

Practice guide: the participation of adult service users, including older people, in developing social care



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Practice guide: the participation of adult service users, including older people, in developing social care

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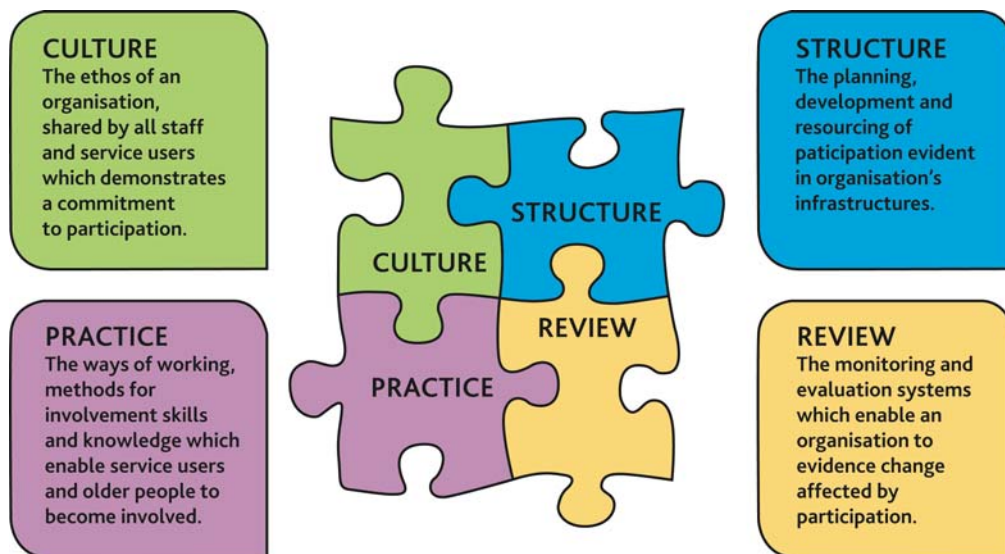
Introduction

The right of participation in decision-making in social, economic, cultural and political life should be included in the nexus of basic human rights.
(Lister, 1998, p228)

About this guide

Service users now play an increasingly important role in efforts to improve social care services. This guide focuses on how practitioners and managers can initiate and sustain the participation of adult service users, including older people, in ways that empower service users and reflect a shared commitment to developing social care services in a more democratic way.

Whole systems approaches have become a popular way of thinking about the steps that organisations need to take in order to achieve change. Taking a lead from the Social Care Institute for Excellence (SCIE) guide on the participation of children and young people in developing social care (Wright *et al.*, 2006), we propose that organisations adopt a whole systems approach to developing participation. This involves looking at organisations as a jigsaw consisting of four pieces: These are:



Each piece of the jigsaw has its own section in the guide. The sections summarise some of the main findings from research, include messages from practice and from people using services, and give details of some of the resources about participation that are available. Each section begins with a set of action points based upon the experiences of people using services.

Aim of the guide

This guide focuses on how practitioners and managers in social care can initiate and sustain the participation of adult service users, including older people, in developing social care.

Although it has been designed mainly for practitioners and managers in social care, we hope that the guide will be useful to everyone involved in promoting service user participation, including people using services and family carers.

Why the guide was compiled

The last decade has seen an increasing recognition and acceptance of the right of service users to participate in developing social care, especially given the new responsibilities that key government legislative and policy initiatives have placed on organisations to consult with service users. As a result, service users are being asked more and more to take part in the planning, provision, and evaluation of services. This has created increased interest in what works in participation and why. The guide offers social care organisations a framework for systematically examining how they are supporting service users to participate in the design, delivery, and review of social care services.

How the guide was compiled

To develop the guide, the project team reviewed the literature and policy documents, undertook a practice survey to identify examples of current and emerging practice, and consulted with service users.

The guide draws on the following types of social care knowledge:

- Service user knowledge based on the expertise of service users who participated in the consultation events held by Shaping Our Lives and the Centre for Citizen Participation.
- Organisational and practitioner knowledge based on the experiences of people working in the organisations who gave us information for the practice survey which was subsequently used to compile the Practice Examples.
- *Policy community* knowledge derived from material produced by different government departments and national organisations.
- *Research* knowledge derived from the collective experiences of the project team and from the literature identified in the literature review.
(Pawson *et al*, 2003)

Approval for the project was sought from the Association of Directors of Social Services (ADSS) and advice was sought on whether the project needed ethical approval, which it did not.

See Methodology Section.

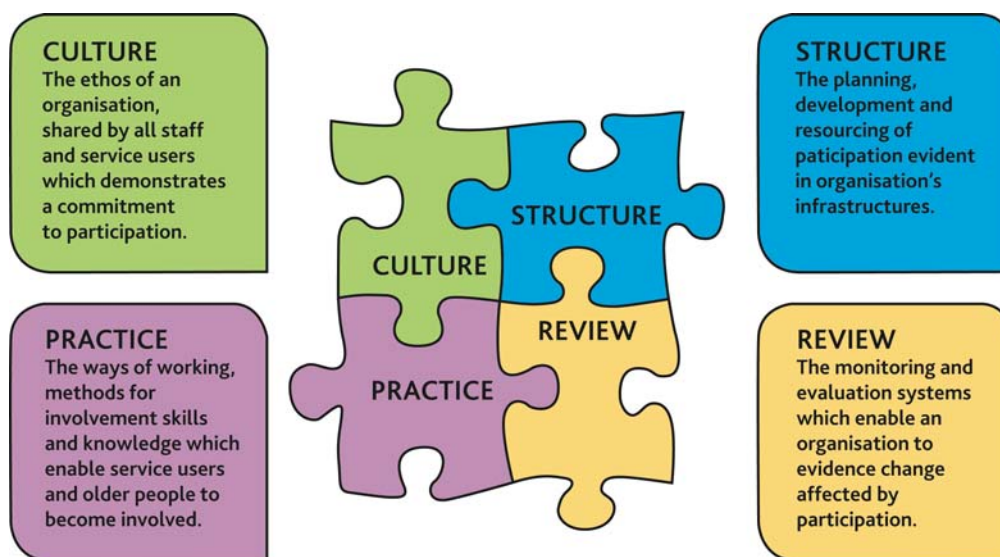
Whole systems approach

- Whole systems approaches involve identifying the various components of a system and assessing the nature of the links and relationships between each of them.
- Whole systems approaches are a useful way of looking at participation because:
 - > Organisations must change at every level, from senior management to front line staff, if they want to achieve meaningful participation.
 - > Participation should become part of daily practice, not a one-off activity.
 - > Participation operates at different levels. There are many ways to involve service users in different types of decisions.

(Kirby *et al.*, 2003b, p144–145)

Wright and colleagues (2006) suggest that different elements of participation can be brought together in a single framework, like a jigsaw puzzle. We thought that this was a useful way to look at participation and will go on to consider each one separately.

Figure One: A whole systems approach to participation



(Wright *et al.*, 2006, p12)

Key messages

- Service user participation has become an increasingly important part of social care. Organisations need to consider how well they are doing in this area and where improvements need to be made.
- The guide shows how this can be done by using a whole systems approach examining culture, structure, practice, and review (Wright *et al.*, 2006).

Culture

- Participation is more than developing a policy and implementing it. It is about ensuring that all members of an organisation are committed to participation and recognising that it will involve sharing power with service users.
- Cultural changes need to occur throughout an organisation.
- Staff may need training and support in developing a more participatory culture.
- Attention needs to be paid to formal and informal ways of supporting service users.

Structure

- Participation can be hindered by structural barriers, such as formal meetings or a lack of technological support. Organisations need to consider how they can avoid practices that may make people feel excluded, and how they can build up capacity among service users and service user organisations.
- Many barriers can be removed by good planning.
- Making changes to the system, not simply looking at how to support an individual, is generally a better way of removing barriers.

Practice

- A welcoming and friendly approach is an essential ingredient to good participation.
- Avoid using just one model of participation. This increases the likelihood that some service users are excluded. Specific strategies may be needed to ensure that the voices of people who are 'seldom heard', such as service users from Black and minority ethnic groups, and service users with communication difficulties are included.

Review

- More attention should be paid to reviewing the effects of participation. Although many organisations lack the resources and some of the skills needed to review their practice, using systems to review participation increases accountability both

to funders and to service users and helps in developing a more outcome-focused approach to participation.

- The lack of emphasis on review means that we still have limited ways of identifying changes that have resulted from service user participation.
- We also need to know more about how participation is undertaken effectively for all service users, including those who are 'seldom heard'.

Meaning and importance of participation

Summary

- The background for service user participation.
- Why participation has become important.
- The tensions between different approaches to participation.
- The benefits of participation for service users and social care organisations.

The emergence of the service user movement over the past 20-30 years has been one of the most important developments affecting social care policy. Up until this point, social care provision was largely shaped by politicians, managers, academics, planners and practitioners, with service users and citizens generally having little or no say (Beresford, 2001).

Some of the reasons why service users and citizens now have more opportunities to share in decision-making include:

- concern about the nature of public services and their capacity to respond to the needs and aspirations of increasingly knowledgeable and diverse 'consumers';
- greater questioning of the authority traditionally attached to professionals or other 'experts';
- more appreciation of the significance of 'lay' knowledge and knowledge that has been gained through experience.
(Barnes, 2005, p246)

Meanings

Service users

In this guide, we shall use the same definition of 'service user' as used by Beresford (2001), while recognising that it has limitations:

The term 'service user' [is used] as a shorthand...to describe people who receive or are eligible to receive...social care services...without seeking to impose any other meanings or interpretations upon it or them.

(Beresford, 2001, pp9-10)

- Service user controlled organisations such as Shaping Our Lives argue that 'service user' is an active and positive term with multiple meanings.
- The term includes people who are not currently using services and is based on self-identification as a service user.

- Alternatives such as 'consumer' are believed by some to be a restrictive term techniques associated with market-led approaches, such as consumer satisfaction surveys (Beresford, 1988; Twigg, 2000).
- Carers, that is people who are providing unpaid care to a family member or friend, have separate and different needs for participation, and there is a separate SCIE resource on this (Roulstone *et al.*, 2006).
- The interests of family carers and service users do not always coincide and we recognise that there are issues that may be of concern to both family carers and service users and that service users may also take on caring roles and vice versa.

See Practice Examples for the Alzheimer's Society, Hafal, and the MS Society.

Participation

- Participation is a contentious term that is often used interchangeably with words such as 'consultation', 'partnership' or 'involvement' (Croft & Beresford, 1992; Roberts, 2002).
- Some commentators have become concerned about the increasing use of the word 'participation' in ways that they feel devalue non-participants, and do not take account of barriers such as poor housing or low income that might prevent participation (Colley & Hodkinson, 2001; Fergusson, 2005; Taylor, 2005).
- Participation operates at many levels; it can range from individual control over day-to-day decisions about what to wear, what to eat and how to spend one's time, to collective decisions about service governance or commissioning (Joyce & Shuttleworth, 2001; Mordey & Crutchfield, 2004).
- Participation is not simply about being present or taking part but should be based upon having some influence over decisions and action (Kirby *et al.*, 2003a).
- A contrast is often drawn between 'consumerist' and 'democratic participation'. The former is based on the idea of market forces in public services, while the latter is favoured by service user movements with an emphasis on civil rights and citizenship (Beresford, 2002a).
- The consumerist approach aims at improving the quality of services by making them responsive to the needs and preferences of those who use them. It does not seek any transfer in power and control.
- The democratic approach aims to give service users the opportunity to participate in decision-making in the planning, management and review of services. It seeks to transfer power and control. (Andrews *et al.*, 2004 pp306-307)
- Service user groups often feel ambivalent about consumerism and there is a particular concern that involvement with the professional agenda will take precedence over their own priorities for campaigning and empowerment (Barnes *et al.*, 1999; Evans, 2004).

Part of the problem about getting involved is that you see the care organisation as the organisation that [funds] the service...so if you want to speak out you feel quite vulnerable if you are being directly supported by the organisation about which you want to complain or make an observation.

(Managers, service user organisations)

- Participation can vary between organisations that are *user controlled*, that is where service users comprise the majority of those in charge, and organisations that operate *on behalf of* service users, such as those that provide support to service users.
- Another way of describing this difference refers to *management-centred user involvement*, where service users take part in existing structures using an agenda defined by the organisation, and *user-centred user involvement* where service users' objectives and priorities became those of the organisation (Robson *et al.*, 2003).
- Differences in interpretation about what participation really means and the concerns about relationships between participation and funding show why it is important to set out clear aims and objectives for participation.

Legislation and guidance

- The United Kingdom government sees greater participation as a way of increasing the numbers of people who are 'active citizens' (Millward, 2005; Morris, 2005).
- Examples of legislation (www.dh.gov.uk/en/Policyandguidance/index.htm)
- Health and Social Care Act 2001. Its purpose was to:
 - > Improve the performance of the NHS.
 - > Provide better protection for patients through a faster, more effective and fair system for regulating practitioners.
 - > Strengthen the way the public and patients are involved in the way the NHS works.
 - > Modernise pharmacy and prescribing services.
 - > Extend direct payments for social services users.
 - > Provide a fairer system of funding for long term care including measures to reduce the need to sell one's home on entering residential care.
- National Health Service Reform and Health Care Professions Act 2002 which established patient forums and the Commission for Patient and Public Involvement in Health, soon to be replaced by Local Involvement Networks (LINKs) (Department of Health, 2006b).
- Guidance where there is an explicit requirement for service user participation includes the White Paper *Our Health, Our Care, Our Say* (DH, 2006); the *Valuing People* White Paper for people with a learning disability (Secretary of State for Health, 2001); the National Service Frameworks (NSFs) for older people (DH, 2001); for people with mental health problems (DH, 1999) and for people with

long term conditions (DH, 2005), and the requirements for the social work degree (DH, 2002).

- Legislation and guidance documents bring benefits because social care organisations are required to show evidence that they have consulted with service users. This may be used as levers for introducing changes, however there are concerns that legislative and policy pressures have sometimes led to a 'tick box' or tokenistic culture of participation (Newman *et al.*, 2004; Beresford, 2005b).

Outcomes of participation

Service user participation has resulted in a number of positive outcomes. By outcomes, we mean evidence that service user participation has had an impact upon service users themselves, the organisation itself, and what the organisation does.

Benefits for individuals and communities

Good participation increases confidence. Through dealing with professionals in consultations and other user initiatives, people can get more confidence to deal with their own health and social care professionals.

(Service user)

- For individual service users, the benefits of participation may include increased confidence and self-esteem, the chance to acquire new skills, and improved material resources if, for example it helps them to acquire paid employment (Attree, 2004). This is not to imply that these aspects were absent from their lives beforehand, rather that some service users feel that they have been improved.
- Participation leads to greater satisfaction (Department of Health & Farrell, 2004) and improved quality of life (Wallerstein, 2006). For instance, older people (Bull *et al.*, 2000), mental health service users (Carpenter *et al.*, 2004), and people with disabilities (Hagglund *et al.*, 2004), who have had greater control in decisions about the support they receive, report greater satisfaction and better health than those who have not.
- Beyond benefits to the individual, the participation process may also help create a stronger sense of community (Barnes, 2005; Collins, 2004; Wallerstein, 2006).

See Practice Examples for Hafal and Surrey County Council Adult Community Care.

Changes to services

- Service user participation can be used to make improvements to services.

See Practice Examples for Omnibus Partnership, Swansea Directorate of Social Services and Housing.

- Service users are more willing to participate when they feel confident that participation will result in definite changes (Beresford *et al.*, 2005).
- By contrast, where changes are not made or where service users are not informed of the changes, they may feel that there is little point in participation. This is often termed 'consultation fatigue' (Butt & O'Neil, 2004).
- More could also be done on ensuring that service users are involved in all aspects of service delivery in that, for example it is easier to find examples of service user involvement in recruitment and selection than in service evaluations (Diamond *et al.*, 2003).

Generation of new knowledge

- In reality, service users have always had knowledge; what is different is that there are now formal expressions of interest in it (Beresford, 2000).
- Service users have a particular role to play in the production of knowledge for health and social care because of the experiential nature of their knowledge and through their position as 'experts in their own experience' (Branfield & Beresford, 2006).
- Examples where service user knowledge has contributed substantially include:
 - > challenging and improving traditional ideas about research (Fisher, 2002; Glasby & Beresford, 2006);
 - > social work theory (Beresford, 2000; Beresford & Croft, 2004; Beresford & Evans, 1999; Wilson & Beresford, 2000);
 - > new ideas about citizenship (Beresford, 2005a; Morris, 2005).
- Research projects are increasingly based upon partnerships with service users and these collaborations bring strong benefits in terms of creating new knowledge, but care must be taken to avoid exploitation or reinforce power differentials (Miller *et al.*, 2006; Reed *et al.*, 2004b; Smith, 2004; Reed *et al.*, 2004b; Rose, 2003).
- Many service users and service user organisations feel that service user knowledge is still not valued sufficiently, thus denying policymakers, practitioners and researchers a key source of information and evidence (Branfield & Beresford, 2006).

See Practice Example for the Alzheimer's Society (Quality Research in Dementia).

Successful participation

Despite the benefits listed above, it is important to recognise that when participation is handled poorly, the chances of achieving positive changes will be reduced.

I hate being the only service user present. It is horrendous.
[Tokenism makes me] feel I'm being used.
(Service user)

Although originally written in the context of work with people from Black and minority ethnic groups on the need to move beyond traditional forms of research, and make progress in bringing about change in practice, these messages could equally be written about trying to achieve successful service user participation.

Success means ensuring that people:

- are involved right from the start in initiatives;
 - have than just one or two token members on a group;
 - have a real say in decisions;
 - meet regularly and receive regular updates on progress;
 - are supported in the process and not simply left with a series of inaccessible papers to read;
 - are given the results [of the participation] – not simply being the subjects whose knowledge is taken;
 - have a say in the meaning of the results and how these will be used.
- (Butt & O'Neil, 2004, p18)

There is still a shortage of published materials recording the outcomes of service user participation (Carr, 2004). Reasons why this has not happened include:

- Developments have been written up in a descriptive way, focussing on the *process*, rather than its effects (Bickerstaff & Walker, 2005), or they have not been written up formally in books, journals or reports.
- Evaluations often remain confidential to the organisations concerned and are not shared with others.
- The mechanisms for participation have rarely been linked to the mechanisms for improving services (Baggott, 2005; Beresford & Branfield, 2006).

However, there are now signs that this is beginning to change:

- Electronic publications increase the availability of materials to a wider audience.
- Evaluations including service users tend to focus very directly upon the quality of services (Banongo *et al.*, 2007; Kotecha *et al.*, 2007).

See Practice Examples for Leonard Cheshire and Rochdale Metropolitan Borough.

- Funding may be linked to a requirement for participation, or specific funding is allocated for service user participation through contractual arrangements with service user organisations.

See Practice Examples for Cedar Foundation, Exeter Senior Voice, Leonard Cheshire, and Surrey Users' Network.

Action points

- Agree a clear set of objectives for participation in consultation with service users and service user organisations.

You need to be told exactly what the participation is for, what realistically they want, and what realistically they will do with the information gathered. We need to know if it is just going to produce a report which will sit on a shelf gathering dust or whether change will come about as a result of your participation.

(Service user)

- Identify the outcomes that service user participation is planned to achieve. Organisations and service users need to be able to see evidence of 'what's changed'.

It's about feeling it's going to make a difference.
[Seeing] something coming out of it – good decisions!

(Service user)

- Make sure that everyone in the organisation is aware of the reasons for improving service user participation and the benefits of doing so. If necessary, set up training or information sessions to help members improve their knowledge and skills.

You feel pleased that somebody recognises you for your experiences.

(Service user)

Culture

Summary

- How organisations can develop more participatory cultures.
- Essential ingredients of committed leadership, staff training and informal and formal arrangements.
- Taking different organisational cultures into account.
- How organisations can redress the imbalances of power between them and service users.

Introduction

There are two things needed for an organisation to succeed in participation. One is the determination to make it work. You must really want this to happen; you must really want to hear the views of service users and take them on board. It has to become part of the aims of the organisation. The other thing is the willingness to ...[change]. You can't simply carry on working in the time-honoured ways of organisations.

(Chief Executive, voluntary organisation)

Organisational culture describes the set of beliefs, values, and norms that represent the unique character of an organization, and provide the context for its actions (Fincham & Rhodes, 2005). Many people believe that an organisation cannot change without first changing its culture (Davies *et al.*, 2000; Hughes, 1996; Hyde & Davies, 2004). This section looks at the cultural changes that organisations need to make in order to promote service user participation. Subcultures may also develop within organisations (Hofstede, 1998) within different functions, by profession, practice areas, or by level (Adkins & Caldwell, 2004), so it is important to identify if there are any discrepancies in how different parts of an organisation view participation.

See Practice Example for Bradford Metropolitan District Council.

Developing a culture of participation

Managers can't just decide on a policy and implement it like any other. It is a hearts and minds thing and needs a culture change, so there needs to be a lead from the top, lots of training for staff and lots of independent support and training for the service users.

(Manager)

Although different types of organisation have different cultures of participation and what may work for one organisation may not be right for another (Kirby *et al.*, 2003a), there is still considerable agreement about some of the changes that any organisation will need to make to improve the culture of participation. These extend through the organisation and include formal and informal systems.

Leadership from the top

- The commitment of senior management is a key reason why organisations succeed in participation, especially in statutory organisations, which may have a number of different priorities.

See Practice Examples for Bradford Metropolitan District Council and Southern Health and Social Services Board.

Champions within the organisation

- Champions within an organisation help promote good practice and encourage others to change their ways of working (Townesley *et al.*, 2002).

See Practice Example for the Cedar Foundation.

Support and training for staff

I think all organisations, certainly those that work in the care sector should have on going disability equality training, not awareness training, and delivered by suitably experienced and qualified disabled people.

(Service user)

- Recognition of service users' expertise has led to the increasing use of service users as consultants and trainers in education and training. One study found that 69 per cent of a sample of 318 mental health service users and survivor groups reported that they were involved in this type of work (Wallcraft *et al.*, 2003).
- Professional education programmes such as social work increasingly involve service users in delivering parts of curriculum. For example, the Department of

Health *Requirements for Social Work Training* (2002) calls for service users and carers to be involved in all stages of the degree, from recruitment and selection, through to teaching and learning provision and preparing for practice learning, and this development has been well received by social work students themselves (Waterson & Morris, 2005), as well as contributing to improved social work practice (Beresford, 2004; Tew, 2006).

See Practice Examples for Surrey Users' Network, Rochdale Metropolitan Borough, and Leonard Cheshire.

Using formal and informal arrangements

In addition to formal systems for consultation and involvement, organisations need to find informal ways of helping service users to participate. This reflects the reality that different people wish to participate in different ways and ensures that those who do not wish to participate in formal systems are able to make their views heard.

See Practice Examples for Guildford Action.

Power dynamics

Until we have secure financial footing, we will not be able to help bring about changes. We always have to chase the money and cut our cloth to fit. And now with all the non-service user organisations tendering against us it is likely we will be forever the poor relation begging at the door. That hardly results in good participation practice.

(Service user)

Service users are in an unequal position with social care organisations (Barnes *et al.*, 1999; Rummery & Glendinning, 2000). Additionally, they may experience what are termed 'multiple oppressions' through being a service user and being a member of a minority group on the basis of ethnicity, gender, sexuality, age or people with HIV/AIDS (Butt *et al.*, 2005; Carr, 2004; National AIDS Trust, 2006). These existing power imbalances are often reproduced when social care organisations involve service users.

1. The process of participation may itself be exclusionary if it is undertaken on the basis of an acceptance of a disempowered identity. For example, descriptions of particular types of service user, such as 'socially excluded', are stigmatising and may actually deter people from participating (Newman, 2002).
2. Some participatory structures may reproduce ways of operating that are exclusive rather than inclusive, for example, by having very formal agendas and rules of debate (Barnes, 2005).

3. Social care organisations may retain power by defining who is a 'legitimate' or 'representative' participant (Beresford & Campbell, 1994; Millward, 2005), for example by controlling who is invited to consultation events and meetings.

This third point has become an increasingly important topic of debate. As social care organisations become increasingly concerned about representativeness, it has been suggested that this is less about extending involvement but more about organisations wanting to define who is representative.

You start off as a raw service user and as you become better at saying what you want to say, you get excluded from the list of who to invite because they call you a 'professional older person'.

I have been at meetings and they have listened to what I've said but you know that they're going to tick a box saying, 'Have you consulted with service users?' when they have only talked to me. My voice is valid but I don't represent everyone else as well.

(Service user)

Harrison and Mort (1998) identified how some officials used the views of service users to give legitimacy to their own opinions when they were faced with another group of officials with whom they disagreed. In these circumstances, they would highlight the legitimacy of service users, a process they (the officials) described as 'playing the user card'. Conversely, where they disagreed with the opinions of service users, they started to question service users' legitimacy, dismissing them as extremists or unrepresentative.

Changing power relations

You find that there is a lot of time given over to what people in authority want, not what we want, so our wishes don't get discussed.

(Service user)

One of the main ways in which participation has been used to achieve cultural changes *at the head* of an organisation has been through the appointment of service users and service user representatives onto Boards of Trustees or management committees.

See Practice Examples for the Alzheimer's Society, Bromley Health, Social Care and Housing Partnership Board, Leonard Cheshire, MS Society, People in Action (Leeds), RNIB, and Values into Action.

It may also involve identifying whether existing systems are failing to meet the needs of some groups. For example, the Alzheimer's Society has introduced an inclusion policy aimed at ensuring that people with dementia, or groups of people with dementia, such as Black and minority ethnic people or lesbian, gay, bisexual and transgendered (LGBT) people with dementia, and their carers are more fully involved in all aspects of the Society's work.

See Practice Example for the Alzheimer's Society.

In terms of the relationship that organisations have with *individual service users or groups*, some organisations have arranged formal systems for service users to take decisions, for example through individual and group meetings.

See Practice Example for Swansea Directorate of Social Services and Housing and Threshold.

Others employ people who have had experience of being a service user.

See Practice Examples for Swansea Directorate of Social Services and Housing and Values into Action.

However, where service users have been supported to become paid workers in the same organisation in which they were previously service users, it is important to recognise that adjustments in relationships between the two may need to be made.

See Practice Example for Guildford Action.

Action points

- Map the different levels at which participation occurs, ranging from how service users are involved in daily decisions to strategic decision-making. This will help identify participation 'champions' and areas that need improvement.

This morning [support worker] gave me cup of tea, give me breakfast. I say, 'Hello', no [reply], nothing, did not speak to me and did not sit next to me, sat a couple of seats along...I don't feel like I'm in control of my own life.

(Service user)

- Identify which attitudes lead to service users being excluded and develop ways of changing them.

I know that sometimes I can come across as the 'angry disabled person' which confirms all their negative stereotyping but is usually more about me feeling very vulnerable and confused because my access needs are ignored.

(Service user)

- Agree on shared values and be honest about what is likely to result from participation.

It is about being empowered. It is about recognizing that [organisations] understand and have acted from a social model understanding. It is important to listen to what disabled people say. It should be an information exchange.

Need to be honest, for example, 'this is what we hope to achieve'.....'Your views will be fed to [practitioners] in such and such manner.'

(Service user)

- Make sure that there are mechanisms for accountability and admit when mistakes have been made or when there are problems with the service.

Whoever is running it must report back to the service users.

They don't listen. All they say [is that] they are not responsible for whatever it is you are talking about. It is never their fault. You are forever talking to the wrong person. They always have excuses.

(Service user)

- Acknowledge the contribution made by service users.

Partnership needs to be there, not workers hijacking ideas. [We] need to be equal partners.

(Service user)

Structure

Summary

- Barriers that prevent participation.
- Improving structures for service user participation.
- Supporting people to participate.

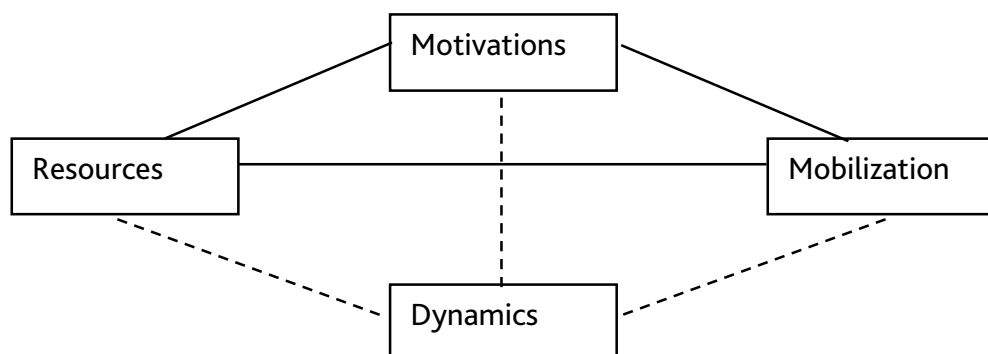
Introduction

Since 2004, I have gone from being a service user to the secretary on the User Forum and now working for [the organisation] as an independent facilitator...I work for eight hours a week. I get paid for those hours, and I get my benefits on top of that. I have a team of people here who support me through everything that I do...I have four support workers. If I want to work 12 hours a day, they will support me for 12 hours a day. If I get too tired and I want to go home, I can work from home. I am supplied with an office, a computer, and a laptop. I also get a travel allowance and so does everyone else on the Forum.

(Worker in voluntary organisation)

Even when an organisation is actively committed to participation, its attempts may fail if the right structures are not in place. Simmons and Birchall (2005) suggest that one way of looking at participation is to see it as a chain whereby each link must be made as strong as possible (see Figure Two).

Figure Two: Participation chain



(Simmons & Birchall, 2005, p278)

- The *resources* link stands for the resources necessary to set up the system for participation, such as providing training and advocacy schemes to help build participants' skills and resources.

- The *mobilization* link refers to the systems for encouraging people to participate. If people feel that the subject is relevant to their lives and is likely to result in changes, then they are more likely to want to become involved.
- People's *motivations* to participate are varied. Although they sometimes think that it will bring benefits to themselves, they are more likely to see it as benefiting the wider group or community. It is important to make the participation process work *with* their motivations than *against* them.
- The *dynamics* link refers to the relationship between the organisation or provider and participants. Organisations must be aware of the power dynamics between them and participants, and must be honest about their own motivations.

Simmons and Birchall also argue that the chain metaphor highlights the need for all the links to be joined together as each depends upon the other. For example, there is little point in training people in participation skills without providing them with opportunities to use them.

However, there are powerful factors that act as *barriers* to participation, thereby weakening the participation chain. These may be grouped under the following themes:

- **Personal barriers**, for example the sense of personal powerlessness that stems from long-term reliance upon others and the costs of involvement to participants.
- **Institutional and political barriers**, for example a formal meetings culture and the use of language that does not encourage dialogue.
- **Economic and cultural barriers**, especially in communities where there is decline and fragmentation.
- **Technical barriers** such as the lack of accessible formats and technological support for groups to enable service users to participate effectively or difficulties in getting small amounts of funding for support costs.
(Beresford & Hoban, 2005, pp19-21)

The next section describes the ways in which attempts have been made to try and overcome some of the barriers described above.

Dealing with barriers to participation

Personal barriers

Service users can be supported in overcoming some of the barriers to individual participation in three main ways. These are through:

1. training;
2. policies aimed at **minimising the costs** to service users; and

3. **systems that are flexible** enough to take account of the way in which a person's circumstances or disability might influence his or her ability to participate.

Training for service users

Supporting service users through training is an example of capacity building whereby, as service users become more confident, their capacity for activity is increased. This has been a key feature in the development of user-controlled organizations (Postle & Beresford, 2007). However, investment in capacity building has remained low or poorly co-ordinated and this has been identified as a major reason why communities and service users remain excluded from systems for decision-making (Duncan & Thomas, 2000).

The practice survey identified the three following types of training for service users.

1. *Campaigning and lobbying skills*

Campaigning skills, and being able to put one's views across effectively, are very important for service users, especially if they are taking part in formal settings, such as being a representative on a local authority strategy group. Although many service users are experienced campaigners, others are not. Training in campaigning and lobbying skills helps those without experience in this area.

See Practice Example for Alzheimer's Society.

2. *Assertiveness training*

Assertiveness training can be used to help service users become more confident at expressing their views.

See Practice Examples for Bradford Metropolitan District Council and RNIB.

3. *Workplace skills*

Training can be used to support service users who would like to become paid workers or volunteers. This includes training in counselling and presentation skills, project management and staff recruitment.

See Practice Examples for Bradford Metropolitan District Council.

Offering training is especially important where service users are involved in specialist roles, such as teaching on social work education programmes (Duffy, 2006) or working as co-researchers (Miller *et al.*, 2006; Smith, 2004; Walmsley, 2004).

Minimising the costs of participation to service users

Service users who can't work go along to these meetings where everyone else is being paid as part of their salary to be there and we are not paid and we sometimes are not even paid expenses. This is hardly equality.

It often isn't done with any intention to discriminate service users, which is the sad thing. Often they just don't have a clue about participation so they don't take into account payment when they are putting the budget together and then it is too late and they don't have the money. It is ignorance and a lack of thought.

(Service user)

Organisations can help overcome barriers to individual participation by developing clear and efficient systems for minimising the costs to service users of participation. This is about more than the actual monetary value because it demonstrates a commitment to equalising relationships between service users and professionals. An important starting point is having a policy for participation that makes things clear from the start and spells out what will be paid and how. This helps to prevent differences in the way that people are treated and reduces the difficulties that might be caused by informal arrangements when there are organisational or staff changes.

See Practice Example for Southern Health and Social Services Board.

Linked with this, is the need to have a policy for paying support workers, and/or personal assistants, and reimbursing the expenses of volunteers if they are needed to help the person participate, or to cover replacement support costs for family carers.

See Practice Examples for Bromley Health, Social Care and Housing Partnership Board, MS Society, People in Action (Leeds).

It is vital to make sure that expenses are paid as quickly as possible, either by fast-tracking claims through the organisation or by bringing along cash to reimburse people on the day. Service users should be reminded in advance if they need to bring receipts or provide invoices.

See Practice Examples for Bradford Metropolitan District Council and Help the Aged (Speaking Up for Our Age).

Payment

[What's needed is] changing the benefits system so people can get involved without fear and worry. It is undermining participation and people's chance to get involved now.

(Service user)

- There is considerable variation in the way that organisations deal with the issue of payment and there are many examples of unfair treatment where individuals work for no payment alongside others who are being paid (Turner & Beresford, 2005). For example, service users and carers are increasingly involved in professional education but may receive only token payments for their involvement (Bamber & McKeown, 2003).
- The question of payment is an extremely complicated area and solutions will depend on the personal circumstances of individual service users. The Department of Health (2006a) has issued a guide on reimbursement for service users which outlines good practice in terms of paid involvement and gives an overview of the current regulations on permitted work for people on benefits.
- While some organisations offer payment in kind, such as complimentary copies of newsletters, reports, or other publications, a meal or refreshments, or the opportunity to take part in a conference, training or other activity, these may be defined as taxable benefits by the Inland Revenue and so this needs to be considered if payments in kind are to be made (Faulkner, 2004).
- The complexities of payment should not be used as an excuse to avoid supporting service users who want to move into paid employment as consultants, researchers, or advisors.

Devolving budgets to service user organisations

Power is seen in monetary terms and service user organisations don't have much money. It's another reason why service user organisations should be put on a better financial footing.

(Service user)

- Most of the organisations included in the Practice Examples had developed policies for reimbursing expenses and, to a lesser extent, support costs. Fewer organisations had devolved budgets to service users so they could control how the money was spent themselves.

See Practice Examples for the Cedar Foundation and Leonard Cheshire.

Systems that are flexible

- This can range from flexible employment policies to providing quiet areas for people to rest or take time out. Similarly, there should also be recognition that service users with conditions which have periods of remission, may have times when they would like to increase their involvement.

See Practice Example for MS Society.

Institutional and political barriers

Many organisations have an understanding of participation that positions service users as external consultants rather than partners in the development process (Carr, 2004). Since the majority of service users involvement takes place at the consultation level, where policymakers, officials and professionals generally outnumber service users considerably, this explains why some systems for participation may actually *reinforce*, rather than *alter*, existing power relations (Hodge, 2005).

Three of the most commonly used ways of preventing these problems include:

1. Appointing service users onto management boards or as trustees or as co-chairs on Partnership Boards. To work well this requires careful planning and provision of appropriate training and support. Service user co-chairs can be especially effective as they help ensure that service users are at the heart of decision-making and demonstrate that an organisation is committed to participation (Fyson & Simons, 2003).
2. Setting out standards for service user involvement through a compact or charter for service users.

See Practice Examples for Hafal, The Cedar Foundation and Leonard Cheshire.

3. Changing the style of meetings by dividing into small groups, using more inclusive language by avoiding jargon, abbreviations or technical terms, making sure that there are support workers who can go through meeting papers and documents in advance with service users, and sticking to agreed timetables.

See Practice Examples for Bromley Health, Social Care and Housing Partnership Board, Rochdale Metropolitan Borough, Southern Health and Social Services Board, Surrey Users Network, and Values into Action.

Not sticking to times is also an access issue. They say the meeting is going to end at 3.30 so you organise all sorts of things to enable you to travel at that time, a taxi is waiting, assistance with rail travel is booked and you have to give them 24 hours notice and if you turn up half an hour late, you miss your train, but then the booked assistance isn't there to meet you on arrival, or your prearranged transport. But if you leave the meeting early because it is running late not only do you miss some of the meeting but you are made to feel that you are being the awkward disabled person by insisting that you leave 'early'.

(Service user)

Economic and cultural barriers

Broader issues, such as working in areas where poverty and deprivation have hindered the development of a thriving voluntary and community sector, a lack of trust between organisations and service users, and consultation fatigue can all act as barriers to participation (Beresford & Hoban, 2005).

- Research has pointed to the role here for professionals to act as mediators between organisations and the wider 'public' of potential participants; supporting people to take part in developments that involve and empower them (Barnes *et al.*, 2003; Postle & Beresford, 2007; Postle *et al.*, 2005).
- We found that it was more likely to be service users or user-controlled organisations that were more conscious of the need to overcome economic and cultural barriers. They were also more likely to set participation within a broader citizen rights or social exclusion context.

I think the greatest changes are when you go to meetings which are not for [service users]. I think that is where we can influence the political agenda and we are not doing it under the banner of disabled people, maybe under equality or regeneration.

(Service user)

See Practice Example for The Omnibus Partnership.

- In some areas, the establishment of Community Empowerment Networks, which bring community and voluntary sector groups together in deprived communities and enable them to influence and shape decisions of public sector bodies in Local Strategic Partnerships, has been one way of trying to achieve greater local involvement in strategic decision-making, but progress in this area has been uneven and there are concerns about future funding (National Audit Office, 2004; Taylor *et al.*, 2005).

See Practice Examples for Lewisham Community Empowerment Network and Rochdale Metropolitan Borough.

- Small community organisations are often grounded in their locality and have developed systems for consulting more widely within their communities.

See Practice Examples for Adaab, Exeter Senior Voice, The Omnibus Partnership, and People in Action (Leeds).

- National membership organisations provide an important role in providing information, campaigning on behalf of their members, and in co-ordinating responses to national or local plans.

See Practice Examples for Alzheimer's Society, Hafal, MS Society and Values into Action.

- Membership organisations can be important intermediaries between statutory organisations and service users. Many voluntary and community sector groups have good links across organisations, credibility, and experience. They are often the recognised channels for consultation, particularly in processes such as audit and inspection. This is because service users generally respond better to requests from those they trust than, for example to general posters or other types of publicity (Simmons & Birchall, 2005).
- Black voluntary and community organisations which, despite funding problems, have been one of the main resources for capacity building, civic engagement and social inclusion of Black and minority ethnic communities (Butt, 2005; Chouhan & Lusane, 2004).

See Practice Examples for Exeter Senior Voice and Surrey Users Network.

Technical barriers

Lack of local British Sign Language (BSL) signers [is a problem].

Lack of notice of meetings makes it difficult to make proper arrangements, for example book signers.

(Service user)

Always check that electronic equipment such as hearing loops work because they often do not.

PowerPoint and overhead projections and everything is not accessible to me and if you raise a question about it you are often made to feel that you are a nuisance.

(Service user)

- Technical or practical barriers may include the shortage of workers with experience in participatory work, the lack of accessible formats and technological support for groups such as disabled people to enable them to participate effectively, and the pressures on voluntary and community organisations to respond to official agendas rather than their own (Beresford & Hoban, 2005). This last dilemma may actually have increased as government policies have encouraged them to move from a traditional 'outsider' role to become 'insiders' (Craig *et al.*, 2004).

Ways of attempting to overcome these barriers include:

- Helping practitioners to build better relationships with individual service users and local communities.

See Practice Example for Lewisham Community Empowerment Network.

- Increasing the numbers of workers with direct experience of being a service user.

See Practice Example for Swansea Directorate of Social Services and Housing.

- Making sure that materials are accessible either by using non-technical or 'Easy Read' summaries and providing materials in different formats such as large print or Braille.

See Practice Examples for Help the Aged (Speaking Up for Our Age), RNIB, Southern Health and Social Services Board and Values into Action.

- Establishing a named 'link' person within an organisation with a liaison role between service users and the organisation. This can help to reduce the problems that can occur with personnel changes or restructuring.

See Practice Example for Bradford Metropolitan District Council and Rochdale Metropolitan Borough.

Action points

- Plan in advance, use accessible venues and make sure that service users have time to prepare for the meeting.

It's a good experience when the venue is accessible; that the information you are given is in the accessible format.

(Service user)

- Avoid exclusionary practices in meetings.

Timing is never seen as an access issue. They say, 'Come at 9 o' clock.' They just don't think what that means for service users. Everything about the rush hour makes it really difficult for us.

(Service user)

- Draw up a clear set of 'ground rules' that operate across all levels of participation which aim to create the right atmosphere for working together respectfully.

Excluding users deliberately [by using jargon is] a form of bullying. We show them a red (a warning) and yellow card (to stop them) at our meetings if they do that in their presentations.

(Service user)

- Write documents in plain English and make them available in different formats and languages. Provide support for service users who need help reading complex or long documents.

[Papers] should be short and concise with no jargon and no acronyms.

(Service user)

- Agree agendas and notes of meetings in advance and give service users an opportunity to include items that they would like to discuss.

Build in an earlier deadline so that papers can be available in any format needed and so they go out prior to the meeting.

[Meetings are all] about money and we don't get to discuss issues we want to talk about.

(Service user)

- Develop a clear policy for the reimbursement of service users which covers the costs of participation, transport, and support costs. Providing cash payments on the day. Where payments are made by cheque, or by transfers to a bank account, make it clear how long it generally takes for the organisation to process them.

I have just been paid for attending a meeting nearly a year ago.

(Service user)

Practice

Summary

- A range of types of participation.
- Networking and support.
- Creative approaches to participation.
- Inclusion of 'seldom heard' groups.

Introduction

It's about good manners. Service users can feel ignored and it can be stressful in meetings. It's important to greet people at the beginning of a meeting and say goodbye at the end of it.

(Service user)

Evidence from many service users is that, despite the best intentions of social care organisations, their experience of participation can be patchy and tokenistic (Turner *et al.*, 2003), or actually negative (Barnes *et al.*, 2006). Sometimes this stems from the model of participation that has been used. For example, consultative arrangements can draw in a wide range of views but may not be effective if the results of the consultation are ignored or used to legitimate an agency's own pre-set agenda. By contrast, small and experienced user groups and direct action can be an effective way of getting things done but may also leave out the wider group of service users (Carter & Beresford, 2000).

However, many bad experiences have their origins in poor practice.

They just stare at me, look at you nasty, so I just say, 'What you looking at? Haven't you seen a person with learning difficulties coming to a meeting?' [They] think you haven't got no feelings.

(Service user)

Types of participation

Different people want to participate in different ways and there is widespread agreement that successful service user participation is based upon having varied and flexible approaches that allow this to happen (Collins, 2004; Truman & Raine, 2002; Waldman, 2005).

Consultation meetings

- Consultation through meetings, questionnaires and focus groups is probably the most frequently used model of participation, although it is most criticised by service users because there are concerns that consultation meetings may operate according to a fixed agenda and there is no guarantee that people's views will actually be used to change a service (Carter & Beresford, 2000).
- Ways in which organisations have tried to improve the quality of consultation meetings include:
 - > having meetings in which there is a formal system for accounting for decisions that have been taken and an opportunity for discussion and planning for the future;

See Practice Example for Swansea Directorate of Social Services and Housing.

- > using different ways of collecting information, such as focus groups and questionnaires, in addition to formal meetings; and

See Practice Examples for Bradford Metropolitan District Council and Exeter Senior Voice.

- > meeting at different times and in different venues.

See Practice Examples for Southern Health and Social Services Board.

- The choice of venue is something that can make meetings simultaneously more *inclusive* for some groups and *exclusive* for others. For example, meetings in pubs can reach people who would not want to travel to 'official' locations such as the town hall, but would exclude others who would not go to pubs on religious or moral grounds. This means that it is important consider carefully the choice of venue.

See Practice Examples for Bradford Metropolitan District Council and Southern Health and Social Services Board.

Do not assume a venue is accessible because the website says it is. Ask to see the access audit. Always visit the site with a suitably qualified person to check the access.

Make sure the venue is easy to find, accessible and on an accessible bus route and near an accessible station.

Make sure car parking can be reserved for service users who are not necessarily blue badge holders.

Give plenty of clear and accurate directions to venue.

Ensure that there are enough accessible toilets. Many service users need to use an accessible toilet not just wheelchair users.

(Service user)

Forums

- Forums for specific service groups, such as national and local older people's forums or local and regional forums for people with learning disabilities, may avoid some of the difficulties about power raised by consultations because they are run *by* service users *for* service users.
- Forums are more democratic in that they have a recognisable 'voice' and they have been able to effect changes to services, despite barriers persisting for some people. (Barnes, 2005; Carter & Beresford, 2000).

See Practice Examples for Help the Aged (Speaking up for Our Age) and Rochdale Metropolitan Borough.

Campaigning organisations

- Campaigning organisations range from large national to small grassroots organisations.
- Larger organisations are sometimes seen as coalitions *for* service users, rather than *of* service users, although they can offer a less time consuming way of becoming involved, while creating a sense of solidarity and shared interests among their memberships. In addition, service users are able to increase their levels of involvement by becoming volunteers, paid workers or trustees. (Carter & Beresford, 2000).

See Practice Examples for Alzheimer's Society, Hafal, MS Society, The Omnibus Partnership, and RNIB.

Advocacy

- There are different models of advocacy services (Rapaport *et al.*, 2005) but each share similarities in that they all aim to speak on behalf of another person or, in the case of self advocacy groups, to speak on behalf of themselves and fellow members.
- There are disagreements about what is meant by advocacy and the understandings and expectations of people who use advocacy services may not be the same as the service providers (Bowes & Sim, 2006; Forbat & Atkinson, 2005).
- While advocacy services are available in most parts of the country, not all service users have equal access to advocacy services. For example, advocacy services for people with dementia (Cantley *et al.*, 2003) or people with communication difficulties (Lewington & Clipson, 2003) are less developed than those for people with learning difficulties or mental health service users.

See Practice Example for Adaab.

See Resources Section Action 4 Advocacy and People First.

Service user led groups or networks

- Participation led by service user controlled groups or networks has the advantage of being more firmly rooted in the actual aspirations and preferences of service users but has often faced barriers in terms of funding (Beresford *et al.*, 2006; Carter & Beresford, 2000).
- Consulting directly with service user led groups or networks, or asking them to undertake consultations on behalf of another organisation, has greater credibility with service users (Banongo *et al.*, 2007) and leads to better quality results because of their greater experience and expertise in identifying what is important to service users (Evans & Carmichael, 2002; Fisher, 2002).

See Resources Section on Service User Researchers.

See Practice Examples for The Cedar Foundation, Leonard Cheshire and Surrey Users' Network.

Individual involvement on a daily basis

- It is easy to forget that, for many people, the most meaningful participation is being able to take more control over their everyday lives.

It needs to be recognised that the bulk of service users' participation is on a personal level based on individual situations and requirements. This is

understandable and should not be considered negatively. Most people in the UK do not take an active role in developing services and strategic planning. (Begum, 2006, p19)

See Practice Examples for People in Action (Leeds), Swansea Directorate of Social Services and Housing, and Threshold.

Networking and support

As a service user, you can feel isolated, so it is a good opportunity to meet other service users. That in itself, can be very empowering whatever the meeting was about. It is good when they allow time for service users to network with each other.

(Service user)

- Service user organisations and individual service users can be, and often are, isolated, with little knowledge of, or contact, with other service user organisations, locally, regionally or nationally (Branfield & Beresford, 2006).
- Developing systems for peer support can help avoid consultation fatigue or burnout and enables service users who have less experience in participation to benefit from the support of those who are more experienced.
- Many service users feel that networking is a key route to strengthening service user knowledge and increasing its credibility and visibility, both in services and policy and among service users and service user organisations.

See Practice Example for Leonard Cheshire.

- Where service users have been involved over a fixed period of time, such as helping on a time-limited project, it is important to think about creating a positive ending, such as completing a final report or having a celebratory meal (Porter *et al.*, 2006).

See Practice Example for The Cedar Foundation and Help the Aged.

Creative approaches to participation

- Involving service users is not always achieved through meetings or postal questionnaires. Using other approaches to participation is based upon the recognition that service user participation should allow different forms of expression (Barnes *et al.*, 2006).

We have a storyteller in Lewisham...so where people are unlikely to relate to [an official strategy document]...by getting them to tell a story about their experiences as a tenant on a block, they may tell you very important things around a...number of issues like anti-social behaviour, or housing maintenance or asbestos removal or anything else. We managed to get funding to go out and talk to groups and reflect back to them what they had said, produce a resource pack. We use them at all our events when we feel we are getting stuck in the dogma or the detail. It's a useful way of breaking things down for people, it provides a bit of light relief. We also use 'Playback Theatre' or music or local musicians just to give people the experience of not being in a formal meeting, and getting them to communicate in different ways. So, we have used theatre and acting and mime as a way of communicating people's experiences.

(Manager, Community Empowerment Network)

See Practice Example on Lewisham Community Empowerment Network.

- Drama has also become an increasingly popular way for service users to express their views, such as through the *Old Spice* drama group, a group of older people based in Newcastle upon Tyne (Reed *et al.*, 2004a) or by using sketches as a way of introducing important themes (Turner *et al.*, 2003).
- Other options include participatory appraisal techniques first used in developing countries but increasingly used with marginalised communities in Europe and North America. Where they have lessons for social care is in their avoidance of the written word and use of creative approaches such as photography (Wang, 1999) or video (Lunch & Lunch, 2006).
- Examples such as providing disposable cameras to people with learning difficulties so that they could show what they thought about social and horticultural therapies (SHT) (Aldridge, 2007) or by helping people with dementia attending a drop in centre to take photographs so that they can record what was important to them (Mitchell, 2005).

See Resources Section for PEANuT and PhotoVoice.

- Technological advances have also supported more creative types of participation. For example, the Surrey 50 plus network <http://www.surreycommunity.info/surrey50plusnetwork/> allows people to respond to online surveys and take part in discussion boards.
- Another development that is likely to develop further is the use of game show technology as a way of giving instant feedback to people taking part in consultation events (Audit Commission, 2003).

Working with 'seldom heard' groups

- Until recently, little attention has been paid to ensuring that systems for participation take account of the diversity that exists among service users in terms of their ethnicity, sexuality, and life experiences (Beresford, 2002b; Carr, 2004).
- Now, there is greater awareness of the need to include 'seldom heard' or so-called 'hard to reach' groups. The three main reasons why this should take place are:
 1. All service users have equal rights as citizens to make sure that their views are heard.
 2. Service users comprise an extremely diverse group (Begum, 2005; Beresford & Branfield, 2006) and this should be reflected if participation strategies are to be both inclusive and representative.
 3. Members of seldom heard groups may have separate or differing needs for participation (Begum, 2005).

The lack of more inclusive approaches to participation means that while some groups complain of 'consultation fatigue' and the lack of action resulting from participation (Butt and O'Neil, 2004), others argue that no attempts are even made to consult with them (Afshar *et al.*, 2002).

There is also a danger that service user participation is seen as applying only to those who are currently receiving services and fails to address groups of people who are under represented or who do not receive a service.

There are some groups of users who are more stigmatised than others and they may feel reluctant to disclose their status as a service user. In these instances, it may be necessary to use methods aimed at providing an individual and collective voice for service users at risk of being excluded from more mainstream traditional types of involvement. For example, separate focus groups for people with a learning disability have been used as part of Best Value consultations (Cambridge & McCarthy, 2001).

People from Black and minority ethnic groups

Many participation exercises have failed to engage effectively with people from Black and minority ethnic groups (Butt, 2005). Reasons for this include:

- the unsuitability of many mainstream services, leading to lower levels of uptake (Chahal & Ullah, 2004);
- racism and stereotyped attitudes among many service providers (Chahal & Ullah, 2004; Evans & Banton, 2002);
- insecurity of funding among many Black organisations meaning that service user involvement is seen as a lower priority when compared with their primary aim (Evans & Banton, 2002).

These help to create situations whereby many people from Black and minority ethnic groups feel reluctant to participate at any level, whether individual or more strategic (Begum, 2006).

Research undertaken with Black professionals and service users has suggested the following ways of removing these barriers:

- recognising the impact of multiple oppression (such as being Black and having a disability), raising awareness of issues, better working across organisations, and using Black and bilingual workers;
- using various communication techniques (especially audio tapes), providing transport and an accessible venue, meeting cultural needs and holding regular meetings/events;
- building relationships with individuals and families, having a dedicated role to develop the work, providing specific services for black disabled people and active outreach;
- providing varied opportunities for involvement including consultation, evaluation and policy development, offering training and respecting the skills that Black disabled people have.

(Evans & Banton, 2002)

It can also help to use local organisations that already have credibility within their communities.

See Practice Examples for Adaab and People in Action (Leeds).

Strategies for improving participation among service users from Black and minority ethnic groups also need to recognise the diversity within them. While progress has been made in engaging with some communities, others remain under represented. For example, many service users are unwilling to criticise a service in case it is withdrawn, such fears may be even more common among groups such as asylum seekers and refugees (Begum, 2005).

There is also evidence that participation strategies have been less effective in reaching more newly arrived communities or very dispersed communities, such as those living in rural areas (Butt, 2005).

Earlier parts of this section have suggested how care should be taken in the choice of venues for participation activities and that account should be taken of religious and cultural preferences and the timing of holidays or periods of religious observance.

A further consideration is that interpreters may be necessary for some service users whose first language is not English. However, the quality of interpreting services varies and there are risks of over-reliance upon family members or interpreters who

have not been trained to report accurately what has been said to them (Gerrish, 2001).

Research carried out with people using interpreting services showed that:

- good interpreting is about more than language proficiency and the literal exchange of words; it is about the interpreter putting forward the user's view of their situation;
- interpreters' personal qualities and attitude may sometimes be more important than their gender, age, and nationality for some service users;
- people need to feel that they can trust an interpreter and this is why they sometimes prefer family and friends to professional interpreters, even though they may be less familiar with technical terms and jargon (Alexander *et al.*, 2004). Nevertheless, services need to be confident that individuals really do want members of their family and friends to act as an interpreter and need to be ready to offer and provide trained interpreters.

Lesbian, gay, bisexual and transgendered (LGBT) service users

- Attention to the needs of lesbian, gay, bisexual and transgendered service users has been neglected in many mainstream participation initiatives (Carr, 2004).
- It has been suggested that until recently, equality on the basis of sexuality has been given less priority than other equalities issues (Carabine & Monro, 2004).
- The role of 'champions' within organisations has been identified as crucial to improved levels of participation among lesbian, gay, bisexual and transgendered service users (Davies & River, 2005).
- An important issue for these service users is that worries about homophobia and heterosexism among service providers, or other service users, may mean that they do not want to disclose their sexuality, even when it may have implications for the sort of services they would like.
- For example, in a series of consultations with more than 1800 people aged 50 and over, undertaken on behalf of the Healthcare Commission, it was striking that nobody disclosed being lesbian, gay, bisexual or transgendered in the discussions with generic groups of service users. It was only in individual and group interviews held with service users recruited via groups for lesbian and gay people that participants felt able to comment on how well services were meeting their needs (Moriarty *et al.*, 2006).

People with a communication impairment

When [social work assistant] came for my review, he couldn't read my communication board well, so I finished the answers off on my computer for him. He never brought a full report with him, so I don't know what he put about me on the form. When I complained to the social care offices, his line manager backed their worker up....I am still waiting to see my review papers.
(Service user)

- Many systems for consultation privilege people who are able to communicate without any difficulties. Loop systems, signers, and communicating through a support worker are some examples of some technical solutions for people with communication impairments.
- Some people prefer to communicate directly themselves. SCOPE has produced a guide written by people with communication impairments for support workers and personal assistants but the guide has a wider relevance for anyone communicating with a person with a communication impairment (Abel *et al.*, 2002).
- The service users thought that it was important to have:
 - > Someone who gets to know us well.
 - > Someone who is respectful.
 - > Someone who recognises that it is our right to communicate, and that they are responsible for facilitating that right.
 - > Someone who looks at the skills we already have.
 (Abel *et al.*, 2002, pp 10-13)

People with dementia

- Although there is a considerable amount of research highlighting that only a very small minority of people with dementia cannot express their views, people with dementia are seriously under represented in the majority of systems for participation (Cayton, 2004).
- There is a lack of systems to support participatory practice so that care managers and social workers are often asked to make life changing decisions on behalf of a person with dementia, such as deciding whether or not to recommend a move into a care home, without having had time to build up a personal relationship with him or her (Brannelly, 2006).
- There are now several research-based resources which highlight the multiplicity of methods that have been used with people with dementia including:
 - > questionnaires;
 - > interviews;
 - > observation;
 - > advocacy; and

- > focus groups.
(Wilkinson, 2002)
- Even with questionnaires, a method that might be seen as among the least suitable, better results can be obtained if they are completed with a volunteer or helper rather than through self-completion (Cheston *et al.*, 2000).
- The work of Cantley and colleagues (2005) provides detailed practical advice on involving people with dementia in different service settings and also summarises what research has shown.
- Other advice includes:
 - > spending time before collecting any information so that the person with dementia feels more relaxed (Stalker, 1998);
 - > using photographs as a prompt for discussion (Allan, 2001; Bamford & Bruce, 2000);
 - > using several techniques and supplementing formal discussions with informal conversations (Bamford & Bruce, 2000).
- It is also possible to give feedback to people with dementia about the results of discussions. Proctor (2001) found that when she talked to women with dementia about her analyses of her interviews with them, they did not remember her or the interview but they were still able to comment on the content of what was said.

See Practice Example for Alzheimer's Society.

People isolated at home

- The dominance of meetings-based models of participation means that people who find it difficult or impossible to leave their homes are often excluded from participation.
- Others may prefer to be consulted in their own homes (Patmore, 2001). Service users in this position can be identified through local media, newsletters and service providers (O'Keefe & Hogg, 1999).
- They may then be supported through technological means, such as tele-conferencing, or through the help of volunteers or support workers meeting them in their home.

See Practice Examples for Exeter Senior Voice, Rochdale Metropolitan Borough, and RNIB.

- Some service users are reluctant to attend public meetings or venues in which different service user groups are present and there is an expectation that people will define who they are in terms of their experience as a user of social care services.

There are also things like if you have a hidden impairment people don't necessarily treat you as a service user and then talk about your 'impairment group' in a very negative way and then you can't say you are a mental health service user because you already know what they think of mental health service users and everyone would be embarrassed and you know what they really think, whatever they then try and tell you. It can be very isolating.

(Service user)

What not to do!

The older people who are members of Exeter Senior Voice have prepared a *Brief Guide to Total Failure or How to Make Sure that Marginalized People Stay Marginalized* aimed at all organisations that are reluctant to work towards meaningful participation. Unfortunately, there is only space here to include one or two examples for each point but, although the tone is light-hearted, the extracts give a sense of some of the practices that prevent participation from becoming meaningful. Their use of the pronoun 'they' to refer to service users is deliberate.

Brief guide to total failure or how to make sure that marginalized people stay marginalized

1. Make sure they realise that this consultation is purely lip service.
 - > Ask people for their views when the decisions have already been made.
 - > After the first meeting, always send a deputy or better still your apologies.
2. Keep them guessing.
 - > Be vague about what might or might not happen as a result of the consultation.
 - > Management terms, jargon and abbreviations should be used throughout – the more the better.
3. Make it clear who is in control here – they must appreciate they are only here on sufferance.
 - > Never divulge how you will be using the information you get from them.
 - > Choose a venue with only two lavatories – on another floor.
4. Make people pay for the privilege of being consulted.
 - > Do not reimburse expenses, or if you really must, make them ask about it.
 - > Make them put in a travel claim through the usual system so they don't get anything back for several weeks.
5. Keep it simple – you only have to be able to say you tried.
 - > Limit your consultation to one public meeting in the evening.
6. Remember the 'easy to reach' are easier to reach.
 - > Exclude people who cannot complete your questionnaire.
 - > Only invite the 'usual suspects' – they understand how meetings work.
7. Keep it bureaucratic (see Kafka for more tips).

- > Make sure that every letter comes from a different person.
 - > Never give a contact number.
8. Bear in mind that these people are marginalized for a reason – they can't speak for themselves.
- > Never ask them what they prefer – they'll only make unrealistic demands.
 - > Talk over their heads to their carer.

Action points

Good practice involves making sure that service users feel valued and welcomed.

[It's difficult] when people [that is, professionals] all know each other but don't introduce themselves to you so you feel left out.

[It's important that people without learning difficulties] treat you as an equal and don't talk down to you.

(Service user)

Use different and more imaginative approaches to help prevent service users feeling excluded and encourage them to become involved.

Identify which groups of service users have been under-represented in participation and see what steps need to be taken to reach out to them.

No one [without a learning difficulty] understands people with learning difficulties. People with learning difficulties understand how you feel, because they are the same as you.

(Service user)

Review

Summary

- The importance of review.
- An evaluation checklist.
- Ways of reviewing progress in organisations.

Introduction

Be honest and clear about what you are consulting on and don't make promises when you know you can't deliver on them.

(Manager)

Review plays an important part in monitoring the progress that has been made in involving service users in developing social care, in recognising the achievements that have been made, and in identifying what improvements still need to be done. Without it, it is impossible to assess the quality of any participatory strategy.

Review broadly consists of the mechanisms for collecting information about a programme to make a judgement about its quality, value or importance (Davidson, 2004). Now that there is much greater recognition of the case for the involvement of service users on ethical and democratic grounds and as a way of improving service quality (Beresford, 2002b), it should be an increasingly important stage of any strategy for participation. However, given the greater emphasis upon looking at the process of service user involvement, rather than outcomes, it remains a neglected area (Carr, 2004). Perhaps this is because organisations do not set aside specific resources for the process or it is because an organisation's participation strategy has not included a formal commitment to review. This section outlines some of the approaches that can be taken to establishing what progress has been made. There is a separate SCIE resource on developing measures for effective user and carer participation.

Evaluation checklist

There are many different models of evaluation. However, in the context of evaluating participation, they would usually include the following:

- Who are the actual or potential service users served by the (participation strategy)?
- What resources are available to create, maintain, and help it?
- On what basis have you determined whether the strategy is of high quality or value? Where will you get the criteria and how will you determine 'how good is good?'
- How good, valuable or efficient is the design and delivery of the strategy (process evaluation)?
- How good or valuable are the impacts on service users or other stakeholders (outcome evaluation)?
- How costly is it to service users, staff and so on compared with alternative approaches (cost effectiveness)?
- What elements could be used in other settings (exportability)? (Davidson, 2005, p86)

Who should undertake the evaluation?

- External evaluators are thought to offer greater independence and may have greater expertise but there may be issues of ownership in terms of implementing their findings.
- Internal evaluators are part of the organisation that is being evaluated. They have insider knowledge and are more likely to be in a position to implement their findings but they may be seen as more subjective. (Patton, 2001).

External evaluation

- External evaluation can be undertaken in a number of ways by commissioning:
 - > Organisations that undertake research or consultancy.

See Practice Examples for Leonard Cheshire, Lancashire County Council, and Lewisham Community Empowerment Network.

- > Peer evaluation by people from outside the organisation from a similar sphere of work.

See Practice Example for Alzheimer's Society and Threshold.

- Membership of a wider network or quality assurance accreditation scheme, such as *Investors in People*, can also form a way of ensuring that steps are taken to review progress.

See Practice Example for People in Action (Leeds).

Internal evaluation

- Internal monitoring systems or audit are generally the most usual form of internal evaluation.

See Practice Examples for Bradford Metropolitan District Council, Hafal and Values into Action.

- Another way is to ask service users to complete questionnaires or evaluation forms.

See Practice Example for MS Society and Surrey Users' Network.

External and internal evaluation

- A distinction is often drawn between *formative* evaluation, which aims at finding areas for improvement, and *summative* evaluation, which is undertaken primarily for reporting or decision-making processes (Scriven, 1991).

See Practice Example for The Omnibus Partnership.

Using specific evaluation programmes or measures

There are numerous programmes which have been developed to measure public service quality. However their appropriateness for the evaluation of participation is untested. Examples identified in the practice survey included the Cedar Foundation, which has used SERVQUAL, a questionnaire which measures gaps between consumers' perceptions of quality and organisations (Parasuraman *et al.*, 1988; 1991), and which can be used across different service organisations (Francis & Netten, 2004), including the public sector (Wisniewski, 2001), People in Action (Leeds), which uses PQASSO (Practical Quality Assurance System for Small Organisations), a quality assurance system developed by Charities Evaluation Services (CES) (Charities Evaluations Services, 2006) and Threshold, which uses a quality of life measure that includes involvement in decision-making as part of the Community of Communities (CofC) is a standards-based quality improvement network which brings together therapeutic communities (TCs) in the UK and abroad (<http://www.communityofcommunities.org.uk/>).

See Practice Examples for Cedar Foundation, People in Action (Leeds) and Threshold.

Involving service users

- An increasing number of service users are involved in internal or external evaluations. For example, the Sainsbury Centre for Mental Health has developed a toolkit which uses mental health service users to evaluate the experiences of other service users (Kotecha *et al.*, 2007).
- Service user evaluators or researchers remain under utilised. This may relate to issues about power, or to the shortage of experienced service user researchers, and the lack of systems and resources for capacity-building research skills among service users.

See Resources Section on Service User Researchers.

- The practice survey identified two organisations that have involved service users in the evaluation process.

See Practice Examples for Leonard Cheshire and Rochdale Metropolitan Borough.

Feedback

- Feedback is an important stage in any review process as it helps ensure that changes become ongoing (Wistow, 2005, v).
- Service users say that user involvement in social care should not just be 'a passive process of feedback but should be a continual and ongoing activity' (Beresford *et al.*, 2005, p19).
- Different ways of giving feedback should be used so that all service users can share in the process.

Action points

- Use reviews to assess progress, and provide evidence of the changes, have been made as a result of service user participation.

From where I am coming from, [organisations have] got to get their finger out and act, instead of giving it all the talk and no action. Start doing things. Make it work.

(Service user)

- Service users must be involved in the review process.

[They] didn't listen to people and do the job they were meant to do. They were meant to talk to us and find out what we wanted from day services and put us somewhere where we wanted to go.

(Service user)

- Reviews should be based upon realistic goals.

Need to be honest, for example, 'this is what we hope to achieve...'
Your views will be fed to [practitioners] in such and such manner'

(Service user)

- Set a clear timescale for measuring change.

[What needs to change is] taking ages to do things they have promised to do, for example talking about setting up a database... and never doing it.

(Service user)

- Identify whether changes are needed at individual or strategic levels.

On an individual level, yes, you can see changes. They might put something on tape for me or get it in Braille. But no mass change.

(Service user)

- Develop a system for sharing the results within the whole organisation.

When information is fed to managers, systems need to be sorted out to make sure it filters down to the workers.

(Service user)

Conclusion

What we know about participation

- The literature, practice survey, and consultations with service users showed that there is now a growing understanding of what service user participation means.
- Organisational knowledge often tends to focus upon structures and procedures for participation whereas service users tend to be more interested in the processes and outcomes of participation.
- The two strands of participation and quality improvement need to become more linked (Beresford & Branfield, 2006).

Dominance of consumerist models

- Evidence from the literature, practice survey, and service users all suggested that consumerist models of participation continue to predominate over democratic approaches, hence less power and control is transferred to service users.
- This means that most service user participation is currently achieved through consultation meetings – this format rarely leads to increased accountability and may exclude many service users.
- While almost all organisations included in the practice survey had developed policies for the reimbursement of expenses, support costs, and payment for service users, comparatively few had devolved these funds to service user organisations to manage themselves.

What constitutes good practice?

- The consultations with service users and the practice survey highlighted the difficulties of translating knowledge into practice.
- Service users, managers, and practitioners identified the importance of making sure that service users felt valued, knew that their contribution would make a difference, and received feedback on the outcomes of their participation.
- They also agreed on the importance of choosing accessible venues, making sure that documents were available in multiple formats, avoiding jargon, being welcoming and friendly, and providing support to service users throughout the process.
- Consultations with service users suggested that, while these practices did exist, they were not implemented consistently.
- It is not clear to what extent participation means helping service users in making choices about their daily lives. There is a danger that it is seen as a 'one off' activity rather than something which should be embedded in an organisation's everyday practice.

Recognising the expertise of service users

- Service users wanted to have their expertise acknowledged.
- The research for the guide highlighted the need not to assume that participation *creates* expertise, although it may do, but to recognise that people using services also *bring* knowledge and experience with them.
- The practice survey suggested that the most frequent way of building on the expertise of service users was by involving them in staff training but that service user involvement at strategic levels remained comparatively rare outside of service user-led organisations.
- Much of this training was aimed at frontline staff, rather than at managers or service planners.
- Service user knowledge is also extensively used in the voluntary sector when service users become active in organisations campaigning or providing services. However, we continue to know very little about how these transitions from service user to volunteer, or from service user to paid worker, are managed and what the experiences of service users who make these changes have been.

Participation and the wider agenda

- This guide has identified that service user participation in social care must be considered within the wider agenda.
- Policy aimed at reducing social exclusion has highlighted the way in which different factors influence each other. For example, disabled people see access to transport as a key factor in promoting participation.
- A key concern among service users is the impact of the benefits and taxation systems upon payment for service users and the receipt of benefits in kind (Turner & Beresford, 2005).

Uneven progress

- The number of service users who are 'seldom heard' in participation initiatives is considerable.
- We currently have very little information about what works for service users with a communication impairment, who are lesbian, gay, transgendered or bisexual, who are from a Black or minority ethnic group or who are living with dementia. Strikingly, although there is a growing body of research on how to engage people with dementia (Wilkinson, 2002) which has not been incorporated into mainstream participation strategies.
- Much participatory activity seems to take place within a single group of service users when there are benefits from looking at participation across different service groups and across different sectors.

Social care could also learn from the community development field where there have been many attempts to experiment with innovative ways of involving people, such as drama or music.

The changing face of social care

- The changes to social care such as the advent of integrated teams, extension of direct payments, and individual budgets mean that changes in the type and nature of participation are likely to take place.
- Despite being the major provider of social care services, there is still very little evidence about service user participation in the private sector.
- A concern for service user controlled organisations is that they will be increasingly expected to compete for funding with organisations that are less committed to participation.
- We need to integrate participation into the wider quality improvement programmes mentioned earlier, (Beresford & Branfield, 2006), so that organisations are competing on equal terms and ensure that participation does not become lost as new service configurations emerge.

Different models of participation

Currently there are many different models of participation and what is right for one organisation may not be right for another (Kirby *et al.*, 2003b). The following practice ideas and examples show how different agencies have tried to improve practice and solve problems. In some cases, organisations were run or partly run by service users themselves and participation was seen as one of their main activities. In others, the resources necessary to support greater service user participation were lacking or participation was seen as just one of the many activities taking place in the agency. It was considered important to include relatively large agencies in which service user participation occurred, as part of their broader remit alongside smaller operations for which it was their main area of activity.

The examples below only consist of organisations included in this guide.

User controlled organisations

Service users comprise all, or the majority of, those who manage and control the organisation.

- The Omnibus Partnership
- Surrey Users' Network (SUN)

Devolved user controlled organisations

These organisations are part of a larger agency, which has allocated resources and authority to a team with a specific remit to support service user participation within the organisation as a whole.

- The Cedar Foundation
- Leonard Cheshire

User-led organisations

Although sharing many similarities with service user controlled organisations in that service users are involved in all areas of decision-making, service users are not necessarily exclusively involved.

- Hafal

Consultation

These organisations are agencies where the majority of service user involvement is based around consultation.

Statutory agencies

- Bradford Metropolitan District Council
- Bromley Health, Social Care and Housing Partnership Board
- Rochdale Metropolitan Borough
- Southern Health and Social Services Board

Voluntary agencies

- Exeter Senior Voice (Age Concern Exeter)

Campaigning and advocacy

These organisations aim to represent the interests of service users and may include service users as members and in decision-making. Some campaigning organisations may also be involved in service provision but these examples focus on their work in providing information and campaigning.

National

- Alzheimer's Society
- Help the Aged (Speaking Up for Our Age)
- Multiple Sclerosis Society (MS Society)

- Royal National Institute of the Blind (RNIB)
- Values Into Action

Local

- Adaab

Service providers

These organisations provide a range of services. In these examples, the focus is on ways that service users can be involved in day-to-day decisions.

- Guildford Action
- People in Action (Leeds)
- Swansea Directorate of Social Services and Housing
- Threshold (Richmond Fellowship)

Other

There are other types of participation outside those found in social care services such as the models of participatory research used in developing countries. There is also increased interest in using the social enterprise (broadly defined as a business trading for a social purpose) model for the delivery of care services (Department of Health, 2007). Finally, community empowerment networks work with Local Strategic Partnerships to help local residents and community groups to become more directly involved in neighbourhood renewal. Learning from these is not just an example of cross fertilisation of ideas but recognises that service users' ability to participate can be influenced by wider issues, such as access to resources or living in a safe neighbourhood.

- Lewisham Community Empowerment Network

Practice Examples

1. Adaab
2. Alzheimer's Society
3. Bradford Metropolitan District Council
4. Bromley Health, Social Care and Housing Partnership Board
5. The Cedar Foundation
6. Exeter Senior Voice (Age Concern Exeter)
7. Guildford Action
8. Hafal
9. Help the Aged (Speaking Up for Our Age)
10. Leonard Cheshire
11. Lewisham Community Empowerment Network
12. Multiple Sclerosis Society (MS Society)
13. The Omnibus Partnership
14. People in Action (Leeds)
15. Rochdale Metropolitan Borough
16. Royal National Institute of the Blind (RNIB)
17. Southern Health and Social Services Board
18. Surrey Users' Network (SUN)
19. Swansea Directorate of Social Services and Housing
20. Threshold (Richmond Fellowship)
21. Values Into Action

Practice Examples

1. Adaab

Characteristics of service users involved

Adaab is an acronym for Asian Disability Awareness Action in Bradford but is also an Arabic word whose meanings include courtesy and etiquette. Adaab is an advocacy and campaigning organisation providing help, support, and advice to disabled people within the metropolitan district of Bradford.

How service user participation within the organisation is ensured

Adaab aims to represent the disabled communities of Bradford at every level, in every cultural and faith group as long as the person has a disability or is a carer. Service users are encouraged to play a practical part at every level and there are four main mechanisms for participation.

1. People using the service are asked to complete a questionnaire asking their opinions about the organisation.
2. Service users are involving planning and running events held by Adaab and attending consultation meetings.
3. There is a strong community reference group that advises on future plans and policies and gives feedback about the needs of people with disabilities in Bradford.
4. People with disabilities are represented on the Board of Trustees.

What policies on service user participation has the organisation formulated?

Policies include an equal rights and a disability policy.

How are service users supported?

Volunteers and administrative staff help people who cannot read or write. There are translators for all the Asian languages spoken locally and everything is translated into Asian languages. Home visits are made to people who cannot leave their homes.

Adaab will also support service users by:

- providing information;
- helping fill in forms;
- representing service users at tribunals;
- making applications on behalf of service users;

- arranging seminars to raise awareness about specific health issues;
- lobbying MPs, ministers and local government officials;
- raising public awareness through writing articles for local newspapers and giving interviews to the media.

How are the effects of participation monitored, audited, and evaluated?

There is regular monitoring done, and reports are made to the Trustees every six weeks.

What makes organisations succeed in participation?

Sincerity, dedication, and empathy for service users.

Contact details

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Email:

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2. Alzheimer's Society

Characteristics of service users involved

Cross national voluntary organisation for people with dementia and carers of people with dementia in England, Wales and Northern Ireland.

How service user participation within the organisation is ensured

The Alzheimer's Society is a membership organisation with over 25,000 members across the UK. Participation takes place at local, regional, and national levels through local branch committees, regional area forums, and nationally as elected members of the Advisory Council.

In 2000, the Society established a distinct programme to ensure the inclusion of people with dementia in all aspects of its work, especially in the contribution to policy and strategy within the Society. Carers and people with dementia are involved in:

- Campaigning and lobbying;
- Making decisions about funding, monitoring and reviewing research funded by the Society through the *Quality Research in Dementia* network;

- Delivering a variety of training and education events.

What policies on service user participation has the organisation formulated?

Recent work has resulted in a fuller inclusion policy to support those groups of people with dementia and carers who may be marginalised or currently excluded within the organisation.

How are service users supported?

The Society offers sessions through its training programme to those who want to improve their lobbying and campaigning skills.

How are the effects of participation monitored, audited, and evaluated?

The services directorate is currently revising its service standards framework to ensure greater inclusion and improved measures of the impact of the Society's work on people affected by dementia. Monitoring and evaluation are encouraged through informal, and more formal, means across the organisation using individual discussion, focus group work, stakeholder events, peer evaluation from professionals outside the Society.

What makes organisations succeed in participation?

Vision and demonstrating that the person with dementia and the carer are at the heart of all the Society does as an organisation.

Contact details

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Web address: <http://www.alzheimers.org.uk/>

3. Bradford Metropolitan District Council

Characteristics of service users involved

Local government agency for adults living in Bradford.

How service user participation within the organisation is ensured

The most longstanding development is the *Older People's Focus Group* (OPFG) which started about 10 years ago. It has grown to a group of about 150 people who meet with the Manager of Service Coordination and Communications on a monthly basis. The group acts as a:

- mechanism for conducting consultations;
- meeting point for organisations to talk to other organisations;
- resource for other types of involvement, for example members of the group have been recruited to become involved in care home inspections.

There is also an alliance of all the older people's organisations called *Bradford Older People's Alliance* (BOPA), which stands independently from the council and is run by older people. They represent service users on the Older People's Strategic Partnership Board, which has been running since 2005.

The involvement of people with disability has been mainly achieved through an annual event attended by around 200 disabled people who meet to hear what the council has done over the previous year and say what should be done over the coming year.

Service users are involved on other standing committees and take part in consumer surveys.

What policies on service user participation has the organisation formulated?

There is a written policy on participation called *We're Listening* and there are policies and procedures about reimbursement.

How are service users supported?

Travel expenses are paid and arrangements are made to reimburse people on the day. If people are attending specific committee meetings over a period, expenses and a small fee for each meeting are paid.

Service users have been sponsored to go on courses such as assertiveness training and meetings skills. Regular support groups are held if necessary.

How are the effects of participation monitored, audited, and evaluated?

A calendar of events recording all the consultation meetings that the voluntary sector, health, and social services run is kept centrally. The aim is to make sure that events do not clash and avoid duplication.

What makes organisations succeed in participation?

Success in participation is about valuing people and enjoying what is being done. It is about getting recognition that people are valued for what they are, not only for what they do and letting them know that they have got some influence over what happens.

Contact details

Contact person: Nick Farrar (Manager of Service Coordination and Communications)
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4. Bromley Health, Social Care and Housing Partnership Board

Characteristics of service users involved

NHS, housing and local government agency for adult service users living in the London Borough of Bromley.

How service user participation within the organisation is ensured

Service users and carers are represented on each of the four partnership groups which report to the Health, Social Care and Housing Partnership Board. Fifty per cent of the Learning Disability group are service users. The Mental Health partnership group employs paid service user consultants but also has volunteer users on its service user sub-group. The other two groups, the Older People and the Physical Disability and Sensory Impairment group both include a number of service users and carers.

What policies on service user participation has the organisation formulated?

The Partnership Board has introduced a set of policies to be adopted by these four groups with regard to service user and carer participation. The policies cover:

- conduct of meetings;
- support for individual service users;
- briefing sessions.

A reimbursement policy for out of pocket expenses for service users and carers has been introduced. This covers travel, childcare costs, support and replacement care costs, and stationery.

How are service users supported?

Service users and carer representatives have been asked whether they would welcome training in how best to put forward their viewpoint during meetings, and effective consultation with their fellow service users. There is a reimbursement policy for out-of-pocket expenses. There are plans to bring in induction packs for new service users and carer members. In the case of the Learning Disability group, service users have support workers who assist them in going over the agenda and meeting papers before the meetings, in accompanying them to the meetings, and 'debriefing' afterwards.

How are the effects of participation monitored, audited, and evaluated?

Monitoring has begun recently. It will look at the numbers of service users and carers attending meetings and how they have been enabled to make a contribution.

What makes organisations succeed in participation?

Contact details

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5. The Cedar Foundation

Characteristics of service users involved

Voluntary organisation for people with physical disabilities and acquired and traumatic brain injury in Northern Ireland.

How service user participation within the organisation is ensured

The organisation has an established User Forum. Its aim has been to move involvement from the 'consumerist' model towards participation at policy level. Members of the Forum are involved in a number of project steering groups. They have taken over evaluation of the residential and supported living units and have shaped recommendations for improvements and future developments.

What policies on service user participation has the organisation formulated?

The organisation's 2005-2008 strategy is focused on making sure that involvement is more than just consultation and seeking views, and also includes involvement in policy making not only within the Foundation but in the wider environment. Service users are involved in all public celebrations of achievement and are involved in the recruitment and selection of staff.

In addition, one of their key objectives for this year is professional development around disability awareness training. Service users will take a lead role in this.

How are service users supported?

There is a Local Champion in every service setting. This person is usually a member of staff and he or she provides assistance to service users, such as helping in with the production of newsletters or creating space on the website for publishing information on the activities of the Forums.

The User Forum has its own budget.

How are the effects of participation monitored, audited, and evaluated?

The Foundation has a service user charter that outlines the commitment to involvement and against which practice is measured in service user audits.

It uses a number of evaluation tools, including SERVQUAL which is an evaluation method developed with the Queen's University, Belfast that investigates the degree to which service users feel involved in decisions about services. In 2005, the Foundation also invited 'Community Change' to undertake an evaluation of service user involvement in the Cedar Foundation.

What makes organisations succeed in participation?

A commitment to making it happen is the most important thing in leading an organisation to succeed in user involvement. It is a matter of pride for the Foundation that users are involved. In addition, there are now funding reasons for making a success of participation.

Contact details

Contact person: Eileen Thomson

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6. Exeter Senior Voice (Age Concern Exeter)

Characteristics of service users involved

Local voluntary organisation for older people living in Exeter. Membership has always been targeted at older people who are frail and seldom heard or who have a long-term illness or disability.

How service user participation within the organisation is ensured

Older people can participate through Senior Voice in three different ways:

1. Through becoming a member. When they become a member, people sign up to completing a questionnaire four times a year covering up to three topics. While about 75 per cent are sent out by post, the rest involve volunteers assisting in the filling out of the questionnaires.
2. Through becoming a member of the panel. In the past, panel members were selected by the co-ordinator but now they are elected. The panel meets monthly and is a consultation mechanism. The panel plays a part in deciding on our campaigning issues.
3. By attending an annual conference jointly organised by social services, the Primary Care Trust, the City Council and Senior Voice.

Focus groups are also organised on issues brought to Senior Voice by other organisations, and participants are targeted using a database of members' information.

What policies on service user participation has the organisation formulated?

There are no formal policies on user participation.

How are service users supported?

All expenses are paid and transport is arranged, including wheelchair accessible transport. For focus groups, transport is arranged door-to-door, and refreshments.

Agendas for outside meetings are received in advance so that issues can be talked about beforehand and delegates are briefed appropriately.

How are the effects of participation monitored, audited, and evaluated?

There is no formal evaluation.

Contact details

Contact person: Cathy Pelikan

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Email: reception@ageconcernexeter.org.uk
Web address: None

7. Guildford Action

Characteristics of service users involved

Local voluntary organisation for people at risk of social exclusion living in Guildford (Surrey), with a particular focus on people living on a low income and people who have substance abuse problems.

How service user participation within the organisation is ensured

There are support workers who go out into the community and they have been very successful in encouraging service users to give opinions about the sort of support they want and need. Before new initiatives are developed, the support workers survey service users so that the service can be developed in consultation with them. Service users who are in recovery have been employed as paid workers.

What policies on service user participation has the organisation formulated?

This has mainly been through a requirement from some funders that only volunteers from among the service user clientele may be used within the service. The idea is to promote user participation in those particular services.

How are service users supported?

Service users have ongoing relationships with the individual workers assigned to work with them. There is no funding to pay service users to participate.

How are the effects of participation monitored, audited, and evaluated?

As a small organisation, there are no resources financially or in terms of staff time to pay for evaluating service user participation.

What makes organisations succeed in participation?

The only way to encourage people to participate is to have good relations with them in the first place, so there is already a level of trust. Once service users participate in any sort of management structure, then the relationship changes and both sides have to be prepared to deal with the difference in the dynamics.

Contact details

Contact person: Sandra Curran

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5NR

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Email: None

Web address: None

8. Hafal

Characteristics of service users involved

National voluntary organisation for mental health service users and their families and carers in Wales. (Hafal means 'equal' in Welsh.)

How service user participation within the organisation is ensured

Hafal is a service user led organisation managed by trustees who are themselves mainly service users and carers. A programme, led by the Empowerment/Recovery Co-ordinator, works with clients, volunteers, staff and trustees in identifying practical ways to achieve a better quality of life by opening up greater opportunities for self-determination.

What policies on service user participation has the organisation formulated?

These can be found in Hafal's Recovery Programme. Services are expected to hold meetings with service users at least monthly. All services are expected to involve service users but the level of involvement may vary according to the type of programme.

How are service users supported?

Hafal has developed a Partnership Compact which outlines its commitment to working with service users and the standards that service users can expect.

How are the effects of participation monitored, audited, and evaluated?

Hafal has produced a report, *You're the Expert*, based on questionnaires returned by over 300 service users and carers living in Wales. Other means of appraisal include Hafal's annual operational audit, a complaints and comments system, and informal talking and listening by the Recovery Co-ordinator and the Hafal Trustees.

What makes organisations succeed in participation?

Hafal encourages engagement at every level, from their own course of recovery, to the running and management of the local Hafal service, taking part in local consultation, and the wider activities of the Wales-wide activities of the charity, through to campaigning on major mental health issues.

Contact details

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9. Help the Aged (Speaking Up for Our Age)

Characteristics of service users involved

Speaking Up for Our Age (SUFOA) is a programme run by the national voluntary organisation *Help the Aged* (HtA) which operates across the UK. Its purpose is to help to set up, and support, independent older people's forums which themselves enable the participation of older people in service planning and provision.

How service user participation within the organisation is ensured

Speaking Up for Our Age was set up with the help of a steering group that included older people from around the country and *Help the Aged* staff. Feedback from people involved in Older People's Forums is requested regularly about the service that is provided. A UK symposium was held to ask forum representatives about how they would like SUFOA to support them in future.

What policies on service user participation has the organisation formulated?

The policy covers:

- reimbursement of expenses incurred;
- making written materials available in other formats, such as large print;
- using accessible venues, hearing loops and other aids for people to attend meetings;
- as a UK-wide programme, endeavouring to involve older people in participation from all nations as much as possible;
- use of plain English.

How are service users supported?

The service to support forums includes:

- regular newsletters;
- training events and conferences;
- support for individual forums.

The support offered to service users includes the following:

- clear information about how to get to places for meetings;
- encourage them to use taxis where appropriate;
- prompt payment of expenses;
- approachable, helpful staff;
- efficient updating of the forums database;
- circulation of reports on our conferences;
- clearly written newsletters with useful information;
- healthy refreshments at events;
- provision of information which will help their forum to be more effective.

How are the effects of participation monitored, audited, and evaluated?

There have been two full evaluations of the programme.

What makes organisations succeed in participation?

The forums are run by older people for older people and are open to all older people in their areas.

Three important points to remember when asking people to participate are:

4. Think about what *you* would want and expect if you were being asked to participate, and provide these things accordingly.
5. Listen to what are participants are saying, change your service accordingly and feedback what has changed and why
6. Saying thank you for people giving their time freely as participants, such as providing a nice lunch and sending thank you letters to show appreciation to each and every participant.

Contact details

Contact person: Debbie Beale (Programme Manager)

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10. Leonard Cheshire

Characteristics of service users involved

Leonard Cheshire is a voluntary organisation providing services to people with disabilities across the United Kingdom. The Service User Support Team supports service user involvement within the organisation.

How service user participation within the organisation is ensured

The Service User Support Team is a team of disabled people who work as one-to-one mentors, as well as providing training opportunities and information. Around £1m per year is allocated to service user involvement, including the costs of running the team and support costs for service users coming to meetings.

There is a Central Committee of service users elected by the constituency of service users. They work at national level to influence Trustees (the Chair is a User Trustee).

What policies on service user participation has the organisation formulated?

The work at Leonard Cheshire has been mostly bottom up, though a formal policy is now being developed, partly written by service users. This will be linked to a users' charter saying what standards service users can expect within their service in relation to participation and an accompanying set of guideline standards for staff.

How are service users supported?

Service users receive considerable support in relation to training, peer support and financial help in getting together. It is important that this is independent of their service, as they may be afraid to speak out in front of the manager.

How are the effects of participation monitored, audited, and evaluated?

In evaluating the service, Leonard Cheshire has a service audit scheme which visits the service once every four years and service users are part of the team who visit. An

external evaluation on user involvement has been completed by a team based at Northumbria University. A set of standards for participation is currently being drawn up and this will form the basis for evaluating progress in the future.

What makes organisations succeed in participation?

Managers cannot just decide on a policy and implement it like any other – it is a hearts and minds thing and needs a culture change. There needs to be a lead from the top, lots of training for staff and lots of independent support and training for the service users.

Contact details

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11. Lewisham Community Empowerment Network

Characteristics of service users involved

Residents of the London Borough of Lewisham. The Community Empowerment Network was set up through central government funding to deprived areas to help them support voluntary and community-sector involvement in local strategic partnerships.

How service user participation within the organisation is ensured

The Network aims to create a partnership between various voluntary community sector groups and residents. The aim is to enable them to come together to network, to share information, to advocate, to campaign.

What policies on service user participation has the organisation formulated?

The Network seeks to meet its obligations in relation to the *Disability Discrimination Act (2005)* and is sensitive to the needs of the various cultural groups within the service user community, for example in the provision of appropriate food and in the choosing of venues for meetings.

How are service users supported?

The Network aims to act as a bridge between the wider voluntary and community sector and the statutory sector. By putting people in contact with each other, they

can educate each other, creating communities of interest and communities of place. Different ways of sharing information, such as storytelling and music are used as these may help people relate to the issues better.

How are the effects of participation monitored, audited, and evaluated?

The Network is monitored by Lewisham Council using a set of performance indicators developed as part of the *Single Community Programme*. There have also been events for people to give feedback by means of group discussions. The Network does some monitoring and has also been externally evaluated by Edge Hill College.

What makes organisations succeed in participation?

Communities get fed up being consulted if there's not a real purpose to it, so it takes a lot of the bitterness out of it if the parameters are explained first. Be explicit about power, about what power they will have in the setup. If there is no trust in the integrity of the consultation process, or if there is no fundamental clarity of purpose then things are undermined.

Contact details

Contact person: Matthew Scott

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12. Multiple Sclerosis Society (MS Society)

Characteristics of service users involved

The MS Society is a cross national voluntary membership organisation for people affected by multiple sclerosis (MS) across the United Kingdom.

How service user participation within the organisation is ensured

People with MS are central to the work of the MS Society and are encouraged to get involved in all aspects of our work and at all levels. The organization has over 40,000 members, the majority of whom are people with MS. Many become involved in branch activities, regional committees, as Trustees, on grant and research panels, as assessors and reviewers of publications from the Society, as service development volunteers, volunteer helpline operators, fundraisers, and as paid members of the staff team.

What policies on service user participation has the organisation formulated?

Since user involvement is an essential and core aspect of the MS Society's ethos, it is built into all policies, procedures and working practices.

How are service users supported?

Users involved in the running of the organisation are supported by way of: training; provision of a named contact; regular reviews; opportunities for feedback and to discuss any concerns; and organising events and newsletters. Expenses are paid for overnight stays and travel.

How are the effects of participation monitored, audited, and evaluated?

This is an on-going process involving collecting feedback from those the MS Society supports and assessing what can be done to further improve their experiences as service users, and as active participants in the running of the organisation.

What makes organisations succeed in participation?

The key to successful participation lies simply in valuing the input of the service users – understanding that it is their engagement that enables the organisation to achieve so much.

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13. The Omnibus Partnership

Characteristics of service users involved

Service user controlled organisation of disabled people using, or wishing to use, public transport in Northern Ireland.

How service user participation within the organisation is ensured

The Omnibus Partnership is an organisation of disabled people, including people with communication impairments, mobility impairments, sensory impairments, learning difficulties and mental health service users.

The Omnibus Partnership campaigns to educate transport providers, professionals, and politicians about disabled people's public transport needs.

What policies on service user participation has the organisation formulated?

The Omnibus Partnership is a service user controlled organisation. It is stipulated in the constitution of the organisation that disabled people will constitute the majority of its members and eight of the ten members of the Partnership's Management Committee are disabled.

How are service users supported?

The Omnibus Partnership ensures that members receive and can send information in the format they need. Meetings are arranged in consultation with members and with the needs of those attending in mind, in terms of timing, transport, and the accessibility of the venue and information provided.

How are the effects of participation monitored, audited, and evaluated?

The first three years of the Omnibus Partnership were assessed by researchers from the local NHS and Social Services Board who did a participatory research study which was very positive. Beyond this, there is informal monitoring of the membership's concerns.

In terms of the outcomes of participation, the Partnership was originally set up with an immediate aim in mind. It was awarded government and European Union funding which was used to obtain two mainstream public service buses, but accessible to wheelchair users and other disabled people and of a size that meant they could be taken into small streets. The Omnibus Partnership worked with the local transport provider to enable that service to operate.

What makes organisations succeed in participation?

Success comes from being a grassroots organisation. It is very important that the people that are affected by the issues are the people who lead the way with them and that they are assisted in doing so.

The provision of accessible information is very important, as is accessible transport and access to venues and facilities.

A readiness to listen to the members needs to be there. There needs to be a willingness to open the mind to the needs of others.

Contact details

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Web address: None

14. People in Action (Leeds)

Characteristics of service users involved

Local voluntary organisation representative of the diverse communities of Leeds. It supports people with learning difficulties, and people with mental health problems and/or challenging behaviour

How service user participation within the organisation is ensured

The management committee includes service users so they have a direct input into the way the organisation is run from the very top. Service users also work in the office and do various jobs in the field as sessional workers and as volunteers. The organisation gets feedback from service users at an annual members' meeting.

There are steering groups that consist of people from particular local communities, along with professionals and local residents, who suggest what they might want specifically for their community.

What policies on service user participation has the organisation formulated?

The organisation has developed policies and procedures which are person centred and this is the basis of all funding applications. An interactive accessible website and a regular newsletter promotes achievements of service users. Other initiatives include involvement of service users in training, giving presentations at meetings conferences. Employment opportunities have been created through the establishment of a Community Interest Company.

How are service users supported?

People in Action (Leeds) employ sessional workers and support workers to help people depending on the type of group or project in hand.

How are the effects of participation monitored, audited, and evaluated?

All projects produce regular, monthly reports for the management committee. The organisation aims to build in external evaluation within all its funding applications, especially those that run over a number of years.

What makes organisations succeed in participation?

One measure of success should be the ability of the organisation to attract people from diverse cultural groups. People in Action (Leeds) has developed an expertise in involving service users from diverse communities such as the African Caribbean and Asian communities. It is important to make the service as flexible and as open as possible, and make it friendly so that anyone feels that they can approach that organisation or service no matter what their cultural background.

Contact details

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15. Rochdale Metropolitan Borough

Characteristics of service users involved

Statutory local government agency for all people aged 60 and over living in Rochdale.

How service user participation within the organisation is ensured

Older people participate in service planning and development on a number of different levels.

1. There is a long established Service User and Carer Action Forum which meets monthly in which Pensioner Associations across the borough are represented. This group was involved in the development of the borough strategy for older people and is also involved in the review of progress of its implementation. The Forum also meets with officers, practitioners, and senior managers at an annual workshop to discuss issues of current concern.
2. The Forum is represented on the Local Implementation Team of the National Service Framework for Older People, and in the specific multi-agency service development subgroups, such as Stroke, Falls, and Older People's Mental Health.

3. Rochdale has piloted a number of initiatives to test out different ways of involving seldom heard older people, such as:
- > the 'Have Your Say' project, which trained up frontline home care workers in listening and communication skills to get feedback from service users who are isolated at home;
 - > older people and carers providing age awareness training to staff in nursing homes.

What policies on service user participation has the organisation formulated?

A strategy and good practice guide for involvement and consultation in community care services was produced in 2004.

How are service users supported?

The Service User Carer Action Forum is supported financially, covering the cost of meetings, hire of rooms, administration, and travel expenses. A named involvement officer from the council's Adult Care Services provides advisory support to the Forum to ensure older people's involvement is both effective and meaningful.

In addition, older people involved in service development groups have made recommendations on practical ways of supporting involvement in meetings. These are being implemented, and include, for example members' information packs, named involvement champions and pre-meeting briefings.

How are the effects of participation monitored, audited, and evaluated?

These are monitored by the Action Forum itself. There are systems and processes for feeding back the outcomes of consultation and involvement. Senior managers are invited to attend the monthly Forum to give regular updates on performance.

What makes organisations succeed in participation?

By developing a culture of involvement throughout the organisation and through an 'open ear' policy which empowers frontline staff to engage with service users as part of the involvement process, so that it becomes 'everybody's business'.

Contact details

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 Website: <http://www.rochdale.gov.uk/>

16. Royal National Institute of the Blind (RNIB)

Characteristics of service users involved

The Royal National Institute of the Blind (RNIB) is a membership voluntary organisation for people with sight problems operating across the United Kingdom.

How service user participation within the organisation is ensured

Membership currently stands at about 1,000, and these members are actively involved in both campaigning and service provision. RNIB sends out a regional newsletter, which acts as an information exchange and where recipients can ask about particular issues.

Approximately 75 per cent of RNIB's executive board are themselves either blind or partially sighted people (BPSP). The charity seeks to recruit as many service users as volunteers as possible. It has a workforce of about 3,000 and about seven per cent are blind or partially sighted.

What policies on service user participation has the organisation formulated?

There is a business plan target called *Putting BPSP at the heart of our work* but there is no standardised way that this is being implemented at present.

How are service users supported?

The Royal National Institute of the Blind has offered assertiveness training to support people. Expenses are paid where necessary. Service user focus groups are paid to come in and are provided with lunch.

Taking on volunteers does not attract statutory funding for equipment or personal aid in the way that paid employment does. Therefore, RNIB has to limit the number of volunteers it takes on to avoid the costs of making such provision itself.

How are the effects of participation monitored, audited, and evaluated?

Particular projects are evaluated, but otherwise it is down to the individual services to monitor and report back since there is an expectation that service users will be involved as far as possible.

What makes organisations succeed in participation?

First, participants need to be assured they are going to be listened to – effective feedback would have to be a part of this. Second, there should be effective support enabling people to overcome difficulties. The Royal National Institute of the Blind's

teleconsultation service using teleconferencing to enable people who are isolated at home to participate would be an example of this.

Contact details

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17. Southern Health and Social Services Board

Characteristics of service users involved

Southern Health and Social Services Board is one of the four health and social services boards in Northern Ireland which are responsible for planning, and commissioning and purchasing health and social care services for the residents in their area. Most of the work undertaken to date has been with people with physical disabilities and sensory loss.

How service user participation within the organisation is ensured

Service users can be involved at different levels:

- at an individual level in the planning, delivery and monitoring of services provided at home, in hospital and in the community;
- as part of a family, group or community;
- on an issue-specific group (for example, brain injury services);
- as a member of a planning teams;
- in management, for example by applying to become a non-executive Director.

In practice, service users want different levels of involvement. It's important to find different ways of working with different people, depending on the project itself and the service users involved.

What policies on service user participation has the organisation formulated?

The Board has formulated a policy on service user involvement called *Together, we make a difference*. The Board has also developed an expenses policy in which service users are paid a £10 attendance fee and transport costs are reimbursed. Replacement care costs are also met.

How are service users supported?

Flexibility in the way that the Board tries to engage people is important. As well as formal sit down meetings in the Board Room, some service users prefer to be telephoned to give their views. Some meetings have been held at 9.00 pm in a local pub. Others have been held on a Sunday afternoon in a different venue. One of the biggest barriers came from using medical terminology and jargon. Instead, summaries are made rather than sending out 40 page documents, which people are not going to read. Minutes or action points are put into Braille or large print.

How are the effects of participation monitored, audited, and evaluated?

Changes to services have been made because of participation. People with sight loss were asked how they found the service, what was good, and what was bad. As a result, instead of people having to travel to Belfast to attend a low vision clinic, a number of clinics have been set up locally. Across the Board as a whole, the user participation policy will be formally reviewed in 2008. Service user participation is also written into the Board's 5-year plan.

What makes organisations succeed in participation?

Organisations have to want to engage in user participation and it has to be driven from the top. The Chief Executive, Chair, and the entire Board are totally committed to participation. It really helps if there is commitment from the top down. Service user participation is an integral part of the way the organisation works.

Contact details

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18. Surrey Users' Network (SUN)

Characteristics of service users involved

Service user controlled organisation for people with physical and sensory impairment, learning disabilities, mental health problems, and older people who happen to have an impairment as well, living in Surrey.

How service user participation within the organisation is ensured

Surrey Users' Network is a grant-funded organisation made up entirely of service users, and so the management board are all disabled people. The organisation's purpose is to support its 600 members so that they are empowered to be involved in processes that will help to improve their lives and their services.

What policies on service user participation has the organisation formulated?

Surrey Users' Network has a contract with the county to provide a member organisation that provides service users to get involved in the council's procedures. At the moment, SUN has service users involved in induction training for new staff into health and social care.

How are service users supported?

A policy on the reimbursement of expenses is important. Other types of support would include: ensuring that at meetings there are personal assistants available; recognising that at meetings aids like hearing loops might be necessary; documents being in large print, or other accessible format that, people might need and that they are available before meetings so that there is time for people to prepare and understand the issues; perhaps providing them with a briefing written in simple language so that they can remember what they want to say. At the moment there is a problem in that equipment is available to enable paid employees to do their work but not for volunteers.

It is also important for chairs of meetings to have had some training to ensure a more inclusive environment at a meeting, to learn ways of involving people who may be reticent, or who may not be able to see them. Training in empowerment for service users is important to build confidence and learn different ways of making an impact or contribution.

How are the effects of participation monitored, audited, and evaluated?

Surrey Users' Network relies on focus groups and questionnaires in relation to particular projects, to check whether there has actually been any service improvement as a consequence of the service users' involvement.

What makes organisations succeed in participation?

There has to be a planned and coherent process of involvement. Surrey Users' Network has existed for about eight years, but latterly various *ad hoc* projects have been poorly co-ordinated: a structured approach is important to avoid wasting people's time.

Participant users do have to be competent. In addition to training in empowerment, users should develop their skills to avoid the dangers of ineffectiveness or tokenism.

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19. Swansea Directorate of Social Services and Housing

Characteristics of service users involved

Statutory local government agency for people with mental health problems living in the city and county of Swansea.

How service user participation within the organisation is ensured

Service user involvement takes place at individual, operational, and strategic levels.

- At an individual level, service users and carers are fully involved in development of the care programme and selection of the services to meet their needs. Each service provider holds service level user groups, where users are engaged in discussions about the service.
- At an operational, or service level, there are a number of day service providers within Swansea. There is a scheme called Community Rehabilitation Employment Assessment Training Enterprise (CREATE), which is an umbrella organisation bringing together all the day service providers in mental health to work under one umbrella. It is overseen by a central management group.
- At a strategic level, there are two organisations; one is the Cefn Coed (Psychiatric) Hospital Patients' Council, the other is the Swansea Network of User Groups (SNUG), which is an umbrella organisation for all community based mental health services. SNUG is represented on the CREATE management group, so service user representation goes right through from the personal, through the service level up to the strategic management level. SNUG is also represented on the mental health planning groups and the development groups, all of whom are the policy and decision-making bodies within mental health in Swansea.

On an annual basis, there is a joint business planning exercise, which involves all the voluntary and statutory sector services and service users. It examines issues within the service, identifies gaps, and agrees an action/business plan for the following year.

What policies on service user participation has the organisation formulated?

At the personal level, key workers and care coordinators are responsible for ensuring service users' participation in developing the care plan. Service managers are responsible for ensuring that the consultation process, the wider process within each service area, is implemented and information is disseminated there. There is an agreement with the Local Authority for a number of paid employment posts which are purely for service user use. Access to those posts is only through our employment team.

How are service users supported?

A development worker attached to SNUG accompanies service users to planning meetings. Travelling expenses, and out of pocket expenses are reimbursed. Service users with the employment service are assessed and agreements are made with the host department to offer them a fixed term appointment up to a maximum of twelve months. They are then supported by the employment team. During this time, the individual develops a work record and work experience on the payroll of the local authority so they can approach potential employers with a work record and references. Almost a third of the paid staff in mental health day services in the local authority are either current or ex-service users and this has been very successful.

How are the effects of participation monitored, audited, and evaluated?

At the personal level, the number of care plans issued agreed by service users are monitored. At the service level, meetings are recorded and minuted, and attendance of service users at strategic groups is included in the minutes. Measuring the effects of participation comes into the annual business planning feedback exercise where SNUG undertakes a survey of service users, and they then feed back opinion and issues from service users directly into the business planning.

What makes organisations succeed in participation?

Success in participation is probably having the basics of values and principles to start with. Service users are the most important part of the service, and services are there to support and assist them as individuals. This ethos is fairly well embedded in services in Swansea. The success of the employment service in helping service users to become paid members of staff breaks down the 'us and them' barrier between staff and service users.

Contact details

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Web address: <http://www.swansea.gov.uk/> or <http://www.createswansea.co.uk>

20. Threshold (Richmond Fellowship)

Characteristics of service users involved

A therapeutic community for mental health service users in Northern Ireland which is part of a national voluntary organisation.

How service user participation within the organisation is ensured

Currently, service user involvement occurs much more at service level than at strategy level. For example, they neither serve on the agency's committees nor on the board, though these are possibilities under discussion. The three main ways in which service users are involved are:

1. on a daily basis – all the residential units are therapeutic communities and this means that residents are involved in most decisions about the house in which they live.
2. when needed – service users are involved in adjudicating cases where a member has infringed the house rules and deciding whether a person should be given notice to leave.
3. annually, the Threshold director meets all the residents on an annual 'awayday' to hear their views.

At present service users are not involved in decisions about staff appointments.

What policies on service user participation has the organisation formulated?

Threshold has policies about involvement, the decision-making processes within the houses, and the rules that are made by the staff and residents together. Threshold is developing a strategy on which the residents will be asked for their views formally in a letter and by way of meetings.

How are service users supported?

Therapeutic communities have an underlying ethos on involvement that is part of the philosophy of care.

How are the effects of participation monitored, audited, and evaluated?

There is an annual audit called the *Community of Communities* (an international research project run by the Royal College of Psychiatrists into therapeutic communities). This assesses the agency against a set of standards, much of it to do with user involvement.

Teams of at least five residents and five staff go each year to audit and monitor communities in England, and similar teams come over from England to monitor and review communities in Northern Ireland.

For the past two years, residents have been completing the *Wisconsin Quality of Life* questionnaire which asks about the quality of their life over the last six months. Threshold is mapping what areas of improvement users are seeing in relation to their quality of life so that can services can be shaped to reflect the outcomes.

What makes organisations succeed in participation?

There has to be a respect for and a belief in people. The basic principle at Threshold is that people have equal value, though they may have different abilities.

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21. Values Into Action

Characteristics of service users involved

Values Into Action (VIA) is the UK-wide campaigning voluntary organisation for people with learning difficulties.

How service user participation within the organisation is ensured

Values Into Action does not itself provide any services, rather it is a campaigning organisation through research and development, with the objectives of promoting the rights of people with learning difficulties and improving the quality of service provision.

People with learning difficulties are involved throughout VIA, including one of the co-chairs, the vice-chair, other trustees, and two members of staff.

In undertaking its research and development work, VIA involves people with learning difficulties, often by means of an advisory group set up with the particular project in mind.

What policies on service user participation has the organisation formulated?

Values Into Action does not operate a quota system in any part of its work or organisation because the emphasis is on inclusivity, and the notion that there should be a certain number of people with learning difficulties would involve labelling people. However, it would be unsatisfactory not to have any people with learning difficulties on the board, for example there is a continual process in VIA of looking for new Board members including people with learning difficulties.

How are service users supported?

There is an established practice of trustees supporting each other, for example, going through issues before meetings as well as general psychological support.

Values Into Action has also recruited dedicated support workers for staff members with learning difficulties.

People with learning difficulties on advisory groups are offered an honorarium. Reasonable expenses are paid.

How are the effects of participation monitored, audited, and evaluated?

Appraisal takes place routinely at board level. The board will look carefully at the methodology of projects, the way they are being carried out, ensuring that proper account is being taken of the involvement and contribution of people with learning difficulties. This is reported on by project workers to the board and it also forms part of the Chief Executive's regular report to the board.

What makes organisations succeed in participation?

Two factors are important: determination to make it work and flexibility. Time-honoured practices may have to be relinquished. For example, at VIA, the board will often split into groups during its meetings to discuss issues and then re-form, because a lot of the members find it hard to discuss complex issues in a large group but find a small group easier. Organisations need to take responsibility to change themselves in respect of user involvement rather than expecting outsiders to do it for them.

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Resources

As well as the resources listed below, the References include links to electronic versions of many of the books and reports mentioned in the text.

Acting Up

Acting Up, part of Matchbox Theatre Trust, has been working with people with communication difficulties since 1987, and has pioneered multimedia communications' training with services in the voluntary and statutory sectors. Acting Up is committed to working in ways that are person-centred and led by service users.

<http://www.acting-up.org.uk/actup.htm>

Action 4 Advocacy

Action for Advocacy (A4A) is a resource and support agency for independent advocacy schemes. Their website includes details of publications, fact sheets and details of advocacy groups in England and Wales.

<http://advocacy.prokmu.com/advocacy/index.jsp>

Audit Commission

The Audit Commission has produced two reports with advice on how to achieve better consultations.

Audit Commission (1999). Listen Up! Effective Community Consultation. Abingdon: Audit Commission Publications. http://www.audit-commission.gov.uk/Products/NATIONAL-REPORT/EA01768C-AA8E-4a2f-99DB-83BB58790E34/archive_mpeffect.pdf.

Audit Commission (2003). Connecting with Users and Citizens. London: Audit Commission. <http://www.audit-commission.gov.uk/reports/AC-REPORT.asp?CatID=&ProdID=F1B75570-9AA7-469E-8BA6-3354AA457D61>.

Better Regulation Commission

The Better Regulation Commission (BRC), formerly the Better Regulation Taskforce, has produced a report on participation in social care regulation, including a version in an accessible format.

<http://www.brc.gov.uk/publications/bridgegap.asp>

Care Services Improvement Partnership (CSIP)

The Health and Social Care Change Agent Team, who are part of CSIP, have produced guides to user involvement with older people with mental health problems. It is also possible to access the Dementia North report on involving people with dementia (Cantley *et al.*, 2003) via this link.

<http://www.cat.csip.org.uk/index.cfm?pid=232>

Citizens' juries

Citizens' juries have been used in some areas to discuss issues of local importance with a panel, or jury, of citizens. While many of these initiatives have been 'top down', some have been developed and run by local communities themselves.

<http://www.juryworld.com/index.htm>

Department for Education and Skills

The Department for Education and Skills have funded the *Participation Works* gateway which provides a single access point to comprehensive information on children and young people's participation including policy, practice, networks, training and innovative ideas from across the United Kingdom.

<http://www.participationworks.org.uk/>

Department of Health

The Department of Health website includes a number of resources relevant to participation including:

Department of Health (2006). *Reward and Recognition. The Principles and Practice of Service User Payment and Reimbursement in Health and Social Care: A Guide for Service Providers, Service Users and Carers.*

<http://www.dh.gov.uk/assetRoot/04/12/68/65/04126865.pdf>.

NHS Modernisation Agency (2002). *Improvement Leaders' Guide to Involving Patients and Carers*. London: Department of Health:

http://www.modern.nhs.uk/improvementguides/reading/involving_patients.pdf.

Expert patients programme

http://www.dh.gov.uk/AboutUs/MinistersAndDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/fs/en?CONTENT_ID=4102757&MULTIPAGE_ID=5929085&chk=Udz8BI

Disability Alliance

The Disability Alliance is a campaigning organisation concerned with poverty among disabled people. Its website offers advice on benefits and links to its publications such as the *Disability Rights Handbook*.

<http://www.disabilityalliance.org/>

The Disability Archive UK

The Disability Archive UK is hosted by the Centre for Disability Studies at the University and provides freely accessible papers on disability issues. They are not to be used for commercial purposes without permission.

<http://www.leeds.ac.uk/disability-studies/archiveuk/>

Improvement and Development Agency (IdeA)

IDEA Knowledge delivers in-depth improvement news and examples of good practice from councils across England and Wales, and provides access to the IDEA's range of tools and services. It includes details on initiatives to engage with local communities and discussion forums.

<http://www.idea-knowledge.gov.uk/idk/core/page.do?pagelid=1>

INVOLVE

INVOLVE is a national advisory group, funded by the National Institute for Health Research, which aims to promote and support active public involvement in NHS, public health and social care research. It produces reports and newsletters, maintains a research database and runs a network called invoNET, which is a network of people working to build evidence, knowledge and learning about public involvement in the NHS, public health and social care research.

<http://www.invo.org.uk/index.asp>

Joseph Rowntree Foundation

The Joseph Rowntree Foundation is one of the largest social policy research and development charities. Short summaries of the research that it has funded are freely available through the *Findings* series or as Acrobat pdf files.

<http://www.jrf.org.uk/default.asp>

National Centre for Independent Living (NCIL)

National Centre for Independent Living (NCIL) is a not for profit company controlled by people with disabilities offering information, training, expertise and policy development on all aspects of direct payments and independent living.

<http://www.ncil.org.uk/about.asp>

Neighbourhood Initiatives Foundation (NIF)

Neighbourhood Initiatives Foundation (NIF) is an organisation covering the United Kingdom specialising in community participation, training and development. Details of resources, publications and training can be accessed through the website.

<http://www.nif.co.uk>

PEANuT (Participatory Evaluation and Appraisal in Newcastle upon Tyne)

Participatory appraisal is a community-based approach to consultation that gives precedence to the views and attitudes of local people as experts within their own communities. The PEANuT website gives an introduction to the concept and gives details of training in participatory appraisal.

http://northumbria.ac.uk/sd/academic/sas/sas_research/pa/

People First

Central England People First is a service user controlled rights-based organisation for people with learning difficulties. It offers training and consultancy and the website hosts various internet based mailing lists and online conference services. There are also links to other self advocacy organisations.

<http://www.peoplefirst.org.uk/>

PhotoVoice

PhotoVoice aims to encourage the use of documentary photography by enabling those that have traditionally been the subject of such work to become its creator while simultaneously learning a new skill that can enhance their lives. Projects involving social care service users in the UK include work with people with learning difficulties, mental health service users, refugees and homeless people.

<http://www.photovoice.org/>

Sainsbury Centre for Mental Health

The Sainsbury Centre for Mental Health works to improve the quality of life for people with mental health problems by influencing policy and practice in mental health services. Details of events, resources, and publications are available on the website.

<http://www.scmh.org.uk/80256FBD004F6342/vWeb/wpKHAL6S2HVE>

Service User Researchers

There are an increasing number of Service User Researchers. Examples include:

Centre of Excellence in Interdisciplinary Mental Health

<http://www.ceimh.bham.ac.uk/>

Service User Research Enterprise (SURE)

Service User research Enterprise (SURE) is an academic unit at the Institute of Psychiatry which produces both collaborative and user-led research into mental health issues.

<http://www.iop.kcl.ac.uk/iopweb/departments/home/?locator=300&context=main>

Older People Researching Social Issues (OPRSI) <http://www.oprsi.co.uk/>

Shaping Our Lives (see below)

Shaping Our Lives

Shaping Our Lives National User Network is an independent user controlled organisation. Details of its publications and projects are available on the website. The website includes the *Shaping Our Lives* guide to making meetings accessible.

<http://www.shapingourlives.org.uk/>

Social Perspectives Network

The Social Perspectives Network is a coalition of mental health service users, carers, policy makers, academics, students, and practitioners interested in the social factors that contribute to people becoming distressed and play a part in promoting recovery. They hold study days, publish papers, campaign and provide information.

<http://www.spn.org.uk/>

United Kingdom's Disabled People's Council (UKDPC)

The United Kingdom's Disabled People's Council (UKDPC) was set up by disabled people in 1981 to promote the full equality and participation of disabled people within society. The website gives news of campaigns, projects and also hosts a number of forums.

<http://www.bcodp.org.uk/>

Valuing People Support Team

The *Valuing People Support Team* support people with learning disabilities and their families. It has links to resources and publications.

<http://www.valuingpeople.gov.uk/>

Wiltshire and Swindon Users Network

The network was founded in 1991 and exists to promote user involvement and to disseminate examples of good practice in user involvement in community care purchasing, provision and evaluation. The website includes a diary of events in the Wiltshire and Swindon areas, press cuttings, and a newsletter.

<http://www.wsun.co.uk/>

Methodology

Literature review

A review of existing literature on service user participation was undertaken drawing on information held in the following electronic databases:

- Social Care Online
- AgeInfo
- Sociological Abstracts
- Social Services Abstracts
- PsycINFO
- Medline
- Embase
- Cinahl

Initial searches were made using subject headings and thesauri for each database. For example 'user views' and 'user participation' were used in searches of Social Care Online, 'users', 'involvement' and 'involving' for AgeInfo, 'client participation' in PsycINFO, and 'patient participation' in Embase. This review was commissioned only to cover literature relating to the United Kingdom. In addition, web searches were made to identify grey literature, that is electronic and print publications produced by organisations and government departments but which is not available through commercial publishers.

Practice survey

A practice survey, one of SCIE's methods for identifying details of emerging and developing practice, was undertaken to identify examples across:

- England, Wales and Northern Ireland, ranging from national organisations to local groups;
- organisations working with different groups of service users;
- statutory and voluntary organisations;
- organisations using different models of participation, ranging from those that mainly followed a consumerist model based on consultations, to those that were service user led, or service user controlled organisations.

A proforma was developed for the collection of information from each organisation. From this, examples were selected on the basis that they could demonstrate clear systems for supporting service user participation and that they provided contrasting examples of the different approaches that organisations adopt to involve service

users. The practice survey, consultations with service users and the literature review all showed that consultation-based models still predominate and that service user participation is often seen as a *process*, rather than something which is outcome focussed, meaning that service user participation has been used to make direct changes to services. Practice examples were chosen to reflect this situation.

Consultation with service users

Shaping Our Lives and the Centre for Citizen Participation held two consultations with service users. The first was held at an accessible venue in London and was attended by 14 people with a broad range of experience of different services. This included service users from different parts of the country, living in both urban and rural settings. It included older people, people with physical and sensory impairments, mental health service users, a palliative care service user and people with speech impairments who communicate differently. A second separate smaller consultation meeting was carried out with people with learning difficulties, in order to ensure that they were fully able to express their views. Five people with learning difficulties took part. The consultation was facilitated by an experienced self-advocacy supporter. Three of the participants were women. Three people were black. The five people had different types of learning difficulty and used a range of current services, including living independently with some support and living in a residential home. All the participants had previously been involved in groups that aimed to improve services for people with learning difficulties.

Participants were provided with advance information to prepare them for the consultation meeting. Access, support, and travel costs were met and participants were paid for sharing their expertise.

Synthesising the findings

Information from the five different types of knowledge used in this guide: service user knowledge, organisational and practitioner knowledge, policy community knowledge and research knowledge (Pawson *et al.*, 2003) was organised under the broad themes of culture, structure, practice, and review. The next stage involved identifying the themes around which there was a consensus, for example in the areas of agreement about what constitutes good practice. Then we looked at topics on which there were diverging views or where a subject had been considered by one group but not by others. For instance, service users and researchers whose research has been grounded in the expertise of service users have been more likely to emphasise the need for participation to be considered in a wider social context, such as having access to an adequate income or the opportunity to take part in everyday leisure and social activities. Finally, we identified areas where there are gaps in our

knowledge or where more work needs to be done, such as how to engage more effectively with seldom heard groups.

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