

Older people speaking out

Developing opportunities for influence

Patricia Thornton

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Patricia Thornton
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OLDER PEOPLE SPEAKING OUT

Introduction

This paper is about how older people are involved in influencing their environment, services that affect older people and the society they live in. The paper focuses on *organised* opportunities for *having a say*.

The paper does not consider how older people can influence *by doing*, although we know it is important for older people both to be and be seen as contributors as well as consumers (see Bright *et al.*, 1998, for accounts of six projects run by older people). Nor does it look at how older people can have an influence informally as individuals, through involvement in family life or community activities. It is not about how older individuals are involved in deciding how services can support them personally, although this is an area where organised and individual opportunities for influence need to be developed.

Terms

We use the word 'involvement' because it is both neutral and inclusive. Other words, such as 'participation', 'consultation' or 'engagement', mean different things to different people. Academic writers have distinguished terms for different 'rungs' on a ladder of participation (from information to control) but ordinary people have rarely been asked what different words mean to them and which they prefer.

A research study of older sheltered housing tenants explored how they interpret the terms and found they preferred 'involvement' to 'participation' because the latter term appeared to restrict the issues, while the word 'consultation' caused confusion (Riseborough, 1996a).

If involvement is to be effective, more preliminary work is needed with other older people in different contexts to explore their preferred terms.

Opportunities for involvement

Evolving opportunities for involvement

Organised opportunities for involvement have developed since the early 1990s and dramatically so since the Labour Government came in. Early opportunities mostly involved people who use, or might use, community care and health services. The main aim was to try to make services more effective and efficient by relating them more closely to users' needs. Now people are beginning to be involved as citizens, recognising the democratic right to have a say in matters that affect communities or the public at large. Practically every public body is now being urged by Government to consult or involve users and/or the public. The authorities have tended to decide on the topics on which they want users' or the public's opinions.

In parallel to 'top-down' initiatives, self-organised groups have sprung up and are asserting the right to put over their point of view on matters they identify as important. Voluntary organisations, and grant-giving bodies, are now supporting the development of older people's groups and forums.

Public bodies are increasingly trying to enable people to organise themselves, especially in local communities – strengthening their capacities with funding, training to be effective

influences and support workers, for example, through Single Regeneration Budget (SRB) funding. Special efforts are being made to enable those people who are often left out to contribute as citizens. The New Deal for Communities has made participation of local communities in development schemes a criterion in the bidding process.

Public consultation or user involvement has often been an 'add-on', needing extra people or money to make it happen, and has not been built into an organisation's usual activities. A lot of time-limited special projects have been set up to involve users of different services. And different arms of a whole range of organisations at local level have been doing their own thing. Even within a single organisation, it is hard to know who has been consulted about what, who is involved and who is not, what people have said and what has happened as a result. If efforts are not co-ordinated and results are not shared, it is not surprising that some groups complain that they are overloaded with requests to give their views and that little seems to happen as a result.

The lack of a local strategy might explain why the public is mostly unaware of a seemingly vast amount of activity (DETR, 1998a). Now the idea is to get departments, services and local organisations to join up – both to avoid 're-inventing the wheel' and to include people who have been left out – and develop co-ordinated strategies for user and public involvement.

A joined-up approach to involvement also recognises that people's concerns are not 'service-shaped' but cross the boundaries of departments and authorities, and require a joined-up response.

Opportunities for older people

With so much going on, so much being written in published and unpublished forms, and so much not being written up at all, it is

hard to give a precise account of where older people fit into all this activity.

Our impression is that 'top-down' initiatives are extending the involvement of older people as service users, or potential users, particularly in local services which are designed for them or in which they have a major stake. Older people who use home-care services, day centres, sheltered housing, residential care homes, long-stay hospitals or GPs' surgeries are target groups which are relatively easy to identify and reach. Now there are some attempts to involve older people in central government services, notably by the Benefits Agency in eight of the 28 Better Government for Older People (BGOP) pilot project areas.

Older people are, of course, users of services open to a wider public, such as leisure facilities or public libraries. There appear to be fewer examples of providers involving older people as a special group of users. (But it is hard to say whether this is also true for other groups.)

In general, it seems that older people are still being expected to be involved as service users although the BGOP programme is encouraging consultation of older people on open agendas (BGOP evaluators' seminar, September 1999).

It seems that few 'top-down' efforts are being made to include older people in matters relating to other 'administrative categories' of service users, or to the public at large. Generally, if older people are not seen as having a special interest, they are excluded as citizens. Younger people might be consulted on issues that relate to their future, but older people are rarely consulted on issues that affect younger generations. For example, the older generations are rarely asked for views on education policy, employment policy, or even on policy to support carers.

We know very little about the kind of things older people might like to have a say about, outside matters that affect them directly.

In a growing number of local older people's groups and forums,

older people have the chance to form their own agendas and priorities, with their peers. This 'bottom-up' movement is facilitated by national voluntary organisations. Help the Aged has a programme of grants called Speaking Up for Our Age. Help the Aged in Northern Ireland is assisting older people to be effective activists and campaigners, through training in skills for community activity and in getting their message across (Help the Aged, 1998). Non-local funding sources are important to older people's forums wanting to remain independent of local authority funding but without enough resources to organise effectively.

Accounts from self-organised groups of older people show that they home in on issues which directly affect the mass of retired people – ageism, pensions, transport, the street environment, safety, community care charges, rationing of health services. This is perhaps not surprising, given that they have organised out of generational solidarity. Older people also report that, with limited energy, they want to focus on the quality of older people's lives and, in turn, of the lives of generations which follow.

But the issues they take up may not reflect their highest priorities. Older people's forums may concentrate on relatively small issues which appear easiest to influence, as success may pave the way to take forward more critical concerns (Carter and Nash, 1995). The members of the Northern Ireland Help the Aged Senior Panel decided to concentrate on areas where they had the best chance to influence policy makers, and focused on free public transport because they felt they could achieve it (unpublished draft). The BGP evaluation team reports a tendency to go for 'quick wins'. For some projects, pressure to achieve results by focusing only on areas of likely success can actually distort the picture of what matters to older people (Whitton, 1999).

Older people's organisations report the dilemma of whether to respond to questions of the authorities' choosing. Being asked

to give a view is a chance to make your presence felt and gain credibility, but can divert organisations from pursuing their priority issues.

People setting up initiatives often assume that they know already what issues older people will be willing to engage in. But experience shows them wrong, and some more flexible projects have changed tack to follow the directions the older participants want. A project in Kirby, Merseyside, for example, began by wanting to find out more about older people's experiences of home support services, but it soon became clear that experience and perception of services are closely linked to overall life experience, and so the project set about gathering people's accounts of their lives and not just of the services they got (Blunden, 1998).

In some places, older people are now being asked (through a battery of research techniques) to say what matters to them and what they want to prioritise. *It seems important that older people play a part in analysis, so that younger paid workers' implicit assumptions do not distort the interpretation.*

The clear message from older people is that social care and health services are only part of a bigger construction of facilities and services affecting quality of life. The idea that older people's needs can rarely be compartmentalised into the categories of existing services is behind the BGOP programme and its pursuit of 'holistic strategies and citizen-centred services' (Bennington, 1998). Some pilot projects (such as Middlesbrough) are adopting a community approach and are encouraging older people to identify and explore all the major themes which, taken together, affect the environment they live in. This sort of approach brings out concerns – such as staying fit and well, or feeling safe at home and in the neighbourhood – which require co-ordinated responses from a whole range of actors.

Methods of involvement

Throughout the 1990s, a huge number of guides have been produced on how to consult or involve users and/or the public. Just in the last two years, a vast amount of guidance has emanated from Government – on consulting the public (Seargeant and Steele, 1998), on consulting users of public services (Cabinet Office, 1998), on involving the public in local authority decisions (DETR, 1998b), on patient and public involvement in the NHS (DoH, 1999). These guides tend to treat the public as a homogeneous entity, while reminding us about ‘hard-to-reach’ groups. There is guidance for primary care groups, clinicians, health promotion, social housing providers, social services, and guidance on involving users of specific services (e.g. cancer services, maternity services, sheltered housing) and on involving user groups (e.g. carers, people with sensory impairment, black and ethnic minorities, older people) in specific service areas.

In addition, innumerable projects have produced accounts of their experiences of public or user involvement, and some guides have drawn on them. There are also countless research evaluations of user or citizen involvement, many offering lessons for more effective practice. But only a minority of these recent ‘how to’ guides derive from the experiences of participants (a notable exception is Seargeant and Steele’s guide, based on 14 case studies of public sector consultation projects, although projects involving older people are not included).

In general, we are swamped with information on techniques for involving people and illustrations of initiatives. There are also a number of practical guides based on older people’s experiences – some of which are written by older people who took part – for organisations wishing to consult or involve older people in planning new services (Brown *et al.*, 1998) and for older people’s organisations getting involved in community care issues (Tozer, 1995).

'How to' guides may give a different picture if they draw more on older people's experiences. The lack of comprehensive guidance on involving older people may be a gap, but we first need to discover how useful 'how to' guides really are. Reading and hearing the direct experiences of people who took part may have more influence on practice than abstract guidance.

A choice of method

Surveys have found that 'top-down' approaches to involving users and the public use an increasingly wide repertoire of techniques and are adopting multiple methods (DETR, 1998b). People are less likely to be expected to respond or participate in standardised ways – despite the decision to make social services departments conduct surveys of satisfaction among service users and carers (Secretary of State for Health, 1998).

Guides tend to advise that methods should suit the purposes of consultation. The prevailing idea of 'fitness for purpose' makes it difficult for people to choose between alternative opportunities.

We still know rather little about which methods older people prefer for different purposes.

Researchers at the Social Policy Research Unit asked older users of home-care services how they would like to put over their views on services. Written self-completion questionnaires were widely disliked and most preferred one-to-one interviews at home. People wanted the space to deliver their own considered message, with advance notice of the questions, rather than impersonal questionnaires with ready-supplied answers. Group discussions were also a popular choice, but less so among people aged over 80. Interestingly, older people in this study wanted senior managers of their service to interview them, because they thought that was the most effective way to exert influence. They believed that senior managers needed 'direct, eyewitness

education in older people's everyday realities to be able to influence and act on policy' (Patmore *et al.*, 1999). This suggestion is being tried out in one social services department.

Some projects have put forward options for older people to choose from, based on research findings that showed them to be acceptable methods. Guided by the examples reported by Thornton and Tozer (1995), the 'Have Your Say' project in Southwark offered a choice of a postal network, a telephone group and home visits which ran concurrently (BASSAC, 1997). But a BGOP pilot project found very little interest in a similar set of options.

There may be scope for drawing together what has been found out about older people's preferred methods for involvement, supplemented by research as required.

But it seems important to consult older people locally about their preferences, rather than impose methods from elsewhere, although doing so adds yet another layer of consultation. Exeter Senior Voice established an advisory group to choose the most appropriate methods of involving older users. They consulted local older users, leading to a system of questionnaires and a visiting scheme to assist those who could not fill it in alone, in addition to a user panel (Whitton, 1999). Rather few of the BGOP pilots report that they are looking at how older people want to be involved. The Devon project older people's advisory group, however, has the ambitious remit of designing a strategy for involvement, with a large-scale consultation on options being planned.

Despite these examples, many projects still set out to implement pre-decided methods. One obstacle is funding: the plan usually needs to be clearly spelled out in funding proposals and it can be difficult to finance exploratory work with older people in the early planning stages.

Innovative methods

The search for 'innovative' ways of involving users and the public has not abated, although we still know little about the effectiveness of more standard methods. Examples include 'visioning events' and 'citizens' juries'. Innovation is driven, in part, by the need to appeal to people who appear sated by once-novel approaches, such as focus groups. But is it the method or the lack of outcomes that puts people off taking part?

Many conventional methods of getting people's views are dull and unrewarding for those who take part. Drama projects allow older people to get their message across and have fun at the same time – see, for example, Toffaleti (1997) for The Greater Manchester Centre for Voluntary Organisation Voices for (Housing) Choices drama project. Some BGP pilot areas are exploring the use of drama.

Two trends in methods are worth singling out: new ways of reaching out to older people in their own homes; and the active involvement of older people in enabling others to have a say and gathering their views. Telephone discussion groups (as evaluated by Thornton and Tozer, 1995) are increasingly being tried, to reach older people at home. 'Three-way calling' is a simple way of linking older people by telephone and, once the idea is introduced, older people can take control themselves without the need for an external organiser (Gomm with Thornton, 1996). Postal networks (as evaluated by Thornton and Tozer, 1995) and 'letter-writing circles' are also being tried out, as are Internet discussion groups. These methods also have potential to be led by older people themselves.

More active older people are coming to recognise that they cannot speak for older people who do not want to, or are unable to, join in organised activities outside the home. The older people's forum in Wakefield and District helped to instigate the 'Talk-Back'

project. Volunteers of all ages visit older people in their own homes to talk to them about their experience of services and record their views in a diary. The project worker then systematically and regularly feeds their views to planners and providers (Willis, 1999, 2000).

A different approach was adopted in a project in Kirby, Merseyside, set up by the King's Fund (Blunden, 1998). Older people and officials in a joint working group worked in pairs and visited older people in their own homes (as well as groups of older people) to hear from them what life is like and what they think about the support they get or need. What they found out was reported back. There are also examples in BGP projects of older people going out to people's homes to work with them to fill in questionnaires.

Most of these initiatives are involving older people who use, or are likely to use, services. *They could be developed to make sure that older people stuck at home have a chance to have their voice heard as citizens.*

Issues where older people miss out

There is a fair amount of consensus about what matters to older people: transport and mobility, income, community safety, health, affordable warmth, options for care and housing, better co-ordination between services and – running throughout all these issues – information.

Older people are comparatively neglected in *health-led* initiatives. A very small minority of activities within the 26 Health Action Zones in England are focused on older people, who seem to be a low priority (Bauld with Zeilig, 1999). None of the 12 research projects on user involvement in the NHS, commissioned in June 1999, focuses on older people. None of the resources or practice examples cited in the September 1999 paper on *Patient*

and Public Involvement in the New NHS (DoH, 1999) refers to older people.

Community Health Councils and local voluntary organisations appear to be greater champions of older people's involvement than the NHS. For example, Age Concern London set up a two-year action research project (funded by the National Lottery) in which five London GP practices held meetings with their older patients to discuss how the surgery worked from their point of view (Sheppard, 1999).

Older people are keen to give their informed view in health service planning and priority-setting decisions and older people's forums have taken the initiative, in setting up panel discussions, for example. Health authorities have set up 'citizens' juries' to allow for public discussion and deliberation (see McIver, 1998). The aim in citizens' juries is to bring together a representative cross-section of the local population (usually based on age, gender, employment status and geographical area) for up to two days to hear and debate evidence from experts. The characteristics of participants are not reported but it seems likely that the format effectively excludes those older people who cannot get out without help. The same criticism applies to the popular 'panel' method used by Health Authorities.

Older people may like to consider whether they would like more opportunities to be included in these ways, or whether special older citizens' juries might be developed. A panel of 40 older residents in the London Borough of Harrow has proposed a citizens' jury to consider the impact on elders' services of the planned merger of two local NHS Trusts (Better Government for Older People, 1999d).

Who misses out?

Writing in the first half of the 1990s, Carter and Nash (1995) commented that *women* were under-represented in older people's organisations. Women-only groups were set up because women's demands and issues (particularly in health) were subsumed by those of male pensioners (Curtis, 1995) but older women's groups still do not seem to be widespread outside London. *We need to find out if there is a demand for older women's groups.*

Getting the views of *people with dementia* is being shown to be possible, not just through a third party but directly through informal conversations, individual interviews and group discussions. Social Policy Research Unit researchers found that group discussions could work well in communal settings and that participants generally experienced them as enjoyable and supportive (Qureshi *et al.*, 1998). But there are very few examples of older people with dementia being involved in this way. *This is one area where guidance would be helpful.*

There are a lot of reports of difficulties in including *older people from minority ethnic groups* in 'top-down' initiatives. Some BGP pilot areas are commissioning ethnic minority groups to carry out consultations. But it is difficult to find examples of minority groups themselves organising involvement of older people. We need to understand why this is so. A study in London (cited by Boaz *et al.*, 1999) found that Bangladeshi elders felt they were not part of society and were under-educated, and they saw community leaders as speaking on their behalf. *More work needs to be done to understand the barriers to participation of ethnic minority elders.*

There are special barriers to involving *older people in rural areas*. Collective organisation is difficult and they may find it difficult to find peer support. Ways of reaching out are being tried in some

BGOP pilot projects. *Learning from experience needs to be disseminated.*

As already noted, 'bottom-up' community approaches encourage involvement of people who are not already actively involved, although it is still proving difficult to get them on board. Some BGOP projects have deliberately sought out 'ordinary people' rather than those who already have a voice but it seems that activists are still in the majority. This may be because of a continuing lack of resources to support people who are not used to active involvement, or because opportunities still depend on a commitment to continued participation which many ordinary people cannot sustain. There is little evidence of a more realistic model of fluctuating commitment advocated following research with older people (Thornton, 1994).

Effects of involvement

Most work has looked at the way in which people are involved (the 'process'). There are rather few studies that have evaluated involvement in terms of end results. It is important to do both, not only because the processes of involvement contribute to the end results but also because we should consider the effects on those who take part.

We can look at the effects (or outcomes) of involvement in three ways: the effects on the people taking part; the effects on organisations involved; and the effects on what people wanted to influence.

Effects of the first type are more likely to be intangible – increased self-confidence, knowledge or sense of control, for example. People taking part tend to emphasise benefits in terms of what some researchers call 'personal development' and increased understanding (DETR, 1998a). Evaluations of initiatives involving older people have found that they value personal

empowerment and collective empowerment as much as tangible achievements (Barnes and Bennett-Emslie, 1997; Thornton and Tozer, 1995).

Changes in the 'culture' of an organisation are often thought to be desirable outcomes but are very difficult to identify or measure. Senior managers appear to be influenced by direct contact with older people (Blunden, 1998), and less influenced by their views if they are passed through an intermediary, such as a project worker (Barnes and Bennett-Emslie, 1997). The evaluation of the Fife User Panels Project recommended that reports, and where possible oral presentations of issues, should come directly from panel members, rather than in the name of project staff (Barnes and Bennett-Emslie, 1997). The Kirby project also recommended mechanisms by which senior managers actively engage with service users (Blunden, 1998), and, as already noted, older home-care users themselves recommended that senior managers should interview them at home (Patmore *et al.*, 1999).

On the face of it, it might seem easier to identify changes that have come about from user or public involvement. But studies show that citizens, officials and local elected politicians find it difficult to pinpoint specific service or policy-related outcomes (DETR, 1998a). Changes reported as resulting from involvement of older people are often practical and 'one-off' – the siting of a pedestrian crossing, and so on. Of all the issues raised by the Fife User Panels Project, those about hospital discharge appeared to be the most wholeheartedly welcomed and most constructively responded to by service planners and providers. The evaluators note that the timeliness of the document produced by the panel was an important factor (Barnes and Bennett-Emslie, 1997). Getting views into the system at the right time is a continuing challenge facing organised groups of older people, requiring insider knowledge that is difficult to access.

Evaluating involvement

Very few user or public involvement initiatives are formally evaluated. Local authorities argue that they cannot afford the time or staff, and that it is difficult to identify criteria by which to judge effectiveness (DETR, 1998a). Now there are increasingly calls in government documents for evaluation to be built in.

If evaluation is taken seriously in top-down initiatives, then we need to make sure that older people's criteria are taken into account.

It is also important that older people themselves are involved in evaluation. Increasingly, older people are taking on roles as researchers, with a say in the analysis as well as the conduct of research.

Conclusion

This paper has highlighted some of the areas that might be developed to improve opportunities for older people to have a voice. But involvement requires effort and stamina. Retired people say that they also want space to enjoy family life and leisure. Fatigue and disillusion can set in if involvement becomes burdensome and leads to few tangible results. Bodies trying to encourage and facilitate involvement of older people have a responsibility to be clear about the purposes and about what people can expect as a result. Too often the purposes are 'fudged' and the outcomes are not identified and fed back to those who take part.

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- * See also 75 references on user involvement listed in Thornton and Tozer (1994).

