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

Executive summary for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

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Executive Summary

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 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.

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.

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**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 overarching 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 organisational 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 exists 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 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.

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 concepts 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, are 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 reinforce 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 that 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 marginal 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 exusers 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 different 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 quite 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 status 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 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 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 both 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 in 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 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 participation of people experiencing mental distress.
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