

Engaging Older People in Reviewing the Influence of Service Users on the Quality and Delivery of Social Care Services

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Abstract

This paper summarises the results of a research review (Janzon and Law, 2003, Social Care Institute for Excellence, 2004) commissioned by the Social Care Institute for Excellence (SCIE) to explore the influence of older service users in shaping social care services. A key dimension of the review was the active involvement of two reference groups of older people. The central question of the review was how the involvement of older people has succeeded in promoting change and enhancing quality in social care services. The main conclusion is that, while involvement has resulted in considerable knowledge development, this understanding has yet to percolate into the delivery of mainstream social care.

Keywords: older people, service users, social care, user involvement.

Background

This is a report of a research review commissioned by the Social Care Institute for Excellence (SCIE, 2004) to explore the extent to which the views of older service users have been able to influence and shape the delivery of social care services. The review was commissioned as one of a set of four, covering older people, children, people with physical and sensory disabilities, and people with learning difficulties.

Involvement of Service Users in the Review

A key element in the review process was the engagement of two reference groups of older service users, crucially enabling us to test the review findings against users' actual day-to-day experience of receiving social care services. In setting up these groups we recognised that they would be small, and could not reflect the broad range of characteristics encountered among the population of older people receiving care services. We therefore sought to recruit people who would be knowledgeable *about* service user involvement and in particular about the range of needs and preferences which service users represent, whilst at the same time having themselves first-hand knowledge of receiving social care services. With the help of the Better Government for Older People (BGOP) network, two reference groups were established – one in the north of the country and one in the south. The southern group had a membership of four older people, including two direct service users (one a wheelchair user) in receipt of home care and day centre services, the coordinator of a team of older people acting as lay assessors of home care services, and a member of the Older People's Council. The northern group

had a membership of seven, including representatives from a range of the local BGOP groups. All were older people's service users, receiving home care and attending resource centres; they represented a range of ages and were fairly equally split in terms of gender; four were wheelchair users; all were concerned in one way or another to play an active role in promoting older people's involvement in a range of issues. We had hoped to be able to include at least one ethnic minority member within this group, but there were no evident candidates; it was recognised and acknowledged that there were lessons to be learnt within social services about making effective contact with ethnic minority elders.

We used a half day workshop with these groups at the outset of the project to test out our approach and methodology, and further ones towards the end to check out the key emerging themes. Participants were sent an explanatory letter setting out who we were, the purpose of the SCIE project and the role we hoped the advisory group would play. We also offered assistance with transport and a fee for participation in each half-day event.

The purpose of the first workshop was to outline and discuss our approach to the review. We invited participants to share their personal views and experiences of being able to influence local social care services, and their views on how responsive services are to the needs of different groups of users. We then presented our ideas of how we would approach the review and followed this with an open discussion to help shape what we should be looking for. The purpose of the second set of workshops was to present some of the emerging findings of the review and discuss these in the context of participants' own experiences. All sessions were tape recorded and the advisory groups also provided specific material for the review, including *inter alia* a guide to services

produced by older service users and a video on the subject of involving older people. The groups were not involved in writing the review, but direct quotes from the discussions were used in the report.

The contribution of the groups added a crucial dimension to the outcome of the review, grounding the project in reality, and enabling us to balance the material in the research literature against the day-to-day experiences of a sample of older people receiving 'routine' social care services. Participants also gave positive feedback about their experience of being involved in the advisory group, suggesting that this had been both a constructive and enjoyable process.

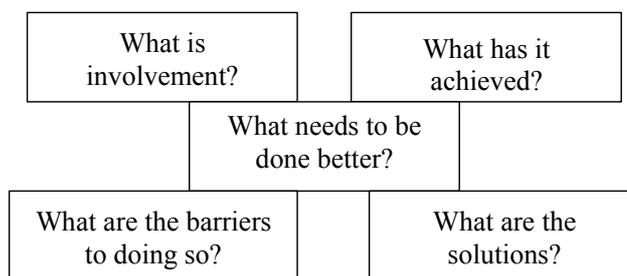
Review Findings

The review considered a wide range of written material, focused primarily on the past five years but also including formative material from throughout the nineties; it included formal research and evaluation, SSI and Audit Commission inspections, and descriptive accounts of practice. The emerging findings may be broadly grouped under the themes:

- the process of engagement
- older people determining the agenda
- recognising and responding to service user expertise, and
- enabling quiet voices to be heard.

In each of these areas the review identified general developments in professional knowledge and understanding, brought together specific examples of good practice, and highlighted – especially in mainstream services – things we need to learn to do better.

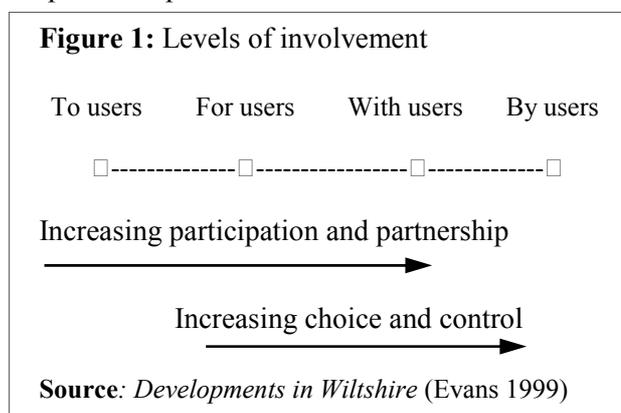
We here consider these aspects by summarising the overall learning from the review under the following framework of questions:



What is Involvement?

The review demonstrates how the term 'involvement' has been used to cover a whole spectrum of activity, with passive receipt of services (no involvement) at one end through increased opportunity to influence the services received, to users actually planning, managing or organising services themselves.

Referring to the development of user involvement in Wiltshire (Evans, 1999) observes that there is a need for a *range* of models of involvement (Figure 1), depending on the level of activity which participants wish to commit. What is important is that the choice is there, and that the involvement - or partnership - is real.



By the same token, there is a wide range of possible *means* of supporting client involvement in the shaping of the services they receive (Carter and Beresford, 2000). These range from basic information and/or advocacy in whatever form or language it is required – essential minimal support for any form of effective involvement – through various forms of consultation and facilitation, to support for development of user-led services and clients managing their own care packages through Direct Payments.

What has Involvement Achieved?

This really is the issue at the heart of the review – the question of what has changed as a result of user involvement. The benefits identified through the review may be summarised under the headings of:

- intrinsic benefits of participation
- knowledge development
- models and examples of effective involvement

Intrinsic benefits

Members of our advisory groups were strongly convinced of the intrinsic benefits to older people simply by virtue of *being* actively involved. It not only gave them opportunity for engagement, but actively demonstrated that they still had a positive and valued contribution to make. One of the major benefits of the BGOP movement is the very fact that one of its central aims is to better listen to the views of older people and recognise their contribution.

There is also general – if patchy – evidence of increased use of the *processes* of participation and partnership, as well as some shift away (though more for other groups than for older people) from an agency-led focus on involving users simply as consumers, towards their participation as fully contributing citizens (Thornton, 2000).

Knowledge development

The review reveals how the involvement of users has contributed to the development of knowledge, which can inform and enrich the professional perspective. For example, there is evidence (assuming willingness for the lessons to be learnt) of a greater knowledge and understanding of:

- what makes for effective involvement - including the key importance of appropriate training and support (Carter and Beresford, 2000; Thornton, 2000), and
- older people's own preferences for the means by which they are consulted.

Crucially there is also a better understanding of older people's priorities in terms of what they actually want – including independence rather than care, reliability and continuity as key aspects of quality in domiciliary care, and personally defined

services (Qureshi and Henwood, 2000).

Finally, there is better understanding of the *ways* in which the traditionally quiet voices in particular may become heard – including frail housebound older people (Barnes and Bennett, 1998; Patmore and Qureshi 2000) and – strikingly - people with dementia (Allan, 2000).

Models of effective involvement

There are many individual examples of practice developments enabling service users to have a real and effective say in the nature and quality of the services they receive. For example, a number of projects have demonstrated effective ways of reaching out and enabling the collective voice of frail and housebound older people to be heard, for instance through teleconferencing, through the use of diaries, through engaging senior managers to interview older people in their homes, or through physically enabling people to be brought together. There are examples of the active involvement of older people themselves in enabling others to have a say – as in the Brighton and Hove lay assessors scheme (Janzon and Law, 2003) - representing a move away from the tendency reported in earlier reviews of speaking 'for' older people. There are also some good examples of older people being involved as partners in research, review and monitoring that demonstrate the added value which older people bring to such partnerships (Godfrey, 2002).

What Needs to be Done Better?

However, while *individual* examples of good practice in engaging older people abound, the resounding message from the review is that there is little evidence that involvement of older people is transforming services *overall* to reflect their expressed preferences and/or priorities. Our advisory groups identified strongly that the learning and development illustrated in the formal evidence covered by the review were rarely to be found in the day-to-day experience of the average older user of social care services.

Moreover, there is still a strong element of presumption that professionals know best. This is nowhere clearer than in the case of Direct Payments, where the predominant view of

professionals is that older people will not want to be burdened with the responsibility of managing their own services. At this stage it may be too early to say whether Direct Payments do give older service users a route to real empowerment, but what is clear is that interest among older people would be much higher than assumed if the appropriate support mechanisms were in place (Miller, 2002).

Generally speaking, the focus to date has been largely on the *processes* of engagement. This needs now to be matched by an increased capacity within mainstream services

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- (a) to *listen* to what is being said, and
- (b) to *respond* to what we hear.

What are the Barriers to Doing So?

The review indicates that the main barriers for service users in affecting change in services relate to how ready social and health care agencies are to respond to the increasingly clear messages from users about the type of services that are important to them and the way they are delivered. The review raises serious questions of political, organisational and professional commitment and/or capacity to act on users' views.

More fundamentally, *central and local policy direction* may work against what users want. For example, it is now quite clear what is important for service users in terms of quality of home care. Yet, both of our advisory groups, expressed major concerns about the continuity and competence of care staff - key aspects of quality. These, they felt, were being eroded by the drive for privatisation, a matter over which they had no say. Another example is the high value service users put on assistance for independence; again this is an area that has been seriously eroded, with mainstream services largely targeting people with high dependency.

The latter point links to the issue of shortage of mainstream *resources* available for preventative service development. More generally, resource shortfalls impact on the quantity and quality of services across the board.

What are the Solutions?

As evidenced by the review, there is a wealth of best practice principles, guides on how to involve service users, and illustrations of ways of engaging people from projects and initiatives. Some of these are generic, others focus on ways of overcoming barriers to involving those with particular needs, others again on involvement for particular purposes or in particular settings. There is recognition that there is no one-size-fits-all blueprint for what works, that real involvement must recognise diversity and that some people need support to enable them to participate.

The understanding of diversity is crucial. The group termed 'older people' encompasses an age range of three decades and more, and as full a range of characteristics in terms of degree of mental or physical frailty, presence and degree of physical or sensory disabilities, cultural and ethnic origins, sexual orientation, and natural preferences as for any other sector of society. Whether services are delivered in a domestic or a residential setting, the voice of the *individual* needs to be able to be heard on a day-to-day basis.

If organisations are serious about listening to users, they also need to be prepared to make radical changes of approach in order to take on board what older people are saying and address this within mainstream services. The slow development in recent years suggests a need for a *step change* in responding to what service users are saying. Organisational capacity building and a commitment to honestly examine the consequences of current policies must be at the heart of this.

Organisations need to be upfront about the scope for users to influence services, and also about the constraints. Lack of honest information can create confusion and disillusionment as well as preventing meaningful engagement and change.

Change cannot just rely on success in individual projects. The need for a strategic approach to change, including involvement and influence at a national level has been strongly emphasised by BGOP. A comment from our advisory group makes this point:

Why is there so much difference? If social services in one place are doing something right, why aren't others doing it? Social services who are not doing it shouldn't be able to say 'we don't want to do it.'

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