

The participation of adult service users, including older people, in developing social care



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Service user participation has become increasingly important to social care. SCIE's Practice Guide 11¹ shows how social care organisations can use a 'whole systems' approach to tell how well they are involving adult service users, including older people, and where improvements could be made. The guide is based on a literature review, a practice survey and a service user event. It sets out key messages, practical action points and includes detailed case studies.

The whole systems approach to participation looks at organisations as a jigsaw consisting of four pieces: culture, structure, practice and review. (See figure overleaf.)

The practice guide aims to help social care organisations:

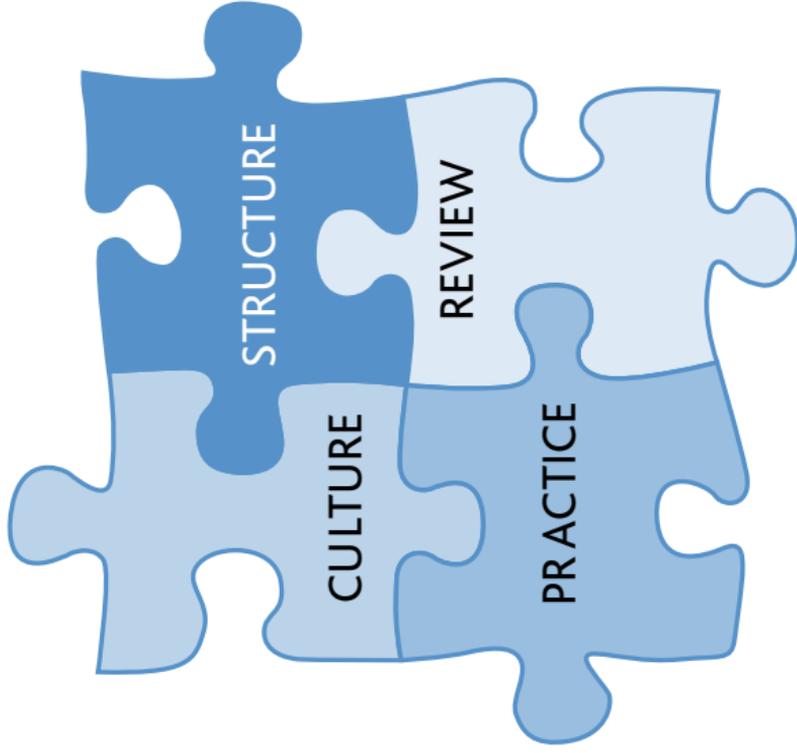
- develop a *culture* of participation, giving service users more power over decision making
- support service users to overcome *structural* barriers to participation, including personal, institutional and political, economic and cultural, and technical

CULTURE

The ethos of an organisation, shared by all staff and service users which demonstrates a commitment to participation.

PRACTICE

The ways of working, methods for involvement skills and knowledge which enable service users and older people to become involved.



STRUCTURE

The planning, development and resourcing of participation evident in organisation's infrastructures.

REVIEW

The monitoring and evaluation systems which enable an organisation to evidence change affected by participation.

- engage with service users to devise a participation strategy and improve practice in supporting different kinds of participation
- make a commitment – including specified resources – to collect feedback and *review* progress on service user participation.

The whole systems approach to participation in social care was first developed for SCIE in Practice guide 06.²

The purpose of participation

There is now a growing understanding of what service user participation means. Participation operates at many levels, 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 how services are run or commissioned. It is not simply about being present or taking part but also about having an influence over decisions and action.

Successful service user participation can lead to:

- changes and improvements to services
- benefits for individuals and for communities, for example increased confidence and new skills
- the generation of new knowledge, including challenging and improving traditional ideas about research, social work theory and citizenship.

A whole systems approach to participation

Whole systems approaches are a useful way of looking at service user participation in social care.

Culture

'Organisational culture' describes the set of beliefs, values and norms that represent the unique character of an organisation, and provide the context for its action. Many people believe that an organisation cannot change without first changing its culture.

Developing a culture of participation

Commitment from senior management is a key reason why organisations succeed in participation. Champions within an organisation help promote good practice and encourage others to change their ways of working.

Recognition of service users' expertise has led to their growing role in formal systems for consultation and involvement. However, organisations also need to find informal ways of helping service users make their views heard.

Power dynamics

We need to be aware of and acknowledge that there are differences in power between users and

professionals. Put simply, professionals generally have more power, resources and capacity than users. Successful engagement with users is about trying to equalise these power differences.

It is important to recognise that some users may experience 'multiple oppressions'. For example, if a mental health service user is also a member of a minority group (on the basis of ethnicity, gender, sexuality or age or having a stigmatised condition such as HIV/AIDS). Power imbalances can be accentuated when social care organisations exclude certain groups of people during the process of participation, for example:

- by having very formal agendas and rules of debate
- by defining who is a 'legitimate' or 'representative' participant, for example by controlling who is invited to consultation events and meetings.

Changing power relations

Organisations can achieve cultural change at the top by appointing service users and their representatives to boards of trustees or management committees. They can arrange formal systems to enable service users to take decisions, for example through individual and group meetings. They can also directly redress the power balance within the workforce by employing people with experience as service

users, both at operational level and in staff training and development.

The culture of participation: action points

- **Map** the different levels of participation, ranging from how service users are involved in daily decisions to strategic decision making.
- **Agree** clear objectives and outcomes for participation, in consultation with service users and their organisations.
- **Identify** the reasons for and benefits of improving service user participation, providing any necessary training, support or information.
- **Identify** attitudes that lead to service users being excluded and develop ways of changing them.
- **Agree** shared values and be honest about what is likely to result from participation.
- **Make** sure that there are mechanisms for accountability and admit when mistakes have been made or when there are problems with the service.
- **Acknowledge** the contribution made by service users.

Structure

There are some powerful factors that act as barriers to participation. Specific measures to tackle these barriers and to develop structures

that facilitate user involvement should be part of an organisation's participation strategy.

Personal barriers

Service users can be supported to overcome barriers to individual participation through:

- *training* for service users, including campaigning and lobbying skills; assertiveness training; and workplace skills such as counselling and presentation, project management and staff recruitment
- minimising the cost of participation to service users, making sure people know how and when their claims will be reimbursed, and paying expenses promptly ideally providing cash payments on the day where possible
- *flexible systems*, ranging from flexible employment policies to providing quiet areas for people to rest or take time out. Service users with fluctuating conditions may like opportunities to increase or decrease their involvement.

Institutional and political barriers

Commonly used ways of preventing institutional barriers to participation include:

- setting out *standards* for service user involvement through a compact or charter for service users

- changing the *style of meetings*, for example dividing into small groups, using more inclusive language and sticking to agreed timetables
- providing appropriate *resources and support* for service users, including dedicated members of staff.

Economic and cultural barriers

Poverty and deprivation, lack of trust between organisations and service users, and consultation fatigue can be barriers to participation. While professionals may have a role as mediators, service users or user-controlled organisations are more aware of economic and cultural barriers, and can be important intermediaries between statutory organisations and service users.

Technical barriers

Technical or practical barriers to effective participation include a shortage of workers with experience in participatory work, lack of information in accessible formats, insufficient technological support or equipment/aids and pressures on user-led organisations to respond to official agendas rather than their own.

Structure: action points

- **Ensure** service users are involved right from the start, and include more than just one or two token members in a group.
- **Plan** in advance, use accessible venues and make sure that service users have time to prepare for the meeting.
- **Draw up** a clear set of 'ground rules' that operate across all levels of participation to create the right atmosphere for working together respectfully.
- **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.
- **Agree** agendas and notes of meetings in advance and give service users an opportunity to include items that they would like to discuss.
- **Develop** a clear policy for prompt reimbursement of service users' expenses, covering the costs of participation, transport and support.

Practice

Evidence from many service users shows that participation can be patchy and tokenistic, or even negative. Practice can be greatly improved if organisations engage with stakeholders to develop a strategy for supporting participation.

Types of participation

Different people want to participate in different ways. Successful service user participation includes varied and flexible approaches.

- Participation led by *service user-controlled groups or networks* is more firmly rooted in service users' aspirations and preferences, but often faces funding barriers.
- National, regional and local *forums* for specific service groups, such as older people or people with learning disabilities, may avoid some issues about power because they are run *by* service users *for* service users. However, large organisations can influence such forums through funding or by setting a political agenda.
- There are different models of *advocacy services* but all aim to speak on behalf of another person or, in the case of self-advocacy groups, on behalf of their members.
- Organisations can improve the quality of *consultation meetings* by ensuring a formal system of accounting for decision making; using different ways of collecting information, such as focus groups and questionnaires; and meeting at appropriate times and in accessible venues.
- Larger, *campaigning organisations* are sometimes seen as coalitions *for* service users, rather than *of* service users. However, they can offer a less time-consuming way of becoming involved, while creating a sense of

solidarity and shared interests among their members.

- For many people, the most meaningful participation is individual involvement on a daily basis, giving them control over their everyday lives.

Networking and support

Service user organisations and individual service users often have little knowledge of or contact with other local, regional or national service user groups. Many service users feel that networking is a key route to building knowledge, credibility and visibility, both within services and among service users and their organisations. Peer support can help avoid consultation fatigue or burnout, and empower service users who have less experience of participation.

Creative approaches to participation

Meetings or postal questionnaires are not the only ways for service users to express their views. The community development field offers innovative ways to involve people, for example through drama and music. 'Participatory appraisal techniques', first used in developing countries but increasingly used with marginalised communities in Europe and North America, use creative approaches such as photography or video.

Working with 'seldom-heard' groups

Until recently, systems for participation have taken little account of diversity among service users in terms of ethnicity, sexuality and life experiences. People who are under-represented or who do not receive a service are often excluded.³

- Failure to effectively engage with *people from black and minority ethnic groups* leads to lower levels of service uptake, racism and stereotyped attitudes among service providers, and insecurity of funding for black organisations. There is evidence that participation strategies have been less effective in reaching more newly arrived communities or very dispersed communities such as those in rural areas.
- The needs of *lesbian, gay, bisexual and transgendered people* are neglected in many mainstream participation initiatives. The role of 'champions' within organisations is crucial for improved levels of participation. Concerns about homophobia and heterosexism may mean that service users do not want to disclose their sexuality, even if that has implications for the sort of services they need and/or receive.
- *People with communication impairment* can be enabled to participate by using loop systems, signers and support workers, although some people prefer to communicate

directly themselves. Many systems for consultation privilege people who are able to communicate easily.

- *People with dementia* are seriously under-represented in the majority of systems for participation, although research shows that only a very small minority cannot express their views. Appropriate support includes spending time with the person so that s/he feels more relaxed, informal conversations and using photographs as a prompt for discussion.
- *People who find it difficult to leave their homes* are often excluded from meetings-based participation. Isolated service users can be identified through local media, newsletters and service providers, and supported through technological means such as teleconferencing or by volunteers or support workers.

Practice: action points

- **Ensure** that service users feel valued and welcomed, and are supported throughout the participation process.
- **Explore** innovative and imaginative ways such as drama or music to help service users feel included and encourage them to become involved.
- **Identify** which groups of service users have been under-represented ('seldom heard') in participation exercises, and develop ways to reach them.
- **Recognise** that not all service users have equal access to advocacy services.
- **Ensure** that service users are able to meet/network effectively.
- **Recognise** the impact of multiple oppression (such as being black and having a disability), and raise awareness of ethnic and cultural issues.
- **Provide** trained workers and bilingual interpreters for those whose first language is not English.

Review

Systematic evaluations of participation are still fairly rare. But this is a rapidly developing field and process of participation will benefit from monitoring progress, recognising achievements and identifying areas for improvement.

Organisations need to identify specific resources for review within their participation strategy.⁴

Evaluation checklist

There are many different models of evaluation. Evaluation of service user participation should consider:

- Who are the actual or potential service users served by the participation strategy?
- What resources are available to create, maintain, and support the strategy?
- How are criteria selected for determining the quality and value of the strategy?
- How good or valuable or efficient are the design and delivery of the strategy (process evaluation)?
- How good or valuable are the impacts of the strategy on service users or other stakeholders (outcome evaluation)?
- How costly is the strategy to service users, staff and others compared with alternative approaches (cost effectiveness)?
- What elements of the strategy could be used in other settings (exportability)?

Internal versus external evaluation

External evaluators are thought to offer greater independence and have greater expertise, but there may be issues of ownership in implementing their findings. External evaluation can be commissioned from an independent

organisation or undertaken by people outside the organisation from a similar sphere of work (peer evaluation). Internal evaluators (part of the organisation being evaluated) have insider knowledge and are more likely to implement their findings, but may be seen as less objective.

Feedback

Providing feedback to participants following an evaluation is an important stage in any review process, helping ensure that change is ongoing and engagement is sustained.

Review: action points

- **Use** reviews to assess progress and provide evidence of the changes that have been made as a result of service user participation.
- **Involve** service users in the review process, including interpretation of results and how these will be used.
- **Set** realistic goals for review, linked to planned outcomes.
- **Set** a clear timescale for measuring change.
- **Identify** whether changes are needed at individual or strategic levels.
- **Ensure** service users receive regular updates on progress.
- **Develop** a system for sharing the results with service users and with the whole organisation.

What next?

The findings from Practice Guide 11 highlight a number of issues about the future of service user participation in social care.

Process versus outcome

While there is a growing consensus about what service user participation means, organisations often focus on structures and procedures for participation whereas service users are more interested in processes and outcomes. Social care organisations need to strengthen the links between participation and quality improvement.

Service user control

'Consumerist' models of participation (chiefly consultation exercises) are still more common than 'democratic' approaches (active involvement and decision making). Social care organisations need to transfer more power, control and accountability to service users.

Knowledge into practice

Research highlights the difficulties of translating knowledge about participation into practice. Social care organisations need to ensure that service users feel valued, are supported throughout the process and know their contribution will be taken seriously and make a difference.

Service user expertise

While participation creates expertise, service users also bring knowledge and experience with them. Social care organisations need to acknowledge service users' expertise, and involve them at all – including strategic – levels.

The wider agenda

A key concern among service users is the impact of the benefits and taxation systems on payment to service users and the receipt of benefits in kind. Service user participation in social care must be considered within the wider policy agenda.

Uneven progress

Many service users do not participate in the development of social care. Social care organisations need to learn more about what works for service users who are 'seldom heard', about the benefits of working across different service groups and sectors, and from innovation in the community development field.

The changing face of social care

Integrated teams, direct payments and individual budgets will bring changes in the style and nature of participation. There is currently little evidence about service user participation in the private sector. Service user-controlled organisations may need to compete for funding with organisations that are less committed to participation. Social care organisations need to ensure that service user participation can thrive as new service configurations emerge.

References

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- ³ Robson, P., Sampson, A., Dime, N., Hernandez, L. and Litherland, R (forthcoming 2008) *Supporting the practice framework on participation of seldom-heard users of social care services*. London: Social Care Institute for Excellence.
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