

Has service user participation made a difference to social care services?



Social Care Institute for Excellence
Better knowledge for better practice

What is this Position paper about?

The Social Care Institute for Excellence (SCIE) wants to bring together a lot of knowledge about social care, so that information on what works best is available to everyone. This Position paper is about how social care services can be made better by the people who use them – that is, the service users themselves. It brings together the main findings from six reviews that looked at whether service user participation made a difference to changing and improving social care services.

What doesn't this paper cover?

While user involvement in research, training and education are important in making a difference to services, they are not covered in this Position paper. The experiences of carers, supporters and parents will be covered in other work to follow later on.

Who organised this research?

SCIE asked people to do reviews on older people, children and young people, people with learning difficulties and disabled people. The NHS Service Delivery and Organisation Research and Development Programme (NHS SDO) asked people to review mental health service user participation and user participation in general.

Introduction

The difference that service users can make to social services planning and development is now recognised in government policy. Service users are taking an active role to improve both health and social care services. But, how much service user participation results in changes and improvements to services can vary. SCIE's research shows that at the moment there is very little monitoring or evaluation of the difference service user participation is making, although there is quite a lot of information about ways to involve service users. There is less information about the effects of this

participation, so although much is going on, we do not know whether it is leading to a lot of service change, a little service change or no service change at all.

How was this research prepared?

SCIE did not want to duplicate work that was already being done by other people, so it made sure that the new research included work that was already being done. The reviews drew on information about user involvement in England and Wales and relevant information from Northern Ireland and Scotland, dating from 1992 to 2002. Most of the work looked at statutory and voluntary social care services, with only a little about the independent sector. There was service user participation at all stages of this research, including representation on the tender board that chose the people who would be doing the reviews. Service users also had a role in researching, writing and assessing the reviews.

What does this research tell us?

Although there is a lot going on, there are still some problems. The research also tells us how we can improve things.

Users need to get feedback on their participation:

service users say that they need to receive feedback as an important part of being involved, but this does not always happen. This can have a bad effect on how people feel about being involved in participation and the difference they can make.

Change can start with just one person:

sometimes it is difficult to feel part of making change happen if you don't feel like you are part of the group being affected by it.

For example, people who are from black or minority ethnic backgrounds or who are lesbian or gay may not be getting the support they need, and can find it difficult to speak up

about it. Local authorities, such as councils, have official ways to make a complaint to help people to feed back on the quality of services. But research shows that people do not always know about ways to make a formal complaint or they find the procedures are difficult and intimidating.

Involving users in different ways:

sometimes service users are part of a consultation group to approve of service plans or policies, but this doesn't let service users actually get involved in shaping the plans or policies in the first place. Service users are now being asked to develop services in partnership with organisations, but this doesn't always happen in practice.

Making sure everyone gets the chance to be involved:

more people of different backgrounds, abilities, cultures, races and sexualities should be involved in participation. All service users need to be included, including people who belong to what are called 'minority groups'.

Power relations: there can be differences in power and influence between service users and social care professionals which make it hard for service users to be listened to seriously. Things are not always structured so that service users feel that they can make a difference. There may be ways of working or jargon that makes it difficult for service users to join in. Research has shown that sometimes, if a service user is thought to be too confident in what they are saying, they are seen as not typical of the service user group and they can be ignored.

What the organisation wants and what the service user wants: sometimes what a service user wants and what professionals or organisations want are different. Sometimes there is not enough money or staff to carry out the ideas that service users come up with or to change things to the way service users have suggested. Organisations should

make it clear from the beginning about what can and cannot be done. Also, service users should be given support to say what they can do.

Getting people to participate takes time and resources:

organisations and service users need to discuss timetables and ways of working that would let everyone join in properly. Organisations and their managers should support workers to think about user concerns and understand the importance of service user participation.

Organisational commitment: organisations should be responsive – that is, they need to be open to what service users say. Organisations need to be keen to change if they are going to make things better as a result of user participation.

Benefits of participation: at the end of participation, there is a tendency to look at what users have gained personally from their experience getting involved – this is fine, but we must also look at the change achieved.

How to make things better

We can improve some of the issues above by using different ways to involve people all of the time and by letting service users decide how they are represented. Service users should feel comfortable participating and feel that it is worth their while making a contribution.

The following are things to think about when planning and putting into place service user participation to make services better:

- Be clear about what you want to achieve and any limits there might be (such as time and money) before starting.
- Aims and limits should be clear and understood by everyone involved.
- Look for local and regional user activities and get them involved.

- Before the participation begins make sure that the organisation is prepared to respond to things that service users might suggest.
- Participation should be about local service users, not about what managers or other people want.
- Be aware of the relationships between the practitioners and the service users and the power involved.
- Look at ways to deal with any problems in the relationship between practitioners and service users.
- Make sure that information is shared by all.
- People who use services have a very valuable contribution to make. Make sure they are comfortable with the way you are using the information they tell you.
- Be flexible about different ways of working.
- Make sure there is enough time and money to support participation.
- Have a system to see how successful the participation has been and what changes it has made to services.
- Ask participants how they would like to be given feedback.
- Talk to service users about how to make sure that everyone that should be represented in the participation is included.
- Think about different ways to involve people who might not usually feel involved in services.
- Make sure all staff understand the value of having service user involvement and have the support to make it successful.

Next steps

The findings from this piece of work will make a base for SCIE Practice guides on service user participation.

These guides will give examples of how to learn from and build on what has already happened in service user participation.

SCIE also plans to do some work looking at what difference the participation of carers, supporters and parents has made to creating better social care services.

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