

Developing user involvement

Working towards user-centred practice in
voluntary organisations

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Contents

Acknowledgements	iv
<hr/>	
1 Introduction	1
What user involvement means	1
The project	3
<hr/>	
2 Summary of findings	4
<hr/>	
3 Enablers of change	6
A focus on users and a focus on users' priorities	6
Vision and commitment	7
Sustained leadership	9
Quality of dialogue	10
Presence of users	11
Resources	12
Policy and funding context	13
External support and scrutiny	14
Equality of opportunity	15
Continuous monitoring and evaluation	15
<hr/>	
4 Barriers to change	16
Fragmentation	16
Leaders with a control style	17
Inconsistent leadership and support	18
Glass ceiling	19
Fashion and rhetoric	19
Involvement of the few	20
Staff turnover	21
<hr/>	
5 Overview and issues	22
Overview	22
User-centred user involvement	22
Influential supporters	26
Working with difference	26
<hr/>	
6 Conclusion	28
<hr/>	
References	29

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Introduction

This report presents the findings from an action research project funded by the Joseph Rowntree Foundation and which ran from late 1998 to June 2000. The aims of the project were to:

- support the implementation of increased user involvement in the governance and management of traditionally structured charities;
- develop and demonstrate methods for the management of change that include users, staff and trustees;
- monitor and evaluate the impact of increased user involvement from user and organisational perspectives.

The impetus for the project was the belief that it is important for both service users and those organisations which set out to benefit them to increase the levels of user involvement in their governance and management. We wished to assist progress towards the priorities and aspirations of service users being at the centre of every aspect of the work of the organisations that participated in the project.

There is a growing demand and need for an improved understanding of the processes of change in this area. Parts of the user movement have demanded for some time that traditional voluntary organisations should become more strongly influenced (Morris, 1994) or controlled (Oliver, 1998) by service users. A review by voluntary sector leaders stated that “users are vital stakeholders” in voluntary organisations and that “their rights are central to the future role of the sector and their involvement is crucial” (CFVS/NCVO, 1996). The Association of Chief Executives of Voluntary Organisations (ACEVO) has had a working party on user involvement and an initiative for chief executives to identify and publicise good practice (Taylor, 1999). One study concluded by urging that, “it is essential for the voluntary sector to address non-

accountability to users as a matter of urgent priority. It needs to look at issues of organisational structure, systems, procedures and culture in relation to user accountability” (Kumar, 1997, p x).

Despite widespread agreement about the broad direction for more traditional charities in the voluntary sector, the route to user involvement and services that achieve desired outcomes, as defined by users, is less clear (Robson et al, 1997). A previous project which assisted 11 voluntary organisations with a reviewing and planning exercise on user involvement confirmed the need for support to users, front-line staff, managers and trustees to enable them to understand the issues and develop tailor-made practical solutions based on sound principles (Robson and Devenney, 1998).

The findings of this project are not a precise recipe for managing change or increasing user involvement in voluntary organisations. The accounts from the participating organisations form a collage of experiences from longer continuing journeys. The lessons we draw out, under the themes of enablers and barriers to change, are intended to stimulate ideas about the kind of journey and destination that would be appropriate to other organisations. Before describing the project and its findings in more detail, we shall briefly set out and clarify some of the key concepts and issues.

What user involvement means

In a night-shelter for homeless people, a member of staff said that, to him, more user involvement would mean users helping to tidy up their beds in the morning. In a voluntary organisation providing services for disabled people, one user of its services thought that getting involved

meant “being able to voice opinion, being *heard* and acted upon” and another user said that involvement meant “making friends”.

The above examples illustrate how involvement can mean different things to different people. On its own, the term ‘user involvement’ is too imprecise to be of much help. At the start of this project we defined user involvement as the participation of users of services in decisions that affect their lives. We also wished to focus on decisions about services and organisations, as opposed to decisions about an individual’s use of a service. Our experience of working with users during the project led us to use a broader definition of involvement to accommodate users’ perceptions that involvement could include almost any kind of engagement with the organisation. This was one way in which we attempted to be ‘user-centred’ rather than focus on our own preconceptions of what user involvement was about.

This report, however, focuses on increases in involvement in decision making within organisations. User involvement, in running or controlling voluntary organisations, has become an important issue for a combination of reasons. First, service users have organised campaigns around demands for civil rights, which have impacted on statutory, private and voluntary sectors. Second, the 1980s and 1990s saw a cultural shift that emphasised the rights of individuals as consumers of goods and services. Third, concepts of self-reliance and individual responsibility have permeated the practice of welfare professionals who therefore expect their clients to ‘participate’ in solutions to problems. Fourth, trends in the private sector towards being ‘customer facing’ and ‘close to the customer’ have influenced public sector management approaches. Fifth, user involvement is increasingly enshrined in official policy for example, in the conditions set by statutory and charitable funders, in quality assurance checklists and in central government policy and guidance. Last, but not least, it seems like common sense that the people using services, who it is intended should benefit from them, should be involved in deciding what those services should be and in ensuring that they are of high quality.

In short, users of services should be able to demand accountability from providers of services. And further, there is a need for formal

mechanisms to achieve accountability so that it is not dependent on the goodwill of service providers.

Support for increased user involvement at the levels of governance and management of voluntary organisations is not universal. A range of arguments are put forward against user involvement. First, there is a view that users will be biased and make decisions either to benefit themselves individually, or to benefit current users without consideration for future users. It is assumed that where there are such conflicts of interest they should be avoided by exclusion of users rather than managed. Second, some question the competence or expertise of users to make decisions about complex issues, for example relating to finance and strategy. Third, some think the costs of consultation and participation in decision making are an inefficient use of charitable or public resources. Fourth, some fear that users would make irresponsible decisions and not take into account the legal and resource constraints on a service-providing organisation.

While we have encountered these arguments, they are rarely voiced in public, probably because we are in a climate that strongly supports user involvement. We are concerned that if questions about user involvement are not raised openly the issues cannot be properly debated. Additionally, we would not be able to learn about the impact of resistance to processes of change.

All the arguments that centre on why implementation of user involvement might not work can be countered by examining the self-help dimension of the voluntary sector. Self-help organisations of all sizes, from small local groups to national service providers and campaign groups, are run by and for people with a common experience and problems that need attention, as defined by them. Many of these organisations have governing bodies where service users make up all or most of the membership. Some self-help organisations have policies to employ chief executives and/or other staff who have the same condition or are in the same circumstances as the membership. These organisations do not appear to experience significant problems as a result of high levels of user involvement.

The project

We were committed to developing user involvement and to helping organisations to change. We worked with organisations that had a stated intention to increase user involvement in their governance and management. Our commitment was translated into action by collaborating with four voluntary organisations and providing facilitation, consultancy and research resources. The application of these resources was planned with each organisation to blend in with existing initiatives while at the same time offering an opportunity to stimulate change. Approximately 20 days were allocated to each organisation for contact with a combination of users, staff, managers and trustees.

We aimed throughout to work jointly with users and staff. In practice, who we were able to contact and develop relationships with varied. A written plan was agreed with each organisation and included objectives, tasks, timetables and expectations about the working relationship between researchers and people in organisations.

Direct contact between members of the research team and service users was an explicit objective. We knew from our previous work that developing user involvement could become a management-led activity or 'management project'. There were some issues of access to service users. There were also questions about the users' level of interest in taking part in this project since it had started with managers and ourselves as researchers. However, we found that once we had direct contact with service users they seemed reassured that this project was a genuine attempt to support them with progressing their own objectives. From our point of view it seemed that our independence, joint management of the project by one disabled and one non-disabled researcher, involvement of a user as an interviewer and willingness to focus on service users' priorities, helped to enable their participation.

We wanted to bring service users together with those who currently made the decisions (managers, staff and trustees). This happened to some extent in all the organisations. However, the main method of communication between users and current decision makers in three of the

organisations was for service users, mostly in groups, to talk confidentially to the researchers and for the researchers to report, usually in a written summary, to managers.

The action research activity previously described was complemented by contact with an associate group of seven organisations. We shared information and experience with these groups and in one case provided some facilitation for a service user event.

We held a practice exchange event for a range of participants from the action research and associate group organisations. The aim of the exchange was to draw on the experiences of organisations involved in the action research project and to identify the key lessons to be learnt that will enable others to increase user involvement. The participants considered the following questions: What difference has user involvement made in our organisation? What has made user involvement work well? What have been the obstacles to user involvement? What needs to happen to build user involvement into the foundations of an organisation?

2

Summary of findings

There was a rich variety of journeys towards increased user involvement in this project. We have found the journey metaphor a useful aid to understanding the development of user involvement. This summary of findings describes the themes and issues which emerged from the four action research organisations and seven associate group organisations. The body of the report contains detailed discussion of the enablers of and barriers to change, and case examples to illustrate them.

We propose that it is possible to distinguish between two broad approaches to user involvement. Some of what we observed in organisations we would define as ‘user-centred user involvement’; where user involvement meant that service users were able to pursue their own objectives and priorities and had opportunities to organise and meet in ways that suited them. This kind of involvement led to benefits for them as individuals and their groups. There were also benefits for the service providers in terms of effectiveness, responsiveness and relationships with funders.

The second approach to user involvement we observed was where user involvement meant that service users took part in existing structures and the agenda was defined by the service-providing or campaigning organisation. We propose that this type of user involvement could be defined as ‘management-centred user involvement’. We suggest that in these cases, while the organisations experienced less actual change and pressure to change, they may have enhanced their reputation and public presentation.

A variety of factors appeared to influence the processes of change. While all the factors, enablers and barriers described in this report are important, we identify some as particularly vital.

A belief in and commitment to a user-centred approach was an essential starting point. However, only where this commitment was consistently translated into practice at many levels did we see the build up of a critical mass of experience and activity, which could lead to a perception that involvement had become part of the organisation’s culture. Furthermore, it was rare for the depth and breadth of change to be sufficient for people in the organisation to say that they felt there had been a change in its culture.

People in leadership roles who were influential within existing power structures in the organisations we studied were central to the process of change. Where they operated with a facilitative leadership style they opened up opportunities for users without retaining control of all aspects of an involvement initiative and throughout its life. Leaders were obviously necessary to drive the process of change. However, where they had a control style of leadership, user involvement initiatives would often be seen as ‘top down’ or, in our terms, management-centred.

User-centred initiatives and opportunities opened up by facilitative leaders were connected through good quality communication. A dialogue between users and managers was fundamental to most of the changes we observed in this project.

The ingredients described above – commitment to user-centred user involvement, facilitative leadership and good quality communication – could be seen as building towards strong relationships between those in decision-making roles and those who were not in such roles, at least not yet. We also think that relationship building is underpinned by a commitment to work with difference. The charitable tradition from which many modern voluntary organisations come is based on differences

between groups of people. Much charity work was about the paternalistic benevolence of one group in relation to the other, for example, those who were wealthy, giving to those who were poor. And, it was not expected that the structure of relationships between these groups would change as a result of contact with those charities. This is radically different from the work of some voluntary organisations now, which aim to incorporate notions of civil rights, accountability, mutual support and self-empowerment.

In the organisations we worked with there were many people who worked positively with difference, and particularly the differences between the roles and experiences of staff and users. We also observed practitioners who viewed service users as unlike themselves and this led to an 'us and them' atmosphere which acted as a barrier to increasing user-centred user involvement.

In contrast, we also observed the fragility of sustainable progress. If, for example, the dialogue broke down or a facilitative leader was replaced by one who was more controlling, or a user-centred initiative was under-resourced, then progress could be slowed or halted.

A final issue which emerged was the degree of clarity about who the organisation is for. Organisations that had a clear commitment, usually over many years, to one clearly identifiable group of users or constituents seemed to be able to make progress with all levels of user involvement. In contrast, organisations that have two or more user groups, whose interests and priorities did not always coincide, experienced some conflict regarding a variety of policy and resource decisions. Sometimes they experienced conflict over the values, direction and purpose of the organisation. Consequently, where there were two or more user groups, for example relatives/carers and disabled people, it was more difficult and complicated to progress user involvement.

The identification of enablers of and barriers to change came from observations and discussions with users and staff in the organisations. These characteristics could be used to assess whether the conditions for change are present in other organisations. However, achieving change that resulted in a real shift in power usually meant doing more than, say, recruiting a facilitative

leader, allocating some resources and having a clear vision. The long and often slow process of change was usually driven by consistent and persistent pressure, from leaders and external sources, to introduce and maintain the enablers of change and to remove the barriers to change.

Evaluation of whether user involvement had been implemented successfully or not evolved as a continuous process. There was a tension between a commitment to focusing on the experiences and priorities of users and the objective of monitoring and evaluating user involvement from a management perspective (Robson and Begum, 2003).

3

Enablers of change

A focus on users and a focus on users' priorities

Users and managers experienced change in organisations where there was a focus, not only on encouraging users to participate in discussions and decisions, but also on the issues identified as important by those service users. Our observations suggested that it was necessary to have the presence or active participation of users as well as the focus on their agenda. In some cases staff and managers were very aware of users' needs and aspirations. However, the personal and individual nature of care and support service provision meant that to maximise responsiveness there was a need to minimise the separation between users and people who made decisions about their services.

Practitioners have found it useful to think about three levels of focus on users. First, thinking about users, second, opening channels of communication and, third, enabling users to use those channels to communicate their priorities.

At the first level, organisations were concerned and thinking about the issue of involving users and finding out what they had to say. The aim was not to allow user involvement to slip off the organisation's agenda. In most of the organisations in this project, involvement of service users or integration of users' views into organisational processes did sometimes slip down the list of priorities or off the agenda completely.

In one or two organisations influential figures such as active members or senior managers ensured that users' views or user involvement were always integrated into organisational processes. These were also the organisations that we observed achieved deeper and broader change.

The second level of focus on user involvement was getting users to participate in the structures and processes of involvement. Participation ranged from the informal (for example chatting about services and issues with a volunteer) to the highly structured (for example meetings of service users to decide a mandate for a delegate to attend a governing body meeting). The lesson learnt during the action research was that to increase user involvement these voluntary organisations needed to ensure that a range of communication mechanisms were developed and maintained.

Participants in this project reported that developing user involvement felt like a never-ending process or journey with new possibilities turning up all the time. We observed that once user involvement had progressed beyond the level of a new project or idea and a range of people were involved, there were in effect many journeys happening at the same time.

The third level of focus was on the issues, concerns and priorities identified by service users. Users may express interest and support for management ideas about progressing user involvement, for example, a policy on involvement, a user forum, or users participating in an annual general meeting. However, we observed that users were more likely to get involved and were more interested when asked about their own experiences, needs, wishes and aspirations. Further, where users set up their own mechanisms for getting involved, and were supported by the organisation providing services if necessary, motivation was usually higher.

At all three levels there was an important question about ownership and control. This emerged more clearly at the third level, which was precisely about whose agenda was being addressed by 'user involvement' activities. At the first two levels, thinking about user involvement

and getting people involved, it was possible to make choices about ownership and control or, put another way, the balance between management-centred and user-centred user involvement.

Case example 1 illustrates the difference between management-centred and user-centred orientations. The managers had good intentions but their analysis of user involvement in the organisation and how it should be developed was imbued with a manager's perspective. Crucially, the external facilitators of the focus groups saw their first loyalty as being to the disabled people who participated. This resulted in a focus on users' experiences and priorities rather than the management's draft policy document.

In this case, moving towards being user-centred consisted of managers starting a process that was predominantly owned and controlled by them. However, they were sufficiently committed and open to accepting a shift away from what they expected to happen. The change to being more user-centred and more focused on users was also enabled by vision, commitment and a facilitative style of leadership.

Case example 1

From management-centred to user-centred

A manager in an organisation providing services to disabled people decided to develop user involvement beyond a six-monthly audit of services and satisfaction survey. A small working group of managers and one service user met to draw up an overview of current user involvement activities and produced a position statement with recommendations. The working group was confident that the organisation as a whole was responsive in its services and had developed strong mechanisms for user involvement using a consumerist approach. However, there was a commitment to taking user involvement further and so the main recommendation was to develop a democratic approach to user involvement which would include a policy statement on user involvement, exploration of individual membership and training for staff.

Agreement of a policy on user involvement was felt to be a good starting point as it would set out clearly to everyone the intention to change. A draft was produced by the managers for consultation. External facilitators were used to run focus groups of service users to consult on the draft policy. Over 50 service users (from a total of approximately 300) took part in five different groups.

The messages from the focus groups were that:

- improvements could be made to existing services;
- some users were very satisfied with services;
- new services were needed;
- more opportunities for users to express their views were needed;
- there was pressure on a small number of users to speak for others;
- not enough disabled people were employed by the organisation.

A small number of comments were made about the draft policy on user involvement. The management of the organisation responded positively to the results of the user focus groups by planning to support a user forum and to employ a disabled person to facilitate it and other initiatives.

Vision and commitment

Change was enabled by leaders of user involvement, and leaders of voluntary organisations, who provided a vision that was strong enough to act as a primary goal, while allowing sufficient opportunity for a variety of changes. The commitment of leaders was important. To ensure user involvement became part of the fabric of the organisation, leaders defined the principles of user involvement and enabled others to translate them into actions.

Although vision and mission statements often came out of senior management or governing body deliberations, this did not preclude them from being informed by users' views. Firm statements about user involvement had a value in starting debate or providing a standard against which general progress or lack of it could be measured.

A key dimension to vision and commitment was clarity about who the organisation was for and therefore who it was trying to involve. For some organisations there was no difficulty in defining who benefits from their existence, because there was only one group or category of service user. For other organisations this was not a straightforward issue.

Some organisations had been set up by relatives or carers of people with a particular impairment or medical condition. These organisations had started at a time when it was assumed that disabled people and mental health system survivors could not and should not speak for themselves. Consequently, carers and relatives occupied most, and in some cases all, of the positions of power in the democratic membership structures of some voluntary organisations. Carers and relatives mostly became involved in these organisations to improve conditions for their relatives (frequently their sons and daughters) and also because no one else was going to fight their corner. However, they naturally shaped services and policies from their perspective and based on their interpretation of what was best for their offspring.

As disabled people and survivors developed their own perspectives about services and policies they found that organisations set up with the stated aim of benefiting them were in practice focusing on their relatives. Further, users, as opposed to carers, found that often they did not have access to decision-making processes and positions of power, for example membership of a committee. This exclusion was partly due to the fact that carers and relatives were in those positions and believed in good faith that they were acting on behalf of users and carers.

We found that some users wanted more say in organisations that had been set up by, and were still mostly run by, carers and relatives. While the priorities and perspectives of the two groups often coincided, sometimes they did not.

A vision of user involvement that is inclusive of different categories of users, for example disabled people and their carers and relatives, was an important signal to all participants in an organisation.

Case example 2 shows how a strong vision can be part of a process of fundamental change. The vision included the adoption of a model for approaching all the work that could be translated into specific practices in a variety of ways.

Case example 2

A vision with a history

A large national organisation, which began as a network of self-help groups, focused on the needs of people with a specific medical condition. The original aim was to enable its members to live independently, to stay in employment and also to increase awareness about the condition.

Over time the organisation drifted away from the founder's vision, with more emphasis on social and recreational activities and a tendency to base its work on the medical model of disability. The founder was a service user, but over time the organisation had moved away from having users in leadership positions.

Pressure from a group of users within the organisation, combined with commitment from a new senior manager, led to the development of a vision of the organisation as user-led once more. The new vision – which reflected strongly the original one – included emphasis on the personal development of users and the involvement of users in all aspects of its work. The new vision included the explicit adoption of the social model of disability as a guiding principle for the organisation's internal and external policies.

Through 10 years of change, the organisation overcame tensions between users and carers, power struggles, feelings of displacement and being devalued, lack of appropriate support and training, inaccessible buildings and meeting arrangements and legal and constitutional difficulties. The result was a user-led organisation. The majority of trustees are service users elected in open ballots to a streamlined governance structure. Users are involved as paid staff and volunteers at all levels of the organisation and in all areas of work. Personal development training is a cornerstone of service provision that is about empowering people to live independently. The organisation is active and influential in the public policy arena.

Case example 3 demonstrates a vision of more limited change. However, it could be argued that the approach taken resulted in more involvement, more change and more responsive services than if the organisation's leadership had assumed that having users on the committee was the only or best method for achieving user involvement.

Case example 3

Clear vision and strong commitment

In an organisation providing support to people with problems associated with drugs, housing, offending and employment, various attempts had been made to involve users. One method tried was to appoint a user representative to the management committee as a trustee. The experience had not led to the outcomes that the committee and manager expected or wanted. Consequently, new plans to increase user involvement excluded the option of users becoming trustees. Despite this apparent setback, the commitment of the manager and staff to develop a range of other methods of involving users was not diminished.

A review of user involvement in the organisation led to a clear vision and plans for user involvement, which were agreed by the trustees. The vision was of broad involvement at a number of levels but within defined limits. In particular, there were no plans for user representation on the management committee.

Service users were involved in a survey of their views about services every six months. They also took part in a review of methods of participation in the running of services and the organisation. The review revealed that service users were aware of and satisfied with the range of methods of getting involved that existed. There was some criticism that a few users seemed to be favoured by staff for consultation.

Feedback from users on the role of the management committee focused more on the committee coming to meet them at their drop-in service. Alternatively, as one user suggested, they could "sit down with the management committee and tell them what we want at one of their meetings".

Alongside vision and commitment as enablers of change, we observed that a positive attitude to involvement gave rise to an atmosphere in which people thought "we can do this", "we want to do this" and "user involvement will improve our services and our jobs".

Sustained leadership

People in leadership roles who adopted a facilitative style – as opposed to a control style – created the conditions in which others could develop and implement change. Some of these leadership roles were formal positions either in the management structure of an organisation or part of a user group structure. Others were unofficially leading by promoting user involvement among users or staff.

We observed that leaders who had more of the following characteristics enabled more user-centred activity:

- showed commitment to making their organisation more user-centred;
- communicated a broad vision of what a user-centred organisation would look like but without categorically including or excluding any particular idea;
- created space, openings and opportunities for users and staff to debate user involvement and to develop and try out ideas;
- asked for and listened to a full range of views;
- encouraged and supported users and staff;
- allocated resources for user involvement;
- learnt from and with others;
- took risks;
- balanced getting involved and standing back to get an overview;
- stepped aside to make space for individual users and user groups to have more influence.

In addition to a facilitative style, we found that in the organisations we studied some people who occupied leadership positions for a number of years made a sustained effort to promote and implement user involvement.

Strong relationships were developed and maintained where key personnel did not move on frequently. While fresh thinking may be introduced when key people move on, consistency of approach, trust and being part of

an organisation's history (even if it spans only the past five years) were valuable assets. Where a leader was committed to user involvement and was able to champion the issue over a period, they helped to build up a body of support among users, members and staff. Their continued presence was seen as a role model for others to follow.

There are many fashions in management thinking across sectors. User involvement is at risk of becoming one of those ideas equated with being, for example, 'close to the customer' or 'customer facing'. Leaders who remained helped ensure that user involvement was understood as a fundamental value and as a way of doing things in the voluntary sector. User involvement was thus prevented from becoming a management project that was in vogue today and not tomorrow.

Case example 4

Forging ahead and stepping aside

A senior manager in a membership disability organisation had a vision of returning to the original values as a self-help organisation. This meant a shift away from a medical view of people with this impairment. A group of members who were all service users set up their own group internally to encourage participation of younger people with the condition. This group developed and explicitly adopted the social model of disability as a policy and put pressure on the rest of the organisation to do the same.

The senior manager agreed with this view and initiated changes at a number of levels including a review of the governance of the organisation. The user group had the aim of winning places on the governing body through open elections. The manager made various proposals to advance moves towards being user-centred. The existing governing body was large and was dominated by medical and social welfare professionals. There was some resistance and on one occasion the manager was told he had gone outside his legitimate remit by supporting fundamental changes to the governance of the organisation.

Meanwhile, at the grass roots level, significant change had taken place with the introduction of personal development training for disabled

members and recruitment of disabled people as volunteers and staff.

After constitutional changes, elections resulted in the governing body having a majority of its members who were service users. A survey of new trustees showed that they expected to have a stronger role than their predecessors in setting the direction and priorities for the organisation. One trustee stated that: "The Board of trustees body is making decisions and not just relying on the staff".

The senior manager who had championed increased user involvement then faced a reduction in influence and opportunities to initiate projects. This was readily acknowledged by the manager who saw this change as a major achievement for the organisation.

Quality of dialogue

Good quality, two-way communication between users and decision makers benefited users and promoted change in organisations. An emphasis on dialogue highlighted not only that communication was two-way, but also that the views of both parties were equally valid. The quality of dialogue was increased by mutual respect between the participants. This represented a challenge in the context of user involvement in many organisations since politics was always present whether below or above the surface.

Many users' relationships with managers in voluntary organisations were characterised by an 'us and them' divide. The inequalities in knowledge, resources and power were undeniable, but conscious efforts to put these to one side, to enable an honest exchange of views and ideas, were crucial for enabling change.

Our project found that commitment to high quality dialogue was variable but, where it was achieved, significant changes took place. Commonly, there would be some dialogue, but within a wider picture of messages being sent, but not heard or even avoided. Naturally, much of whether communication was effective or not relied on individuals committing themselves to it as givers and receivers.

Case example 1 'From management-centred to user-centred' (page 7) shows how in one organisation managers encouraged and supported a series of user focus groups. One service manager saw some of the material produced by one of the groups. His reaction was that the participants always came up with the same old gripes about services and lack of involvement. However, the group of managers and one service user who had commissioned the feedback responded positively. This example illustrates how change depended on messages being sent and received without prejudices clouding the content.

Presence of users

Maximising the presence of users in a variety of settings enabled organisations to change and represented a significant change for some. Users' presence at an event or meeting or simply through their use of a service did not necessarily mean that they were engaged or influential in what was going on. However, the presence of users at organisational activities, whether a formal meeting or social event, had potential impacts on four levels:

- it gave opportunities to influence formal decision-making processes;
- it demonstrated that users were interested in getting involved;
- it gave opportunities to become part of networks of users and others;
- it gave opportunities to learn about each other's experiences and priorities.

A number of users in different organisations perceived that, at one level, what they understood by involvement included their use of the service itself. While some users accepted that to influence services beyond their own individual situation, they would need to become involved in particular activities, for example, meetings or responding to documents, *in addition to* their normal contact with the service. In contrast, some users had strong views about services, both positive and negative, but did not expect to become involved beyond their use of the service.

Figure 3.1 aims to illustrate the relationship between presence and influence. We have said that presence was a prerequisite for influence but

Figure 3.1: The relationship between the presence of users and their influence

High influence	Symbolic	User-centred
Low influence	Exclusion or marginalisation	Tokenism or seen, but not heard
	Low presence	High presence

that physically being at a meeting did not mean having a lot of influence. Presence without influence seemed to describe many users' experience of tokenism. If users were present and had influence, then the process and outcomes of an activity could be described as user-centred. Where activities, especially decision-making processes, occurred and users had little or no presence or influence, then they experienced varying degrees of exclusion or marginalisation.

The figure suggests that there may be a position in which users can have a low presence while also having a high influence. In a few examples in the project, an individual user was the focus of attention from managers. They were frequently asked their views and invited to meetings while other users were not. The influence of individuals in this situation seemed to vary considerably. Sometimes they were able to influence decisions and on other occasions were asked for their opinions but with little effect. This might be termed as 'symbolic involvement'.

A senior manager reported that going on a long-distance journey to a conference with a disabled colleague had made a big impact on his understanding of the implications of involving disabled people in all aspects of the organisation's work.

Spending time together revealed how much time and effort was required to ensure a smooth journey. The manager was then able to think about the changes that would be needed to make some or all of the jobs, both paid and

voluntary, in the organisation accessible to disabled people.

Meetings to consider user involvement issues, which included service users and staff, were valuable for two reasons. First, these meetings were an opportunity to make development of user involvement user-centred. Second, there was a value for many participants in spending time together. Sometimes the atmosphere was adversarial and characterised by users criticising managers and demanding changes. On other occasions there was an atmosphere of solidarity based on assumptions about the equality of all the participants.

In the smaller organisations in the project, managers, as well as the frontline staff, often knew about the day-to-day experiences of many of the users as a matter of course. This knowledge about users' experiences could be used in service development decisions but other factors could intervene, for example, restrictions on the use of funds.

To guarantee responsive service development, users needed to have a high presence and a high level of influence.

Resources

Allocation of human and financial resources enabled change but had to be appropriately applied to increase user involvement. In one large organisation in the project a number of departments had user-involvement initiatives running with varying amounts of staff time allocated and budgets for expenses for service users to attend meetings. However, the impact of the contributions to consultations and research exercises from users appeared to be dissipated because the different initiatives were not coordinated. In this case, there also appeared to be an emphasis on user involvement *activity* for its own sake with the result that the potential benefits for individuals personally or in terms of improvements to services were lost. In this case, resources alone were not enough to make a difference.

Designation of a specific budget for user-involvement activity in general or a particular project clearly enabled change. Sometimes there

was also a symbolic element to the allocation of money because it demonstrated, more than words, a tangible commitment to user involvement.

Although money was important, staff time (which, of course, had to be paid for) was the ingredient that meant relationships could develop. Specialist posts or designated parts of job descriptions that focused on user involvement did give impetus to enabling communication with users. However, the question of how much time *all* managers and frontline staff spent getting user feedback, getting people involved and doing things that were empowering was a key determinant of the breadth and depth of change.

Case example 5

Paying for participation

During the planning of some focus groups (see case example 1), some members of the working group predicted that apathy was widespread and that the groups would be poorly attended. In order to prevent this, the head office of the organisation made a concentrated effort to publicise the groups to users and staff in all services. They also provided venues, transport, refreshments and personal assistance. The predictions of low turnout were not fulfilled and nearly 20% of service users took part.

Another organisation paid for an enabler who gave personal assistance to a disabled man so that he could fulfil his responsibilities as a trustee and take part in a variety of other activities concerning the running of the organisation.

This organisation set up a central budget to contribute to the costs of enabling disabled people to participate in certain committees. The subsidy of costs from a central budget aimed to encourage local projects to implement practical involvement through attendance at meetings. The fund could be used for travel, accommodation, personal assistance, advocacy and carers' support. The procedure for claiming expenses was published in a guide that set out clearly what an individual could claim for and how.

In another case, a small community-based organisation set up a user group. The user group

was given control of a £3,000 grant for its activities. This proved to be a valuable resource in itself but also a catalyst for the group to develop their own ideas. The group had to learn quickly about processes for making collective decisions and the need to be accountable to all users – including those who were not present at all the meetings.

There was some tension between the organisation's staff and the researchers about how the grant could be used. A question arose about different perceptions of the 'proper' use of the money and accountability for it.

This situation was resolved through discussion between the researchers, staff and service users. It was agreed that translating of the principle of increasing user involvement in decision making would mean that there should be no constraints (other than legal) on how the user group could spend the money.

Policy and funding context

The adoption of user involvement as official policy by central and local government and purchasing and funding bodies, for example health authorities and trusts, has acted as a lever for change in all the voluntary organisations in this project. The nature of the internal responses to changes in the external environment varied depending on the organisation's stage of development of user involvement, the intentions of the external agency and the degree of commitment to user-centred user involvement on both sides. Case example 6 and case example 1 illustrate the range of responses.

Some organisations experienced user involvement as a current that swept them along without much opportunity for thinking about what was expected to change in practice. In one example a funding body had included a requirement for evidence of user involvement as one of its criteria for grants. Applicants were asked to supply a copy of their user involvement policy. The deadline for applications was close so, rather than miss the opportunity, a policy was rapidly drafted by a manager and approved by the trustees.

It is possible that there could be positive outcomes from such a process. For example the issue of user involvement had to be considered, at least superficially, by senior managers and the governing body. Members and users could have used the formal policy as a means of raising questions about practice or demanding that the leadership of the organisation now implements the intentions of the policy. Alternatively, it is possible that a policy on paper can remain just that and the outside observer could be left with the impression that both the funder and voluntary organisation are committed to user involvement while in fact not much has changed on the ground.

Case example 6

Developing parental involvement

A regional voluntary organisation supporting families and children affected by unemployment, offending and poverty had pursued a policy of parental involvement for some years. Parents were involved with the organisation's staff in resolving their own problems and were supported in their dealings with other service providers and government agencies. One ground-breaking project, in partnership with an education authority, offered education and support to a group of pregnant and mothering young women under school leaving age. From the outset the project had an advisory committee with representatives of local agencies and parents. All project committees now have a parent representative. The agency had also undertaken research with children to get their views on services.

Outside agencies perceived this organisation as progressive because it had tried hard to develop parental involvement. On the other hand, staff felt that while there had been progress, the organisation was restricted by a past based on a traditional professional-client relationship and wanted further change.

The organisation continued to develop parental involvement because of its own commitment to it. The arrival of government initiatives on childcare, which were in sympathy, meant that this agency was at the forefront of developments in its region and able to build its involvement of parents further.

External support and scrutiny

The purpose of the project was to provide support to organisations that had plans to increase user involvement, to help them do so and to learn from the experience. In three of the four action research sites the involvement of external researchers and consultants had a clear impact.

Participants in these organisations reported that external involvement gave added impetus to their activities. A timetable agreed with people outside their organisation was perceived as more difficult to alter than if internal people were involved exclusively.

Direct contact between the researchers and service users appeared to raise the profile of user involvement internally. Consequently, for the period of the project at least, the potential for change was increased because of an element of external scrutiny. However, whether the views and ideas of users gathered by external researchers would lead to change seemed to be contingent on other factors as well. The capacity of users, or allies among staff, to check up on and chase changes either recommended or promised might not have been sufficient to ensure full implementation.

External support for user involvement can also come from the user movement. Few of the users who participated in the action research were strongly connected to independent user organisations. This meant that they lacked external points of reference or benchmarks against which to compare their own experiences and expectations of involvement. Connection to a user movement could also have provided scrutiny of a voluntary organisation service provider from a user perspective. Many users were reluctant to criticise services that they depended on or used regularly. Users in this project often expressed appreciation of staff and appreciation generally about the services they used. Some, however, had mixed experiences and voiced criticisms in addition to praise.

Voluntary organisations, especially in fields where user involvement was a topical issue, appeared to compete with each other to demonstrate their credentials. This seemed to be

driven by a desire to maintain their legitimacy as contributors to policy debates and also with funders who had user involvement as one of their criteria for allocating money. Two of the organisations in this project seemed concerned that they should be seen to have a reputation for high levels of user involvement. On one hand the motivation to 'look good' was likely to lead to cosmetic or tokenistic involvement. However, the public commitment to user involvement by the leadership of an organisation did enable those interested in real change to ask questions about whether and how intentions were translated into actions.

Case example 7

Diversify networking

Senior managers in one organisation took steps to develop links with the wider user movement to which a small proportion of their users already belonged. The managers aimed to provide a flow of up-to-date thinking and expertise from a user's point of view, based on experiences of a wider group than their own service users.

Informal meetings led to the development of training for staff and trustees by trainers and consultants who were also members of the user movement. Later, to strengthen the user voice in the governance of the organisation, a leading member of the user movement was co-opted to the governing body.

One organisation in the project appeared to have made strides by increasing the visibility and presence of service users and members of the wider user movement in decision-making structures. However, some users reported that despite their presence at meetings they felt they lacked influence compared to other stakeholders.

In two organisations service users reported that they felt that user involvement had passed a point of no return. Commitments made by the organisations had been picked up on by service users who systematically scrutinised progress and demanded accountability. Crucially, some of the service users in these organisations were politicised and had support internally and externally, mainly from service users but also from allies.

Equality of opportunity

The breadth and depth of change in one organisation in this project demonstrated that equality of opportunity could be achieved for users at all levels of the organisation, both within the democratic membership structure and the paid staff, including senior management.

An active user group and the chief executive shared a vision of the organisation moving towards becoming 'user-led'. For them, part of being user-led meant that a majority of the trustees on the governing body should be either service users or people from the organisation's constituency of intended beneficiaries. The vision also included the assumption that every position, paid and voluntary, could be held by someone who was a service user. Further, some paid posts were designated for the recruitment of a person with direct experience as a service user. This approach and action had the effect of raising expectations of potential candidates and gave out a clear message to everyone in the organisation that the contribution of service users was needed and expected in all roles.

In some cases, joint work between the research team and participants emphasised evaluation of different methods of involving service users. Again the lesson here was that evaluation of involvement could not be separated from getting involved itself and, crucially, addressing the issues that were priorities, for both users and managers, at that particular time.

Continuous monitoring and evaluation

Where participants in organisations continuously monitored and evaluated their policy and practice in relation to user involvement, this supported the implementation of change. By frequently asking themselves and others, 'What is it that works well?' and 'Why is this working well or not?', users and managers developed systems of continuous feedback that enabled them to learn and adapt.

At the outset of the project there had been plans to set up parallel groups of managers and users in each organisation to evaluate the progress and impact of change. In practice, monitoring and evaluation of the different user-involvement activities became a continuous and evolving process undertaken by all who participated. In the organisations that had a steering group for user involvement or action research, more time and focused effort was spent on the questions of what works and why. However, we found that it was useful to encourage all participants to ask these questions.

4

Barriers to change

The organisations in this project all had positive intentions and practical plans for increasing user involvement. Further, they all intended that some change should occur in order to increase user involvement in the governance and management of their organisations. However, progress did not always happen according to plan. Implementation of changes was more difficult or slower than anticipated and in some cases plans were not carried through.

In this section we describe the barriers to change identified during the project.

Fragmentation

Even when there was a strong commitment to user involvement in one part of an organisation, it was often undermined by a fragmented structure or approach. In the larger organisations there were many valuable initiatives which involved users, but size and complexity mitigated against the different parts gelling together. All the larger organisations in this project with a national remit, except one, were unable wholly to coordinate user involvement or to develop an overview which could be used to plan a strategy for change.

The fragmentation of user involvement policy and practice was affected by a number of factors:

Diversity of activities: in one organisation different approaches were being developed in four different departments: campaigning, care services and information and education.

More than one group of users with a distinct identity: where an organisation had, for example, both disabled people and their carers as intended beneficiaries, there was confusion about the relationship between the different groups. There

was tension and conflict about whether one user group was primary and another secondary. A history of one group of beneficiaries having more control made it difficult for some participants to develop a vision of equality between different groups.

Complex structures: the relationship of democratic membership structures to line management of professional staff who operated contracted services caused confusion in some organisations. Membership implied a degree of ownership to some individuals, who were sometimes also users. Expectations that professional staff and managers should be accountable in some way to them, conflicted with formal line management structures and accountability to agencies purchasing services.

Diversity among regions: different historical roots, priorities and approaches to service development in different geographical regions led to a difficulty in achieving coherence at a national level.

Disagreement over the meaning of 'user involvement': for some users 'user involvement' meant empowering themselves individually and collectively. Self-empowerment would in turn enable them to influence care and support policy and practice internally and externally. Other users felt that the responsibility for involving them lay with the organisation that was providing them with services. Managers' conceptions of user involvement spanned both these approaches too.

Some organisations felt a pressure to pursue 'community involvement' or participation of a wider range of stakeholders than users of current services. The idea of community involvement was increasingly on the agenda of statutory and voluntary health and social care organisations during the project. Some organisations became

entangled in growing expectations to undertake different kinds of democratic or participatory activity and take account of a wide range of views about their work. A strategy of *community* involvement in one local group led to the development of a diverse range of projects and services. An initiative to increase *user* involvement within the group as a whole revealed different priorities between the users of different services and varied expectations about user involvement itself.

Case example 8

Primary and secondary users?

A large national voluntary organisation had two groups of people formally stated as its beneficiaries – or users – in its constitution. The organisation exists to benefit both people with a particular condition and their carers and relatives.

The organisation undertook many activities that had benefits for both groups and were not controversial. There were, however, points at which the interests of the two groups did not coincide and this presented decision makers and decision-making bodies within the organisation with a dilemma.

The two groups of users tended to differ on some important policy issues. In this case, the organisation had historically been run by and for the carers and relatives. Consequently this group had more influence in policy and priority decisions.

However, some change was achieved when a senior manager introduced constitutional changes on grounds of the organisation needing to reflect current good practice in the sector.

Case example 9

Frustration about fragmentation

A group of service users expressed confusion and frustration as a result of their experiences of trying to participate in the committees and consultative structures of a large national voluntary organisation.

There were five types of committee or forum and three tiers in the formal democratic structure of the organisation. These all had different functions and different methods for becoming a member. The organisation had also recently introduced individual membership.

The users consulted said they were:

- uncertain about how the structure worked and how to become involved;
- unclear about whether they were formal members of the organisation or not;
- critical of the support available and information about meetings;
- worried that they would not be taken seriously or that their questions would be viewed as 'silly';
- concerned that the numerous groups and committees were fragmented.

Leaders with a control style

One of the key features that distinguished management-centred user involvement from user-centred user involvement was the style of those leading the change. We have identified a facilitative style of leadership as an enabler of change. On the flipside of the leadership coin is a control style which was a barrier to change.

We observed a control style of leadership in situations where the goals and intentions of all the participants, including the people in leadership roles, were strongly in favour of increased user involvement. The people in these roles had many qualities, such as determination to implement change, commitment to keeping user involvement on the agenda of the organisation, an abundance of ideas and energy and a positive 'can do' approach. However, in tandem with, and possibly inextricably linked to, these qualities was a tendency to retain most, if not all, of the control over decisions on user involvement.

In most organisations there was not a clearcut distinction between leaders with control or facilitative styles. Most individuals used both styles but usually had a predominant way of working.

Inconsistent leadership and support

Some people in positions of influence seemed to turn their support for user involvement on and off during the course of this project. For some leaders, who were mostly middle or senior managers, user involvement appeared to some extent to be a fashionable 'management project'. In other cases, it appeared that other priorities took managers' attention away from user involvement.

In two examples from the project there was consistent support for developing user involvement from one part of the organisation, but this was not reflected by support at senior levels. At the start of our involvement with these two organisations there was consistent support for participation in the project; however, when there was an opportunity to become more involved, the situation had changed.

In one case a senior manager did not support continued participation in the action research. It transpired that he had not had time to read a paper produced by one of his own staff describing the aims, activities and potential benefits of the project. However, when he did read the report he changed his mind, but the deadline for applications to participate had already passed. In the other case, funding for an advocacy project had been withdrawn and this left a middle manager as a lone voice in support of developing user involvement in the face of considerable resistance.

While individual leaders did make a difference to whether user involvement was progressed or not, organisational constraints were also significant. The perception that chasing new projects and contracts was a priority squeezed out user involvement in one case. Elsewhere, the 'caring' attitude of the current trustees prevented a manager developing initiatives that encouraged the independence of service users. Whether or not leaders were able to provide consistent leadership and support to user involvement was dependent on the nature and scale of the other demands placed on them and the extent to which they were supported by users and colleagues.

Case example 10

Patchy progress

A manager in a community organisation initiated a user group and negotiated a grant so that it could operate autonomously. The group met regularly and much of the time was focused on the question of how to spend the budget.

The user group started off by focusing on issues that were important to them, such as social activities for families and education for children. Some individual users benefited from the experience of becoming involved in that they gained influence and confidence they had not previously had.

There were disagreements about how to use their resources and how the group should be run. These were resolved by the members of the group, with support from a staff member who acted as a facilitator. After one year most of the grant had been spent and issues arose regarding the future:

- Some users of the organisation's services did not take any active part in the new user group, which undermined its legitimacy.
- There seemed to be a generally heightened expectation that users could play more of a part in the running of the organisation. At the same time wider development of user involvement in the organisation was being discussed by the staff.

The momentum of the user group became dissipated following uncertainty about what to focus on next and the increasing burden on a few individual volunteers who ran it. The manager who had initiated the group took the lead in preparing a proposal for funding a worker who would develop user and volunteer involvement activities but when this bid was unsuccessful she did not have the time to pursue it. Apart from the funding bid the manager appeared to keep a distance and, with other staff, expressed frustration at the group's 'dependence' on them for facilitation and administrative support.

The lack of consistent support for user involvement from the leadership of the organisation was confirmed at an AGM. When some service users attempted to ask the management committee questions, what they were asking was dismissed as irrelevant.

Glass ceiling

In some organisations there was a level of seniority in democratic membership structures and in senior management above which service users were not present. It also appeared that it was unlikely that users could rise above a certain level of seniority.

In many organisations there appeared to be an underlying assumption that user involvement had natural limits. For example, in one case the involvement of users in local membership groups or on some committees was useful but it was not appropriate for them to be on the board of trustees. In another case, periodic consultation about services was the limit of involvement. Lastly, we found evidence that users might work for an organisation as volunteers assisting paid staff, but there was no expectation that they might become employees themselves.

Case example 11

Looking up at the glass ceiling

A national forum of users was an established part of the structure of a large service-providing disability organisation. The forum members undertook a review of their work and identified how they saw their position in relation to the other parts of the organisation. A summary of their analysis illustrates how their group, as a national forum with links to the structures of governance, remained limited in its influence. The group identified a mix of problems and possible solutions:

- lack of understanding of issues from a user's perspective on the part of the governing body;
- inaccessibility of the governing body;
- the governing body consults users after decisions are made;
- poor communication;
- lack of involvement by users in decision making, policies, mission statements and management;
- expertise of users is not recognised;
- absence of a partnership between the governing body, other committees and the user forum;
- more users are needed on the governing body.

Case example 12

Whose steering group is it anyway?

In an organisation providing services to disabled people, a steering group was formed to coordinate a project to develop user involvement and to bring together the activities of the various parts of the organisation.

The group consisted of three managers and one service user. The senior manager present took the lead on most issues. The other staff and the service user representative were regularly asked for their input. The user representative made efforts to engage other users in discussion about getting involved at the centre where he attended regularly. This had proven difficult and he concluded that apathy was widespread among users in the organisation.

There was some discussion in the steering group about increasing the service user membership but the managers felt after a few meetings that it would be better to keep the group small. Additionally, they felt that, from their knowledge at the time, there were not any suitable candidates among the current group of service users, of which there were over 300.

The group's assumptions about participation were challenged when nearly 60 people took part in a series of meetings for users to give their views about getting involved. Discussions at the meetings also revealed that there were people who would have been able to play a role on the steering group.

Fashion and rhetoric

Some user-involvement initiatives appeared to be more about image than substance. The selection process for the final phase of the project involved four organisations being selected from eleven. During the process a senior manager from one organisation indicated to a member of the research team that their main motivation for wanting to be in the final phase was because a 'competitor' might be selected.

One of the smaller organisations that took part had been successful in setting up a number of

partnership projects with universities and other agencies. A particular manager specialised in this approach and, while it brought in resources and increased the profile of the organisation, it was not clear that, given the choice, users would have chosen these initiatives as priorities, or even that users would have chosen to put their energy into user involvement.

Approaching user involvement as something that an organisation needed to be seen to be doing represented a barrier because it gave the impression that more was happening than there was in practice and it diverted resources.

Involvement of the few

We observed that the involvement of a small proportion of service users could present a barrier to others getting involved. This pattern occurred to different extents in each organisation.

Occasionally a comment or action indicated that there was a conscious lack of effort to extend involvement beyond a few users. Any lack of effort seemed to be born out of a resignation that only a small number of users would ever be interested in formal and visible ways of being involved in decision making, such as meetings. Users, who were already participating in the systems of consultation and decision making, and many staff both expressed frustration that more users did not come forward.

Our contact with users during this project suggested that there was a pool of people who were perceived, by staff or actively involved users, as apathetic or reluctant but who, with the right opening, would have spoken up and got involved. The perception, by staff and active users, of most users as indifferent was often based on the experience of trying to get people involved without great success. This situation seemed to echo those from other areas of voluntary and political activity; that is, the common perception that inevitably the majority always leave the work to a small minority.

We found that organisations can take steps to break down the barriers of involvement for users who appear to be uninterested.

Case example 13

Reaching out to build confidence

In one small organisation user meetings were usually attended by the same 8 to 12 people. It was common for one or two people to use up a lot of the time by raising issues that were not particularly relevant to others because it was of a personal nature or because it did not relate to their experience of using that service.

Other methods of users having a say in the running of the service included:

- a suggestion box;
- a newsletter;
- interviewing applicants for staff vacancies;
- meeting management committee members when they visited.

A six-monthly user satisfaction survey was carried out, usually by a student, to get feedback from as many users as could be seen over a three-day period. The one-to-one interview method for the satisfaction survey proved to be effective at getting responses from a range of users. However, apart from these periodic formal surveys, only a few users engaged in a regular dialogue with staff and managers.

Following discussions about the overall progress of developing user involvement, it was agreed to review the effectiveness of the different methods of involvement. To ensure that a range of users would be reached, one-to-one informal interviews were carried out in order to obtain users' views.

An interviewer who had similar life experiences to the users of this service spent some days making contact with them and becoming familiar with the service and local issues. The interviewer's rapport with users, independent status and informal approach led to some frank feedback about current methods of involvement.

The service users as a whole showed very high levels of awareness about the different methods but many said they lacked confidence to use them and expected staff to approach them for their views rather than speak up spontaneously. There was a clear perception from some users that there was a clique of users who got asked to take part in staff recruitment or who dominated meetings or got the interesting volunteer jobs.

Staff turnover

Three aspects of staff turnover have acted as a significant barrier to developing user involvement. First, departures of personnel who have specific responsibility for promoting or implementing user involvement led to initiatives having to be put on hold or in some cases being stopped completely. Someone leaving a post was often also an opportunity for managers to review the job specification. We observed that many middle and senior staff had considerable discretion about the extent to which they promoted user involvement. This led to situations where individuals became champions of user involvement. This was beneficial for implementing changes but also meant uncertainty about continuity.

Second, turnover of staff in a team or section or in a smaller organisation took up considerable staff time in both covering for vacant posts and in recruitment, selection and induction. This had an adverse impact on the existing tasks that these staff had to carry out. Any pressure on staff time resulted in the need to make decisions about priorities. It was commonly reported that in this kind of situation certain activities were seen as soft targets or low priorities regardless of whether these decisions were made following careful reviews or by default. Development work, planning, training, staff supervision and user involvement all seemed to become less important than, say, funding applications or direct service delivery when staff resources were insufficient.

The third aspect of staff turnover that affected progress on user involvement was that, in many settings, continuity of relationships between staff and service users was a crucial dimension of the service and this was disrupted. In some of the organisations in this project, support staff acted as advocates, interpreters and facilitators. The ability of users to communicate their views was therefore partially dependent on the relationship they had with the frontline staff who worked with them. In one day centre, users and staff identified that there was a considerable amount of trust that had built up between them. This trust meant that their everyday communication about people's experiences, problems, ideas and aspirations provided valuable data, which could be used for planning and feedback about

services, provided by both that agency and others. It was recognised that the information gathered in this way was probably more valuable and accurate than that which could have been obtained from a formal survey.

Case example 14

Inconsistent contact

A member of staff with a broad remit to develop quality of services interpreted the brief largely in terms of involving service users. He was located in the national office of a national disability organisation and had access to considerable resources for communicating with service users and staff through newsletters, meetings and communications technology.

Many initiatives were agreed by a users' committee and implementation commenced. The activities included: developing a service users' charter, involvement in staff recruitment, training for users in recruitment and selection techniques, improving accessibility of communication methods, monitoring service quality and user input into staff training. In addition, publicity was produced targeting users which, as well as advertising the above projects, requested users to put themselves forward to contribute to policy and service development. Over 100 service users responded in the first few months.

The member of staff responsible for servicing the user group that oversaw all these activities, left only a few months after they had started. There was a gap of a few more months before the user involvement brief was passed on to a temporary manager who had a broad portfolio of duties. This manager interpreted the role of 'user involvement specialist' differently from his predecessor and decided that there were not sufficient resources to facilitate the involvement of all the people who had responded to the advert requesting their involvement. As a result, most of the users who made contact with the initiative and who had expected to be able to contribute their experience to the organisation, were not actively followed up.

5

Overview and issues

Overview

This action research project worked closely with voluntary organisations to examine the processes of change towards increased user involvement. The project has led to the identification of enablers and barriers to change.

We believe that the value of this project is that it explored processes of change in depth and from a range of perspectives. We do not claim that the factors affecting change we have identified represent a comprehensive list, but we do conclude that they constitute a basis for making progress.

We found that users and managers shared a view of developing user involvement as something that incorporated two contrasting features. On one hand, user involvement was viewed as a set of concrete activities that were building towards a definable goal. On the other hand, developing user involvement was experienced as an unpredictable, haphazard and risky business with no clear destination. We think the metaphor of a journey undertaken by both organisations and individuals continues to be valuable in understanding the development of user involvement.

A key question for those on these journeys was the extent to which they felt they could intervene to influence the direction in which they travelled and the speed at which they were moving. Some participants clearly felt that they could and should act to increase user involvement. In effect, these users and managers maximised the enablers and minimised the barriers. While most participants felt that they wanted to act positively to change things, some were less able to make progress because they were disenchanted, disempowered or unconfident or met organisational constraints.

In some cases an enabler and a barrier are the flipside of each other, so that one offers a way of overcoming the other. For example, a control style of leadership could be replaced by one that is more facilitative through the introduction of professional development or recruitment criteria. However, some barriers, like a fragmented organisational structure, would need to be tackled by a combination of enablers over a considerable period of time.

The enablers and barriers reveal something about what helps change happen or not. These are all actions or behaviours which individuals could choose to modify or which an organisation could make policy or rules about; they are, at least potentially, controllable. So, an organisation can take action to maximise the presence of enablers and reduce the number of barriers to change. But as we have seen, change can be fragile and so we also need to ask how change can be sustained. Three factors emerged as underpinning whether an organisation could guarantee or sustain change:

- a user-centred approach;
- influential supporters;
- a commitment to work with difference.

These three factors are discussed below.

User-centred user involvement

On the face of it the term ‘user-centred user involvement’ may appear to be unnecessarily stating the obvious. In contrast, ‘management-centred user involvement’ seems like a contradiction in terms. What, after all, is user involvement about if managers and their agendas are central rather than those of users? Yet, we concluded that it is a useful distinction which sheds some light on the problem of defining

what user involvement is and is not. We suggest that voluntary organisations, operating within a traditional charitable structure (that is, not founded by and for users nor controlled by users), can change in a fundamental way.

Few discussions about user involvement last for more than a few minutes before someone asks: but what do we mean by ‘user involvement’? Attempts to answer this important question often include qualification of the broad term ‘user involvement’ with ‘real...’, ‘meaningful...’ or ‘genuine...’, to indicate that, conversely, user involvement can be ‘tokenistic...’, ‘plastic...’, or ‘cosmetic...’.

But ‘management-centred user involvement’ encapsulates what user involvement consists of in many organisations. The term recognises that, from wherever and however the pressures for user involvement have come, what has been decisive is that management have accepted the challenge and led the reforms.

The key question is whether management-centred user involvement is enough. Must the initiative and control of process and procedures lie with management? Will that deliver the main aim?

We believe that we should be working for ‘user-centred user involvement’ and offer this term as a development of the ideas and sentiments behind terms such as ‘real’ or ‘genuine’ user involvement. We develop what we mean by user-centred user involvement in Table 5.1 by giving examples of how its essential characteristics might be translated into practice. We also give comparable examples of management-centred user involvement. For example, if a meeting held for disabled residents was mostly taken up with a manager giving out notices about the running of the home and getting reactions from users about these, we would define this as management-centred user involvement. However, if a group of users, convened by managers or users themselves, discussed users’ experiences of services or anything else they wanted to talk about, we would define this as user-centred user involvement. The two approaches could lead to the user group doing different things and to different outputs and outcomes.

Further, we think this distinction is important for evaluating user involvement. The existence of user groups in various settings is often used as a measure of user involvement. In both the cases previously mentioned there is a user group; however, they are doing different things in different ways and probably with different outcomes. Which is the ‘real’ or ‘genuine’ user involvement?

But, does this mean that an organisation which engages in sufficient user-centred user involvement will arrive at a desired final destination and what is that destination? Total user involvement? User control? Peter Linnett gives an insight into the elusiveness of user involvement as a destination rather than a continuous journey, or a product rather than a process. He poses the idea that user involvement is like a utopia in the sense that the closer you get to it the more you realise that it cannot exist in an absolute and definite way. He states that “as soon as [user involvement] is done genuinely, it becomes something else.... The organisation/people concerned move beyond fixed roles, and permanently change the balance of power” (Linnett, 1999, p 19). For the majority of voluntary organisations working in a traditional charitable framework there is always more that can be done and further to go.

How can we tell whether an organisation has made progress on this journey? A measure of the degree of change could be defined as the extent to which every activity in an organisation is centred on the experiences of its users. If planning, fundraising, recruitment, operations, quality assurance, contract negotiations, premises management, personnel and everything else, always includes users’ experiences and demands, and often incorporates their direct participation, then user involvement might cease to be a separate activity or just one aspect of the organisation’s governance and management. When user involvement is second nature to enough people in an organisation it becomes ‘the way we do things round here’ and in a sense does cease to exist as a separate or optional activity.

Table 5.1: Comparison of management-centred and user-centred user involvement

User involvement characteristic	Example of management-centred user involvement	Example of user-centred user involvement
Whose experiences, demands, wishes, aspirations and agenda are the subject of user involvement?	Meetings held for disabled residents are mostly taken up with a manager giving out notices about the running of the home	Groups of users convened by managers discuss users' experiences of services
Who is involved in the processes of involving users?	A steering group of managers and staff plan a questionnaire for users about existing services	A member of staff with a brief to develop user involvement visits users individually and in small groups to ask them what is important to them, how they are involved at present and how they might like to be involved
Who are the structures of user involvement designed for?	<p>A voluntary organisation's board of trustees decides to get user input into its meetings by holding a user forum two weeks before each of its meetings. Selected users are invited by the chair of the board to come to discuss items from their agenda chosen by the chief executive</p> <p>Managers of a large organisation with a diverse set of activities are concerned that users need help to get involved in committees and working groups. They produce a 100-page set of guidelines on what users and staff, particularly meeting organisers, can do to make meetings more accessible</p>	<p>A survey of users' views about services and ways of having a say in the running of a drop-in centre is conducted by an interviewer who is a service user, who spends time in the centre getting to know about how it works and who chats informally with users as well as giving them an opportunity to give their views. Users develop a rapport with the interviewer and are sufficiently comfortable to speak about their experiences</p> <p>The results are fed back by the interviewer and discussed with users and staff</p> <p>Managers meet with service users at times and places to suit the users to work out guidelines for making meetings and information accessible for all users</p>
Who are the timetables for decision making and consultations suited to?	A marketing consultant advises a chief executive of a voluntary organisation to change the logo and image of the organisation in time for the next annual report and annual general meeting in three months because the fundraising market is getting more competitive and a new round of contracts which they could bid for is about to be announced. They put an advert in the next newsletter requesting that members and users write in with their views	A marketing consultant proposes to a chief executive that consideration of changes to the image, name and logo of the organisation should be done in conjunction with a review of the values and mission and should involve users and members. A two-stage process is planned over 12 months, starting with active involvement of users to set the priorities for the review and consultation

(continued)

Table 5.1: contd.../

User involvement characteristic	Example of management-centred user involvement	Example of user-centred user involvement
Whose language is used to discuss users' experiences, services, policies, campaigns and user involvement?	<p>Managers of a drop-in centre advertise a meeting for users. A small number of people attend and spend most of the time arguing about the term 'user'</p> <p>A disability charity runs an education programme about the needs of disabled people</p>	<p>People who regularly attend a drop-in centre refer to themselves as members</p> <p>An independent user group campaigns for recognition and implementation of the <i>rights</i> of disabled people</p>
Is there comparable and sufficient preparation for all stakeholders (managers, users, trustees, staff, volunteers) to participate in decision making?	<p>A joint working party of managers, staff and users discusses priorities for service development in their area. Options are put forward by all those present. An idea presented on an overhead projector by a manager is adopted because it fits best with the funding available, the organisation's strategic plan and the work of other agencies in the area</p>	<p>A joint working party of users, staff and managers spends its first meeting hearing from users about their experiences of current services and ideas for improvements. Before the second meeting all the members of the group spend time talking to more users</p> <p>The third meeting generates a shared picture of the constraints on developing services, such as money, legal requirements and existing organisational commitments</p> <p>The fourth meeting decides on priorities for service development and plans ways of feeding back to other users</p>

Influential supporters

Looking back at the organisations that participated in this project, we would identify that, in each, progress towards involving users has, of course, been dependent on the actions of users. In most, but not every case, stimulated by users' demands, progress has also been dependent on the role played by a key manager. This has been a manager in a position of sufficient influence to put user involvement on the agenda, to keep it there and to drive a process of change. The process may, at an early stage, be simply about ensuring that staff, users and trustees talk about, think about and become concerned about the issue of user involvement.

For organisations where a debate about user involvement has led to some actions, the influential manager has played a role of supporting existing initiatives, developing new ones and promoting the sharing of experience around the organisation. Those organisations we encountered that made significant progress had managers with a facilitative style who placed equal importance on working with service users, senior managers (many were senior managers themselves), other staff and trustees.

Overall, the balance of power between most service users and those who occupied influential positions such as trustees and managers (who were not service users) was weighted against service users. Sometimes groups of users who exerted influence from within or outside an organisation achieved change against the odds. However, where there was an ally with influence already established within the formal and informal power structures, then users' potential to influence decisions increased dramatically.

The trouble was that managers could say they 'supported', 'enabled' and 'facilitated' user involvement but ultimately they allowed users to become involved. Managers and people in other influential positions (for example, chairs, senior trustees) had the power to open and close the door that led to the corridors of power. They also had the power to tell the world outside that the door was open to users but, at the same time, could make sure it was not the door that led to the place where the decisions were made.

So, the combination of users expressing demands and people in positions of influence giving practical support was a powerful lever for change.

Working with difference

We think it may be useful to go back to the starting point of any user involvement. What are the features of the situation in a voluntary organisation and the characteristics of the different players when people start to consider the idea of user involvement? Or, more fundamentally, why should there be a need to think about user involvement in the first place?

The usual starting point is that there is a recognition that some or all decisions that affect the lives of the people an organisation exists to benefit do not involve those people. There is also recognition either that this is morally wrong, because people have a right to be involved in decisions that affect their daily lives, or that it is not an effective way to run services.

Thus, the starting point is about recognition of an inequality between the power of those who use services and those who plan, provide, regulate and finance them. User involvement is about redressing this inequality so that service users have more power within the systems and structures of service provision. The empowerment of users individually and collectively is partly the means to the end of influencing the provision of services, although empowerment is also an important end in itself as it gives users the opportunity to participate in many other areas of social, political and economic life.

Like other movements to redress inequalities, such as those between races and genders, the user involvement movement faces a crucial dilemma. On one hand, service users may be perceived as able, knowledgeable, expert, willing, skilled, organised and professional in their approach. This characterisation may lead to the perception that it is not necessary to change anything about decision-making processes for them to take part. Equally, existing decision makers may view this type of user as a valuable resource with whom it is straightforward to engage and work alongside.

On the other hand, service users may be perceived as lacking in the skills and knowledge needed to take part in decision making, as having priorities other than the effective management of services, historically excluded and self-interested. This characterisation may lead to the perception that users need support and resources to enable them to take part in the decision-making process. However, it is also possible that this perception of users may lead to assumptions that they are unable and unwilling to participate and need others to decide about services on their behalf.

The perceptions those with power have of those without power will affect the extent to which the balance of power is redressed, and the conscious and subconscious factors involved in these perceptions are undoubtedly complex and hard to unravel.

One explanation may be in terms of perceptions of 'otherness' of the service users rather than of common identity. Thus, some trustees and staff may maintain the 'otherness' of service users as part of the preservation of their own self-identity. At some level of consciousness, they may feel threatened and so resist opportunities to re-evaluate their own self or to celebrate diversity.

It may be helpful to be aware that some factors affecting user involvement may run deep in people's psyches. While this may suggest a different theoretical framework, in practice we found a range of perceptions about users and a range of responses. Additionally, as noted in this report, the process of promoting dialogue and face-to-face contact between users and managers did lead to changes of perception.

The evidence of this action research shows that progress can be and has been made through a combination of such practical steps with a vision or dream of the direction in which they lead. There has been, as we identified at the start of this report, a 'tide of change' and the journeys made by organisations and individuals have depended on multiple decisions and commitments on how to navigate the currents and how to share the work.

6

Conclusion

During this project and beyond we have met very few people who think that more user involvement is not a good thing. Many think that it is very important and that it should be developed a lot further. One of the reasons for undertaking this project was to explore the processes of change in depth because we had previously observed a gap between intentions and actions. Or, put another way, a gap between saying user involvement is important and making progress towards user-centred user involvement on the ground so that users and staff could actually touch it and feel it.

We suggest that the presence of the enablers of change and the absence of the barriers to change identified in this report are key conditions necessary for an organisation to see a fundamental shift in how it works. However, for change to be sustained we conclude that individuals and ultimately organisations need to believe in user-centred user involvement as a means of redressing inequalities in the balance of power between service users and others. Where there is sufficient strength of belief, sustained change could develop user involvement from an optional management project to 'the way we do things here'. What worked in the organisations in this project was a combination of a user-centred organisational mindset and a customised process for change.

Management-centred user involvement can achieve limited change. And, it goes further than a consumerist approach to user involvement (Robson et al, 1997). However, management-centred user involvement is potentially misleading in that it claims to deliver more in terms of a shift in power and influence than it does. For voluntary organisations that are not aiming to become user-led, then user-centred user involvement is the approach that will deliver what users want.

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