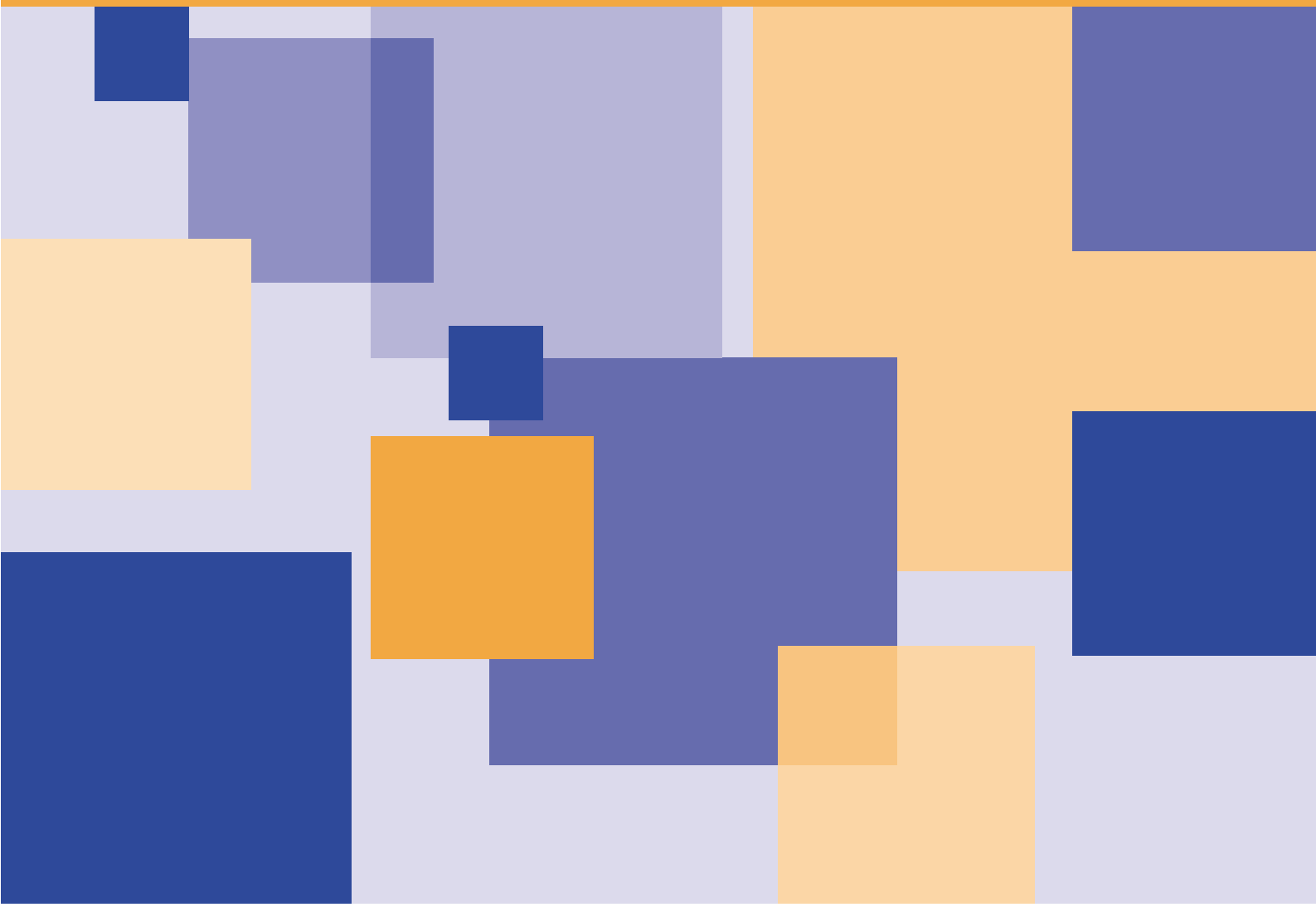

Users at the Heart

User participation in the governance and operations of social care regulatory bodies

SCIE

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Better knowledge for better practice

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This report is published by SCIE as part of our programme of work on user and carer participation. Other projects in the programme include a knowledge review on service user involvement in social work education; a review gathering material on effective user participation, which will form the basis of a good practice guide; and joint work with Shaping Our Lives, the national user network, to map service user organisations and networks.

This project was supported by the Joseph Rowntree Foundation as part of its programme of research and innovative development projects which it hopes will be of value to policy makers and practitioners. The Foundation has itself played a leading part in promoting user participation through the involvement of service users in decision-making about its research priorities and programmes. Its Older People's Steering Group, in which older people have taken the lead in deciding which research projects the Foundation should support and fund, is an example of innovative good practice. The facts presented and views expressed in this report are those of the author and not necessarily those of the Joseph Rowntree Foundation.

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Chapter One
Overview Report

This chapter introduces the project and summarises its findings and conclusions.

INTRODUCTION

This was a one-year project to examine the involvement of service users in the governing boards of the bodies set up to regulate service, workforce, education and training standards in social care.

Aims

The aims of the project were:

i working with user networks, the new regulatory bodies and other stakeholders, to identify and present best practice in enabling and enhancing user representation and participation in the governance and operations of national and local bodies;

ii to promote, encourage and support the implementation of strategies for effective participation by service users in the governance, standard-setting and regulatory functions of the new bodies set up to regulate and improve service, conduct, practice, training and occupational standards in social care;

iii to develop and advocate cost-effective models for implementing best practice in preparing and supporting user-members of governing bodies, committees and panels, enabling them to communicate with and represent the views of the wider user constituencies, and ensuring access to the information and back-up services they need to make an effective contribution.

Background to project

The project grew out of the General Social Care Council (GSCC) Development Project, based at NISW (National Institute for Social Work, a predecessor of SCIE) between 1996 and 1999. One of the outcomes of that project was a set of principles for the involvement of service users in the new social care regulatory bodies. This project was a logical follow-on from the first, testing how things had worked out in practice.

When the project was originated by NISW, it was to be jointly managed with Shaping Our Lives, the national user-controlled organisation and network which played a key role in contributing to the early planning stages of the project. Shaping Our Lives is core funded by the Department of Health and works at national and local level to increase the effective involvement service users have in public policy and to improve the quality of the support and services they need. The governance project has subsequently been based at the Social Care Institute for Excellence, and the Shaping Our Lives input has been at advisory level. The project is supported by the Joseph Rowntree Foundation (JRF).

The project forms part of SCIE's programme of work on user and carer participation. It is linked to other projects, on mapping user and carer networks and on developing guidance on good practice in implementing effective user and carer participation.

Methods

The project was envisaged in three, overlapping phases:

- Phase one – reviewing the experience of current "user" governors on national social care bodies, and those of fellow governors, to identify best practice and emerging issues
- Phase two – capacity building within user networks, to produce a "new generation" of users to sit on boards; a range of training and support will be offered
- Phase three – developing links between user governors and local user networks, to facilitate communication between those on governing bodies and the wider constituency; links will also enable users to specify the sorts of working arrangements that will best enable their participation.

As the project developed it became clear that the original planned three phases were not the best approach, and plans were modified. The work of the project incorporated three main elements:

- A literature review
- Interviews with current user governors on social care bodies, and with other key stakeholders
- Seminars bringing together user governors, researchers and practitioners with responsibility for promoting user participation, to develop strategies for effective participation.

Who was involved?

The project was carried out by Frances Hasler and overseen by Don Brand, both of SCIE. Advisory input came from Shaping Our Lives National User Network and from Engage.

The national organisations surveyed were:

- Care Council for Wales (CCW)
- General Social Care Council (GSCC)
- National Care Standards Commission (NCSC)
- Northern Ireland Social Care Council (NISCC)
- Scottish Social Services Council (SSSC)
- Scottish Commission for the Regulation of Care (SCRC)
- Social Care Institute for Excellence (SCIE)
- Training Organisation for Personal Social Services (Topss, England)

MESSAGES FROM THE LITERATURE

User participation general

- Models of participation – tried and tested ones exist
- Being explicit about type and level of participation being planned
- Diversity – "marginalised" groups are still under-represented in user participation
- Concern about "over-representation" of disabled people, under-representation of drug users, children etc.
- Contested "representativeness" – a tendency to dismiss the voices that services do not want to hear
- Fragile status of user-led organisations
- More user involvement can lead to less power for user-led organisations.
- Outcomes often consist of small practical differences rather than major change
- Other changes are incremental (therefore hard to track)

- Good practice found in local developments
- Better Government for Older People a good practice example
- Satisfaction with process and outcomes – greater among professionals than users
- Debates about models of involvement – consumer or citizen?

User governance

- Some strong models from disability and survivor organisations exist and could be utilised more by mainstream organisations
- Diversity – some groups are facing particular challenges in being supported to take governance roles. These include people with learning difficulties and drug and alcohol users.
- Contested "representativeness" and concerns over effective representation are issues at governance level
- Dangers of representation fatigue
- Properly resourced user representation is needed
- Fragile status of user-led organisations – user governors need strong back-up networks
- Outcomes of user representation are not systematically evaluated
- Resistance or ignorance from senior professionals still a barrier
- General citizen participation initiatives are not prioritising social care or particularly targeting social care users.

The literature review is in chapter five; a full bibliography is included as an appendix.

KEY MESSAGES FROM INTERVIEWS WITH BOARD MEMBERS

Experience

Almost all of the people interviewed had previous experience of committee work, at varying levels. For a few, their previous work had all been on local bodies. But most had previous experience on national or large regional bodies. This previous experience has been important in enabling them to be effective on the new boards.

Recruitment

The interviews for the board posts were felt to be models of good practice; several people praised the commitment to equal opportunities.

Access

Disabled users were asked specifically about their access needs. Most felt these had been dealt with satisfactorily although some frustration remained. Some users reported having to explain issues such as personal assistance or access for blind people to the staff of the organisation. This had been a barrier at first, but one year on they all felt they were being responded to appropriately.

Representativeness

One thing almost all concerned were agreed on is that user or carer members are not "representatives" of users or carers. They bring a user perspective, but there is no formal accountability to users. (The situations in Topss England and the NISCC are slightly different.)

Relationships with other board members

These were generally very positive. A few users had found that negotiating their role with some other board members had required both assertiveness and diplomacy in the early stages, but no one reported ongoing problems in working relationships.

There were apprehensions about dealing with jargon, and many made comments about being scared initially, with the perception that other board members were professional, expert, at home in this world. However, this had generally dissipated after a few meetings, with users feeling that every effort was made to include them. Some board Chairs were singled out for praise for the way they had promoted an inclusive approach.

Several people mentioned problems with defining the role of the board and getting too bogged down in operational matters. One suggested that the board needed to adapt more: *"it always seems as if users have to fit in with the structure that's inviting them in."*

Networking

Members were asked about if and how they linked to user networks. There were varied responses on this issue. Several people found it problematical. They did not have the personal resources to communicate with networks. But for some the relationship was more positive, and they used local groups as a forum for reporting back and getting feedback. Several people made the point that it is not the user members' responsibility to ensure user participation in the organisation: this is a corporate responsibility. There was also some frustration with the lack of action on user participation at corporate level.

Paperwork

The volume and complexity of paperwork was mentioned by almost everyone. Several queried whether they needed such long papers. In particular, papers about internal policies were seen to be too numerous and too detailed. There were also comments on the volume of e-mail and the assumption that everyone has access to it and is happy to use it.

Workload

Some users felt that they were under pressure to work harder than "professional" members. When anything about service user participation comes up *"you are automatically singled out to fill that gap…"*. Others suggested that how much work you take on is related to how influential you want to be.

Money

An issue that was not in the original interview plan, but swiftly emerged during interviews, was the payment of fees and expenses. For people on benefits, taking the fee was problematic.

There was also criticism of some organisations for not being proactive enough in offering expenses, although all praised the fact that expenses for travel, personal assistance etc. were met in full. (This had not always been their experience on other bodies.)

Support

We asked about various ideas – a peer support e-mail network; action learning sets on specific topics; one-off training sessions.

There were very mixed responses to this. Some users felt a network would be very helpful, but some were sceptical about finding the time.

Some members felt their training needs were being dealt with adequately by the organisation.

One person suggested a training agenda for prospective board members that included assertiveness, IT skills and "how to work with suits" as well as information on social care.

One suggested that the whole board needed training. *"If users are in at the heart, we should all change."*

Lessons

We asked users for their lessons for other prospective board members:

- Go for it
- Be assertive
- Get support
- Be prepared for lots of paperwork.

Other issues raised by interviewees

People with learning difficulties:

"We might have to look for participation in different ways. We may have to decide that some people are not suited to being on boards. We worry sometimes at being misconstrued, we don't want to face these issues."

Independence

Topss members raised this issue:

"I'm quite sad the way the other boards have been set up, depending on experts selected by civil servants. The way Topss was set up by nomination system in your own sector you get practical people. If you're appointed you are governed by the minister. At least with Topss I know at ministerial level we have the ability to speak unrestrained."

KEY MESSAGES FROM INTERVIEWS WITH OTHER STAKEHOLDERS

We spoke to a range of other stakeholders. They include Chairs of boards, Chief Executives of organisations, previous board members of precursor bodies, representatives of user-led organisations in the voluntary sector, and officers from the Department of Health.

Overall, user participation on boards had been fairly smooth. One or two felt that users were "more demanding" than non-users but in general the inclusion of users had not been experienced as a problem. (The "demands" related either to access needs or to users' desire to be involved in every topic, unlike most board members who were more content to be involved where they had specific expertise.)

Users were felt to contribute a vital perspective to the work. When asked what difference users had made, most Chairs or Chief Executives described it in terms of ensuring the user focus was always to the fore, that user considerations could never get overlooked.

Facilitating the involvement of users on the board had not presented many problems. Several people said they had good systems for producing accessible material. All had policies on paying expenses.

This was in contrast to the experience of a former member of a precursor body, who had left because of insufficient facilitation, difficulty in getting expenses, and not being allowed to job share the role. As a disabled person she found this discriminatory.

All the people surveyed were concerned that users on the board should be seen as just one strand of user participation; there needs to be a user focus throughout the organisation.

These interviews are reported in chapter three.

MESSAGES FROM THE SEMINARS

We held two seminars, bringing together a range of stakeholders concerned with users in governance.

Starting points

- We have a lot of knowledge by now of what works and what doesn't; the issue is getting it put into practice
- Fragmentation of effort – all sorts of people are pursuing the same goals, trying to involve the same groups, with little or no co-ordination
- Importance of not viewing users as inevitably "vulnerable"; moving to position that expects users to be equal and empowered.

Pooling information

Ideas for better information sharing:

- Establishing some sort of "one stop shop" for information and expertise on user participation
- Producing a list of who is doing what in user participation.

Designing a framework for participation

- Exploring what is blocking user involvement (resources, attitudes etc.)
- An involvement strategy across the social care sector; relating to the strategy in health
- Putting resources into service users' organisations to enable users to participate on their own terms.

Culture change

- Recognise importance of process as well as outcome; allow for varied processes, not just one model
- Users defining the process as well as the outcome; agree with users what changes they are seeking, and shape user participation to support those changes
- Training for staff in process, including making space for emotion
- Being clear – where is the power, who actually makes the decisions? Working on basis of equally valued inputs.

Evaluation

- Need to monitor what changes as a result of user participation, assess benefits both to services and to users.

Tools to be developed

- Shared database
  Owned by a user-led organisation with suitable quality standards.
- Evaluation framework
  For national organisations, to help audit how well their participation aims are progressing.

ASSESSMENT

The project aimed to:

- Identify best practice in user participation in governance
- Support strategies for effective participation
- Develop and advocate cost-effective models for implementing best practice.

How far are these aims met?

On the first aim, the project conclusion is that a number of good models for user participation exist; the key issue is getting them put into practice.

- At national level, users need to bring broad experience to the board. This can be gained in local or regional organisations
- A good application of equal opportunities recruitment methods will deliver good candidates but organisations need to do more targeting to ensure a wider range of participation, especially by black users and by children's and family service users
- All staff need to have knowledge of access needs, so that unnecessary barriers are not created
- A review of board paperwork and of board practice (number, duration and pattern of meetings) is needed if people with learning difficulties are to get equal access; current practice largely excludes them. (Some of these considerations apply to all service users.)
- But users need to be prepared for the mundane aspects of a board's work: part of their role is ensuring the organisation operates legally and remains solvent
- There needs to be a corporate strategy for user participation, with adequate resources to support it. It should not just be the responsibility of user members.

The other two aims can only be met in partnership. In supporting strategies for effective participation, the project has involved a number of other bodies, including health regulators, to share expertise. SCIE is also working closely with Shaping Our Lives on developing a national database of user-led organisations.

In working to develop and advocate cost-effective models for implementing good practice and in ensuring access to the information and back-up services users need to make an effective contribution, we have concentrated on three areas:

- National approach to payment
- User-friendly information on social care
- Links with user networks.

We anticipated setting up action learning sets, but as the project progressed it became clear that take-up for these would be limited. (Most user governors had their learning needs met by the relevant organisation.) We anticipated developing formal training on capacity-building in user-led organisations. In the event, the long-term work needed to establish a network database made this approach impractical within the short-term confines of the project. We opted instead for an information-sharing approach, where users can meet existing board members and also learn about the range of participation support that exists already.

Principles

The project was mindful of the principles for user participation developed by the GSCC project:

- Users should *make up a majority* of Council and sub-committee members
- User membership should be *balanced* in terms of gender, sexual orientation, race, age and disability
- Adequate and *appropriate support* should be provided to enable the widest range of user groups to participate and have their views represented
- Users on Council will need to be provided with necessary *information* and be *resourced and funded* for the task
- User members of the Council should be able to meet together and to *consult* wider user networks
- Council places for users should be open to *individual users* and *representatives of user-led organisations*
- Council members, whoever they represent, must be *people users can trust.*

How far are these principles met?

In none of the bodies are users a *majority*. The notion of "lay" members was adopted in preference to "users". User members on current boards are not "*balanced*" in a formulaic way. More than half are women. Only one is black (although boards do have other black members). The majority have a physical impairment. Ages range from twenties up to sixties. But they are varied in terms of background and previous life experience.

Support is available to user members on boards. But most organisations are still in the process of developing wider support for users to take part in their activities.

Users are getting vast amounts of *information*, often more than they can deal with. Approaches to funding their input are inconsistent: some are paid a fee, and while expenses are paid, there are no general guidelines as to what constitutes reasonable facilitation.

User members in Northern Ireland are a distinct group; they meet and have a formal feedback mechanism. Elsewhere, users are a small minority. Some meet informally, for peer support. Users do not meet across the organisations. A small e-mail network has been set up as a result of this project, which may lead to further meetings. There are no formal methods for users to consult networks. Some consult informally. Others do not have time to do this. Most stress that links with user networks are the responsibility of the whole organisation.

With the exception of Topss England, all user members have been appointed as *individuals*, not as *representatives* of organisations.

On most boards there is no knowing whether the existing board members are people other users can trust, as there are no formal mechanisms for feedback and accountability.

Some of the principles are harder to apply once the first one – a majority of users on the board – has been lost.

CONCLUSIONS

The overall picture is fairly encouraging.

The good news is that the experience of this generation of user members on national boards is overwhelmingly positive. Other board members and in particular board Chairs have been very welcoming.

A question remains about how much difference it is making to the work and the effectiveness of the boards. There are queries about how fully staff in some organisations are signed up to user participation. There are also questions about who is not involved, and how indirect discrimination may be keeping some groups of users at the margins.

There are some remaining practical difficulties over transport and communication, but these have not become insurmountable.

Existing board members are busy and usually working to full capacity. There are very mixed views on what sort of ongoing support would be helpful.

Although there is ample guidance in the literature on user involvement, there is little specifically about user participation in governance. There is little sign that organisations are systematically applying existing good practice in user involvement. But there is a lot of evidence that organisations are committed to developing better practice.

Several examples of helpful practice have emerged. GSCC consultation with people with learning difficulties used a variety of methods of reaching people and took extra time to build relationships before questions were asked. SCIE's seminar on user network databases was planned with a working group of user representatives and was praised as *"the most accessible event I have been to"*. The Scottish Care Commission's programme of training for members is carefully tailored to need and praised for the quality of its delivery. Northern Ireland's Social Care Council incorporates a service-user sub-group to promote a user-centred approach and to maximise user influence in the Council.

Work is in hand to produce some shared resources:

- A consistent approach to payment of fees and expenses
- National database(s) of user-led organisations
- Evaluation framework for user participation in national organisations.

As was found in the literature, satisfaction with progress is varied. Users on boards, and managers of organisations, are fairly satisfied with how things are going. Other users generally take a more critical stance, pointing to the gaps on the boards (black people, people with learning difficulties etc.) and to the unbalanced power relations that still prevail between service users and those who provide and regulate services.

What is clear is that the equivocation of the English minister:

"The direct involvement of service users will be an integral part of the credibility and success of these new bodies… However, some practical difficulties will have to be faced up to. We cannot be sure that there will be suitable service

users who are willing and able to serve as members." (Hansard, 28.3.2000)

was misplaced. There are highly skilled users serving on all the new boards.

What is less clear is what impact they are having. Despite the laudable aim that:

"Social services must become a liberating force in the lives of those that need them… open up new opportunities for people; enable them to live as normal and fulfilling lives as possible; empower them to make choices over their own lives" (Alan Milburn, 1999)

the regulatory framework in which users make their contribution is still based on many welfarist assumptions that limit opportunity. The capacity of one or two users to influence an entire inspection protocol, or to change the basis for a registration standard, is limited. There are encouraging signs: some of the draft codes of conduct were changed following user input.

Doubt persists about how well organisations are tackling participation at corporate level. However, there are some encouraging signs even here. The NISCC has a user reference group that is supporting the users on the board, enabling users to take part in other functions of the organisation (e.g. on conduct panels) and is providing users with the experience that will be very useful if they decide to join the board in the future. SCIE's Partners' Council, in the process of being set up, provides another model for involving a wider range of users at a high level in the organisation.

There is also a concern that users are having to adapt to existing organisational culture, rather than having the organisations adapt to user-friendly practices. This has limited the range of users who have been able to be involved. It is now accepted practice that service users and carers will be invited to take part. Individually, they are respected for their contributions. But we are still some way from them being the chief shapers of services.

The next phase of user participation could be the more important. Now that users are on boards, and all organisations are working on ways of including users at other levels, real difference might be possible.

It is a fast moving scene. One of the people interviewed for this report was sent a copy of her comments to check; she wrote back that *"an interview now might bring one or two different responses"*. I suspect she is not alone in developing her ideas as she – and the organisation – get more experience.

At national level, service user participation is being recognised as integral to service development and delivery. As one participant put it, it is *"not just another task to do, this is the task!"*

This study looked at the experience of a small number of service users, taking part in senior governance positions. It is not necessarily describing typical experiences of user participation. What is encouraging is how much the organisations involved are listening to and learning from the users on their boards.

Chapter Two
Interviews with Board Members

This chapter reports on the interviews with board members, summarising their responses thematically.

Who took part?

A total of 23 interviews were conducted with board members, 21 by telephone, one face to face, one by e-mail. 12 of the interviewees were female, 11 male. 16 were service users, two carers and five others. Three were from minority ethnic backgrounds. 12 were disabled people. Of these, the majority (10) had a physical or sensory impairment. Ages ranged from twenties to sixties.

Interviewees were selected from lists of board members supplied by the organisations. Initially, those identified as "service users" were invited to take part in an interview. In the event, two of the people identified to us as users were in fact carers. We also wanted to interview a small number of other board members, to compare their experience with that of the users. We were able to interview all but one of the people identified to us as service users. The fact that certain people are identified by the organisation as service users or carers does not mean that no other board member has an impairment or is a carer. One thing that became clear during the project was how many board members had experience across a range of service use; of caring; of training; of service management.

(Other interviews, with senior staff and Chairs, took place. These are reported separately, as different questions were asked.)

What sort of organisation were they serving?

Size and composition of the boards varies. Six of the organisations are non-departmental public bodies. (These are government bodies that operate at arm's length from ministers, and have a degree of independence from government. Board members are normally appointed by ministers.) The other two are independent charities, although they were initially set up by government. Boards range in size from 12 to 25 members. User numbers on boards range from one up to five.

All participants were asked the following questions:

- How were you nominated to (name of body)?
- What motivated you to get involved in (name of body)?
- What was your previous experience that made you think you had something to contribute?
- What is your view of the process of board recruitment and of the induction you have had as a board member?

Users (and carers) were asked:

- You are seen as contributing a "user" (or carer) perspective to the board. Is this how you see your role? Do you have ways of consulting other users/links to user groups?
- What support have you had specifically as a user member on the

board? What support would you like to have?

- SCIE is thinking of setting up various sorts of support for existing and would-be board members. For example, a peer support e-mail network, action learning sets, training seminars. Would any of these be of interest/use to you?

Other board members were asked how they saw the role of "user" members.

All participants were asked:

- Is there a tension between being a user member and being a corporate member of the board? If yes, how do you reconcile this?
- What lessons from your own experience would you pass on to other service users who are thinking about getting involved at this level?

As the process developed, two additional questions were asked of users, concerning money (did they get a fee; was this an issue?) and approach (did they agree with the assertion that user members had to work harder than other board members?)

All participants were asked for any other comments at the end.

Responses have been grouped into thematic headings.

How people were nominated

The majority had responded to an advertisement. Several had the advertisement drawn to their attention by a worker in one of the services they use.

I'd not heard of them, but the Care Council sent out leaflets about it and the Development Officer of MIND passed one on to me.

The project manager said, "you could do this job".

Some had used the option of applying via the Internet.

The exceptions were the Topss members, who were recruited via a nomination process. For the service user member, this included a ballot amongst those nominating him.

I was nominated to the post, five years ago. At that time it was a quango, there was no interview.

At the time Topss had two service user reps on the board. I said that two is not enough for credible participation… they agreed to a third user rep and there was an election.

Motivation

Just two people mentioned a conscious motive of obtaining a public appointment. For both these two, the fact it is a paid position was a factor in deciding to apply.

For them, and everyone else, the main motive was a desire to be involved in shaping care services.

Given that we are starting to regulate services, including starting to regulate domiciliary care, and I am a user of domiciliary care, I thought I could do something useful.

I also feel that if social workers describe themselves as a profession then they ought to be regulated and registered, I feel that quite strongly.

I thought it was about time, having spent some 20 years trying to influence, lobbying, setting up organisations, I thought it was time to go in and see about influencing the establishment from a quasi-governmental perspective.

A similar sentiment was expressed by one of the non-user members:

I feel it is so important to have good standards, that people receive a really good service.

Several felt motivated by their own situation and a desire to improve services.

I have a son who is disabled… so I wanted to be involved in setting standards because he needs a good service.

(I was motivated by) my anger about the way things are and a desire to see things better. I have a passion about care standards.

Several also suggested that their personal experience brings an important dimension:

Lots of professionals don't know what it is like.

As a lay person you do see the other side, some people who are full time social workers or whatever don't understand what it's actually like living with the rough end of the stick, so to speak.

This one was about some things I know about, having been a victim of social work. I liked the idea of developing codes of practice.

I was concerned that care was going to be regulated by people who didn't understand how important it was. I thought at least somebody who needs care ought to be in there.

Experience

Almost all of the people interviewed had previous experience of committee work, at varying levels. For a few, their previous work had all been on local bodies. But most had previous experience on national or large regional bodies. This previous experience has been important in enabling them to be effective on the new boards. None had previous experience of non-departmental public bodies and one person commented that this makes a difference:

Only one person on the board had prior experience of public boards – he has a better grasp of the way things work.

A few had no prior experience of committee work:

I had absolutely no previous experience, it was in at the deep end… I am the youngest as well, so I did feel a bit daunted at first.

I had no previous experience as a board member, it has been a learning curve, I had no training for it.

But he felt his business background gave him useful general insights:

I used to see myself as a general manager, I had a general education and a varied career… I can see that I have transferable skills.

Recruitment and interview

Almost everybody had found the recruitment process smooth. The exception was a visually impaired applicant who found that the agency handling applications was not sufficiently au fait with her access requirements. She actually missed the interview date because the interview letter was sent to her home in print format. She felt that the interview panel had responded well to this, by re-arranging the interview on a new date, but nonetheless it had been a stressful start to the process.

The interviews themselves were felt to be models of good practice; several people praised the commitment to equal opportunities. Some had been pleasantly surprised:

It was wonderful – so painless it was unbelievable.

The interview with the minister was a very good experience. She responded in a very friendly way, not intimidating. The whole thing was terrifying but actually she was very facilitative.

A few had found the experience stressful:

The first question went straight into something I had done 25 years ago in my work. That really threw me. If I hadn't been someone so forthright and assertive it would have been difficult. I was interviewed by four white, middle-aged men in suits…

And in Northern Ireland, users found the public appointments process was not well suited to their style:

As a layperson I don't think I should have been expected to know all the jargon. It was not conducive.

Induction

Opinions on the quality of induction received were varied. All participants stressed that any shortcomings in the induction process were due to the newness of the bodies. Some said they had no induction at all. This was said of various boards. Other members on the boards spoke of "some" induction and a few felt they had quite good induction. On one board, both users interviewed described being "talked at" during the induction.

There is induction for new members now, but not then. I figured it out through logic… no matter what the difficulty is, if you are safeguarding the interests of users you can't go wrong.

And for a user who had become Chair of the board, the challenge was particularly great:

There was no book, no guidance… The others were using acronyms the whole time, I felt like the new girl, very exposed to all this jargon – you need a translation book!

Disability awareness

Disabled users were asked specifically about their access needs. Most felt these had been dealt with satisfactorily although some frustration remained.

Some users reported having to explain issues such as personal assistance or access for blind people to the staff of the organisation. This had been a barrier at first, but one year on they all felt they were being responded to appropriately.

They also noted that other board members would now raise access issues, it was not always left to them. A user with a non-visible impairment had found it hard to get his access needs recognised. The wheelchair users just wish people would sit down when they talk to them.

The access arrangements were very, very good. They phoned me at home to check if there was anything I required, arranged car parking, explained how to get there, met me at the door…

I need to take breaks during the meeting, go outside, nobody minds my coming and going.

I have sometimes felt at a disadvantage on other panels, because of my communication. I felt this panel had enough awareness. Maybe that is because they already knew of me.

It is true that I was outside their experience, they were fitting in with my needs. For example, I didn't fill in the form on their form. I use Dragon on my computer and I couldn't use their form.

They didn't know about my support or my PA, not until I went to the interview. I have had to teach them, tell them, you know?

All the time during the induction, visual aids were used, flipcharts and projectors and so on. I found that they made decisions about what you should have – they didn't provide me with everything, they'd say "oh you don't need that, it's just a list". I made it clear I wanted what other people had.

They think because you look all right you are all right. They don't consider other things you get with medication, for instance.

Even though I've written an article about it – they still stand up! Somehow sitting down pins them down. One or two people do it all the time.

Role

One thing almost all concerned were agreed on is that user or carer members are not "representatives" of users or carers.

I'm not a service-user representative. Yes, we're service users, we all have experience we bring, but you can't expect us to represent all service users, it would be an impossible task, an unfair task for the one, two or three people.

I don't like being called a representative. I can't be. In my work involved with (a carers' project) we have talked about typical rather than representative.

My perspective is not just a user perspective. I try to avoid being labelled. I try to say service user "interest", not "representative".

I hate that sort of discrimination, that sort of labelling. I would lay a bet that we all have some sort of experience, some members are diabetic, people have all kinds of disability, my son is a disabled person, everybody has different experiences of being viewed as a user, a recipient.

One interesting thing is this distinction isn't particularly important. There is no sense of a cabal that always talks about user issues and the rest are bureaucrats, there is a real depth and vigour of concern for adopting a user focus and perspective.

One member, who is very active in self-advocacy work, said:

Yes I do see myself as a service user representative, helping other service users.

Another said:

I think I do see my role as a representative of young people looked after now, I work in the field, I am hands on.

Some interviewees were keen to stress that all board members took a user focus.

However, some users found that outside agencies had a tendency to pigeonhole people:

It happens that anything about service user participation that comes up, you are automatically singled out to fill that gap… every member on that board has experience of some sort from themselves or their family or friends; all have relevant experience.

One board member compared it to her own situation as a black person on the board:

I'm not representing the "voice" of black people. But clearly my experience in relation to race and social care adds a dimension. Disabled members on the board add that specific dimension. It doesn't mean it is really only their responsibility, or my responsibility only to raise issues about race. The danger is that you turn to those people each time.

The non-user members were mainly clear that the users were not representative but that they brought a user perspective to the work. However, most also stressed that the users were treated equally with other members, *although one acknowledged that*

People respect their contributions equally

By and large, service users don't have as big a voice.

Relationships with board members

Although there were generally very positive remarks about other board members, one person did report a sense of:

Other board members thinking that what they do is more important than what I do because they are paid to do it and I'm not.

Another had encountered mixed attitudes:

Respect from other board members is very mixed – some think of user reps as a waste of space, a wasted seat on the board… Some people praise you, some people really flatter you for the amount of work you do. It's not standard.

More frequent were comments about being scared initially, with the perception that other board members were professional, expert, at home in this world. However, this had generally dissipated after a few meetings, with users feeling that every effort was made to include them.

You wouldn't get talked down to, but board members try to make it less jargonistic, for those of us who haven't spent years going to bed with a social work dictionary.

Two people described the role of all board members as needing to ask the "idiot" questions, to hold the Executive to account. One user felt that her lay status made it easier for her to do this:

You can see the look of relief on other people's faces. They're not understanding either but they're too scared to say.

One non-user member discussed the importance of the rest of the board responding to issues raised by users:

Support for users is not just the usual practical stuff about taped information and breaks in meetings, it is more important that the board recognises and takes on the issues, does not get defensive, not seeing it as a little platform these people get on.

The role of the board

Several people mentioned problems with defining the role of the board and getting too bogged down in operational matters:

My perception is that I'm dissatisfied with where we have got to so far. We've spent all our time on organisational issues rather than about the philosophy etc.

It's important for boards to decide what they are there to do. If they are frustrated about the minutiae they are not being an effective board.

We get huge reports – they don't need to be that long. They give us every detail. We are there to direct, not to manage – we employ them to manage.

Relationships with staff

Relationships with staff were sometimes more problematic than those with other board members:

I'm not sure whether that is me as a disabled person or that some staff regard all board members as interfering. That's something I've met before. But it does seem that some staff have problems relating to me (as a disabled person).

One or two of the officers were quite difficult about (my access requirements). They insisted on talking about it in the meeting, which I found quite stigmatising.

I think board members are better at this (adopting a user perspective) than the officers.

But again, not all relationships were difficult:

The Council is not patronising. Even if I'm in a "manic" and I ring up the office, the staff are great, they'll laugh with me.

Support from the Commission secretariat is fantastic. I've never been afraid to ask questions or to seek out training, we are positively encouraged.

Links with user groups

Members were asked about if and how they linked to user networks. There were varied responses on this issue. Several people found it problematical:

I have no way of consulting other users, I bang on about this, I get quite cross about it.

I don't have links with user networks. I might find it useful to have links, depending what I need to do; I would not want lots more meetings.

This is one of our main complaints – not just me, almost the entire board. We like to see ourselves as a user-oriented organisation but as a board we have little contact with service users.

But for some the relationship was more positive, and they used local groups as a forum for reporting back and getting feedback:

There isn't a formal relationship between the board and the carers' organisations, but our meetings are open, there is no reason why I can't tell them what is happening.

This is something I feel strongly about. It is a terrible responsibility to do this on your own… It is good to have a place to feed back.

In two organisations, Topss England and the NISCC, there were moves to set up formal links:

I suggested to Topss that the rep on the board needs to have some authority from how that seat is filled, some constituency to report back to, through service user seats in regions, related to Topss regional committees. We will have a small user network, 9 members. They will elect the main member for the board. I produce a Topss service user bulletin.

In Northern Ireland the user reference group plays an important part in supporting and informing the user members on the Council:

We get support from each other in the service-user sub-group.

One person expressed hesitation about feeding back to wider networks, before the Council was making a tangible impact:

It is not relevant to the people on the ground yet.

Corporate responsibility for user participation

Several people made the point that it is not the user members' responsibility to ensure user participation in the organisation: this is a corporate responsibility:

Me just contacting groups is too random, not supported. I would sooner that organisations talk to the whole board.

Two also pointed out that "user" encompasses a very wide group of people. An individual cannot hope to be in touch with such a range of different people and places.

Are you talking about nursery places, after school club, that's the problem, it is so wide… what about all the old people living in care homes?

There was also frustration with the lack of action on user participation at corporate level. This was expressed very clearly in one organisation by all the board members I spoke to.

The executive wants to get the structures right then move on to user involvement. We are trying to get across that it is a quality of how we work, not a stage you reach.

The view in Topss (which has been in existence longer) was slightly different:

I think you should have a person on the board who does the work of facilitating regional representatives, ask the regional reps to select someone with the relevant skills, someone who can go along and contribute. Part of the job should be to produce a newsletter, tell service users what they are doing.

In Northern Ireland the Care Council was able to draw on previous work by Topss, including the existence of a user reference group:

The user and carer reference groups have an overarching responsibility in the Council to quality control everything the Council does.

But users did not want their involvement to absolve the rest of the Council from acting on the issue:

We're representing users, we feel Council should represent users.

At present we have a specific strategy point on achieving a user/carer focus. We hope in time we will not need one, it will be inherent in everything the Council does.

Paperwork

The volume and complexity of paperwork was mentioned by almost everyone. Several queried whether they needed such long papers. In particular, papers about internal policies were seen to be too numerous and too detailed:

Support workers have to break it down; they have to do too much for us, going through these big papers. I think they should have short papers, 2 or 3 pages. A lot of people can't read quickly. I need support. But I am interested in everything.

But I do query whether we need all the information they give us. Each set of papers is like a telephone directory in Braille.

The cognitive load of many documents is needlessly high. It is perfectly possible to write in plain language, on fewer sides of A4… It's a good thing because it makes you boil down and clarify.

There are also practical issues about managing the stuff:

The volume of paper is a problem. I think some guidance would help, on how much you need to keep, what actually you need to read… Storing all the stuff in your house. I look at the people in offices, they've got big computers, filing cabinets etc. I'm doing it from home, I don't have any of that. I don't get a fee, purely expenses. I have three papers to write for the board meeting.

E-mail

There were also comments on the volume of e mail and the assumption that everyone has access to it and is happy to use it:

I get 3 or 4 e-mails a week with papers to read, it can start to feel like too much. Other members have started to complain, too.

I am supposed to have an office and a lap top computer but I have not got them yet. I am doing my paper work in community centres and that.

Users working harder

Some users felt that they were under pressure to work harder than "professional" members:

I feel I have a commitment to understanding the issues and putting in my comments, I have an absolute commitment to reading the papers before I go.

Others suggested that how much work you take on is related to how influential you want to be:

You've always got to be alert that key issues don't pass undiscussed. That's nothing to do with disability, it's just the sort of suspicious person I am.

This pressure affected some other board members, too:

As a black person I do have to keep up with what's going on – otherwise you know something will slip through. There's a pressure to respond and to read everything or it could be too late to influence it… I think we look at things perhaps more critically. We have no choice, from past experience we know that if you don't speak at the time, it is too late.

Money

An issue that was not on the original interview plan, but swiftly emerged during interviews, was the payment of fees and expenses. There were several dimensions to this. For those boards where a fee is payable, there was a varied approach to how much work you could or should do for the money. For people without other paid employment, the fee had only a notional relationship to the number of days they contributed. One reported working three or four days a week, for a fee of £7,000 p.a.

But for those on income maintenance benefits, the fee was unattainable. Income support rules made it impossible for them to accept a fee. They felt this was unfair and in one case had challenged it strongly:

They took it back to the lawyers and they said that I could not get the £7,000 because I am on benefits.

There was also criticism of some organisations for not being proactive enough in offering expenses, although all praised the fact that expenses for travel, personal assistance etc. were met in full. (This had not always been their experience on other bodies.)

Topss members felt that the fact they are not paid guarantees that they are doing the job for the right reasons:

People that do serve on these groups want to be there, they are movers and shakers. I'm giving my expertise for free. People can happily be getting the money and not be active.

Future support

We asked about various ideas – a peer support e-mail network; action learning sets on specific topics; one-off training sessions.

There were very mixed responses to this. Some users felt a network would be very helpful:

More peer support would help. An e-mail support group I would be interested in, yes.

I think a network of disabled people could help.

There are questions I have, where I need guidance – perhaps it would help to talk to other people.

But some were sceptical about finding the time:

My first answer is yes, what a good idea. The other bit, though, is it for free, in our own time? It's a good idea but in practice it's kind of, one more thing to do.

A link on a website is good, and updates in a newsletter, great, but imagine how much you'd need to send, to keep everyone up to date. It would be too much on an inter-agency basis. People wouldn't read it all.

One, a carer, was against the whole idea:

I don't see a reason for that. I can't imagine it helping me.

She had already had to give up some voluntary work in order to make time for board work, and felt that any extension of her present commitments, even for peer support purposes, would be "an imposition".

Two people expressed a preference for telephone contact, the others preferred e-mail.

Training

Some members felt their training needs were being dealt with adequately by the organisation:

We have ongoing training seminars on human rights, social work training and so on.

We've been looking at our training needs as individuals. I've asked to go on a joint inspection of secure accommodation and to a hospice.

Some felt that some participative training would be helpful *(not being talked at)*; the idea of an action learning set on improving user participation in general was supported by two people, and some felt they had skills to offer:

If anybody asks me, I could give answers, I've seen it all.

One person suggested a training agenda, for prospective board members:

I think you need:

- *Assertiveness – you must learn to speak your mind*
- *IT skills – if you can't do e-mail you're not going to get on. It helps if you can go further, know about keeping records, filing things on your computer*
- *If people require assistance to attend, how to recruit distance PAs through agencies*
- *How to do presentations*
- *Note taking*
- *Putting social services in context, what it covers – it is a huge area*

- *How it links with health – partnerships*
- *"Working with suits"– don't expect the same respect if you turn up in a donkey jacket and a baseball cap. If you don't present well people won't take you seriously.*

Lessons

Participants were asked about what lessons they would pass on to others thinking of becoming involved at this level. Responses were mainly very positive, and can be summarised as:

- Go for it
- Be assertive
- Get support
- Be prepared for lots of paperwork.

Comments were also made that people needed to have previous experience of board work at local level in order to take part at this level:

Talk to someone who has done it. I would encourage them. It is incredibly stimulating.

I suppose what I would say is don't be intimidated, you are worth just as much as the others. If you need support in meetings, in the way it is conducted, make sure you get it.

Go for it. It is terrific fun… I think it is about being prepared for the job, you need particular skills and the right approach. Just being a user is not enough. You have to use your experience.

One offered a survival tip:

It's a bit like it says in Crossman's diary, to take a very kind of distanced view of all that paperwork and process – don't let it get in the way. Hold on to the principles that led you to get there.

Another also had advice on paperwork:

The amount of paperwork can be overwhelming but you don't need to read absolutely everything, you can focus on the things where you can make a contribution.

On her board, users had found a solution to some of the problems:

The user reference group persuaded the Council to use colour coded papers… That helps you to prioritise your papers, you can choose what you need to read first.

There were some words of caution, too:

It is not an avenue to make money. You don't get a company credit card.
You have to put in more than you get out. You have to want to be part of it.

For some, it has involved continuous learning:

I have had to learn different skills – how to compromise without compromising principles, articulating ideas, thinking carefully about how decisions will affect things in five years' time.

OTHER ISSUES

Some issues that were not included as specific questions were raised by the participants. One in particular was raised by several people:

People with learning difficulties

We might have to look for participation in different ways. We may have to decide that some people are not suited to being on boards. We worry sometimes at being misconstrued, we don't want to face these issues.

It is unfeasible to expect everybody to be able to participate in every aspect of the process.

Gender

This issue was raised by one person:

Our convenor and our Chief Executive are both women. I think it makes a difference. That was one of my anxieties, that it would be grey-suited men. I think the environment, the culture, is affected by having more women on the board.

Newness

Several people commented that many of the problems they were identifying were due to the newness of the organisation. They anticipated that future board members would get both fuller inductions and more experienced staff responses.

Social interaction

Three disabled members raised the issue of exclusion during informal sessions, particularly at lunch-time, where other participants stood to chat round the buffet table:

Informal interaction is difficult... I'm perfectly capable of mingling, if the environment is right.

Why are people so reluctant to sit down?

Independence

Topss members raised this issue:

I'm quite sad the way the other boards have been set up, depending on experts selected by civil servants. The way Topss was set up by nomination system in your own sector you get practical people. If you're appointed you are governed by the minister. At least with Topss I know at ministerial level we will argue it. Board members need the authority of an election.

A problem, I think, with credibility and authority is when you talk to people who are appointed rather than elected – do they have the same credibility?... If a person is appointed you wonder about their agenda.

CONCLUSION

The overall picture from these interviews is encouraging. A number of aspects were very positive:

- Recruitment had been straightforward and fair
- Relationships with other board members were good and mutually respectful
- Access barriers had been fewer than expected
- Most people were finding the experience stimulating and enjoyable, and would encourage others to do it.

There were some areas where experiences were mixed:

- Some people were getting enough support as board members, some felt the organisation needed to do more in terms of induction and training

- Some people felt they were well linked to user networks, others did not have the time or the individual capacity for this
- Some access needs were still not fully met.

There were some areas where a consensus emerged on what needs improving:

- Volume and complexity of paperwork – all organisations should present short papers in simple language
- Consistent approach to payment of fees – a national policy on this would help
- A corporate approach to user participation/networking – organisations were at different stages on this
- Involvement of people with learning difficulties – most organisations were felt to be struggling a bit with this aspect of participation. It was seen as an important equalities issue.

Chapter Three
Interviews with Senior Staff, Board Chairs and other Key Contacts

This section of the report is in three sections:

- **A summary of interviews held with four Chief Executives, two Chairs and three staff members of the organisations**
- **A summary of interviews with three civil servants, two reference group members and one former board member of Topss**
- **Notes from an interview about Engage, a project to involve disabled people in public life.**

OVERVIEW

Overall, the senior staff interviewed had positive views on the process of putting users on the board. A number of people reported some practical difficulties in the early stages: routines of ensuring wheelchair access, putting documents in Braille and so on had not permeated every organisation. A few mentioned the cost of facilitating user participation: doing it properly is not always cheap. Some mentioned the need for adjusting expectations on both sides – users recognising this was not a lobbying role and other members being prepared to run meetings differently (for example more breaks) in order to accommodate users. All believed that users were treated with equal esteem on the boards and that they were contributing valuable input to the work of the organisation. All agreed that it was not the role of the users on the board to be the contact with wider user networks: a more corporate response is needed.

Two of the civil servants who contributed were involved in setting up the GSCC. The study did not ask the Department of Health (DH) about the setting up of the other bodies. They reflected on the intentions behind setting up the board this way. The process was thought to have gone smoothly. The role of the board in putting users "at the heart" of social care had not been fully evaluated; the aim was that all members had a user focus. (This echoed some other contributors, who stressed that this was a concern for the whole board.)

A former Topss board member recounted a negative, stressful experience; however, the DH view was that lessons had been learned from this, and some of the more basic difficulties (e.g. not being able to get PA expenses) had been solved. This helped to account for the more positive experience of current board members.

The third civil servant works in Northern Ireland. Here the Topss experience had been quite positive. I also spoke to two members of the reference group for users, attached to the NISCC. They were able to make a very full contribution to the work of the Council without being board members.

The notes from a meeting with Ruth Scott, about the Engage Network, are included as they give a very good overview of the issues users are encountering on a range of public bodies.

Interviews with Chief Executives and Chairs

The following questions were asked:

- What (if anything) do you see as the value of having user members on the board?
- Do you think that user governors need specific support? If so, what, and who should provide it?
- What do you see as user governors' role in your overall user participation strategy?
- Have you had any "teething troubles" in getting users on to your board?
- What are you planning to do about recruiting the next generation of user members on your board?
- What lessons from your own experience would you pass on to boards who are thinking about involving users at this level?

Responses are grouped thematically.

Recruitment process

Some of the Chief Executives had not been in post when the board was recruited, so could not comment.

One chair was conscious that the experience had been stressful for some users. Because it was a public appointment and agreed criteria had to be applied, he felt:

It was not necessarily a level playing field, users and carers up against professionals.

This view was echoed by users who had been through the process: it had been daunting.

Valuing user members

Chairs and Chief Executives were asked what they saw as the value of having user members on the board:

They help the Council not to forget that their whole purpose is to ensure services and the workforce properly address the needs of those using services.

When the arrangement is working well, the Council gets a specific perspective on its work, reflecting what users think is important about workers, training, requirements for the job. It makes the Council stop and think.

We have got a number of very good Council members who challenge on everything from language to the amount of paper produced. They can be a bloody nuisance at Council; if I can use that concept positively, they will make us redefine our position.

In debate we have been able to have a strong voice, challenging the professional perspective, on issues where we could have watered down the lay person's input to conduct rules.

One Chief Executive suggested that there is potential danger that users on boards are seen as a substitute for the direct involvement of service users in inspection and regulation generally. On some boards, although there were limited numbers of people appointed as service users there were several members with some experience of services, parents of disabled children for example.

One Chief Executive reflected on the role of a former member:

He really did contribute to the board. It is difficult to judge the impact on other committee members. The whole board is very keen to be a user-focused group. We probably to some degree operated differently because of (his) presence, thinking "how will (he) respond to this?"

It was noted that a few board members have seen themselves as an advocate for service users, others bring a service user perspective along with other experience. This reflects the range of views among users interviewed:

There may be occasions (as a service user) when you use an intellectual understanding of the issue rather than personal experience.

Support for user governors

Do user governors need specific support? If so, what, and who should provide it?

Responses to this question included details of several practical access issues. Organisations had to stop and think how to plan meetings, starting later for example, and building in breaks. One person noted that a lot of accommodation is inadequate for people needing carers with them overnight, and this has eliminated many locations. This had prompted them to start to use teleconferencing sometimes to link a user member in their own home with the rest of the Council; some members have felt this could be extended.

One user (who is a person with a learning difficulty) has a PA, who provides needed help with reading papers, preparing for meetings, working out in advance what to say, as well as providing practical help with personal care.

Another user, who had a speech impairment, also used a PA, who repeated what he said:

One or two members have found that quite challenging, from a patience point of view. And a concern, how do we know he is saying it right?

Others described how before Council meetings they need to alert or flag up areas or issues in different papers of more relevance or importance to users:

We are talking about pre-Council briefings and individual discussions, maybe developing through a telephone conference.

For some, developments in the organisation were making a difference:

The Council moved to a committee structure lately. Quite a lot of work is now taken at committee level. This is making it easier.

And one Chief Executive said:

A couple are still learning their way a bit, we could have done with greater induction.

Again, this reflected remarks made by users, of insufficient induction in some organisations.

Corporate participation strategy

What is the user governors' role in the overall user participation strategy? Organisations were at different stages of development in their thinking on this issue. Although none of the Chairs or Chief Executives expected users to be responsible for the user participation strategy, they were all searching for

ways of ensuring the users played a strong role in developing the strategy.
I wouldn't see making (the user member) the focus of our contact with service user organisations, any more than I would see the accountant on the board taking responsibility for our financial probity.

Some were working on user members' involvement in conduct hearings. Issues here were the fact that panels may go on for some time, require a heavy amount of paper work, etc. and also some challenges from professional groups about the level of knowledge users would bring to hearings.

In Northern Ireland user and carer reference groups have been set up, chaired by Council members. They draw from a wide range of membership and provide a source of peer support for Council members.

They have found that:
Some groups and individuals are keen to contribute on a long term basis but we have often found people who are interested for a while not long term. People tend to contribute for a short time and move on.

A few people raised the problem of tokenism:

The challenge is also trying to develop a shared view in which carers and users are level and helping to drive our agenda, not just tokenistic.

The critical thing you need to make them feel they are not a token one, they are there as a person who is highly regarded in their own right.

Teething troubles

Asked whether there had been "teething troubles" in getting users on the board, most reported "no".

One described the position of a user member who uses a supporter/PA. Nobody had thought through the impact on his benefits status. He was not in a position to employ the supporter. It was suggested that the Council employed the PA, but they felt this was not appropriate; in the event, the national Voluntary Service organisation employed the supporter. There is an important message for government about thinking through the wider implications of their policies.

New generation

We asked, what are you planning to do about recruiting the next generation of user members on your board?

Chairs and Chief Executives raised a number of issues. Attracting younger members was one. (Of the users interviewed only one identified as a young person.)

The age balance of the Council is towards the upper end, and a younger carer nominated felt the environment was not right for him.

A number of other points were made about the process of recruiting. Government should consider what new members of non-departmental public bodies require, and talk to users about the practical implications. Civil servants appointing Council members may need more training, access to HR advice and understanding of people's financial situations, implications of contracts etc.

The "benefits trap" issue must be resolved by sponsor departments with the Treasury:

It is very important to have one, and preferably more than one, user on the Council for their particular perspective on education and training matters, which may not always be welcome but should be heard. Criteria should be skills and personal qualities.

Lessons

What lessons from their own experience would they pass on to boards who are thinking about involving users at this level?

To meet them earlier on, involve them with the Corporate Plan, look at a PI (Performance Indicator) for user satisfaction.

The Chair's contribution has been very important in creating the right environment for all Council members to feel comfortable, on equal terms and treated with respect, ensuring strong personalities don't dominate, taking time to meet individuals and understand their expectations. This counted for more than the formal induction processes.

It's not easy being the only user member – he would have benefited from the support of others.

To appreciate users and carers may require a longer time to get to grips with the structures, the architecture of the NDPB; we may need to invest so they can stay longer than other Council members.

I think my view is the important thing is to have people who can contribute in their own right. You can go overboard getting a balance of member interests.

Clash of interests

We asked whether there was a perceived or actual conflict of interest between the governance role on the board and representing user interests:

We are aware of issues but where it most recently has surfaced is an intense debate about civil and criminal standards in conduct proceedings, and having a lay majority on a conduct committee.

In terms of rules, some querying of lay majority for conduct rules, some professionals thought they shouldn't be. Users and carers very convincingly presented their side of the argument.

The fact that individuals do not fit neatly into one category also came up. On at least one board, one of the users also sees himself as an employer (he employs a team of PAs) and is a trainer.

Other issues

Chairs and Chief Executives raised several points during the interviews.

Representation

The debate about representation came up several times.

Are they there as a good egg in their own right?

Are you making it representative or is there a participation perspective in every debate?

New ways of working

Ways of making the board more accessible, more friendly to users, were being explored. One board was looking at including a question and answer session. Other had looked at use of language. Simple but effective ideas such as colour coded papers were mentioned. (This idea came from the user reference group.)

In the wider work of the organisations, involving users more in social work reforms was the desired outcome. Users had already been involved in drawing up the Codes of Conduct, to good effect.

Involving people with learning difficulties

With one exception, boards had not directly involved people with learning difficulties. There were concerns on this issue:

I'm not sure how involved people can be in the process of regulation and operationalising; strategic development of its nature should be an intellectual exercise.

The suggestion of consultation to ensure that people could express their views in advance of discussion by the board was put forward:

It should be possible to get people with learning difficulties to articulate their issues, focusing on their agenda.

It was noted that during the GSCC consultation on codes of conduct, specific consultation had been held with groups of people with learning difficulties. This involved quite a long period of getting to know the participants before formal consultation questions were raised.

OTHER PERSPECTIVES

An indication of how far user participation has progressed in a few years comes from an interview with a former board member of Topss. For this user, it had felt that:

Everything was a fight. Getting a stand-in for when you were unable to go, being able to access funding for support workers. It was difficult to get expenses.

For this person, the feeling was that the workload was huge. There was a lot of stuff needing to get done, a high, fast turnover. The person employed to support service user representatives left and was not replaced. The user ended up unwell and unable to take part in the board:

They don't take into account how non-disabled people have more energy. The workload is so heavy, and they wouldn't let us share it, we were not allowed to do that. There was no mechanism to spread it. The work was too much. If you are disabled and you are working, being asked to do Topss things 2 or 3 times a week on top of your paid workload – it's not possible.

This user's advice to prospective members was:

Make sure you are fit!
Make sure you've got really good support networks.
Make sure you've got permission, time and energy to do it.
You need to know all the background beforehand, to know what your role is,

what you can and cannot do. Don't let them bully you – you can stand up for users, it is worth doing.

She suggested that training – like the SSI did for lay assessors – would have been really helpful beforehand. And for her:

Knowing other service users doing similar things would help, too. Not necessarily meetings but people you could phone or e mail, so you can talk about things you are facing and other ways of getting round it.

Happily, practical issues such as paying expenses for personal assistants are now routine in the work of the national bodies. (It remains a challenge for people working at local level in some places.) But other considerations, including the use of job share or deputy members, have not been addressed by boards. This means that people with fluctuating health conditions have extra difficulties in taking part.

Policy into practice

Interviews were held with three Department of Health staff (one by telephone, two face to face) to explore the policy objectives behind the appointment of board members and to reflect on the outcomes of this policy in practice. The interviews were informal; individuals were not asked to give an "official" DH view.

Expectations

Expectations of involving service users and carers in the GSCC:

The Department of Health was clear that service users and carers were at the heart of the enterprise. But we were on a learning curve about what that meant.

In the planning process, there were different views on whether service users should be part of the lay majority or the majority:

The newness of service user/carer involvement meant that the capacity of what that would bring was not recognised.

It was suggested that part of the driver for a small Council for the GSCC was a feeling that the Central Council for Education and Training in Social Work (CCETSW) had become unwieldy and ineffective:

People did not want to go back to the CCETSW model where there were 64 members on Council. Even though CCETSW had in fact changed by then there was a general myth about the way CCETSW operated. So there were discussions about having a small executive group overseeing GSCC.

A collegiate approach was envisaged, bringing stakeholders together. It was suggested that there was a fear that if service users were a majority other voices would be completely missing:

So the service user element was downsized.

The different interests on the GSCC are designed to reflect rather than represent each element. All members are assumed to be working from a value base that service users are at the heart of the enterprise.

But having users on the board is only worthwhile if things change as a result:

People did not realise how dramatically things needed to change.

Reflections on the outcome

The culture and the context have changed, so we probably would not do it the same way now.

There is a rawness and immediacy about the service users' experience, organisations need to make space for this.

Part of the change organisations need to make is to recognise that participation is not about enabling users to be involved, it is about changing the content of the work being delivered.

These officials were clear that organisations need to move beyond "involvement" to changing the business of delivery. It is also important to move beyond the platitudes on equalities issues e.g. involving black people and people with learning difficulties. They felt that challenge from service users assists organisations to concentrate on what is important.

The process takes time:

It takes a while to achieve change – it can be frustrating.

Disabled people in public life

Not all service users are disabled people, although they make up a substantial proportion of community care users. For some people, having disabled people on a board is as much a matter of equal opportunities as having women on the board – their "user" status is secondary. An organisation set up to promote disabled people in public life is Engage.

Background

Engage was set up in August 2001 and has just over 100 disabled members, who either have public appointments or are seeking public appointment. Engage defines public appointment quite widely, including elected office. Engage seeks to increase the number of disabled people in all sorts of public appointment. The majority of Engage members have been involved quite a long time; they are politically conscious disabled people. Most of them also have experience of paid work. Many of the issues identified by Engage are similar to those identified by other interviewees.

Barriers

A key issue for Engage is the relationship between welfare benefits and public participation. Many of their members have identified benefits rules as a significant barrier to taking up public appointment.

There are no reliable statistics about the numbers of disabled people in public life. There is no standard monitoring across government departments. Engage has identified a number of other barriers to participation:

- Information about opportunities is not well distributed. There is no central register of everyone seeking an appointment: each department keeps its own register, and the Public Appointments Unit has its own, separate register
- A general perception about quangos is that they are for well-off people who can afford to give up their time for nothing or for very little
- The application process can be

opaque, with no feedback given on reasons for non-selection

- This can intensify lack of confidence or expectation of discrimination among disabled applicants
- There is no standard for remuneration on public bodies; amounts vary widely
- There is little or no recognition of the costs of participation, disabled people have to ask for help with travel and support worker costs; this is rarely (never?) offered
- Advertising is not usually well targeted towards disabled people, except in cases where disabled people are expected to be a majority e.g. the Disability Rights Commission (DRC)
- People with learning difficulties are disadvantaged and often excluded by application processes relying on written information and formal interview.

Issues

Engage identifies a number of issues echoed by other participants in the project:

- Inclusion of disabled people requires a culture shift in organisations. There is no evidence to date that this happening
- Disabled people serving on public bodies are wary of being "ghettoised", seen as only contributing on disability issues. This can mean that they feel under pressure to work harder than other board members, to be sure they understand all the issues under discussion
- The routes into public life for disabled people usually involve committee work at local level, in disability organisations, CHCs, local housing associations etc.
- The fudging of the differences between lay members and user members. The Engage policy is to press for more emphasis on user members.

CONCLUSIONS

These interviews with a disparate range of stakeholders point to a high degree of consensus over the aims of user participation, and a strong commitment to making it work. They do not reflect a desire to see users in a majority or even in equal numbers on boards but they do recognise that more needs to be done to give users a proper level of influence.

To an extent the interviews with Chairs and Chief Executives reflected an ambivalence – they value user participation but are still wrestling with its practical implications. The comments made about involving people with learning difficulties on boards illustrate this ambivalence. This in turn may prompt questions about how far participation in governance is the best way of achieving change. The early signs are that it can focus the organisation on the need for user participation in every aspect of the work – which in itself is a helpful change.

Chapter Four
Seminar Reports

During the course of the project two seminars took place, bringing together participation experts from a range of organisations and backgrounds. The seminars aimed to identify good practice in supporting user involvement and to share ideas on implementing it. They represented an opportunity to share the initial findings of the research, and to test them against other people's experience. They helped to explore the framework within which user governance operates.

Participants in the seminars comprised:

- Officers with a remit to promote user participation in national health and social care regulatory and standard setting bodies, including National Patient Safety Agency, Commission for Health Inspection, Commission for Patient and Public Involvement, NCSC, GSCC, SCIE, Topss, Welsh, Scottish and Northern Ireland equivalents
- Board members from these bodies who take a specific interest in user participation
- Officers (or board members) from national bodies with a strong focus on government policy, governance of services and user participation, including Better Government for Older People, King's Fund, Shaping Our Lives.

The first of these was on 25 November 2002. 30 people took part; about one third of the group were service users.

Themes from the day

Some themes recurred throughout the day:

- What works and what doesn't – we have a lot of knowledge by now, the issue is getting it put into practice
- Fragmentation of effort – all sorts of people are pursuing the same goals, trying to involve the same groups, with little or no co-ordination
- Importance of not viewing users as inevitably "vulnerable"; moving to the position that expects users to be equal and empowered.

Pooling information

Participants were keen to establish better information sharing:

- Establishing some sort of "one stop shop" for information and expertise on user participation
- Producing a list of who is doing what in user participation (on a national level; we recognise there are also numerous local initiatives) including which groups are being reached and which missed
- Co-ordination, collaboration, intelligence gathering (drawing on examples of this happening in London)
- Being as comprehensive as possible (crossing health and social care boundaries, involving children's services, etc.).

Designing a framework for participation

It was agreed that future collaboration would depend on having an agreed shared approach to the topic. This would cover:

- Applying knowledge of what works to achieve specific action by different organisations
- Exploring what is blocking user involvement (resources, attitudes etc.)
- Thinking about an involvement strategy across the social care sector, related to but not necessarily the same as the strategy in health
- Recognising involvement at different levels in systems and organisations for different purposes
- Putting resources into service users' organisations to enable users to participate on their own terms, rather than putting resources into setting up user groups specifically for purposes of consultation
- Working across the social care/ primary care trust boundary and joint working in children and young people's services, older people, mental health, learning disability, HIV/AIDS and substance misuse services.

It was agreed that the work should take account of:

Culture change

- Recognise importance of process as well as outcome; see the effect process has on outcome; allow for varied processes, not just one model; but keep a focus on outcome, don't mistake process for outcome
- Users defining the process as well as the outcome; rather than involving users and then seeing what difference it makes, agree with users what changes they are seeking, and shape user participation to support those changes
- Training for staff in process, including making space for emotion (users often express views in emotional terms, this can be uncomfortable or unconventional but it can also be helpful; use of art, drama etc. can facilitate the process)
- Being clear – where is the power, who actually makes the decisions? Working on basis of equally valued inputs.

Evaluation

- Need to monitor what changes as a result of user participation, assess benefits both to services and to users
- If users have been involved in defining outcome as well as process you have objectives against which to judge whether change or improvement has been achieved.

Networking

- Getting together with others doing similar tasks is useful.

Action plan

Some immediate points for action were agreed on the day.

It was agreed that SCIE would:

- Explore ways of pooling information, including the possibility of SCIE acting as the hub for this
- Work with others to draft a framework for participation
- Hold a further networking event in 2003

- Publish a report of the seminar including participants' contact details and a resource list.

The second event took place on 9 May 2003.

A framework for participation

The seminar explored ways that different organisations could bring a unified approach to involvement. Two key principles were reiterated:

- Getting a sense of ownership of the process – not just box ticking
- Defining the **purpose** of involvement (because this then gives us a better way of deciding the **process** of involvement).

There was discussion on the nature of involvement – patient, user, lay, citizen. It was suggested that lay or citizen involvement was useful for the big picture – assessing the common good; patient or user involvement necessary for the detail – how exactly is this service meeting need?

Foundations for participation

There was discussion on work already being undertaken in some of the organisations. Learning from this included:

- People can wear more than one hat. Avoid being prescriptive – "horses for courses".
- Facilitating participation – take a "reasonable adjustment" approach, rather than laying down what can/can't be provided.
- Working towards a national policy on payment of expenses and fees.

Building blocks – working at different levels

Discussions took place in the context of the work of the Commission for Patients and Public Involvement in Health. This is a work environment where strong drivers for change co-exist with a highly risk-averse culture. This leads to scepticism. Champions of participation need to build trust.

Comments included:

- Competing space for knowledge – where does user knowledge fit?
- The nature of user knowledge – challenges in capturing it, and in validating it
- Shift in authority? Power relations (within NHS) are changing.

Tools for change

1) Shared database

SCIE/Shaping Our Lives are developing a national database of user-led organisations. Part of its function is facilitating user participation at national level; users agree it is important that the resource is "owned" by a user-led group. Comments included:

- Ownership brings responsibility
- Need quality standards for national database
- Overlap with existing initiatives – CHI are commissioning a national database of local health user groups (expected to be 50,000+)
- Sharing information is about more than exchanging a name and address, it should be about building a relationship.

2) Evaluation framework

It was suggested that an evaluation framework for national organisations could be developed, to help audit how well their participation aims are progressing. This was widely welcomed.

Future work

Participants at the seminars agreed that it is useful to meet as a broad interest group, at six-month intervals. In addition to providing peer support (for people pushing user participation agenda in their own organisations) it can help us to provide shared tools, e.g. payment policy, evaluation framework.

Conclusions

This element of the project was considering user participation from a wider perspective than as board members. It aimed to gather strategies for effective participation at levels where decisions are made. This includes standard-setting, regulation, conduct panels in addition to governance. Participants had a range of experience of what had worked. The main messages coming from these events were:

- "Don't let perfect drive out good" – in other words, organisations may not get every aspect of participation right straight away but this is not a reason for not starting to do as much as you can
- There are a lot of users who are both competent and willing to make a contribution at this level
- Enabling their participation in a practical way is straightforward – there is no excuse for not doing it
- Organisations need to improve their overall contact with user networks, and make proper provision to strengthen user networks.

Chapter Five
Literature Review

Introduction

This section reports on a review of the literature and guidance on participation by service users in governance, planning, standard-setting and regulation in social services. The review also looked at references to user participation at this level in other sectors, including health, housing and the voluntary sector.
The review was particularly focused on user participation in governance, rather than on user involvement issues generally. The review focuses mainly on adult services. SCIE is producing further reviews of the literature on participation, focusing on specific client groups. An annotated bibliography is included as an appendix to the report.

Key points

Some themes emerged strongly from the review:

User participation general

- Models of participation – tried and tested ones exist
- Being explicit about type and level of participation being planned
- Diversity – "marginalised" groups are still under-represented in user participation
- Concern about "over-representation" of disabled people, under-representation of drug users, children etc.
- Contested "representativeness" – a tendency to dismiss the voices that services do not want to hear
- Fragile status of user-led organisations
- More user involvement can lead to less power for user-led organisations.
- Outcomes often consist of small practical differences rather than major change
- Other changes are incremental (therefore hard to track)
- Good practice found in local developments
- Better Government for Older People a good practice example
- Satisfaction with process and outcomes – greater among professionals than users
- Debates about models of involvement – consumer or citizen?

User governance

- Some strong models from disability and survivor organisations exist and could be utilised more by mainstream organisations
- Diversity – some groups are facing particular challenges in being supported to take governance roles. These include people with learning difficulties and drug and alcohol users.
- Contested "representativeness" and concerns over effective representation are issues at governance level
- Dangers of representation fatigue
- Properly resourced user representation is needed

- Fragile status of user-led organisations – user governors need strong back-up networks
- Outcomes of user representation are not systematically evaluated
- Resistance or ignorance from senior professionals still a barrier
- General citizen participation initiatives are not prioritising social care

Principles of engagement

Wilcox sets out principles for general user involvement that could apply at all levels in social care:

- Clarity on why organisations want to involve others
- Preparation for participation, i.e. not being token, not putting people in at the deep end, etc.
- Support skills within the organisation
- Appropriate structures.

In its guide to involving users, National Consumer Council talks of the importance of managing expectations:

- Communicate a purpose
- Specify rights, powers and responsibilities
- Clarify the commitment required
- Give precise terms and conditions.

In several of their works, Beresford and Croft point out that involving people is a political activity. They urge organisations to see involvement as a process. They discuss models of participation, consumerism versus democratic input. They advocate an inclusive approach. Marian Barnes (1999) looks at ways disabled people's and survivors' organisations have sought to assert their legitimacy in the face of official responses construing them as self-interested pressure groups. Whilst participation carries the dangers of incorporation there is also evidence of transformation taking place in the processes of governance and the service models emerging from dialogue between users and producers.

Users leading the way

There are historical accounts of disabled people organising to control their own organisations since the late nineteenth century. Yet the literature generally pays scant attention to the part which service users and service-user organisations have played in shaping the history that led to today's emphasis on user participation.

Service users have been reporting on the sorts of service they organise for themselves since the 1980s. The concept of community control of social service departments was discussed by Croft and Beresford in 1980. Disabled people's organisations published reports of user-managed personal care and user-managed information services. These reports showed that users were able to govern as well as influence services. Service users have offered resources to underpin change in social care, contributing to research and training. This work is often recycled and reinterpreted by conventional writers and researchers.

There are examples of where a work produced by users becomes the accepted expert reference. Croft and Beresford's *Getting involved: A practical manual*, published in 1993, remains as relevant ten years later. It has been used in many fields, it is distributed by community development organisations, is based on

involvement and raises issues relating to governance across policy fields, including social care.

At the local level, recent research shows that in the field of independent living alone, there are at least 85 user-controlled organisations providing a range of support services for disabled people, their families and professionals across the UK (Barnes, Mercer and Morgan, 2000). Although varying in size and resources, these organisations are characterised by formal mechanisms that ensure control by disabled people, high levels of accountability to members, and employment policies that favour disabled staff. Work to map the full extent of user-managed services is still underway. The evidence is clear that users both can and do manage social care services. What is not evident is that service providers and commissioners recognise and value this expertise.

Equalities issues

Literature on black service users in governance is scant; most searches for "ethnic minority" and "user involvement" turned up reports which mentioned the need to involve black users or the problems of involving black users rather than discussing successful involvement of black users. Accounts of black-led user organisations stress the difficulty they have in getting funds and in building sustainability. Official monitoring bears this out – a recent review of grants from the Department of Health showed that only 1.7% of total grants had gone to black-led organisations. But as the existence of the CEMVO (Council for Ethnic Minority Voluntary Organisations) database demonstrates, there are thousands of organisations led by black people across Britain. Their relative invisibility in mainstream literature underlines the need for a greater focus on race equality in future work.

Accounts of services led by people with learning difficulties are even more thin on the ground. A JRF-sponsored project *(Creating more choice for people with learning difficulties)* looked at user involvement in services. Only one of the five services studied (all examples of "good" practice) had users in control, as a workers' cooperative. Yet it is clear that people with learning difficulties are self-organising, controlling their own organisations. The website of Central England People First contains numerous links to other People First sites, all controlled by users.

There is more in the recent literature about involving children. The Department of Health has set out principles for this, although at this stage participation is a long way removed from governance. The National Children's Bureau has moved to include children and young people centrally in its governance structures – although children may not be trustees of a charity they can be enabled to take a role in the decision-making process.

People excluded by poverty are not always identified as a user "group" but as the *Commission on Poverty Participation and Power* showed, there are challenges introducing participatory process in organisations not previously geared to it; issues of equal working and personal power need to be worked through.

Driving change

The voluntary sector is often seen as a progressive force, able to innovate in ways the statutory sector can not. The literature shows that although user-led organisations are involving people in a variety of innovative ways, the more traditional voluntary sector is lagging behind in user participation.

Robson et al (1997) found that few voluntary organisations have clear policies for user involvement. Although half the organisations surveyed had users on their governing body, the impact of this was unclear; development was slow and expectations low. Senior management in the organisations surveyed was reported as being cynical about user governance.

There were exceptions to this. In some children's charities, strong efforts are being made to increase involvement of children and young people. In some disability charities (e.g. Mind) an increase in users on the board is linked to a wider user involvement strategy. The lessons of participation from user-led organisations are not well documented. This stems at least in part from the fragile nature of user-led organisations. Barnes et al (2000) found that some of the organisations they surveyed did not have secure funding beyond the current financial year. This made planning difficult and would have made documenting their experience an unaffordable luxury.

The statutory sector is exhorted by government to involve users. Government itself has a mixed record on this. The Children and Young People's Unit is using innovative ways to engage young people. A government-sponsored initiative, Better Government for Older People, is delivering a high level of engagement by older people. But in engaging service users in public service, government departments are not doing very well.

Government's Diversity in public appointments details the numbers of women, ethnic minorities and disabled people serving on public bodies, by government department. It says:

"The people appointed to public bodies need to reflect the rich diversity of the UK and the boards of public bodies will be most effective if they benefit from access to a wide range of skills, experience and backgrounds from among their members."

Each department has set targets on this. As this box shows, while targets for women and ethnic minorities roughly reflect the percentages in the population as a whole, the target on disability is set well under the percentage of disabled people in the population. Given that the majority of adult users of social care are disabled people, this looks like an inbuilt bias against service users.

Department of Health targets

NHS Trusts, Health Authorities and Primary Care Trusts goals (to be achieved by December 2005):

i 50% of appointments to be women (48.8% at 1 January 2002);

ii 43% of Chairs to be women (41.3% at 1 January 2002);

iii at least 10% of all appointments to come from an ethnic minority background (12.1% at 1 January 2002);

iv 8% of Chairs to be from ethnic minorities (6.5% at 1 January 2002);

v 5% of all those appointed to be disabled (3.7% at 1 January 2002); and

vi 3% of Chairs to be disabled (2% at 1 January 2002).

Conclusions

The literature shows that the knowledge on how to engage users as governors is available but that it is being patchily applied. What feel like old, sterile arguments about "who is a user?" are still getting in the way of positive work to change the makeup of boards.

The literature also shows a considerable gap between the ambitions of users and the actual power available to them. It shows that:

- Users have been organising themselves and challenging established approaches for a long time
- Service users are prepared to take on governance roles and competent to do so, if appropriate structures and support are provided
- Professional concerns over capacity of users, liability, sharing power, are still blocking the expansion of numbers of users at board level.

A key theme emerging is on models of user engagement, in particular the consumer model versus the democratic/citizen model. Clearly, the user movement favours the latter while public policy seems weighted towards the former.

The literature gives a fairly encouraging picture of progress in the past two or three years; some barriers have been breached, and a certain momentum seems to have built up around user governance:

- Support for users on boards is vital but still in short supply
- User-managed organisations have valuable experience to contribute, but are so under-resourced that they find it hard to contribute effectively.

Chapter Six
Reflections on Issues

A number of themes emerged from this work, all of which have continuing relevance to the involvement of users. Broadly these concern:

- Modes of participation (user, lay etc.)
- Representation, accountability and governance
- Changing the business (different ways of working)
- Tracking outcomes of user participation.

This section considers the questions and challenges raised by participants in the project related to these themes.

Modes of participation

The NHS talks of patient and public participation, social care discusses user/carer and lay participation. Literature identifies a struggle between a consumer model and a citizenship model of participation. Within the different organisations in this study the involvement of people who are not professionally engaged in social care has been dealt with in different ways.

In the planning for the GSCC, government was urged to appoint a board with a **majority** of service users. In the event, government opted for a majority **lay** board, with only two places reserved for service users. Other organisations were set up in similar ways; some boards have a larger number of users but they are not in the majority on any. The Care Councils in Northern Ireland and Wales were set up to have one third "user and carer" members.

There are ambiguities about who is a "user" or a "carer". The phrase "real users" was used by some people. This may be echoing some of the problems identified in the literature of articulate users being labelled "unrepresentative".

In Northern Ireland there were debates about the use of "proxies", people working with users who represented users; the consensus was that such people would not be counted as service users. In discussion with one Chief Executive, one board member was described as a "real" user, the other (also a disabled person) was not.

On one board a member who is an adoptive parent was described as a carer although she saw herself as a user. Parents often identify themselves as users – professionals often identify them as carers. A board member who is a carer identified herself strongly with the user movement. Many supposedly "lay" appointees and many professional appointees had close personal experience of service use, usually through a family member. And some users have professional experience, as academics or trainers.

Certain parts of the user movement are quite opposed to the elision of users-and-carers in policy terms. The issue of different, perhaps conflicting, interests is often cited. Reconciling people's personal selves (often overlapping identities, relating within a family setting) and their political selves (focus on position as a user or a carer) is not

impossible but an organisational tendency to put people in boxes does not facilitate this.

It is clear that for users, being categorised with "lay" people is unsatisfactory. To them, their stake in services is so direct that it seems perverse to give them a minority voice in planning and monitoring bodies.

Representation, accountability and governance

Debates around representation are highly charged. Disability groups use the slogan "nothing about us without us" to indicate that they should be involved at all levels. User groups often attach strong significance to democracy and inclusive working. But individuals appointed to boards are not democratically chosen.

Different users took different approaches to the issue of representation, most saying that they were not a representative, a few saying they did feel this was part of their function. All said they bring a user perspective, a user sensibility to the role. Some stressed that they were **more** than a user.

Within this project, none of the participants experienced a conflict between being a director on the board and being a representative of users. This was mainly because they are not appointed as representatives, and their accountability to the user movement is informal. The exception is the Topss member, who expressed a clear sense of accountability.

Chief Executives and Chairs reported that a few members had needed coaching to understand the difference between being a member of a campaigning or advocate organisation and being a member of a regulatory body. They have to share responsibility for the whole work of the organisation, not just its interface with users. This was seen as an induction issue, not as a problem.

Linked to the issue of representation is that of who gets appointed. Several of the people reading early drafts of this report have commented that the smooth introduction of users to the boards might be linked to the fact that so few of them had learning difficulties. It was also suggested that any awkward people, who might have presented more of a challenge, had been screened out during the recruitment process:

The present system and the way in which the present government controls it is very unclear and inconsistent when it comes to including people on the edge of society (member of Engage).

It was also suggested that organisations needed to be more open to using the more "able" people with learning difficulties as representative of people with higher levels of impairment. They have experienced discrimination and exclusion to a much greater degree than non-disabled "experts". The doubts expressed by some people about the viability of involving people with learning difficulties at board level demonstrate that this idea has still to gain wide acceptance.

Changing the business

At the heart of the ideas presented in this report is a debate about what changes as a result of user participation. The first element of this is what changes

internally, in the organisation. How far should service users learn about and adapt to the norms of the organisation, how far should/can the organisation adapt its work practices to enable users to be full and equal participants?

Some commentators stressed the aim of user participation is to make a difference. In other words, it is not about "enabling" users to be involved: it is about the content of the work. There is a need to move beyond "involvement" to changing the business of delivery. This includes changing the way boards and large organisations operate:

User participation is not another task to do: this is the task we should be doing.

One commentator said *"people did not realise how dramatically things needed to change".* She included users in this, suggesting that both users and professionals need to change how they work, and to recognise how far organisations need to change. The debate about who adapts and how much is still current. It is now accepted that users are at the table – but as one user put it:

It is someone else's table and someone else is deciding what gets put on the table.

Is it possible for public authorities, with regulatory responsibilities, to adapt to the working practices of the user movement? The democratic and inclusive practices promoted by the user movement can sit uneasily with a target-driven public body. One view is that there will be a division of labour in organisations; it is logical that some people focus more on participation, some on other aspects of delivery. This managerial approach does not sit easily with the idea that user participation should be integral to how the organisation operates.

Engage suggests that people with limited exposure to public life may not have had the opportunities to obtain the relevant skills and experience in order to operate at board level. It is important that organisations such as political parties, trade unions, campaigning groups and other voluntary bodies encourage disabled people to take part in their structures. Disabled people are often excluded because these feeder organisations are themselves inaccessible.

The challenges for the organisations in making themselves accessible include tackling the hidden barriers to participation. Providing a physical change such as a ramp or a document in Braille is easy. But involving people with learning difficulties or young people or people living in residential care is more challenging, it requires ongoing changes in the way business is conducted.

Government says it wants users "at the heart" of social care. Users want to be there. But they are also clear that they do not want to be centrally involved just to make the current system work more smoothly. The balance of power has to shift, the pattern of services has to change.

In 2002 the Chief Inspector of Social Services said that:

Putting service users "at the heart of the enterprise" ensures that the traditional demarcation lines must be a thing of the past.

This means that the demarcation between user and service, between the done to and the doer, has to dissolve. This report shows that although the line may be more permeable than in the past, it is still very much in evidence. One of the titles for this report, suggested by a user, was "Working with Suits". What this reflected was a belief that in order to be effective in participating at governance level, users have to adapt to the dominant culture of the organisation. Some other users suggested that organisations had more to gain by adapting to the creative culture of the user movement. To imagine a new way of working that is user-led, inclusive, fair and effective is a challenge, but not an impossible one. One of the vivid examples of a truly user-planned and user-managed service is direct payments, developed by disabled people as a tool to enable independent living. One of the pioneers of direct payments in the UK referred to this act of imagining as a dream:

Our dream was that disabled people would be enabled to fulfil their roles in terms of taking the opportunities society offers and meeting the responsibilities society requires.

Users of social care services have begun to take both the opportunity and the responsibility of governance. Services have begun to take the gift of user wisdom.

Tracking outcomes

What difference has it made to have users in governance positions? What difference do governors make in any organisation? What are the expectations put on board members?

There are several answers to these vital questions. Having some users in governance positions has not changed regulatory organisations out of recognition. It might be argued that this is because the wrong users, or too few users, are involved. A suspicion has been voiced that the more awkward or challenging candidates are screened out by the public appointments process – *"your face has to fit".*

This view seems unfair on those users who have made it through the process. But it does seem true that the more users there are on the board, the more direct their influence is. Numbers do matter.

Various participants in the project identified an ambivalence about user participation in governance:

Governance is a top down notion, the user movement is bottom up – there is not always an easy fit.

There was also concern about the possibility of users in governance damaging the user movement, by co-opting activists, by downgrading other sorts of involvement. It might be that participation in governance is not the most effective way for users to influence services. It is certainly not the only way. Participation needs to have tangible, user-determined outcomes; having users at the table is not an end in itself. Boards of governors have specific roles; they do not usually influence service development in detail. Focusing on governance, as distinct from management, may distract attention from places where users can truly make a difference to the services they use. One of the challenges for the user movement

is getting used to working with ambiguity, of being both in and outside the establishment.

There may be lessons for government and statutory organisations about managerialism and participation. A consumerist model does not bring about the sort of change in organisations that users are seeking. Users are stressing a citizenship model, where participation is a function of exercising full and equal citizenship. This requires an emphasis on process as well as on outcomes.

There is a need for connecting the structures of involvement with real human beings – recognising that some people want short or one-off participation, others want a longer or more in-depth relationship with the organisation. Participation in governance alone will not meet the ambitions of users. That is not to say that governance does not matter, but that it needs to be viewed in perspective, alongside policy forums, inspection, training and other elements of delivering social care.

Conclusion

There is a deal of positive news in this project. Users are playing a full role as board members at the highest level. But the positive is tempered by the absences – the range of users is not especially broad and doubt persists about how well organisations are tackling participation at corporate level. There is no longer any doubt that people can or should be involved in shaping the services they use; the new challenge is to find how far services and organisations can or should change as a result.

Appendix One

ANNOTATED BIBLIOGRAPHY

Details

This list is arranged in the following sections:

1. Users in governance – general
2. Users in governance – social care
3. Lessons from broader literature on participation in social care
4. Users in governance – other sectors

The list includes both print publications and those that are solely or mainly available on the Internet. It also cites a small number of unpublished reports, on topics where published examples were not found. The body of work studying users in governance in social care is small in comparison with the number of studies of more general user involvement in social care.

1. Users in governance – general

1.1 David Wilcox (1994)
The Guide to Effective Participation
www.partnerships.org.uk/guide

This is a web-based practical guide to community involvement; it is drawn from both experience and research. It was produced in 1994 for community activists and professionals seeking to get other people involved in social, economic and environmental projects and programmes. It was funded by the Joseph Rowntree Foundation. It covers the theories of participation (Arnheim etc.) and includes a helpful resource guide, updated in 1998. Its main lessons on governance concern:

- Clarity on why organisations want to involve others
- Preparation for participation, i.e. not being token, not putting people in at the deep end, etc.
- Support skills within the organisation
- Appropriate structures.

1.2 Common Purpose: *Just Do Something*
www.justdosomething.net

This is another web-based resource on participation. It is part of a wider programme. Common Purpose's stated aim is to help people in leadership and decision-making positions to be more effective: in their own organisations, in the community and in society as a whole. The site focuses on citizen participation rather than user participation. It is based on experience, with lots of well presented examples, and a searchable database of opportunities. It has a section on skills for trustees. Although this is a "how to" resource rather than a research one, it is included in the list because it offers practical, up to date examples of participation.

1.3 National Consumer Council (2002)
Making it work: consumer representation, NCC

This report is one of a series from the NCC. The main lessons it offers are included in the form of a checklist:

Defining purpose
1. Define a clear role
2. Decide how many representatives you need

Finding your representatives
3. Include a variety of viewpoints
4. Use a variety of recruitment methods

Managing expectations
5. Communicate a purpose
6. Specify rights, powers and responsibilities
7. Clarify the commitment required
8. Give precise terms and conditions

Supporting consumer representatives
9. Provide relevant training
10. Manage the flow of information
11. Have dedicated consumer budgets
12. Provide support for representatives with special needs

Accountability checks
13. Monitor effectiveness
14. Help representatives to be accountable

1.4 (a) Hayden and Boaz (2000) *Making a difference – Better Government for Older People evaluation report* www.bettergovernmentforolderpeople.gov.uk

Describes successful initiatives to engage older people.

BGOP now has a formal management structure with a majority of older people, linked to OPAG (Older People's Advisory Group). It is an example of citizen involvement at a strategic level.

1.4.(b) Hayden and Benington (2000) *Multi level networked governance – reflections from the BGOP programme*, Public Money and Management April/June 2000

A critique of government structures for involvement. Illustrates some of the factors that helped BGOP to succeed.

1.5 Barnes and Walker (1996) *Consumerism versus empowerment* Policy and Politics vol 24 1996

This study critically evaluates the approach to user involvement and user empowerment adopted by the British government; they use the term "consumerism" to convey the market analogy underpinning the government's policy and contrast this with genuine empowerment. They outline eight key principles according to which the empowerment of service users could be realised.

This article makes reference to several other key texts in user involvement.

See also
Barnes and Wistow
Researching user involvement (1992) University of Leeds/Nuffield Institute

1.6 Barnes, M. (1999) Researching public participation

Local government studies; discussing evaluation of public (including user) participation.

1.7 Beresford, P. and Croft, S. (1980) *Community Control Of Social Services Departments*, London, Battersea Community Action

This sees governance in terms of the effective involvement of three constituencies (service users, workers and other local people) and anticipates the new government interest in "public" and not only "user and carer" involvement.

1.8 Beresford, P. and Croft, S. (1986), *Whose Welfare: Private care or public services?* Lewis Cohen Urban Studies Centre at University of Brighton

Offers the first study, based on a systematic and in-depth survey, of what say in social services a random sample of people felt they had in a key locality which had pioneered "user involvement"and decentralisation.

1.9 Beresford, P. and Holden, C. (2000) *We Have Choices: Globalisation and Welfare User Movements*, Disability and Society, Vol 15, No 7, pp973–989

Explores the competing pressures from globalisation and internationalised companies and the new user movements to influence and control social care services.

1.10 Beresford, P. (2002) *Participation And Social Policy: Transformation, liberation or regulation*, in Sykes, R., Bochel, C. and Ellison, N. (eds), Social Policy Review 14, Social Policy Association, Bristol, Policy Press, pp265–290

Considers the ambiguous role of user involvement at all levels, including in the governance of social policies, including social care.

1.11 Beresford and Croft (1993) *Citizen involvement: a practical guide for change*, Macmillan

This book is a guide to participation and empowerment which focuses on initiatives in social work and social services. It was based on a two-year JRF project and drew on examples from many policy areas (and included children as well as adults), including land use planning, housing, education, health, regeneration, leisure, child care. Plenty of insights from service users as well as practitioners, and guidelines for agencies. More than other general guides they focus on inclusion, with particular reference to disabled people, including mental health service users.

Key messages are:

- Involving people is political activity
- Involvement as process
- Consumerism v democratic input
- Inclusive approach.

See also:
Croft and Beresford (1990) *From Paternalism to Participation*, Open Services Project, London

1.12 Akpeki, T. (1995) *Black on board Black,* Echo

NCVO note that black people are under-represented at board level in voluntary organisations.

There are various reports on involving black and minority ethnic service users, but little on black-led organisations. One exception is:

1.13 Wenham, M. (1993) *Funded to fail: nuff pain no gain: the under-resourcing of the African Caribbean voluntary sector in London*, L.V.S.C.

This report outlines the challenges facing black-led voluntary organisations.

See also CEMVO website (www.cemvo.org.uk) for organisation developing strategy to tackle this issue.

1.14 Charity Commission (2001) *Users on Board: Beneficiaries who become trustees* www.charitycommission.gov.uk/publications

Taking on trusteeship can restore a sense of ownership and empowerment to users. It can help reduce inequality and discrimination. It can increase support for a charity among other users, and lead to more cohesive communities. It can broaden a charity's contacts and influence.

1.15 Beresford, Stalker and Wilson (1997) *Speaking for ourselves,* University of Stirling

A bibliography covering books, reports and articles produced by individuals and groups experiencing social exclusion, mainly but not exclusively focusing on social care.

1.16 Community Care Needs Assessment Project *"Asking the Experts" – A Guide to Involving People in Shaping Health and Social Care Services* (undated)

An overview of what constitutes good practice in involving service users and carers, contains practical guidelines as well as signposts to some useful resources. www.ccnap.org.uk

1.17 Pagel, M. (1998) *On our own behalf, an introduction to the self organisation of disabled people*, Greater Manchester Coalition of Disabled People

An account of disabled people controlling their own organisations, making the point that some "user-controlled" bodies date back to the nineteenth century.

1.18 Campbell, J. and Oliver, M. (1996) *Disability Politics*, Routledge

Describes the rise of the disability movement, including the difficulties of developing a fully inclusive user-led national organisation while operating in a disabling society.

2. Users in governance – social care

2.1 Department of Health (1999) *Modernising Social Services*, HMSO

This is the document that sets out the intentions of reform, including setting up new regulatory bodies. However, it does not spell out a governance role for users.

2.2 Department of Health (2000) *A quality strategy for social care,* HMSO

Says there is "now a strong body of evidence pointing to the qualities people value in social services (including) services that involve the user, so that choices are informed". It sets out plans for improving services, including improving user involvement, but again stops short of championing user governance.

2.3 Department of Health (2002) *Modern Social Services – a commitment to reform. The 11th Annual Report of the Chief Inspector of Social Services 2001/2002*

This report explicitly sets users "at the heart" of social care.

2.4 Oliver, M. and Hasler, F. (1987) *Disability and self help*, Disability Handicap and Society, Carfax

Describes users designing and managing their own services, notes the "informed attitude" of users.

2.5 Barnes, M. (1999) Users as citizens – collective action and the local governance of the welfare state *Social policy and administration vol 33*

Looking at ways disabled people's and survivors, organisations have sought to assert their legitimacy in the face of official responses construing them as self-interested pressure groups; a very useful overview of the issues. Conclusions include that whilst participation carries the dangers of incorporation there is also evidence of transformation taking place in the processes of governance and the service models emerging from dialogue between users and producers.

2.6 Barnes, M. (1999) *Unequal partners: use groups and community care*, Policy Press

Includes case studies of two user-controlled organisations (a centre for

independent living and a mental health day service); highlights the differences between user involvement and user self-organisation.

See also:
Barnes and Shardlow (1996) *Effective consumers and active citizens: strategies for users' influence on service and beyond* Research Policy and Planning.

2.7 Barnes, C. with Morgan, H. and Mercer, G. (2001) *Creating independent futures,* Centre for Disability Studies, University of Leeds

Three linked reports on user-managed independent living services – strong conclusion about fragility of organisations, precarious nature of the organisation's funding; high level of user support for services, it was felt to be an empowering experience to have disabled people at all levels of the organisation

2.8 Begum and Gillespie-Sells (1994) *Towards Managing User-Led Services*, REU

Report outlining a project where people who are responsible for services and people who use or require services came together to try and develop a model for managing user-led services.

2.9 Brand, D. (1999) *Accountable care – developing the General Social Care Council*, YPS

Based on consultations around the setting up of the GSCC, it identifies government policies favouring user participation and discusses potential difficulties in putting this into practice. Users consulted by the GSCC Implementation Group set out a number of standards for user participation on the Council's governing body (see overview report).

2.10 (undated) GSCC Briefing Paper, *Making it Happen – service user and carer involvement in the GSCC*

Summarises the practical and organisational steps that are needed; includes advice from users and carers to future members.

2.11 CVS (2001) *Evaluation of Comic Relief Special Initiative for Self-Organised Drug and Alcohol User Groups*, unpublished

This internal report describes the development of one national and twelve local self-organised and independently managed user groups. It notes the considerable barriers faced by this group in achieving user governance, and also describes some highly successful user-managed projects.

2.12 Valuing People Taskforce (2002), *Making Things Happen Better*, HMSO

Includes an assessment of how Partnership Boards have included people with learning difficulties; the Task Force itself represents an example of service users in a quasi governance role. www.doh.gov.uk/learningdisabilities

See also:
Could do better, Community Care 28 Nov 2002, critiquing the quality of support and involvement on boards and *Room on the board* (ditto) describing the process on local boards in Norfolk and Doncaster.

2.13 United Response (2002) *UR US pack*

An easy words and picture based guide to how United Response is governed, to help users with severe learning difficulties become involved; not about users in a direct governance role, but representing a serious attempt to give users a meaningful stake in the organisation. Supported by a CD-ROM.

2.14 Oliver, M. and Zarb, G. (1992) *Greenwich personal assistance schemes: an evaluation*, Greenwich Association of Disabled People

An assessment of a user-managed service.

2.15 Davis and Mullender (1993) *Ten turbulent years*, University of Nottingham

An account of the setting up of Derbyshire Centre for Independent Living, a user-managed service.

2.16 Annie Huntingdon (2000) *Refusing to be pigeonholed,* Professional Social Work

Article outlining some (theoretical) problems with having users on the board of GSCC.

2.17 Mind Policy fact-sheets (2001) *User Involvement and User Empowerment*, MIND

Give an overview of developments in involvement of mental health service users, including references to the opening of the first user-run sanctuary in Lambeth.

2.18 NCIL (2003) *ADSS/NCIL Protocol for contracting for direct payments support schemes*

Stating that user-managed organisations should be the preferred provider of direct payments support schemes.

2.19 Brown, M. (1999) *Service Please*, Connections Spring 1999

Discussing discrimination experienced by black disabled people, includes a short account of the user-managed services provided by Asian People with Disabilities Alliance.

2.20 Lanali, M. (1999) *From volunteer to a service provider: a personal journey of an Asian mental health service user*, ReHab Network, Autumn and Winter 1999

Detailing the creation of AWAAZ, a user-managed mental health service for Asian people in Manchester.

2.21 Philip Mason (1997) Keynote speech, *Facing Our Futures*, National Centre for Independent Living

2.22 Wiltshire and Swindon Users' Network (1996) *"I am in Control"*

Research into users' views of the Wiltshire Independent Fund.

3. Lessons from broader literature on participation in social care

This review is not a detailed analysis of the entire literature on user participation. However, as comparatively little work focuses on users in governance, general work on user participation in social care has been considered. Particularly since the NHS and Community Care Act, with its requirement to consult and involve users, there is a slew of reports and guides on this subject. The publications listed here are a selection, chosen where they provide either a helpful summary of the field or where they illuminate a particular aspect of participation.

3.1 Beresford, P. and Croft, S. (1992) *The Politics Of Participation*, Critical Social Policy, Issue 35, Autumn, pp 20–44

An early attempt to identify the distinction between consumerist and democratic approaches to involvement and governance in social care.

3.2 Beresford, P. (1994) *Changing The Culture, Involving Service Users In Social Work Education*, Central Council of Education and Training in Social Work, Paper 32.2

Addresses issues of user involvement, including governance in social work education, based on input from a range of service users and educators.

3.3 Beresford, P. and Harding, T. (editors) (1993) *A Challenge To Change: Practical experiences of building user-led services*, National Institute for Social Work

Offers a wide range of examples of how service users and providers were taking forward user involvement in all aspects of social services, including their governance.

3.4 Lindow and Morris (1999) *Evaluation of the national user involvement project*, Dept of Health

Looks at a four-site development project; concludes that experienced user consultants can be an effective method of assisting local groups to involve a wider range of service users, and that the project helps move perception of disabled people from just "service users to more as experts to be consulted".

See also:
Lindow and Campbell (1997) *Changing Practice, Mental Health Nursing and User Empowerment*, Mind/RCN

3.5 Yee, L. (1999) *Raising voices – guidance on involving black and minority ethnic service users*, LVSC

A compact and well presented guide, many helpful pointers.

3.6 Banton, M. and Evans, R. (2001) *Learning from experience: involving black disabled people in shaping services*, CDP Warwickshire

Exploring how black users experience exclusion from user involvement initiatives; analyses barriers and offers some strategies for involving black disabled people.

See also:
Begum, N. (1995) *Beyond Samosas and Reggae*, King's Fund

3.7 Consumers in NHS Research (2002) *A guide to paying consumers actively involved in research*

A helpful approach to this important issue in participation.

3.8 Boote, Telford and Cooper (2002) *Consumer involvement in health research: a review and research agenda*, Health Policy 61

A review of current ideas on consumer involvement in health research; says that evidence of consumers making a difference is only "anecdotal"; notes rarity of consumer controlled research; calls for further research.

3.9 Harding and Beresford (1996) *The Standards We Expect,* NISW

Based on the responses of a wide range of service users and carers to an invitation to define quality in social service practice, makes the case for fuller involvement of users in designing and monitoring services.

3.10 Beresford, P. (2003) *Identity, structures, services and user involvement,* SSRG
Personal and political considerations in user participation.

3.11 Bewley and Glendinning (1994) *Involving disabled people in community care planning,* JRF Findings

A review of how well (or not) authorities were implementing new requirements to involve users in the planning process.

3.12 Thornton and Tozer (1994) *Involving older people in planning and evaluating community care – a review of initiatives,* SPRU, University of York

3.13 Joseph Rowntree Foundation (2001) *Creating more choice for people with learning difficulties,* JRF Findings, August

Reports on a project looking at user involvement in services. Only one of the five services studied (all examples of "good" practice) had users in control, as a workers' cooperative.

3.14 Ross, K. (1994) *Speaking up, speaking out – involving users in day services* Social Services Research, University of Birmingham

Highlights many of the barriers to meaningful participation; says the implications of user-led services must be understood and properly resourced.

3.15 SCODA (1997) *Getting drug users involved: good practice in local treatment and planning*, Drugscope

Based on local and national surveys, models of good practice to help improve user consultation and involvement – the drug user field includes strong debate about service models (e.g. harm reduction v abstinence) that impact on models of involvement, particularly for "active" users.

3.16 Harding and Oldman (1996) *Involving service users and carers in local services – guidelines for social services departments and others'* NISW and Surrey County Council – practical advice.

3.17 Fiedler, B. (1991) *Living options in practice,* Prince of Wales Advisory Group on Disability

Model for achieving effective user participation in social and health services.

3.18 Morris, J. (1994) *Transferring features of user-controlled services to other services and organisations,* Joseph Rowntree Foundation

Suggests ways that good practice from user-led organisations could be used to promote user-led services.

4. Users in governance – other sectors

As with the previous section, this is not an exhaustive list of work around user governance. A small number of examples have been chosen from a range of sectors. As with the previous section they have been chosen where they provide either a helpful summary of the field or where they illuminate a particular aspect of participation.

4.1 Cairncross, Clapham and Goodlad (1990) *Participation – a tenants' handbook*, Tenant Participation Advisory Service

Written for "tenants" groups and other tenants who may be trying to have more say over what happens to their homes and estates. Distinguishes different levels of participation from listening to control, and deals with some of the methods for involvement that may be used by landlords.

4.2 TPAS (1989) *Tenant participation in housing management*. Institute of Housing and Tenant Participation Advisory Service

A guide to good practice based on research undertaken by Glasgow University. Covers the legal requirements of participation in housing; the pattern of participation found in research; the process; the participants; outcomes and achievements; and standards and performance.

4.3 The Hidden History of the British Tenant Movement, *Models for tenant participation*

Helpful summary of different levels of participation; a web-based resource, found on www.quest-net.org.uk

4.4 Farrell and Jones (2000) *Evaluating stakeholder participation in public services – parents and schools,* Policy and Politics vol 28 no 2

Examines the impact of parental participation as governors; is highly critical, concluding that parent governors are threatened by the position of professionals, excluded from decision making, have crises over who they represent and have difficulties in feeding back decisions which have been taken.

4.5 CYPU (2002) *Learning to listen: Core principles for the inclusion of children and young people*, HMSO

This publication says:

"There is already a lot of evidence... that involving children and young people in the planning, delivery and evaluation of government services brings benefits." It sets out four principles for participation:

- A visible commitment is made to involving children and young people, underpinned by appropriate resources to build a capacity to implement policies of participation
- Children and young people's involvement is valued
- Children and young people have equal opportunity to get involved
- Policies and standards for the participation of children and young people are provided, evaluated and continuously improved.

4.6 Hertz (2002) *Principles For Participation Of Children, Young People And Families In The Children's Taskforce*, Dept of Health, www.doh.gov.uk/childrenstaskforce/participation

Includes advice to "be clear at the outset how much involvement you are offering, why you want children and young people to be involved and what the outcomes are likely to be".

See also:
Carolyne Willow (2002) *Participation in practice: children and young people as partners in change,* Children's Society 2002

4.7 Engage (2002) *Engage News April 2002*, Scope

This is a project to encourage more disabled people to get involved in public appointments. It points out that disabled people make up only 1.5% of the 28,528 people who hold public appointments.

4.8 Cabinet Office (2002) *Diversity in public appointments,* HMSO

This details the numbers of women, ethnic minorities and disabled people serving on public bodies, by government department. It says:

"The people appointed to public bodies need to reflect the rich diversity of the UK and the boards of public bodies will be most effective if they benefit from access to a wide range of skills, experience and backgrounds from among their members."

4.9 Drake, R. (2002) *Disabled people, voluntary organisations and participation in policy making*, Policy and Politics vol 30 no 3

Examines the barriers to influence experienced by disabled people, expresses scepticism about government commitment to user participation.

4.10 JRF, *The Commission on Poverty Participation and Power – an evaluation*, JRF Findings

Examines how "grassroots commissioners" were enabled to take part in the Voices for Change project; discusses the challenges introducing participatory process in organisations not previously geared to it; covering issues of equal working/personal power and practical support such as getting advance payments for travel to meetings.

4.11 SUFOA (2000) *Speaking up for our age – evaluation report,* Help the Aged

Senior citizens' forums are seen as a growing mechanism for participation by older people.

4.12 Carter and Beresford (2000) *Age and change – models of involvement for older people,* JRF

This report offers practical guidance and ideas to increase the involvement of older people. It is based on discussions with older people's organisations and older people who are already actively involved, and draws on UK and international schemes and experience of involvement in a wide range of other fields.

4.13 Robson, Locke and Dawson (1997) *User involvement in the control of voluntary organisations,* JRF Findings

Few voluntary organisations have clear policies for user involvement; half the organisations surveyed had users on their governing body; development was slow and expectations low; useful insights into management's views of the barriers to user governance.

4.14 Kumar and Nunan (2002) *Strengthening the governance of small community voluntary organisations*

Looks at the barriers created by unduly heavy governance requirements on small organisations (which include many user groups).

4.15 Robson, Begum and Locke (2003) *Developing user involvement: Working towards user-centred practice in voluntary organisations*, Policy Press

An exploration of how 11 voluntary organisations increased their levels of service user involvement.

4.16 Department of Health (2003) *Report of a review group established to examine the use of the Power to Make Grants under Section 64 of the Health Services and Public Health Act 1968*

4.17 Dept of Health (2003) *Strengthening accountability – involving patients and the public*

Policy and practice guidance to Section 11 of the Health and Social Care Act 2001. This is a major "how to" guide covering all sorts of involvement including citizens' panels, focus groups, expert patients, etc.

It includes a section on overcoming barriers to involvement. Available in a range of formats, also on the web at www.doh.gov.uk/involvingpatients

Appendix Two

ORGANISATIONS INVOLVED IN THE PROJECT

Care Council for Wales
6th Floor, West Wing
South Gate House
Wood Street
Cardiff CF10 1EW

Tel: 029 2022 6257
Fax: 029 2038 4764
E-mail: info@ccwales.org.uk
www.ccwales.org.uk

Engage Network
c/o Scope Campaigns Department
6 Market Road
London N7 9PW

Tel: 020 7619 7245
Fax: 020 7619 7380
E-mail: engage@scope.org.uk

General Social Care Council
Goldings House
2 Hay's Lane
London SE1 2HB

Tel: 020 7397 5100 (switchboard)
Tel: 020 7397 5800 (information line – open from 10am to 12noon and 2pm to 4pm Monday to Friday)
Fax: 020 7397 5801
E-mail: info@gscc.org.uk

National Care Standards Commission
St Nicholas Building
St Nicholas Street
Newcastle upon Tyne NE1 1NB

Tel: 0191 233 3600
Fax: 0191 233 3569
E-mail: enquiries@ncsc.gsi.gov.uk
www.carestandards.org.uk

Northern Ireland Social Care Council
7th Floor, Millennium House
Great Victoria Street
Belfast BT2 7AQ

Tel: 02890 417600
Fax: 02890 417601
E-mail: info@niscc.n-i.nhs.uk
www.niscc.info

Scottish Commission for the Regulation of Care
Compass House
11 Riverside Drive
Dundee DD1 4NY

Tel: 01382 207100 or
lo-call 0845 60 30 890
Fax: 01382 207289

Scottish Social Services Council
Compass House
Discovery Quay
11 Riverside Drive
Dundee DD1 4NY

Tel: 01382 207101
Fax: 01382 207215
Information service: 0845 6030891
E-mail: enquiries@sssc.uk.com
www.sssc.uk.com

Shaping Our Lives
National User Network
Shaping Our Lives
Unit 57 EuroLink Centre
49 Effra Road
Brixton
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Tel: 020 7095 1159
Fax: 020 7095 1158
E-mail:
information@shapingourlives.org.uk

Social Care Institute for Excellence
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Topss England
Albion Court
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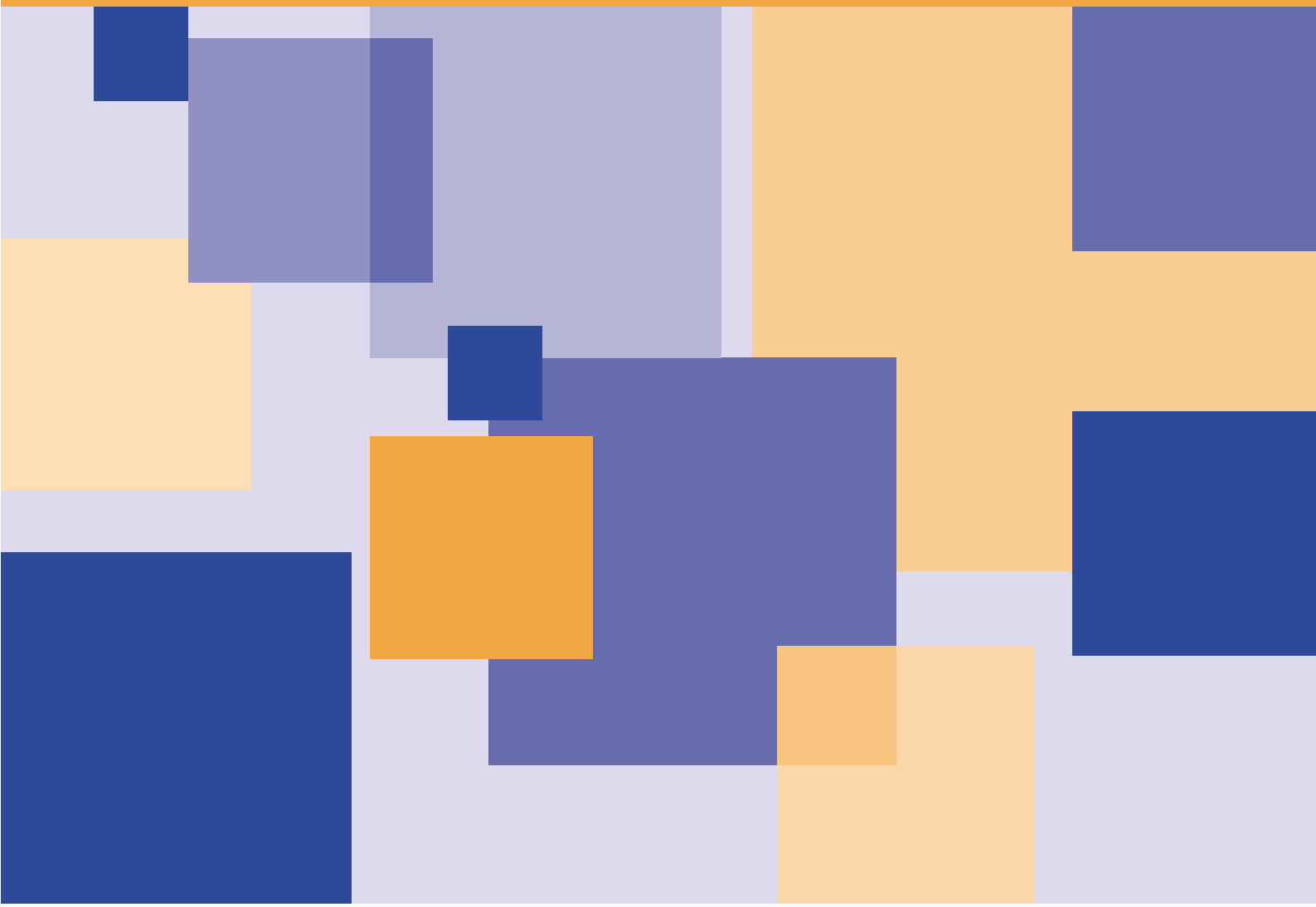

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