

Evidence Cluster: Effective involvement of older people in service planning

Issue It is widely acknowledged that user participation in service planning can ensure that services are accountable and responsive to users' needs. Efforts to involve service users have increased considerably in recent years, and involvement has had important 'intrinsic benefits' for participants, such as improved self-esteem and a sense of empowerment (Carr 2004). However, the central reason for asking users to give their views has often been overlooked: to inform the development of services and subsequently improve user outcomes ('extrinsic benefits' of participation).

Content of this evidence cluster This Evidence Cluster focuses on the involvement of older people in the planning and development of social care services at a local level. It examines the evidence as to whether this has an impact on how services are delivered. Key factors to be considered when involving older people in service planning are highlighted.

This Evidence Cluster does not address approaches to involving individual service users in decisions about their own care, for example through Direct Payments, or their involvement in social care research. National initiatives are not discussed, and papers published prior to 1997 are not included.

Definition of key terms The terms 'participation', 'involvement' and 'engagement' cover a range of activities designed to enable users to have a say in how services are delivered. These activities can be seen as a spectrum, from consultation approaches where users are passive participants, through to user control of services (Carter and Beresford 2000; Carr 2004). Carter and Beresford suggest a number of ways in which older people can be involved, including forums, user panels, consultation, pensioners' groups, and campaigning or direct action.

The definition of 'older people' given in the National Service Framework (NSF) for Older People is adopted: 'those who have completed their career in paid employment and/or childrearing'. The NSF also defines three distinct groups within the broader group of 'older people': entering old age; transitional phase; and frail older people. It is important to emphasise this and to highlight diversity within old age, for example in terms of ethnic group, gender, sexuality, presence of physical disability or learning disability, and experience of collective action (Barnes 2005).

Policy background In 1998 the White Paper *Modernising Social Services* reinforced the government's commitment to user participation in service planning, first introduced in 1990 when the National Health Service and Community Care Act made user involvement in service planning a legal requirement for local authorities. Also in 1998, the Better Government for Older People (BGOP) programme was set up 'to promote the better coordination and responsiveness of public services and...the recognition across Government that for too long older people's interests had been overlooked or undervalued'. In 2001 the National Service Framework for Older People stated that 'engagement with older people and their carers as patients, service users and citizens should inform the whole system of care'.

In March 2005 the Department of Health launched Partnerships for Older People Projects (POPP), intended to test and evaluate innovative and sustainable initiatives that improve outcomes for older people. In the same year the Department for Work and Pensions produced the first report of a long-term strategy for older people, *Opportunity Age: Meeting the challenges of ageing in the 21st Century*, and in 2006, the Social Exclusion Unit Report, *A Sure Start to Later Life: Ending Inequalities for Older People*, aimed to improve the quality of life and increase independence, dignity and choice for older people. Sure Start for Older People was launched later in 2006.

In the same year, *Our Health, Our Care, Our Say* devoted an entire chapter to putting people in control. It recognised the distinct needs of older people, and promoted strategies for involving

marginalised groups: 'finding out what people want and need from their services is a fundamental duty...It is particularly important to reach out to those whose needs are greatest but whose voices are often least heard'.

The Evidence – setting the scene The research literature relating to service user participation is extensive and complex. Much of it focuses on the multitude of approaches to involving people and their experiences of being involved, while evidence relating to the impact that user involvement has on services is harder to find: few studies have addressed this aspect of participation in a clear and rigorous way. Where it does exist, the evidence includes staff views on whether changes have been implemented, service user views on whether they feel they have had an impact on services, and changes to policy identified through documentary analysis.

A number of literature reviews have been undertaken in recent years to explore and summarise the evidence around service user participation. The Joseph Rowntree Foundation review, *Older people speaking out: Developing opportunities for influence* looks at ways in which older people are involved in influencing their environment (Thornton 2000). In 2003, the Social Care Institute for Excellence (SCIE) published *Has service user participation made a difference to social care services?* (Carr 2004), which brings together the findings from six reviews, including two that explore older people's participation. The first, *Older people influencing social care – aspirations and realities* (Janzon and Law 2003), explores the impact of user participation in relation to older people, addressing the question of 'whether, and in what ways, involvement of older people has succeeded in promoting change and enhancing quality in social care services'. The second, *User Involvement in Change Management* (Crawford et al. 2003), explores user involvement in a range of sectors (health, social care, the voluntary sector and the private sector) and includes a chapter exploring the involvement of 'hard to reach' groups: carers, children and young people, older people, and black and minority ethnic service users.

These reviews reveal a wide range of approaches to involving older people, including user panels, forums, elder councils, and qualitative in-depth interviews carried out by service managers in users' own homes (Janzon and Law 2003). They emphasise the importance of ensuring that service user involvement leads to changes to services in line with what users want. However, their findings are on the whole disappointing. Thornton was unable to find sufficient evidence of change coming about from user involvement, and suggests that reported changes are often practical and 'one-off'. Crawford and colleagues reviewed 344 studies of user participation, and found 'a relatively small number of reports that attributed changes in services to the involvement of service users', with no conclusive evidence being found of older people's involvement having an impact on services. Similarly, in the majority of cases, Janzon and Law report that in the reviewed studies, service user involvement did not tend to result in changes to services, and even where it did, real and sustained differences were not achieved.

Crawford and colleagues give helpful insights into the topic area, suggesting a number of possible barriers to successful user involvement which need to be overcome if service user involvement is to be effective. These include:

- organisational barriers, whereby a lack of adequate time and resources mean that it can be difficult to take action;
- professional resistance and negative staff attitudes;
- concerns about the representativeness of service users who participate and the validity of their views;
- difficulty managing the expectations and demands of service users – for example, if the changes users want contradict national priorities, it is difficult for providers to respond.

The Evidence – facilitators for effective involvement Factors that facilitate successful involvement are discussed in detail below, with reference to a number of individual studies.

Facilitator 1:
The service provider has initiated and facilitated user involvement

Where service providers have identified a need for, and facilitated, older people's involvement, initiatives may be more likely to result in changes to services. For example, when the 28 local authorities involved in the Better Government for Older People (BGOP) pilots joined this programme, they initiated projects that had a central aim of involving older people in service planning. BGOP aimed to 'improve public services for older people by better meeting their needs, listening to their views, and encouraging and recognising their contribution' (Hayden and Boaz 2000). The pilot projects adopted a range of approaches to involving older people in their initial consultation stages, and in many cases they successfully ensured that older people had a real impact on the services developed within the project. For example:

- In Kensington and Chelsea, a 'reading group' was established. The council consulted older people on information and publicity material in order to ensure that it was user friendly. Following users' comments on a council tax leaflet, the original was replaced with a new, user friendly one.
- In Bury, older people were involved in developing and carrying out a survey of local residents. Results were fed back through newsletters and conferences, and were used to inform the work of the Bury BGOP project.
- In Coventry, the council was keen to involve previously excluded and isolated groups. A letter writing group was set up, and an Asian outreach worker was asked to develop links with Asian elders. The council reported that they gained valuable information from the letters. It is unclear, however, what the impact of this information was upon services.

Another example is the Fife User Panels Project. The project was organised by Age Concern Scotland, but was initially developed because local health and social care agencies identified a need for the involvement of people who were representative of those using their services - in this case, frail older people (Barnes and Bennett 1998). The impact of the user panels on services was explored in relation to three topic areas: domiciliary services, hospital discharge, and information and complaints procedures. The impact of user involvement in terms of changes to services was mixed: user views were welcomed in relation to hospital discharge, but not domiciliary services, suggesting that other factors also influenced the extent to which user views had an impact.

Where providers have identified specific topics or questions they would like users to address, user involvement may be more likely to be effective, because systems are already in place to facilitate change. Raynes reported on a programme, initiated by a social services department, in which focus groups were held with older people living in residential homes to inform the development of contracts for purchasing residential care (Raynes 1998). Following the initiative, the social services department incorporated the views of service users into the new contract. The success of this approach can largely be attributed to the provider's commitment to including user views into the new contract from the outset, and having set up the project for this very purpose.

However, caution is required, as too much direction by providers could actually disempower users. User-led initiatives may be more likely to bring about 'intrinsic benefits' for participants, such as increased self-esteem and confidence. However, providers sometimes fail to listen to user-views when they are presented by user-led groups, with negative consequences. For example, O'Keefe and Hogg described the experience of HealthLINK, a project based in a Community Health Council (CHC) which aimed to influence health and local authorities with the views of older people, particularly those who were housebound (O'Keefe and Hogg 1999). There was an initial lack of responsiveness to user views, and in fact, the authority unintentionally duplicated the work of HealthLINK by initiating its own Vulnerable Older Persons Project (VOPP). The inadvertent benefit of this was that the local authority recognised the benefit of HealthLINK's approach, which was more successful than VOPP in involving frail elderly people. As a result, the local authority subsequently endeavoured to work in closer collaboration HealthLINK.

**Facilitator 2:
Providers are fully engaged in the participation process**

Involvement of older service users may be more likely to lead to service change if providers are engaged throughout the process, and have a good level of awareness of the aims and methods of involvement. This is demonstrated in Raynes' study of user involvement in contract development, where key factors that enabled user views to be incorporated into the new contract are identified (Raynes 1998). These factors include: the allocation of a substantial amount of time and energy by the individuals responsible for incorporating ideas into the revised contract; some risk-taking by the city in funding the project; and a focus on outcomes rather than process of involvement. As we have already seen, in O'Keefe and Hogg's study of the London HealthLINK project, it took time before service providers became engaged (O'Keefe and Hogg 1999). However, when HealthLINK and the local authority eventually began to work in closer collaboration, there were positive outcomes. The local authority's Senior Policy Officer consulted directly with HealthLINK on proposals to modernise local authority structures and HealthLINK's involvement in planning for a Healthy Living Centre; and its Public Health Report was devoted to the Health Improvement Plan for Older People, giving prominence to evidence produced by HealthLINK.

Greater transparency in the way participants become involved, and how ideas are generated, can ensure staff are aware that users *are* representative and that their views are genuine. This requires constant and clear communication between staff members and user representatives. Raynes suggested that for user views to be successfully incorporated into a contract, communication between users and providers was very important. This was achieved by ensuring all relevant stakeholders participated in a steering group; and ensuring that participants were kept informed of developments and outcomes.

Staff attitudes can greatly influence the impact of user involvement. Where staff are defensive, suspicious, or indifferent, this is a clear barrier to change. This may be addressed both through staff training and through ensuring greater transparency in approaches to involving users. For example, in the Fife User Panels study, in the area of domiciliary care, staff were defensive about what service users had suggested, perhaps because much of it was negative. They questioned the way users had been recruited to the panels, and the way topics had been introduced onto the agenda of User Panel meetings, particularly indicating a suspicion that the facilitator was using the panels for her own ends (Barnes and Bennett 1998).

**Facilitator 3:
Issues are relevant to the service provider**

Provider responsiveness to user views is apparently greater when these views relate to topics already of interest. Barnes and Bennett felt that two factors affecting the ability of users to influence services were the nature of the issue, and its timeliness (Barnes and Bennett 1998). For example, in the Fife User Panels Project, hospital discharge was already a 'topical' issue, of interest to officials at the time. Therefore they welcomed proposals for good practice in hospital discharge, and the users' views contributed to action taken at a local level (Barnes and Bennett 1998).

Where the issues raised by users are not already of interest to providers, the impact on services can nevertheless be increased if users group together and take intense action targeting a single, clearly defined topic. A Help the Aged study, *Speaking up for our age*, gives evidence in support of this (Help the Aged 2002). It describes *Action for Pensioners in Bath and Somerset*, a forum set up in 2000 and run by volunteers. With 1000 members, the forum successfully challenged the local authority using several Action Groups. These focused on different specific issues including residential care home provision, home care charges, and health and social care. They had success in a number of areas, for example, one Action Group objected to council plans to sell off residential homes, the result being that the authority gave a commitment to re-think proposals and retain some residential provision, consulting the forum about what and where this was. Another group responded to a proposal to increase home care charges, with the result that charges were reduced.

Facilitator 4: There is organisational capacity for change

Organisational capacity is the central factor which enables user involvement to lead to real changes to services in line with what users want. Adequate time and resources must be identified to respond to users, if real and sustainable changes are to be implemented. For example, within the Better Government for Older People programme there were positive examples of change resulting from older people's involvement (Hayden and Boaz 2000), but it is important to highlight that much of this was on a small scale, and arguably not sustainable. It was possible for certain changes to be implemented within the context of the pilot schemes, simply because the environment was accommodating and designated funding was allocated. Even within the pilot schemes, it was reported that older people often felt frustration at the lack of action, and questioned whether the decision-makers were really listening to them.

Additional difficulties arise where user views contradict national priorities. The Older Women's Lives and Voices (OWLTV) study in Sheffield sought to involve marginalised groups in research and policy-making (Cook et al. 2003). Discussion groups were set up, aimed particularly at older women from minority ethnic groups. Interviews with service providers showed that providers supported the idea of user participation, but that barriers to change included lack of time and funding, and contradicting priorities and needs across organisations.

It is important for providers to ensure that there is capacity for change not only where providers have identified the questions for consultation, as this is an important way to ensure that service users feel listened to, and services meet the needs of the people who use them.

The Evidence – is missing Evidence relating to the impact of older people's participation is hard to find. However, the recent SCIE Resource Guide, *Participation: finding out what difference it makes* (Doel et al. 2007), may influence further research being carried out in this area. The resource guide highlighted the need for much more evaluation of service user participation, with a particular emphasis on the impact of involvement on the way services are delivered.

Furthermore, as highlighted by Crawford and colleagues, where studies do evaluate the impact of user involvement on service change, it will also be valuable to explore the impact of these changes on *service quality* and service user outcomes.

Conclusion Many innovative approaches have successfully recruited older people to participation initiatives and generated ideas for service development. The following factors have been shown to contribute to user involvement leading to service change:

- The involvement of providers in identifying a need for user involvement and in initiating projects that involve users
- Full engagement of service providers in projects that involve service users, and ongoing communication or partnership with users
- Identification by service providers of issues where service user involvement in decision-making is particularly needed
- Intense targeting of clearly defined issues by service users
- Transparency in methods of involving users, both in terms of how service users are recruited and how ideas are generated
- Education of both frontline and senior staff, in order to encourage positive attitudes to user involvement, including a willingness to receive criticism and an openness to change
- Creation of organisational capacity in terms of time and resources to ensure that it is possible to implement changes in line with what users want

Overall, there needs to be a renewed focus on the possible outcomes of user involvement, rather than simply acknowledging the benefits of the process of being involved.

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