) describe user participation in teaching a post-qualification interprofessional course. Their model of user involvement is that of the 'stakeholder' because they believe, unlike Campbell and Lindow (1997), that 'empowerment' is too high a goal to aim for given the constraints under which the course they

discuss operated. As partners or stakeholders, users were involved in the tendering and contracting process for the course, in curriculu m development, in actually delivering course content and in evaluating the course. The aim of bringing in users as 'stakeholders' was to put the user perspective on a level footing with other perspectives that needed to be taken into account.

Users were chosen somewhat haphazardly for participation in the contracting process. It was necessary to provide a good deal of training, requiring resources, in order to explain the process to the users involved, 'jargon' being a particular problem. One user was involved in appointing the successful contract and was also involved in appointing staff. Since so many other stakeholders were involved in this process, one of the commissioners expressed disappointment that users had not been more involved but said it had bee n important to 'have a go' (p. 193). Nonetheless, when it came to the selection of staff, the authors conclude that the influence of users went beyond the specific questions they asked to changing the culture of the interview panel.

Users were involved in delivering the course although not as full -time members of staff (one user was shortlisted but not ultimately successful). Although delivering the course involved service users in most academic activities – preparation of reading materials, teaching, marking assignments – there were various ways in which the structure of an academic institution tended to mitigate their contribution. 'Expert' forms of knowledge, such as evidence-based interventions, are valued over 'experiential' forms of knowledge and so th e latter have less credibility. The first cohort of students sometimes found the approach of the user-lecturers 'antagonistic'. Other formal requirements of a university such as timetabling and degree regulations also mean that 'partnership … has to operat e within a structure in which power lies with the educational institution, not to mention the course funders, the NHS Executive' (Barnes *et al.*, 2000: 198).

The course organisers attempted to overcome some of these obstacles by creating a shared value base and organisational culture, based on the needs and perspectives of users. Barnes *et al.* consider this to have been partially successful and the second intake of students, after more preparation of the user-lecturers, seemed to have adopted this value base in their practice. They conclude that the users who participated in the various stages of the course had 'influence but not control' (p. 198). Nevertheless they argue that involving users as stakeholders gives added value because users introduce not just their own contribution but create a 'saliency' effect whereby their perspective is influential on other people responsible for contracting, delivering or evaluating educational programmes for community care staff.

Frisby (2001) describes a more modest cont ribution by service users to nurse training. His paper concerns the involvement of users from a local user group in the element of the nurse curriculum focused on client assessment. By bringing service users into client assessment sessions, nurse trainees are enabled to see the predicaments of their placement clients 'from the other side of the fence'. Thus. once again, there is an attempt to break or soften the 'staff/patient' divide.

The approach to learning for nurses taken by Frisby is collaborative. Users are full participants in the training sessions. To this end proper contracts are drawn up and supervision provided. Users are paid and ethical dilemmas are fully discussed with them before the sessions, and debriefing is made available afterwards. Overall responsibility remains with the lead lecturer of the course. If disagreements become very evident Frisby argues that it would, in fact, be tokenistic just to side with the user because they are there to represent the user point of view.

The students' evaluation of these learning sessions is that hearing the voice of experience gives them a new slant on their clinical practice which is invaluable. On the other hand, students were wary of being 'judged' and, in Frisby's view, there were occasions on which acting on a user's assessment might have led to unethical practice.

Frisby is aware that some professional bodies, including nursing, pay 'lip service' to the idea of involving users in training. However, although he has put in place contracts, payments a nd so on, there is no reference in this paper to the power differentials or 'role strain' that may be in play when users take up the role of teacher in relation to mental health professionals.

6.6 Theoretical and discussion papers

Barnes and Shardlow (1997), Smith (1988) and Williams and Lindley (1996) provide examples of new service delivery in the context of conceptual and practical discussion. For Barnes and Shardlow the key conceptual distinction is between consumerism and citizenship. They focus on six user groups – three in mental health and three disability groups. For them, citizenship entails at least two activities – user-controlled services and holding public bodies to account. These arguments are discussed in detail in Chapter 7.

Helen Smith (1988), in an early report for the King's Fund, is concerned with the concept of collaboration and how collaboration between statutory organisations and consumer groups may be brought about. Her report pre -dates the purchaser/provider split but offers several examples of early user groups working with services to improve the quality of care. She too is concerned with citizenship but this time in the sense that de-institutionalisation should mean that users of mental health services are full members of society.

For Smith, the key factors which make collaboration and citizenship possible are staff training, resources, representative structures and information provision. She is particularly concerned with changes in organisational culture including the development of shared values, support for staff in this new environment and the acknowledgement of power differentials. On the question of mental distress itself she makes two points which are rather different. One concerns the safeguarding of users' confidentiality when working in partnership with providers who may know the same person as a client. The other is that in the absence of training in committee skills, users will be unable to find their feet and will be undermined when, for instance, they are seen as 'wandering off the point'.

Williams and Lindley (1996) describe their own efforts, as professionals and academics, to facilitate meaningful user involvement in the form of support for a hospital Patients' Council and then the formation of a consultancy to assist user groups to participate meaningfully in service planning and provision. However, they argue that this is extremely difficult to bring about due to power differentials existing within mental health services. These authors' analysis of power differentials goes far beyond what we have encountered so far in this review as they argue that power differentials in mental health are situated in the context of structural inequalities in society which impact inequitably on users of mental health services. They are particularly concerned with inequalities of employment, income distribution, gender and ethnicity, which they argue structure the wider society and are magnified in power differences between mental health service users in relation to clinicians and managers. This paper will be discussed more fully in Chapter 8.

6.7 Conclusion

In conclusion, the provision of a new service or the delivery of an existing service in a new way is usually a radical form of organisational change requiring new ways of working f rom managers. It is particularly radical if it involves service users themselves as the providers of the new service rather than simply as groups that are consulted about a new service. If the new service exists within mainstream services, and the nurse training initiatives would be included here, then it will only be successful if other forms of organisational change – including cultural, attitudinal and structural – are also brought about. If the new service exists as a user-controlled organisation in parallel to mainstream services there may still be involvement of the mainstream management in the form of grant aid, contracts and monitoring. Many papers reviewed in this section make mention of resources and secure funding – rather than rolling one-year contracts – as vital to the success of new services.

We have spent some time in this chapter reviewing the ways in which new services employing users have been configured in North America. This seems apposite because the employment of users in mental health services is set to increase in the UK in the very near future. Indeed, it is already happening.

Most of the papers reviewed in this section also make reference to power differentials. These may be power differentials between users or user groups trying to establish more equitable ways of working and hierarchical and structural obstacles in mainstream services which mitigate against this. Power may also operate in mental health in quite subtle ways such as the pathologisation of complaints or the under-valuing of experiential knowledge. It may also, rather differently, refer to power differentials *within* user-led organisations. As will be seen in Chapter 7, this can lead to managers undermining the contribution of user groups on grounds of their 'factionalism'. In Chapter 8 we look more closely at the different ways in which power differentials are conceptualised in the literature.

The other factor which was mentioned in most of the above papers refers to mental distress as such. It is not surprising that when a group of people who have been defined socially as not competent start to take on roles defined by this very competence, this issue will be to the fore. The interpretation of the impact of the mental distress of users who are involved in new service prov ision varies. At one pole, psychopathology is seen to prevent an extensive degree of user involvement (Bhui *et al.*, 1998) and at the other it is argued that positive steps need to be taken to support users or ex-users to work effectively in new services (Nikkel *et al.*, 1992; P. Barker 1994). It is also recognised that references to mental distress may be used to legitimate a position which does not take the contribution of service

users seriously (Smith, 1988; Williams and Lindley, 1996; Campbell and Lindow, 1997).

The papers reviewed in this chapter represent probably the 'hardest' form of user involvement in change management encountered in the literature. The examples often involve the employment of service users as staff and/or the setting up of user-led services. These projects arguably pose a greater challenge to managers than initiatives which aim to promote democracy and representation or cultural change. This is because the employment of service users or the development of user-controlled services can represent a fundamental shift in service patterns. However, 'softer' changes such as widening representation or engaging in cultural change may be a prerequisite for the successful execution of more far-reaching developments.

Chapter 7 Theoretical frameworks

7.1 User involvement and approaches to change management

The discussion in this chapter develops key themes that have emerged from our review of the literature on user and carer involvement in mental health services in relation to theorie s of change management. We draw in particular on the approaches outlined in the SDO's review of the organisational change literature for health care managers, professionals and researchers (Iles and Sutherland, 2001).

While the involvement of different stakeholders is central to models of change management, studies of user and carer involvement in mental health services only occasionally engage with the management literature. In bringing these two fields of theory and research together, however, it is possible to identify a number of common themes – if at times these are treated rather differently. Key shared themes include:

- users and carers as 'stakeholders'

- the role of information, communication and consultation

- issues of compliance

- participation and representation.

7.1.1 Users and carers as stakeholders

In public service settings, the interests of users are in principle both the starting-point for strategies of change and the ultimate measure of their effectiveness:

> *To deliver their full potential, change programmes need to begin and end with customers.*

> (Audit Commission, 2001: 71).

However, user and carer involvement represents a specific set of challenges to the management of change in mental health services, and in this context even such a ba sic statement of principle needs to be qualified on three levels:

1   the customer relation

2   the distinction between internal and external stakeholders

3   the linkage of aims and outcomes to processes.

7.1.1.1 The customer relation

The user movement has critically challenged the assumption that mental health users can properly be understood as customers, given the forms of coercion and constraint under which many people 'consume' mental health services (see Armes, 2001). The nature and extent of customer choice is limited in this context, and it is questionable how useful models derived from the market sector are likely to be. While models of (individual and collective) consumerism tend to dominate the literature on change in mental health service provision and delivery, the aims of user and carer movements frequently involve a commitment to 'choice' in a stronger sense, based on an ethos of empowerment that positions individuals as citizens rather than simply as customers, and in this way entails a more robust range of rights than those found in the consumer relation (see Section 7.2).

7.1.1.2 The distinction between internal and external stakeholders

Models of change management commonly position users or consumers as 'external' stakeholders. While they might have a strong stake in the type and quality of the service received, users generally are not seen to have a clear interest in the organisation that delivers the service. Such an assumption becomes highly charged when it is applied to public services, and especially to mental health services. A distinction between internal and external stakeholders tends to frame issues of participation, ownership and compliance in terms of those 'inside' the organisation (management and staff), while those on the 'outside' (users, carers, customers, the community or general public) are engaged via consultation and evaluation. Approaches to user and carer involvement in mental health services, however, stress the importance of participation within organisational structures, as well as broader aims of independent organisation, representation and service provision on the part of user groups (see Simpson e *t al.*, 2002). This constitutes a challenge to accounts that locate processes of change management within bounded organisations whose relations with users are largely external (see the range of models described in Iles and Sutherland, 2001: 25–39). It is uncertain how far mental health users can be seen as standing 'outside' organisational structures – whether due to the role played by user groups in mental health reforms, or to the limited rights of 'exit' available to many individual users (see Barnes and Shardlow, 1997). It follows that issues of consultation, information and evaluation will be rather different for these more 'embedded' users than for external consumers of public services, while issues of

representation, accountability and compliance will not be the same as for other internal stakeholders (management, clinicians, staff).

7.1.1.3 Aims, outcomes and processes of change

The Audit Commission report stresses the way that changes in public services should 'begin and end' with users or customers. At the same time, the literature on user involvement in mental health emphasises real and sustained involvement in organis ational *processes*. In their analysis of user and carer involvement in the commissioning and delivery of mental health services in England and Wales, Firth and Kirfoot (1997) make a distinction between organisational change and 'outcome change'. They adopt a typology of different levels of user and carer involvement in service planning, from one -way communication from staff, through consultation, agenda setting, joint planning and user and carer control (p. 35). Similarly, our analysis of the literature points to a 'ladder' of participation, such that users and carers are most likely to be involved in 'top -and-tail' processes of consultation (at or somewhere near the start of the change process) and evaluation (as or after changes are implemented). Change, in this respect, might 'begin and end' with users, without necessarily involving them in the organisational processes that intervene between aims and outcomes. There appears to be a real challenge in developing strategies that tie user and carer involvement into substantive changes in service provision and delivery, as well as into meaningful forms of representation and/or partnership at the level of organisational processes. As Garcia Maza (1996: 24) puts it, this involves a shift in the ethos of public serv ice from 'provision of service for or to people' to 'provision of service with the involvement of the people it affects.'

This is in line with models of change management that stress the relationships between the *content*, *context* and *process* of change. Here, effective change depends on the relation between the aims and content of change (the 'what' of change), the process by which changes are implemented (the 'how' of change), and the organisational context in which change takes place (see Iles and Sutherla nd, 2001: 32–33, for their discussion of Pettigrew and Whipp, 1991, and the 1992 study of change in health care services by Pettigrew *et al.*). This more extended approach to issues of process and organisational culture informs the discussion in the following sections.

7.1.2 Information, communication and consultation

Our review identifies information as one of the two most important factors promoting user and carer involvement in processes of change. Such an emphasis on information and communication is al so found in the broader literature on change management. Clear strategies for information provision, and for communication between different stakeholders, are seen as central to the effective management of change. Our study also suggests that consultation is the most common type of user/carer involvement in a mental health context. However, it is most often correlated with organisational changes associated with the promotion of democracy and representation, or with strategic planning. It is less often linke d, in these data, with substantive changes in service delivery or provision. The latter, in contrast, tends to link with more active citizenship on the part of users, and specifically with forms of user control (see the discussion in Chapter 3). The category of consultation, then, requires unpacking. Its correlation with the promotion of democracy and representation, but not with more clearly measurable changes in services provision, partly might reflect the way that consultation can be seen as a democratic outcome in itself: in this sense consultation and representation form a virtuous circle without necessarily feeding into wider changes in services or organisation. Our study, perhaps surprisingly, found that information provision and a facilitative organi sational culture each were more important than formal representative structures in effectively involving users in organisational change. This is not to say that the formal representation of users and carers has no positive role in change management, but ra ther reflects a negative view of representative structures that are not embedded in a wider culture of involvement, or which do not provide access to reliable and useful resources of information (see also Bowl, 1996a and 1996b, and the discussion in Chapter 4).

Consultation has come to be seen, in public services and elsewhere, as basic to good management practice, but is often viewed with scepticism by users, carers and staff. Our review of the mental health literature helps to qualify the emphasis on cons ultation and communication found in more general approaches to change management. Several studies in our survey report the tendency of consultation with users and carers to take place after key changes have been decided, or when key professionals have beco me committed to a draft plan (see Bowl, 1996a; Parkes, 2002; Rutter *et al.*, 2001). It can be difficult at this stage either to consider alternatives, or to question the rationale for change and the aims such a process seeks to achieve. This after-the-fact 'consultation' represents little more than a form of reporting – it facilitates user/carer involvement in only a limited sense, and can have more serious negative effects. Where consultation takes the form of report, it is difficult for users/carers or oth er

stakeholders to respond constructively. If their sense is that important questions have already been determined, those consulted have limited recourse to strategies other than passive or grudging acceptance, or potentially damaging resistance. Neither represents 'involvement' in any positive sense, and both tend to indicate poor management of information – even where those charged with communication do not intend to be non‑inclusive. If it is crucial to engage in consultation from an early stage of the change process, it also is important to sustain strategies of information and communication over time, even when – from a management viewpoint – 'nothing' appears to be happening. Bowl (1996a: 291) makes a distinction here between 'one‑off consultations' about specific proposals, and ongoing processes of consultation as an 'established culture' within organisations.

7.1.3 Issues of compliance

The potential for and sustainability of change is highly dependent on the extent to which different stakeholders are prepared to comply with it. Perspectives on compliance have been strongly influenced by Lewin's (1951) force field analysis. This approach identifies counter‑forces at work in relation to organisational change: those *driving* the change process, and those *restraining* it (see Iles and Sutherland, 2001: 43; for the application of this model to a mental health context, see Leiper, 1993, and the discussion in Chapter 5). Driving forces might include new policy or managerial initiatives, new personnel, technological innovations, funding or regulatory changes, increased competition; while restraining forces can include skills gaps, technological lags, entrenched work practices, red tape; low morale, and so on. We might note here that such forces include both:

- technical and social factors

- external and internal drivers

- structural and cultural issues.

The key to effective change management, in this account, is to reduce the forces restraining change from taking place. Increasing drivers, on the other hand, tends also to increase resistance. Managing consent – promoting inclusion, participation, acceptance, compliance – therefore is seen as a more efficient strategy than imposing change in a highly directive manner. Lewin notes that cultural factors within an organisation are crucial in this context, either in enabling or in resisting change.

Lewin's model tends to assume a top‑down structure, where promoting commitment to change is a management problem. Two key issues arise here in relation to organisational change in mental health. Firstly, a top‑down or management model does not easily accommodate those instances where users and carers act as driving forces for organisational change. The mobilisation of service users has been an important feature of change in mental health services over recent

decades (see Barker, 1996; Barnes and Bowl, 2001; Campbell, 1996, 2002; O'Hagan, 1993; Peck and Barker, 1997), and the primary question in this case is not how managers can secure compliance across an organisation, but rather how users might assert a change agenda in the first place. Secondly, and in the context of mental health services in particular, it is important to examine how far users are routinely positioned as *constraints* on change (see Iles and Sutherland 2001: 39) – in failing to accept or understand organisational arguments for change, or in lacking the knowledge and skills to adapt to or handle the stresses of change programmes (see Church, 1996; Harrison and Mort 1998; Kent and Read 1998; Simpson *et al.*, 2002). It might require a certain creativity and commitment on the part of managers, for example, to view user insights or demands as organisational strengths or opportunities rather than as threats – in a context where SWOT analysis remains a 'ubiquitous' strategic planning tool (Iles and Sutherland, 2001: 41; see also Leiper, 1993).

The analysis of forces 'for' and 'against' organisational change more recently has been refined in terms of a continuum of attitudes. Iles and Sutherland cite Senge's (1990) model of 'commitment, enrolment and compliance', which traces degrees of acceptance or resistance to change processes. Senge notes that effective organisational change generally does not require thoroughgoing commitment from all those involved. Rather the objective is to secure the appropriate degree of compliance on the part of different actors. Even non-compliance and apathy might be tolerable in certain quarters (see Iles and Sutherland, 2001: 47). It is questionable how far such a model for managing different attitudes to change on the part of staff can be applied to users of public services, and especially mental health services. The Audit Commission report on change management (2001: 44 –5) suggests that the level of commitment by different actors tends to be a key factor for the depth and durability of change, particularly given that changes must be sustained and reproduced throughout an organisation – and not simply driven by those leading the process. Both entrenched resistance and exclusion from meaningful involvement indicate restraints on change. Grudging compliance on the part of recalcitrant staff in itself is not ideal, but staff ultimately retain rights of exit from an organisation, or can 'do enough of what is asked of them not to jeopardise [their] position' (Iles and Sutherland, 2001: 44 –5). Mental health users often lack similar rights of exit: in this case, grudging compliance will appear more like coercion. Moreover, the relationship of users to public services raises larger questions of democratic citizenship than does the employment contract between organisations and staff (see Section 7.2). A commitment, enrolment, compliance framework is useful for analysing the attitudes of various stakeholders, but is more limited in addressing broader issue s of representation in relation to the involvement of users and carers in change processes.

7.1.4 Participation and representation

Questions of participation and representation are central to perspectives on user involvement in mental health settings. Th ese are often framed in terms of the claims of specific individuals or groups to speak for the interests, needs or rights of other users within formal systems of representation (see Bowl, 1996b). At an organisational level, however, questions of participat ion arise not only in terms of formal representative structures, but also in respect of a wider organisational culture that is facilitative of user and carer involvement. In examining key conditions for user involvement in organisational change, our review of the literature found that cultural factors were cited more than twice as often as representative structures (see Chapter 3). Similarly, a supportive organisational culture is seen in the management literature as a critical factor in promoting effective processes of change. In this section, we consider approaches to change that set strategies of participation and representation in the context of wider organisational cultures.

7.1.4.1 Soft systems methodology

Models of change management drawn from the or ganisational literature place emphasis on both the 'hard' elements of organisational performance (structures, strategy and systems) and the 'soft' dimensions (style, staff, skills and shared values) (Peters and Waterman, 1982; Iles and Sutherland 2001: 28 –9). Such an approach stresses the importance of organisational culture in shaping specific objectives and performance. This distinction appears in the user involvement literature as a contrast between such change categories as new service delivery, restruc turing and policy initiatives (that is, specific or step changes that can be planned and are usually measurable), and those promoting democracy, representation or cultural change (more gradual changes that are harder to measure). Our research suggests that these different categories of change are related in complex ways, but organisational change appears most successful when 'hard' and 'soft' changes occur in tandem.

Models of change management stress the importance of a supportive organisational culture, from management levels down (see Iles and Sutherland 2001: 32; Pettigrew *et al.*, 1992). Our review of the literature adds to this argument: a facilitative organisational culture appeared as a primary factor in promoting user and carer involvement in change management, while a resistant organisational or professional culture figured as the chief obstacle to effective user involvement in change initiatives. User and carer involvement might best be seen as part of a 'soft systems methodology' for managing chang e (see Iles and Sutherland 2001: 34–6); that is, where organisational problems and appropriate strategies of change are defined, developed and implemented in an iterative process that draws on the perspectives and contributions of different stakeholders within the organisation. Problems

are subject to re-definition as part of this process, and the content of and strategies for change are not predetermined. In ideal terms, changes are developed via a deliberative method that applies different models to the initial problem, rather than imposing a model of change from the outset.

This soft systems methodology for designing and managing change gets at the problem frequently identified in user literature: the fact that decisions are too often seen to be taken before 'consultation' takes place. In this respect, a focus on 'soft' organisational factors (people, values, norms) within strategies of change management involves quite specific techniques of facilitation and a systematic approach to problem solving. Consultation, in this framework, can take a variety of forms: meetings, focused discussions, surveys, interviews, organisational audit, mapping of organisational procedures, 'process flows' and relationships (see Iles and Sutherland 2001: 37 –8). In principle, such an approach to change should promote communication and learning between different actors within an organisation (users, carers, different staff teams, managers), and also gives these different interests shared (if not always equal) responsibility for defining problems and developing changes.

7.1.4.2 Organisational learning and development

A related approach to change management is found in the model of parallel learning structures, which goes beyond deliberation over problems and solutions to consider how changes are *implemented* within organisations (Iles and Sutherland, 2001: 54; Zand, 1974; Bargal and Schmid, 1992). Here, group structures are put in place specifically to monitor and guide the change process, creating a parallel organisational structure that should include representatives from across the organisation. The aim is to break away from established hierarchies and procedures, to promote learning between agents within an organisation, and to enable them to take responsibility for the process of change.

Lord *et al.* (1998) describe a process of change in a mental health housing and support agency in Ontario, Canada, which provides a useful example of this approach to change management. The organisation initiated a programme of strategic planning in 1991, based on two key drivers: the rapid expansion of the service since the mid - 1980s and a shift in the mental health field towards greater community integration and user empowerment. The change process therefore had a number of aims, including:

- development of a framework for long-term and short-term planning

- review of the agency's mission and goals in relation to emerging philosophies of community mental health

- review and improvement of provision in light of the new service ethos

- review and change of organisational structure in light of the new service ethos

- development of an evaluation strategy to monitor ongoing processes of organisational change.

(Lord *et al.* 1998: 331)

The change programme was driven initially by the agency's board and executive director. However the implementation strategy was based on a more participatory model of partnership and empowerment that created a parallel organisational structure to guide the change process. A steering committee ('stakeholder long-range planning committee') was established, based on equal representation from users, management, staff and board members. Other aspects of the change process were overseen by an implementation committee and an evaluation committee – both including representation fro m users, carers and family members, staff, management, board members, and community agencies, as well as an external facilitator – while action teams took responsibility for the implementation of specific changes. Leadership roles were assumed by different individuals at different stages of the change programme. Individual and organisational learning was central to the process, both through formalised training and workshops, and through informal learning via teamworking.

The analysis by Lord *et al.* suggests that this model offered an effective strategy for managing change, evaluated in terms of such factors as clarity of aims, sound planning, clear lines of responsibility and accountability, definite strategies for implementation, commitment on the part of different stakeholders, and measurable service outcomes. Moreover, in process terms the change programme itself helped to make real the new organisational ethos of user participation, empowerment and community integration. In this respect, the change programme in this community mental health agency produced both strategic and service changes, and 'transactive' change in respect of power relationships and communication within the organisation.

Set within a change management framework, this offers a positive example of organisational development – where organisational outcomes are achieved in tandem with individual practice – as well as a model of organisational learning – where knowledge is developed and used to promote ongoing change and transformation (see Iles and Sutherland, 2001: 60–6). Similar arguments are made in a British context by Gummer and Furney (1998), who assess the Lewisham and Guy's Joint Consultation Forum for user involvement. A range of different types of user involvement are integrated, from consultation to involvement in staff recruitment. In this context user involvement has an important role in determining change, rather than simply helping to implement or evaluate change. 'Soft systems' approaches – a supportive organisational culture and the promotion of democracy and representation – work in tandem with changes in service delivery, such

that specific or step changes fit into a larger process of organisational development. Hostick (1998) and Rea and Rea (2002 – see the discussion in Chapter 4) also stress the importance of organisational learning in facilitating change, analysing user consultation and information strategies as part of a 'research and change' process in which the ends of and strategy for change are not pre -given, but are refined in a more dynamic process of information exchange and participation.

Bowl (1996a, 1996b) points to a similar model of organisational learning and development in his analysis of user involvement following the National Health Service and Community Care Act 1990 (see the more detailed discussion of this research in Chapter 4). In outlining practical strategies for developing involvement (1996b: 176 –7), Bowl suggests that modes of user participation can shift over a period of time or across a process of change. As trust and confidence are built up in representative forums, as user–professional relations develop, as users enhance their organisational knowledge and skills, the degree of user involvement can increase (for example, from consultation to jo int decision making) and greater power can be transferred from professionals to users.

7.2 Consumerism and citizenship

The preceding discussion began by questioning a consumerist model as a basis for user involvement in change management in mental health contexts. Management approaches to organisational change emphasise the different roles and investments of various stakeholders. Such an emphasis is developed within a broader field of policy debates wherein the individual's relation to public services is increasingly understood as a kind of 'stakeholding'. The language of stakeholding also has entered the literature on user and carer involvement (Garcia Maza, 1996; Harrison and Mort, 1998; Lord e *t al.*, 1998; Ross, 2000; Simpson *et al.*, 2002). It is important to ask what constitutes a 'stake' in this context, as well as to recognise the very differently weighted 'stakes' that various actors have within organisations.

A central framework for analysing the stakeholder relation in mental health services turns on the distinction between users and carers as *consumers* and as *citizens* (see, *inter alia*, Armes, 2001; Barnes and Shardlow, 1997; Barnes, 1999; Breakey *et al.*, 1996; Church, 1996). This distinction has provided an important analytic tool within our review, both as a basis for conceptualising users' and carers' status and stake within organisations, and for tracing correlations between different forms of user/carer involvement and specific types of change (see Chapter 3).

Forbes and Sashidharan (1997) clea rly distinguish between consumerist approaches to user involvement and those liberationist approaches that emphasise self -help and user control. They argue that consumerist

approaches to user involvement are most often concerned with the detail of service provision, rather than with strategic, service and organisational planning. Their approach offers a challenge to the pluralist language of stakeholding, not only because structures of participation frequently reproduce power relations within mental health organisations (see also Williams and Lindley, 1996), but also because users do not represent a unitary stakeholder interest in themselves. In a similar vein, Marion Barnes (1999) argues that official agendas in a marketised system tend to construct users as one self-interested pressure group among others. The aims of user movements, however, are not always consonant with or limited to consumerist interests. Barnes uses an alternative analytic framework to consider user organisation in the fields of mental health and disability in Britain in relation to models of new social movements and theories of citizenship. She argues that service users have a dual identity: as consumers of services, and as citizens to whom such services are accountable (see also Barnes and Wistow, 1994; Barnes and Shardlow, 1997). Such a conception of users as citizens both challenges a view which positions users as 'passive recipients' of services, and equally challenges models of the 'active citizen' based on the figure of an independent volunteer. User movements are not concerned only with pursuing service needs nor simply with articulating citizen rights, they also represent a social movement that seeks to re-define the marginalised identities of mental health service users (see also Kauffman, 1999).

This citizenship or rights-based approach challenges certain professional assumptions that the purpose of user involvement is largely 'therapeutic' (see Barnes and Wistow, 1994; Bowl 1996b; Rutter *et al.*, 2001). That is, user involvement may be endorsed by professionals as performing a therapeutic or rehabilitative function in enhancing individuals' skills, competence and self-esteem. In contrast, understanding user involvement in a social movement or citizenship framework emphasises larger objectives of organisational change, of transforming social attitudes, and of gaining political recognition. Here, collective processes are given priority over individual outcomes. If resistant professional and organisational cultures emerge in our review as the chief factor constraining user involvement in mental health (see Chapter 3), there is also an argument to be made that some 'supportive' professional attitudes can also limit the impact and effectiveness of user participation by reducing this to individual therapeutic outcomes.

Harrison and Mort (1998) consider a different way in which broadly supportive professional cultures can work to reinforce existing power structures within mental health organisations. They set the empirical findings from a study of user involvement in disability and mental health services in Britain within larger debates about organisational change in public policy settings. They suggest that health and social service fields have become increasingly 'pluralistic' in terms of the recognition

and participation of a range of different stakeholders, including users, carers, managers, professionals, politicians and the general public. Strategies of public consultation and user involvement have been crucial to this opening-up of the policy arena, and the development of a market or network model for public service organisations. However, Harrison and Mort (1998) suggest that strategies of user involvement often reinforce the power of professionals and managers – in this sense, they describe user involvement as a 'technology of legitimation' for managerial and professional authority in a more marketised system of public provision.

Their argument works on a number of levels.

1 They note that user involvement is now widely endorsed by he alth and social service professionals. In this context, the 'user card' can be played strategically so as to bolster certain professional interests against other organisational interests. A stated commitment to users, that is, can reinforce the authority of particular professional voices.

2 They note that managers and/or professionals are often selective in taking up users' views. This partly is due to a significant degree of opposition to the 'professionalisation' of public and user forums. 'Professional users' are criticised as unrepresentative or self-interested, but 'unprofessional' users can be dismissed as incoherent, uninformed, or for 'not working like a welfare bureaucracy' (p. 66). This 'Catch 22' for user involvement means that user viewpoints an d demands come to be mediated by the interests and the judgements of professionals and managers.

3 in a 'pluralistic' or network model of public service stakeholders, users become one of many different interests. Their demands must be offset against those of other (including more powerful) stakeholders. In this respect, Harrison and Mort found that professionals and managers did not see themselves as bound by user views or demands: 'User groups were … a recognized feature of the organizational landscape, but not one to which any superior degree of legitimacy was accorded' (ibid.). Moreover, managers retained power at the centre of the network in terms of mediating the competing interests of professionals, users, carers, the public and political actors. A sh ift from top-down hierarchies to more inclusive networks (or horizontal 'markets') in the organisation of public services in these ways produced new techniques for legitimising managerial and professional power.

7.3 Conclusion

- Mental health users are not 'customers'. The limited rights of 'exit' or 'choice' available to many mental health users means that they cannot be understood simply as consumers of services. The user movement calls for a more robust range of citizenship rights than those found in the customer relation.

- Mental health users have a stake in how organisations operate internally, as well as in service quality. Models of change management generally position service users as external stakeholders. Mental health users, however, tend to be more involved or 'embedded' in organisations: the structures and processes through which services are delivered are therefore a legitimate interest on the part of users and carers.

- Processes are important. Mental health users and carers are concerned with not only the aims and outcomes of change programmes, but the means by which these changes are achieved.

- Information and communication are the chief factor promoting user involvement in change in mental health services. In the mental health literature, effective information strategy is cited as facilitating involvement twice as often as are formal representative structures. The timing and quality of information are therefore key issues for effective and inclusive change management.

- A challenge exists for change managers in viewing user needs and demands as drivers for, rather than constraints on, change – as opportunities rather than as threats.

- 'Supportive' professional cultures can skew user involvement to fit with professional agenda. Where professionals see the purpose of user involvement as primarily therapeutic, collective objectives and real organisational changes are downgraded. Key professionals also can 'play the user card' against other professional interests, while being selective in taking up user perspectives on the basis that this represents just one 'voice' among a range of competing interests in mental health services.

Chapter 8 Discussion

8.1 Introduction

This chapter pulls together some issues from the main body of the review that require further discussion. It does not at tempt a critical discussion of the entire literature but focuses instead on four issues which we consider important to bring to the attention of change managers. These have been chosen because of their relevance to change management specifically in a mental health context. In particular, these are issues where users and carers as opposed to professionals and managers may have different interpretations of similar events, processes and outcomes.

8.2 Reference group categories

The main coding frame categories generated by the reference group were virtually absent in the literature reviewed. Key among these were 'change not sustained' and 'champion absent or leaving'. Although it did not form part of the coding frame, the reference group was also very concerned by the emphasis on risk and risk assessment which is central to mental health policy and practice.

The members of the reference group all had many years' experience of user or carer involvement in mental health and in change management in mental health organisations. In contrast, (as we saw in Chapter 3) the change management literature in mental health is largely authored by professionals and targeted at a professional audience. The question then arises as to why there is a discrepancy between the views o f

these user and carer activists and those who write about their activities. We shall take three categories in turn:

1   change not sustained

2   champion absent or leaving

3   risk and risk assessment.

8.2.1 Change not sustained

This category was recorded only twice in the literature. One example has been discussed in Chapter 6 (Truman and Raine, 2002). In terms of the research papers and most of the discussions of practice, this is probably because the material consists mainly of 'snapshots' of user and carer involvement in change. This indicates a necessity for longitudinal analyses to see whether the outcomes and processes of user involvement change over time. In this context, the endeavours of Wallcraft *et al.* (2002) to build a database of user groups in En gland is instructive. The authors found that many groups on the original databases they considered had closed and that new ones had emerged very recently. This is compelling evidence that sustainability is a problem for user groups. The main factor upon wh ich sustainability depended was material and non-material resources. A further factor was 'burnout' on the part of committed activists of whom there are often only a handful upon whom responsibility for sustaining an organisation falls.

The absence of this issue in the literature indicates that professional authors either are not aware that sustainability is a problem for user and carer groups or else they do not write about groups which fail to maintain themselves. There may also be an element of 'publicat ion bias' in that papers describing the disintegration of user groups are less likely to be published in a policy context where user involvement is increasingly part of the policy agenda (see Chapter 1.)

8.2.2 Champion absent or leaving

The 'champions' re ferred to here are not the individuals recently appointed by government who are service users and are meant to push forward user involvement in each region of England. This development is too recent to have reached the published literature. Rather, these 'champions' are managers and professionals who maintain the momentum for user involvement within organisations which are changing in a user-focused direction.

It is not clear why a professionally authored literature should appear to be blind to the importan ce of key individuals whom user groups perceive to be 'on their side'. One possibility is the argument of Parkes (2002) that 'champions' are sometimes cynical individuals who are building a career for themselves out of promoting user and carer involvement. This is also the view of writers such as Harrison *et al.*

(1997) writing from a more empirical point of view. On the other hand, some user authors (such as Lindow, 1993) take a more positive approach to those professionals whom they perceive to have helped sustain the momentum of a user group.

At the very least, change agents need to be aware that developments such as the appointment of professional 'user involvement leads' in trusts may be met with cynicism on the part of user groups if the result is that change is managed in a 'top-down' way and such that the autonomy of user and carer groups is compromised.

8.2.3 Risk and risk assessment

Members of the reference group pointed out that there can be a tension between two recent emphases in mental health policy: requirements for user involvement, and the priority given to managing risk. In their analysis of user involvement in risk assessment, Hird and Cash (2000) recognise that issues of risk often reinforce professional power and control vis-à-vis users. They argue that when professionals (their emphasis is on mental health nurses) assume direct control in contexts where users are considered a risk to themselves or to others, this relation of power should be made clear to the individual involved. If information and communication are seen as central to effective strategies of user involvement, information strategies are also important in contexts such as those surrounding risk and risk assessment, where professional power is retained. The authors propose both the use of advocates and the development of an agreed 'charter of rights' to inform and involve users in the context of risk assessment.

Similarly, Langan and Lindow (2000) stress the importance of information and communication strategies in this context , including: professional education and awareness regarding potentially discriminatory patterns of risk assessment (where mental health workers may be more likely to perceive black service users as dangerous); listening and talking to users in assessing ri sk factors; clear case notes which are made available to the user; and, when it is seen as necessary to break patient confidentiality in passing on assessments of risk, written rather than verbal communication between agencies (for example, using fax or e-mail in emergencies), so that this record can be made accessible to the user. In both these accounts, user involvement is facilitated in a context of restated professional control through transparent and consultative information strategies.

8.3 Ambivalence regarding user involvement in mental health

There is evidence of ambivalence about user involvement in mental health in the literature reviewed here. In terms of SWOT analysis, the term 'threat' appears much more frequently than any reference to 'opportunity'. Returning to Chapter 1 and previous reviews, Rutter *et al.* (2001) claim that the threat posed by user involvement means that changes have remained very much at the level of tokenism. Simpson *et al.* (2002) are very clear that it is the specific characteristics of users of mental health services that make their involvement in service change a problem. The fact of users' distress is repeatedly referred to as a problem of 'coherence' which entails quite specific difficulties for involving mental health service users in what they propose should be a very structured and 'rational' process.

Parkes (2002) makes this ambivalence the major thrust of her entire thesis by entitling it '*Feathers and Thorns*'. She takes this title from a quote by one of her interviewees who said 'I'm a feather in their cap and a thorn in their side'.

8.3.1 Catch 22s

We have already referred in Chapter 7 to the 'Catch 22' that besets the issue of 'representativeness' in mental health. Articulate users are criticised as unrepresentative because 'ordinary' users are not articulate. This stops user involvement in its tracks before it can begin. It is a particular problem that users and carers are asked to be more 'representative' than any other group of stakeholders in the change management process.

There are other 'Catch 22s' which reveal the ambivalence of professional writers to user and carer involvement in change and this was particularly apparent in Chapter 6 on new service provision. What was clear in much of this literature was that the very attributes which make users of value in the change process are held at the same time to constitute a problem. An example may be taken from 'new service provision' literature (such as Dixon *et al.*, 1994). User workers in, for example, case management roles are recognised as better able to empathise with their clients than professionals who have not themselves experienced mental health problems. They are able to empathise because they have 'been there' themselves. However, at the same time this very ability becomes problematic in that it means that user workers may not be able to maintain appropriate 'boundaries'. They may become too close to clients, and form friendships, which may then come into conflict with their professional role.

8.4 Power differentials

We saw in Chapter 3 that power differentials were an important obstacle to user and carer involvement in the change management process. At one level, such a finding seems quite simple to interpret because it is obviously the case that managers and professionals have more power and status than do users and carers. However, on closer inspection of the literature, it emerged that several different analyses of the nature of power differentials were being discussed. In Chapter 7, we reviewed the analyses by Harrison *et al.* (1997) of user involvement in change management as a 'technology of legitimation'. Here, managers in particular may 'play the user card' strategically and to their own advantage. In this way, they retain control over change. As well as obvious power differentials and an approach to user involvement which legitimates existing power relations, there are three more ways in which power differentials are analysed, implicitly or explicitly, in the literature:

1   resolving potential conflicts before change begins

2   structural inequalities

3   forms of knowledge.

8.4.1 Resolving conflict in advance of change management processes

Simpson *et al.* (2002) argue that possible conflicts between users and managers or professionals should be resolved before a process of change begins. Such a position could be argued to misunderstand the nature of power relations between users and managers as well as to misunderstand the change process. Since straightforward power differentials are a standing feature of relations between users and managers and professionals then conflict can be expected in any domain where *process* is important. Areas of conflict at one point in time may be resolved but others are likely to arise as change management proceeds. Once one takes account of the 'Catch-22s' and the ways in which the arguments of users may be undermined by conceiving them as symptoms of mental illness, the process clearly becomes more complicated. Indeed, on this latter point, the arguments advanced by Simpson and colleagues themselves contain the seeds of conflict because of their emphasis on psychosocial 'coherence'.

8.4.2 Power differentials in mental health and structural inequalities

Williams and Lindley (1996) argue that structural inequalities in society are magnified in the power differentials that exist in a mental health context. Those groups disadvantaged in society as a whole – poor people, those from ethnic minorities and women – are over-represented in psychiatric facilities. Those who make the fin al decisions about their treatment – psychiatrists and psychologists – form the opposite poles of the social strata. Williams and Lindley also point out, as we have done ourselves, that the power at issue here is often quite the reverse of the conception of the average 'consumer'. On some occasions, mental health users cannot take their business elsewhere, they have no 'exit', and may be treated forcibly and against their will.

Brandon's (1991) arguments about nursing staff are also relevant here because clearly not all psychiatric staff occupy advantageous social positions. For Brandon, nurses and community workers perceive themselves as of lowly social status. Of the groups with which they come into close contact, only patients occupy a lower rung on the social ladder. So, argues Brandon, community and hospital nursing and support staff have a vested interest in maintaining the power differentials between themselves and their clients.

8.4.3 Knowledge and power

In their review of user involvement in a post -qualification training course, Barnes *et al.* (2000) point out that the knowledge of users tended to be seen by course participants as inferior to the knowledge of professionals. This was not just a question of who was speaking but of the status of the knowledge itself. Since the course participants were constantly being taught the importance of evidence-based medicine the experiential knowledge of users could be dismissed as 'anecdotal'.

There is a more general argument here which links back to the points made above regarding ambivalence. The experiential knowledge of users may be valued for its authenticity but when set beside forms of knowledge which can claim the status of 'evidence', that authenticity occupies second place. In addition, the direct experi ence of users and the way it is expressed may sometimes be dismissed as too 'unsettling' (Church, 1996), distressing or disturbing.

8.5 User involvement as 'therapy'

In Arnstein's ladder of citizenship participation the two lowest rungs are labelled 'tokenism'. These in turn are called 'manipulation' and 'therapy'. As we have seen, authors of the change management literature frequently claim that user involvement leads to greater confidence, skills learning and self-esteem for the involved users themselves. In the view of Rutter *et al.* (2001) this means that much user involvement is conceived as 'therapy' and they accept the idea that this means it is tokenistic.

However, there may be a problem in transferring Arnstein's model, which was devised in a community regeneration context, to a mental health context. This becomes evident in Kauffman's (1999) analysis of social identity theory and new social movement theory. Social identity theory was originally formulated in Europe (Tajfel, 1981) although the literature referred to by Kauffman is more recent and from North America. The importance of this approach is that it indicates that whereas professionals may view user involvement as 'therapeutic', users may conceive of it rather differently (see also Bowl, 1996b). If this is the case, it is important that managers and professionals are aware of the discourse which users are deploying.

Social identity theory starts from the assumption that part of a person's identity derives from the social categories to which they belong. These social categories may be chosen or they may be imposed. In addition, they may have a positive or negative social value. People who belong to negatively valued social categories that are imposed on them can resign themselves to the situation or they can try to change the social situation or re-value the negative aspects of their identity. Tajfel takes as the earliest example of this the 'black is beautiful' movement.

It can be argued that people deemed mentally ill have the most 'spoiled' identity of any social group. This is because it is their identity itself that is seen as flawed. Stigma means that many individuals go to great lengths to hide their mental patient status. The user movement, in at least some of its forms, can be seen as an alternative strategy. The user movement tries to re-frame a negative social identity as positive and strong. This links also to the question of citizenship because those deemed mentally ill have in the past been denied full citizenship rights on the basis of lack of 'competence' (see the discussion of 'coherence' in Simpson et al. (2002)). Citizenship rights are then re-claimed by rejecting the spoiled identity and forming a social movement on the basis of re-valuing aspects of 'madness' or arguing that the attribution of 'incompetence' is largely misplaced. Finally, the rejection of a medical model of mental illness may be part of this process since such a model denies the possibility of 'recovery'.

The reason for this brief foray into social psychology is to bring to the attention of change managers a possible misunderstanding of the 'therapeutic' defence of user involvement in a specifically mental health context. The alternative argument is that some parts of the 'user movement' may be engaged in a more radical form of 'identity politics'. This in turn may be why the undermining of users' contributions to change debates by pathologising them is met with such ferocious denial. If change managers are unaware of the possibilities sketched above, the stage is set for unnecessary conflict in the change management process.

8.6 Conclusion

In this chapter we have developed specific issues that emerged in the substantive review. They were chosen because they have particular relevance to change management in a mental health context. As is evident, the issues are interlinked and speak to some of the difficulties in giving users and carers an equal voice in the change management process.

Chapter 9 Conclusions

The literature assembled presents a complex picture of user and carer involvement in change management. It is very diverse and of variable quality.

Our review suggests that the role of organisational culture is key in both facilitating or impeding user/carer involvement in change management. Change tends to be most successful when 'soft' change at the level of organisational culture occurs together with 'hard' changes in organisational structure, systems and services.

There is a danger that government demands for agencies to demonstrate user involvement may me an that user activities become a formal procedure to be 'ticked off', rather than an embedded and powerful organisational practice.

The threat posed by user involvement means that changes often have remained very much at the level of tokenism.

Mental health users have a stake in how organisations operate internally, as well as in service quality. Models of change management generally position service users as external stakeholders. Mental health users, however, tend to be more involved or 'embedded' in organisations: the structures and processes through which services are delivered are therefore a legitimate interest on the part of users and carers.

There can be tension between workers and users/carers. Managers and other staff may see user involvement as bo th of value and a threat. One way of understanding this is as a conflict between staff and managers' desire to implement a rather limited consumerist agenda and the hunger of many users to reclaim their spoiled identity and reassert themselves as citizens. User involvement in change management will work best when frontline staff and other stakeholders are also meaningfully engaged in organisational processes. However, conflicts will inevitably arise between the various actors.

The literature suggests that the employment of service users as practitioners and the development of user-controlled services are more prevalent in USA and Canada. These practices are at the cutting edge of user/carer involvement in change management and present the greatest potential challenges and rewards. UK services are developing in this direction and it would be prudent to learn as much as possible from the American and Canadian experience.

Further user-led research is required to establish reliable outcome measures for user and carer involvement in change management. Such measures must incorporate the important role of processes and the

difficulty of measuring cultural changes, and acknowledge that different stakeholders will have different perceptions of what represents a positive outcome.

Good practice points

Tables 1 and 2 show factors which facilitate and hinder user and carer involvement in change management. (The factors are not ranked and many individual factors are interlinked).

Table 1

Factors which facilitate user/carer involvement in change management

- Adequate resources present

- Facilitative organisational culture

- Good-quality organisational information strategy

- Autonomous user groups

- Professional champion present

- Staff training by users

- Training of users

- Payment and/or employment of users

- Representative structures

- Recognition and understanding of power differentials

- Acknowledgement of and sensitivity to factors pertaining to mental distress and practical measures in place to minimise these (for example advocacy)

- High-quality, meaningful and measurable involvement processes

Table 2

Factors which hinder user/carer involvement in change management
• Lack of resources
• Resistant organisational culture
• Poor information strategy
• Lack of autonomous user group
• Professional champion absent
• Power differentials not understood
• Factors pertaining to mental distress not acknowledged
• Involvement for the purposes of display only

Table notes

Information

Information and communication are an important factor promoting user involvement in change in mental health services. In the mental health literature, effective information strategy is cited as facilitating involvement twice as often as are formal representative structures. The timing and quality of information are therefore key issues for effective and inclusive change management.

Professional champions – autonomous user groups

It is clear that user and carer involvement in change management requires proactive professional managerial input. However, there is a delicate balance to be struck by managers. On one hand they need to be supportive of involvement both practically and by helping to create a facilitative organisational culture. On the other hand managers need to ensure that they do not compromise the autonomy of users and carer groupings by attempting to manage and control them. Independent user groups are a prerequisite for the development of user-controlled services.

Power differentials

Power differentials are an inevitable consequence of both the mental health system and wider structural inequalities. They can be managed and to some extent mitigated only if they are made explicit. Training, various forms of support, advocacy and ability for structures to be flexible all contribute increasing the possibilities for more equal partnerships.

Factors pertaining to mental distress

Several factors linked to the experience of mental distress can impair people's ability to participate in standard change management processes. Therefore structures need to be flexible and responsive to individual needs. For example, minutes and papers may need to be put onto audiotape, meetings timed around public transport constraints and jargon minimised. The nature of some mental health problems is episodic; therefore systems need to accommodate this, perhaps by ensuring that participation involves as many people as possible. A challenge exists for change managers in viewing user needs and demands as drivers for, rather than constraints on, change – as opportunities rather than as threats.

Recommendations

1   User and carer involvement should be adequately and sustainably resourced. This includes supporting autonomous groups and paying individual users properly for their time.

2   Organisations need to strike the right balance between supporting user and carer involvement and allowing user and carer groups to remain autonomous.

3   Training of staff by users is an important factor to facilitate user involvement; training of users is also important. Research is required to determine how such training can be delivered most effectively.

4   User involvement in change management should begin at the earliest possible stage of a project and should be maintained at every subsequent stage. Users should be engaged not only in consultations prior to change programmes, and evaluations of change outcomes, but in organisational processes of change management.

5   A high-quality information strategy is essential to user and care involvement. Organisational governance and decision making should be as transparent as possible.

6   Power differentials need to be acknowledged, understood and sensitively managed.

7   Change management processes need to be adapted to ensure they are accessible to service users, including making all reasonable accommodations for the participation of people experiencing mental distress.

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Appendices

Appendix A Coding frame

Reference

Type of paper

1 Editorial/opinion

2 Discussion – concepts

3 Discussion – practice

4 Research paper

   (a) quantitative

   (b) qualitative

5 Organisational report

6 Other (describe)

Target audience

1 Academic

2 Professional

3 Users/carers

Focus of user involvement

1 Individual service

2 Local service

3 National service/policy

4 Non-specific

Impetus for change

1 User or carer driven

2 Organisationally driven

3 Policy/funding driven

4 None or not clearly specified

Publication source

Type of service

1 Statutory

2 Voluntary

3 Private

4 Not specified

Country

1 UK

2 US/Canada

3 Europe

4 Australia/NZ

5 Other (specify)

Facilitating user involvement

1 User training

2 Users as trainers

3 Staff training

4 Resources (funding)

5 Resources (other – e.g. staff/facilities)

6 Payment of users

7 Representative structures

8 Facilitative organisational culture

9 Information provision/strategy

10 Other support (describe)

11 None specified

Reference	Publication source
Models of user involvement	***Type of change***
1 Consumerism (individual)	1 Promoting democracy/representation
2 Consumerism (collective)	2 Change of mission
(a) Consultation	3 New service provision/delivery
(b) Representation	4 Restructuring
(c) Partnership	5 Policy initiative
(d) Evaluation	6 Strategic planning
(e) Involvement in staff recruitment	7 Cultural change
3 Citizenship	8 For purposes of display only
(a) Campaigning	9 Users employed
(b) User control	10 Change not sustained
	11 No change or none specified
Target group	
1 Service users	***Obstacles to user involvement***
2 Carers	1 Lack of resources
3 User groups	2 'Champion' absent/leaving
(a) informal	3 Lack of autonomy
(b) constituted	4 Resistant organisational/professional culture
4 Carer groups	5 Power differentials
5 Community/public	6 Factors pertaining to mental distress
6 CHCs	
7 Staff/professional	***Outcomes of user/carer involvement***
8 Special constituencies	1 Positive outcomes
(a) minority ethnic	2 Negative outcomes
(b) women	3 Unclear or not yet known
(c) substance users	
(d) homeless	***Rating***
(e) acute	1 Recommend inclusion
(f) older people	2 Consider inclusion
	3 Marginal – some insights
	4 Reject – not relevant/informative

Appendix B Reference group

The SDO requests that there be consultation in all its literature reviews and therefore a reference group was convened to guide the project. Users and carers who are active in user/carer involvement and academics with an interest in user/carer involvement were invited to join the group. The following were members of the group:

Gloria Brown	Independent user/survivor
Silvio Coutinlto	User, Southwark MIND
Molly Evans	Independent carer
Maralyn Longman	Independent carer
Jan Wallcraft	User researcher Sainsbury Centre for Mental Health
Peter Campbell	Independent user/survivor
Tessa Parkes	Tizard Centre, University of Kent
	(PhD completed on the politics of participation in mental health services).

Owing to the tight timescale of the review, the group met once (Thursday 27 June 2002) but was also available for telephone and e - mail consultation.

The reference group's role was twofold: firstly as an additional source of material for the review; secondly as a source of advice on and interpretation of the review's themes. Many of the group are and have been very active in the field of user involvement and have views about what makes user involvement successful or unsuccessful in practice, as distinct from what is written about in a largely professionally authored literature.

A one-off fee of £200 was paid for attending the meeting in London. There was an intention to circulate a draft to the reference group but time precluded this.

The meeting of the reference group was facilitated by Dr Fran Tonkiss and Pete Fleischmann. An 'areas of talk' protocol was agreed in advance (see below). The meeting was recorded on audiotape and in addition a note-taker took detailed notes. Using this information the themes of the meeting were analysed.

Areas of talk protocol

Change in a mental health context

- Restructuring of organisations
- New policy initiatives
- Changes in service delivery
- Issues of democracy/representation and consultation

Key issues in user and carer involvement in a mental health services context

- What models of user/carer involvement should we look for?
- What kinds of changes have involved input from users and carers?
- How can user and carer involvement be promoted during times of change?
- What are the factors that promote effective user/carer involvement?
- What are the factors that prevent effective user and carer involvement?
- What are the benefits associated with user and carer involvement?
- What are the disbenefits associated with user and carer involvement?
- What, if any, might be the differences between user and carer perspectives?

Appendix C Themes that emerged from the reference group

Sustainability

How sustainable is user involvement, given user/carer fatigue and the contingent nature of various forms of support? Awareness that user involvement was currently fashionable but that this was no guarantee for the future. Sustainability was a particular issue in relation to making the transition from pilot projects to main stream provision. There was recognition of importance of allies in senior management positions. However, improvements in user involvement were often linked to an individual manager and are not sustained once the individual leaves.

Risk

Risks real or imagined had a bearing on how far managers were prepared to involve users/carers. The lower the risks the more likely users/carers were to be involved. Some participants felt that user involvement in practice was being displaced by an emphasis on risk management.

Issues of democracy and representation

Concerns that user involvement could be tokenistic image management rather than genuine democratising of services. There was criticism of the deployment of individual users who were not necessarily representative. Participants were especially critical of the idea of government user champions. 'Top-down' involvement was criticised. Some managers were perceived as concerned with maintaining the status quo and seeing user involvement as a threat to this.

Resources

Resources were viewed as an important underpinning of sustained and effective user/carer involvement. It was essential to build the capacity of user/carer groups. This was seen as including funding for paid workers, for user/carer organisation's premises and equipment, and the infrastructure for regional or national organisations to bring together and support local groups. Funding, however, raised issues of control and possibility of radical agendas being 'neutralised'. There was a need for resources to fund accountability and to ensure that leaders connected with their constituency. Resource issues extended to the

provision of user-run services and a capacity for users to commission services directly. The structures of the benefits system were seen as detrimental to user/carer involvement and also unfavourable to recovery more generally.

Users and carers

User and carers could have different agendas: users typically wanted less control from services and carers more. However, users and carers could also form allia nces to protect existing services.

Cultural change

It was suggested that changes in attitudes and organisational culture were a crucial and potentially far-reaching change that followed from user/carer involvement. However it was extremely difficult to me asure or evaluate cultural change, even where these underpinned changes in practice. The education and training of professionals by service users and carers were seen as important elements in the promotion of cultural change.

Defining user involvement

There is a tension between top-down, bureaucratic user involvement and the radical democratising agenda of some users. Real user involvement was perceived as concerning fundamental shifts in attitudes and power structures. User groups/individual users might have more interest in radical shifts in practice, for example user -run services or user-defined outcome measures rather than 'bureaucratic style' involvement. Gains for users were perceived to be by -products of user involvement structures, for example the de velopment and strengthening of networks. It was felt that navigating the potentially conflicting philosophies of the user movement (which broadly follows a social model of mental health) and the mental health system (which is perceived to follow a medical model of mental illness) was a difficulty for all participants in user/carer involvement. It had to be recognised that power differentials existed between users/carers and professionals.

Benefits of user/carer involvement

Users and carers felt empowered an d more in control of their lives. Users and carers had improved self -identity. Mental health provision and patient outcomes were improved. Services were redefined. Innovation was seen as a key benefit. Original imaginative and flexible responses to problems could result from user involvement. Staff were better trained, more knowledgeable and more effective as a result of

successful user/carer involvement. Networks and alliances were developed.

Disbenefits of user/carer involvement

User involvement had both positive and negative impacts for individuals' health, including burnout. Change could be cosmetic rather than structural. User involvement could legitimate the status quo rather than challenge it. Users and carers could be positioned as one interest group among others, rather than the key stakeholders of a user-centred service.

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Addendum:

This report was amended on 29th September 2011 to update the correct copyright statement and/or correct the publication date. The content of the report has not been changed.