Older people 'getting things done'

Involvement in policy and planning initiatives

Jan Reed, Glenda Cook, Vera Bolter and Barbara Douglas

This study reports on how and why older people became involved in policy and planning initiatives.

The involvement of older people in planning and evaluating services is high on the policy agenda for many organisations. Using five different case studies this report maps out the ways in which older people got involved, offering ideas for other organisations and for older people themselves.

The report explores the key issues that need to be considered, as well as drawing out good practice from the schemes studied. The schemes include: a group which set up care services for older people; a Citizen's jury which developed policy for older people; a project to meet the diverse needs of older people in one locality; a scheme to provide accessible repair and maintenance services; and an initiative to design a house for older people.

A key finding of this report is that older people took part because they wanted to make a difference – not just as a way to pass the time. It will be useful to older people involved in or starting up groups around issues which affect older people, and to those who work with them.

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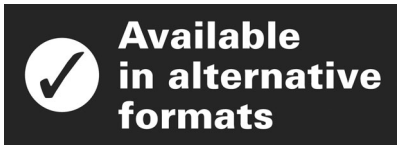

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The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of the Foundation.

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First published 2006 by the Joseph Rowntree Foundation

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ISBN–13: 978 1 85935 456 8
ISBN–10: 1 85935 456 4

A pdf version is available from the JRF website (www.jrf.org.uk).

A CIP catalogue record for this report is available from the British Library.

Cover design by Adkins Design
Prepared and printed by:
York Publishing Services Ltd, 64 Hallfield Road, Layerthorpe, York YO31 7ZQ
Tel: 01904 430033; Fax: 01904 430868; Website: www.yps-publishing.co.uk

Further copies of this report, or any other JRF publication, can be obtained either from the JRF website (www.jrf.org.uk/bookshop/) or from our distributor, York Publishing Services Ltd, at the above address.

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Foreword

This report presents the findings of a study commissioned to explore older people's involvement in policy and planning, with a focus on their activities in a range of different groups. Set up by and for older people, these groups have a range of goals and ways of working. What they do share, however, is a concern with making a difference, and getting things done – which is where the title of the report has come from. In discussions with older people who worked with this project, this concern came through strongly and consistently – involvement was about getting things done. This changes the emphasis from the process of involvement to the outcome. Older people stressed that, for them, an enjoyable process was desirable but not essential, while the mark of a good project, for them, was whether it had made an impact. This takes us away from thinking of group activities as a form of 'diversional therapy', where people are content to take part without a thought to results. Instead, it makes us think more carefully about outcomes and how these can be achieved.

This raises a number of points. First, we can start to realise the 'public spiritedness' behind much involvement. Getting things done is not necessarily just for the people involved but can be for other people as well – other older people and younger people. The benefits of an activity are not always confined to members but can extend to others in a similar situation or in different situations.

Second, we can start to think about the roles and responsibilities of those outside the group of older people – the policy makers, service providers, press and the public. While this report highlights the activity of older people, it is clear that this needs to be matched by the activity of others if changes are to be made. Older people can campaign but, unless others listen, the potential for change is lost.

With the importance of impact to the fore, then, we hope that this report will be useful to older people involved in or starting up groups around issues that affect older people, and those who work with them. We hope that it will be useful in the way that it shapes thinking and action, by pointing to key issues and questions that need to be considered. This does not mean that we would confine the relevance of this report to changing debates – we would also like to see it making a difference to the way things get done. Like the participants in the study, we also value the outcomes of any work and the way in which they can make a difference. If any older person or agency worker reads this report and changes the way they behave, then this would be a good outcome for us.

1 The study

Background to the study

There are now more opportunities than ever before for older people to be involved in decisions that affect their lives and in the development of the services that they use. The involvement of older people has been specifically encouraged by the UK Government and supported through a range of initiatives that aim to promote positive ageing by tapping into their talents and expertise to enable them to contribute. In his Foreword to the report *Winning the Generation Game* (Policy Innovation Unit, 2000), the Prime Minister, Tony Blair, highlighted the importance that the Government attached to this issue:

> One of the most important tasks for twenty-first century Britain is to unlock the talents and potential of all its citizens. Everybody has a valuable contribution to make, throughout their lives. Unless we encourage older people to remain actively engaged in socially valued activity, whether paid or unpaid, everybody in Britain will miss out on the benefits of their experience and social commitment.
> (p. 1)

Five years on from this address the present report investigates older people's experiences of participating in policy and planning activities – what they valued, how they were supported and the difficulties that they encountered. The following discussion maps out issues concerning the involvement of older people in civic activities in contemporary British society, to provide a context for the study as a way of introducing the reader to the project.

The move to engage citizens in local democracy

Involving the public and service users in decision-making processes in local governance and in the services that they use has been high on the political agenda of Western Europe and North America for well over the past 20 years. While many factors underpin the emphasis that has been given to this agenda, Abelson *et al.* (2004) argue that increased interest in citizen participation in complex decision-making processes has emerged at a time when there has been a decline in public confidence and trust in representative democracy and in traditional political institutions, and a growing need for two-way interaction between the public and decision makers.

Within this context, a key driver towards public participation in Great Britain came from being a member of the European Union, which placed a requirement on government bodies in 1992 to consult more widely with members of the public. Various approaches have been taken to fulfil this requirement, with these reflecting different underlying motivations for involving the public and service users in policy and planning activities. As a way of summarising these approaches, it is useful to turn to Carter and Beresford (2000), who helpfully made the distinction between democratic and consumerist approaches to involvement. Democratic approaches emphasise the legitimate right of citizens to have a say in decisions that affect them and, more recently, the citizens' moral duty to take part in the construction and maintenance of their community. In contrast, consumerist-type initiatives bring to the fore notions of consumerism where the public is viewed as a consumer of goods and services, and issues of consumer choice and information are stressed. Involvement, from both of these perspectives, is generally considered to be a good thing – for the participant and for society.

A wealth of recent reports indicate that numerous attempts have been made to successfully involve the public in decision-making processes (e.g. Department of Health, 2004; Social Care Institute for Excellence, 2004). For some groups, however, it is widely acknowledged that barriers that limit their participation persist. Among these groups, older people have been identified as a group that continues to encounter specific difficulties. The Social Care Institute for Excellence (SCIE) report (2004), *Has Service User Participation Made a Difference to Social Care Services?*, states that older people face exclusion 'simply because they are old and [it is] assumed that they cannot perform certain tasks and activities' (SCIE, 2004, p. 5).

Social exclusion has been a widely recognised aspect of life for many older people. Many factors contribute to this, such as living in poverty (the poorest older people are among the poorest members of British society), the way that older people have been forced out of the workforce, and the way that the issues and concerns of the most frail and vulnerable older people are manipulated as if they were commodities in a welfare state, to name but a few. Examination of these issues by social policy analysts has led to the conclusion that social and economic mechanisms are the main causes of exclusion of older people in society, rather than this being a biologically determined fact of life. If this argument is taken one stage further, as Simon Biggs (2001) has done, it could be postulated that it is the social conditions of older people that entrap them. Biggs developed this argument and suggested that, by changing the conditions of later life and viewing older people as part of the citizenry, and by providing supportive approaches that enable them to participate in decision-making processes, they may have the capacity to get involved much more effectively than previously thought possible.

Involvement of older people in policy and planning

One consequence of the unique issues, particularly the negative circumstances, which older people encounter, has been the development of pressure groups, networks and social groups that are organised by older people to work on behalf of older people. These groups tend to fall into one of two categories. First, initiatives that give a voice to older people about the issues that affect their lives by actively campaigning and challenging policy makers and service providers. Second, initiatives that provide services for older people in response to unmet need (such as befriending and handyperson services). These initiatives tend to operate outside of societal institutions and are controlled by older people. Some initiatives are organised independently by older people, whereas others are supported by organisations that work on behalf of older people (e.g. the 430 older persons' forums supported by Help the Aged through the Speaking out for our Age programme; Age Concern forums such as North East Forum on Ageing).

Self-organised older people's groups continue to develop but, at the turn of the century, older people have a voice at the highest level of government. In the late 1990s, an Inter Ministerial Group for Older People was established, which reports directly to the Prime Minister's Cabinet Office. There are also wide-ranging initiatives within ministerial departments, local government agencies and professional communities, which aim to support participatory processes. In health, for example, older people have been encouraged to participate in planning the development and implementation of services through the patient and the public involvement processes that exist in the NHS (Department of Health, 2001a, 2004), and specifically to raise issues of relevance to older people through the structures set up to implement and monitor the National Service Framework for Older People (Department of Health, 2001b).

The Government has also supported specific initiatives directed at the involvement of older people in public decision-making processes. For example, the Better Government for Older People programme (BGOP) was established in 1998, running for three years. This programme aimed to establish partnerships between central government, local government and voluntary sector agencies to support older people to take a central role in interagency issues that affected them. The evaluation study carried out by Warwick University (Hayden and Boaz, 2000a) indicated that integrated strategies for engagement with older people were developed in the 28 pilot projects in the programme, which were led by local authorities. It was argued that these initiatives provided a unique opportunity for older people to be heard by politicians, policy makers and service providers. At the end of the programme, there was some evidence that the initiatives that were set up under the auspices of BGOP

evolved into other structures that supported the involvement of older people in decision-making processes (see Figure 1 later in this chapter for a summary of the evolution of the BGOP initiative in Newcastle upon Tyne to the current Quality of Life partnership between older people and agency staff).

The Older Person Advisory Group (OPAG) emerged during the BGOP programme. This group set out to champion older people's issues, by older people, for older people. The slogan 'Nothing about us without us' developed as the group gained its identity and became the catchphrase for its work and its vision for the governance of their communities. This group also had access to the Inter Ministerial Group for Older People and, at the end of the BGOP programme, OPAG members highlighted their concern that the work that had begun with BGOP would be undone. They campaigned to sustain OPAG and there is now a network of regional committees that link to a national committee, which has a direct link to the Office of the Deputy Prime Minister.

As the Vice-Chair of North East OPAG and the North-East Forum on Ageing, Elsie Richardson works tirelessly to campaign on older peoples issues and to participate in research that seeks to further understanding of the needs and concerns of older people

The initiatives discussed above have led to older people being engaged in different levels and types of decision-making processes. It is not only the decision-making structures that have changed but also the approach to involving people in decision making. The SCIE report (Social Care Institute for Excellence, 2004) indicates that

the way that older people have been involved in decisions has gradually moved from providing them with information or consulting them about agency-led decisions, to the practice of developing active partnerships with the purpose of influencing decisions.

There is little doubt that these combined efforts have led to the engagement of older people in service planning and delivery processes, but success cannot be measured simply by the extent of engagement. What is also important to defining success is that older people have experienced positive changes in their lives – in the quality and appropriateness of the services they receive and in developing the confidence, skills and capacity to assume greater control in making their own life choices.

Older people, influence and power

The impact that an older person or the older community can make within their sphere of influence is dependent on the type of participation processes that exist within the decision-making arena. This varies. In some circumstances those involved may merely be informed of the decisions being made and in other situations they may control decision-making processes. Sherry Arnstein (1969) suggested that the different types of involvement could be described as a 'ladder of participation', with the lower rungs of the ladder representing tokenistic forms of involvement, moving through to partnership activities that are representative of citizen power.

To the outsider, or even to those participating in an initiative who are working towards encouraging involvement, the differences of type and level of influence over decision-making processes may not always be apparent. In addition, those taking part in an initiative may have different views about the type and level of influence that the various participants have in decision-making processes – views that are not necessarily shared among those taking part. The involvement of older people in policy and planning activities, therefore, is a complex process. While much is known about the different ways in which older people have been involved in decision-making processes, little is known about their experiences – what they find satisfying.

In this situation, where involvement of older people is encouraged, but not always understood, the Joseph Rowntree Foundation commissioned this research study to explore the processes and outcomes of older people's involvement in different community activities and, as a secondary aim, to explore their experiences of working as co-researchers on the study.

Older people getting involved as researchers

Members of the research team working together to plan and undertake the study

Creating innovative ways to involve older people in research has captured the attention of older people and policy makers, and has challenged research sponsors and researchers to do this in ways that impact on the quality of the research. Until relatively recently, older people participated in research merely as sources of data. Now, there are efforts to involve them in all aspects of the research process. As members of the public, for example, older people have taken an active role in commissioning research through the NHS Research and Development (R&D) Health Technologies Programme. The Joseph Rowntree Foundation has moved the involvement of older people a stage further by establishing an Older People's Research Advisory Group, which has responsibility for setting the research agenda in the programme, establishing priorities, funding and managing research.

Researchers have responded to this challenge by developing initiatives such as Older People Researching Social Issues co-operative (OSPRI), Lancaster University, and The Centre for the Older Person's Agenda, Edinburgh University. In these initiatives, research programmes have been established that enable older people to train in research methods and undertake research. An alternative approach to this agenda was taken by Help the Aged in the Speaking up for our Age programme. In this programme members of the forums were encouraged to learn research by 'doing it', with their efforts being supported by a research manager.

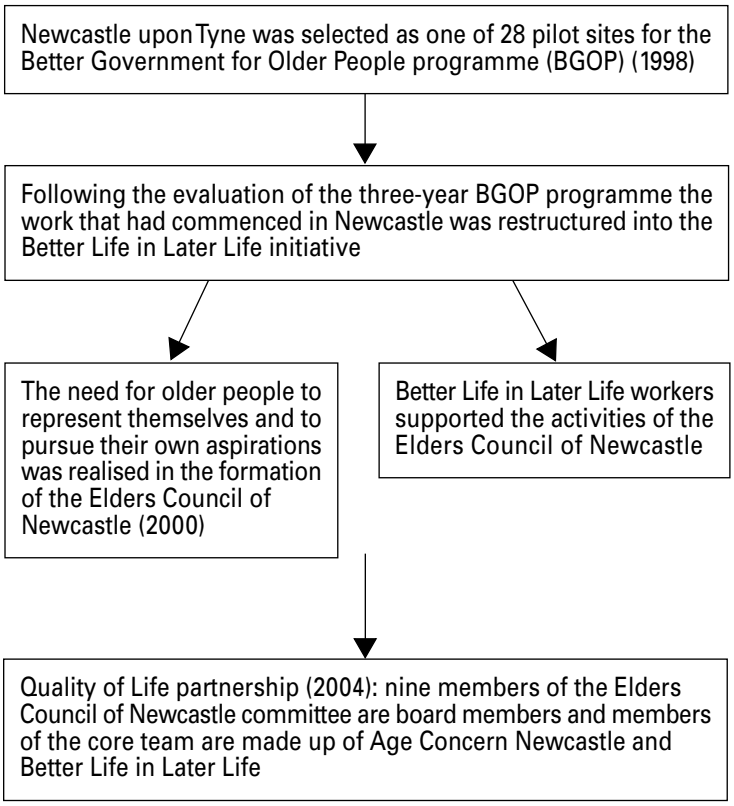
Older people with a range of previous experiences, skills and talents made a full and extensive contribution to the project

The study reported here sought to build on the experience of others and take a different approach to involving older people in every aspect of the research process, from design to reporting of the findings. It was unique in the way that older people participated in it – they were co-researchers working in collaboration with academic researchers from the Centre for Care of Older People, Northumbria University. They were able to use existing knowledge and skills, and they determined the type and level of their involvement in the research process. For some, their key interest was to develop their expertise in research, whereas, for others, their involvement enabled them to learn more about the ways older people participate in civic activities in modern society – an activity that was part of their everyday lives.

The study setting

The study was set in the North East of England and was led by a team of researchers based in Newcastle upon Tyne who had been part of a number of networks and initiatives with older people. Figure 1 describes the process of network development in Newcastle upon Tyne and provides a context for the decision to base the study in Newcastle.

Figure 1 The evolution of older people's participatory structures in Newcastle upon Tyne



Against this background the study was led by members of the Newcastle network, namely the worker leading the Better Life in Later Life initiative (Barbara Douglas), a member of OPAG (Vera Bolter) and two members from the Centre for Care of Older People (CCOP) at Northumbria University (Jan Reed and Glenda Cook). CCOP has a track record in research with older people and in participating in community development activities.

Research design

There were two parallel strands of investigation in this study, which fed back into each other.

1 The first examined the involvement of older people in planning and policy activities through two workshops and the investigation of five case study sites. The sites that were nominated by older people as examples of effective and satisfying involvement of older people were located in the North East of England (see Table 1 later in this chapter for a description of the case study sites).

2 The second strand of the study concerned the involvement of older people as co-researchers in the project and discovering their experiences of this. Older people offered to join the project team at the initial workshops and worked on the case study sites of their choice, as well as participating in the processes of report writing and data analysis. Their roles as researchers and as research subjects were complex and multi-layered – they had different roles at different points in the study.

Figure 2 lays out the research process in diagrammatic form showing the two strands and their main activities.

Initially, then, the study was commissioned by a group set up by the Joseph Rowntree Foundation, which included older people. They decided the focus of the call for proposals, and then evaluated and chose the successful bids. In keeping with this ethos of user involvement, this study involved older people throughout the study – a wide group of older people convened through the existing networks of the project leaders. This could be in an executive or decision-making capacity, such as nominating case study sites, generating a framework for analysis, and commenting on reports and papers. This executive role was developed through workshops and mailing lists involving a wide group of older people, to canvas views and opinions. Summaries of these were also disseminated across the group to check interpretations and conclusions.

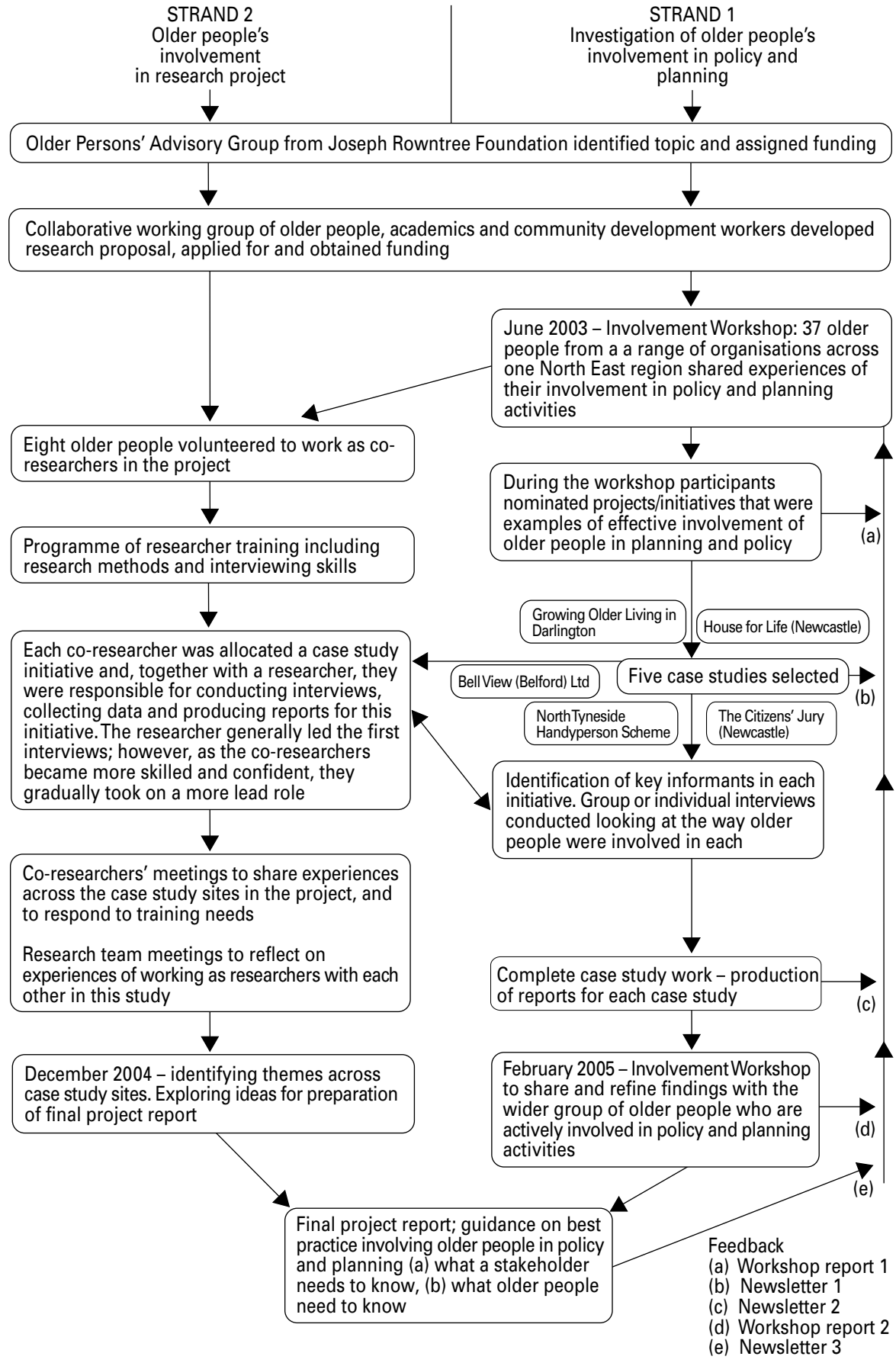
The other type of involvement was ‘hands on’ where older people were involved in the collection of data – the co-researcher group. This group were members of the wider group of older people convened for the study and therefore had executive roles as well. The particular complexities of their role are discussed in more detail in Appendix 1.

There were several points, then, in the research design where older people were involved. These are described below.

Sampling and case study selection

An initial workshop was convened to aid the process of case study selection. This was an integral part of the research design, in that we had argued that in-depth and detailed examination of cases of involvement would be a useful way of exploring the processes of user involvement. In order for this to happen, however, we needed to make sure that the cases chosen reflected the range of activities and that the cases would be approachable, so that we could discuss data collection with members. The

Figure 2 The research process



participants at the initial workshop were those who were known to be active and interested in older people's activities, and it may be arguable that they were not reflective of older people who were not active or interested. The project leaders took the view, however, that this stage was akin to a process of consultation with experts, and so talking to people with ideas and experience would be more useful than talking to people without.

The workshop therefore started off by introducing the project and explaining what we needed of the group. We discussed the aims of the study and the idea of 'case study', and what constituted a case. We agreed that the study would define cases as activities or projects with a collective identity, i.e. named groups of people working together. We were aware that this definition would exclude casual, ad hoc or individual activity, but this would present huge problems in identifying and exploring such cases, and would not produce meaningful findings, as such projects were so fluid that all that could be achieved were explorations entirely dependent on timing and circumstances. More established groups would have clearer points of access and a shared definition of roles and aims, types of cases we would like to examine, namely those led by older people and their needs, across a range of different areas, from policy development to practical help, and with a range of links to other agencies. Workshop participants nominated groups and provided contact details where possible. The project leaders then approached the groups and invited participation. After negotiation, we ended up with five case study sites, which are detailed in Table 1.

Table 1 Case study initiatives selected

Initiative	Description
Bell View (Belford) Ltd	This project was established to help prevent the distress caused when older people are forced to leave Belford and the surrounding area because of social isolation, inadequate support networks or difficulty in accessing services.
The DIY Citizens' Jury (Newcastle)	A Citizens' Jury is a method that engages members of the public in formal deliberation of issues that affect their lives. In the Newcastle Jury the focus was on health technologies in the treatment and prevention of falls – a topic that was selected by older people and co-ordinated by older people.
Growing Older Living in Darlington (GOLD)	This initiative is a partnership between people over the age of 50 within the borough, statutory organisations and voluntary organisations to find out and address the main issues affecting older people.
The North Tyneside Handyperson Scheme	This is a service that provides assistance for older people in need of small repairs or adaptations to their home. Several of the volunteers who provide the service are older people themselves.
Housing for Life, Newcastle	This project enables older people to be involved in housing issues. It combines opportunities for learning about the latest developments in housing design and SMART technology with time for older people to contribute their expertise and experiences to housing design, policy and strategy.

Data collection

For each of the case study sites, a team of researchers was defined, each including a member of the project leader's group and one or more older people researchers. As outlined in the project proposal, data collection was based on interviews and focus groups – with key individuals nominated by the initial contact person for the project. This data collection was, however, responsive to the particular circumstances of each case, and included attendance at meetings, reading of documents and minutes, and conversations with people from other agencies where necessary. The details of the data collection in each site are given in Chapter 2 and the general points about the role of the co-researcher are discussed in Appendix 1. The interview questions focused on the following:

- the impetus for setting up the initiative
- the nature of their involvement with the initiative
- their motivation for participating in the initiative
- the extent to which older people have control over the way that the initiative functions
- the degree of support and facilitation offered and needed
- the impact of being involved with the initiative, either on an individual level or at a group level
- what they valued about their involvement in the initiative
- whether involvement in specific activities had led to further activity and participation in other activities
- recommendations that would enable older people to participate effectively in policy and service planning activities.

The development of the interview schedules was informed by ideas that had formed the basis of previous work using appreciative inquiry (Reed *et al.*, 2002). In this approach, interviews are based on the premise that a useful way of finding out about people's experiences is to ask them about what they have valued and achieved, rather than focusing on problems and difficulties. This approach was taken in order to facilitate interviews that would allow respondents to articulate and reflect on what they had done, in a receptive atmosphere.

Table 2 shows the number of interviews carried out in each case study site.

Table 2 Number of interviews and participants in each case study initiative

Case study	No. of interviews (individual = I; group = G)	No. of participants
Bell View project	15 (5 – G; 10 – I)	30
DIY Citizens' Jury	16 (2 – G; 14 – I)	19
GOLD	21 (2 – G; 19 – I)	30
North Tyneside Handyperson Scheme	20 (20 – I)	20
House for Life	19 (1 – G; 18 – I)	25

Data analysis

The process of data analysis was an iterative one, with ideas for key themes drawn from the executive and co-researcher group, and the data readings of the project team. Summaries and reports of these ideas were then circulated for comment and amended accordingly. This process has led to two main outcomes. The first is a discussion of key themes from the data, which describes the ideas identified in the data by the wider research group about the processes and factors that have shaped involvement in the cases explored. This is a traditional discussion of research findings but, because the participants were concerned that the outcome of the study should be practical, we first developed a list of questions that people could ask themselves when invited to take part in an activity, or considering whether they should join. As the group had many cautionary tales about older people who had become involved in the group but had later regretted this, it was felt that a list of questions to ask would help avoid such a situation – if people did become involved, then they would at least know more about what they were getting involved with.

To mirror this list, we have also developed some questions that groups and agencies could ask themselves if they were inviting involvement from older people – again so that, if they did so, they would be aware of the thought and planning required. Across the wider group there was an expressed dislike of 'tokenism', where older people were invited to be present at activities but were not enabled to make an impact. Sometimes this was attributed to cynical strategies to create the appearance of inclusivity and sometimes to a lack of awareness of what was entailed, but it was felt that the lists of questions would provide a framework for thinking and planning that would make tokenism less likely.

2 Case study reports

This chapter presents the case study reports from the research carried out the by team. Each report includes a description of the case, a list of the sources of data that were used and some of the conclusions drawn from each individual case. Overall conclusions and questions are presented in Chapter 3.

Bell View (Belford) Ltd

Bell View (Belford) Ltd is a complex initiative that emerged from a protest within the Belford community against the decision of Northumberland County Council to close Bell View Home in November 1997. This was an important facility within the village, which served an older population who had poor access to many health and care services. There was concern that, without this facility, the needs of the older population would be unmet and those who required long-term care and day care would face relocation to care facilities some 15 to 30 miles away from their home village. A success of the campaign was maintenance of day care and the meals-on-wheels service. However, the campaigners sadly lost their battle for Bell View Home residential services, which ceased operating in April 1998. As a group, the campaigners continued to pursue alternative ways to provide support for the older residents of Belford. The purpose of this section of the report is to describe the development of the Bell View Resource Centre and the activities of Bell View (Belford) Ltd.

Belford and its services

Belford is a village, which lies at the centre of north Northumberland, midway between Berwick-upon-Tweed and Alnwick. The range of businesses, services, schools, churches, clubs, societies and other activities in the village serve as indicators that this is a potentially thriving community. There are slightly less than 1,000 residents within the village and approximately 500 dwellings in the Belford parish. The 2001 Census indicated that a third of the population was over pensionable age. Consequently, services for older people have a major impact on the lives of those living in the village.

Belford has experienced significant changes in its governance and services during the previous three decades. Following the 1973/74 reorganisation of local

government Belford Rural District Council was abolished and was replaced by Berwick-upon-Tweed Borough Council. While Belford remains within Northumberland County, which retains a strategic policy-making role and responsibility for education, social services and other services, the Belford Parish Council retains its role in dealing with small local issues (Belford and District Local History Society, 1995). The importance of the link between these governing bodies is in the way that it provides a mechanism for Belfordians to voice their views on issues that affect how they live their lives and to influence decision-making processes.

With respect to service provision, Belford has witnessed a slow and continual retraction of these vital aspects of its community. Notable among the reduction of services in the village has been the closure of the Belford railway station in the 1970s, cessation of the cattle market in the 1980s and the closure of the bank in 2000. The village has also faced threatened cessation of other services, such as closure of the middle school, which has been ongoing since the 1980s. These changes have had a marked impact on everyday life and they concern everyone who lives in the village. One response to these types of changes has been insurgence of community effort to campaign against decisions by external agencies, such as the local authorities, which residents perceive will have a negative effect on the village. Previous success in overturning decisions, like the threat to close the school, has fostered cohesion in the village and encouraged residents to stand together and take action against externally imposed decisions. When faced with the announcement that there was a proposal by the County Council to close Bell View Home – a facility that provided residential, respite and day care for older people – the villagers were once again mobilised and were committed to protest against this decision.

Bell View Home

The Bell View Home was located in the centre of the village and had been a feature of the community since its origin as a workhouse in Victorian times (1830s). It had been converted and upgraded to provide residential and respite care to 19 people in single and shared rooms. Day care was provided within the home for a maximum of 12 people at one time, five days per week. The building also provided personal services (i.e. hairdressing) to service users and outreach services to older people in the locality, including meals on wheels. Although a small number of people lived in the home, it was a valued community resource that supported older residents to live independently, enhancing their choice of living arrangements in later life.

When the County Council announced its plans to close the home, the loyalty of villagers to Bell View was demonstrated in their commitment to mount a campaign against the decision. This began with an all-night vigil meeting on a cold November night in the centre of the village. The local support group that developed from the protest, the Friends of Bell View, began to raise funds for Bell View and to formulate a strategy to take their campaign forward. As they were doing this the notice of closure was posted in November 1997. This was followed by a public advertisement by the Social Services Department that it was open to receive expressions of interest for the transfer/reprovision of services on the Bell View site. A private donation enabled the Friends of Bell View to commission architects Jane Darbyshire and Mary Kelly to undertake a feasibility study to design and remodel Bell View to meet national minimum requirements for care homes.

The architects' report highlighted that the service was needed in the village. However, reconstruction of the home would be extensive and would not necessarily meet the needs of service users:

> ... it is thus proving an expensive building to run which at the same time offers more restrictions than advantages to the staff and service users in the building … Additionally the overall planning and arrangement of the accommodation is unsuited to its current use and to the demands by both service users and the staff.
> (Kelly, 1998)

This report and the lack of support from statutory agencies brought into question the viability of redesigning the home, heralding a crossroads for the local campaigners. Should they pursue their commitment to fight against the closure of Bell View Home or should they develop a new objective?

Moving forward with a new vision

After two public meetings where the development of the architects' report was discussed, the Friends of Bell View decided to change their objectives and work more flexibly for the retention of services in the village. This was a complex decision, as it required individuals who had come together to fight the decision to close the residential facility in the village to turn about and accept the loss of the old Bell View Home in order to build a new resource centre and housing for older people.

The first step in this endeavour was to seek charitable status and, following that, to work with the housing officer to establish the housing need for older people in the area. These stages were followed with activity focusing on the formation of an alliance with an appropriate housing association and working to gain Northumberland Care Trust funding to secure the services of a local architect, Duncan Roberts, to develop the new Bell View model. It was important to the Bell View team that the architect was employed by Bell View rather than the housing association, as this situation enabled them to influence key decisions in the design of the model for community resources for older people and the building programme.

While these activities were ongoing, Trust funding was secured to fund Romi Jones' contribution to the project. She worked alongside the Bell View trustees to clarify aims and objectives, undertake demographic research that was required to apply for large-scale funding and facilitated their capacity building. A key outcome at this stage was to apply for funding for a full-time project worker.

The project continued to develop and a housing association partner was identified and an alliance formed. The mission of the project became:

> To ensure the community of Belford retains a facility which provides high quality residential care, respite care and day care for elderly people in the immediate area.

Box 1 Bell View milestones

- Moving from a protest to a creative project.
- Appointment of a project manager.
- Getting the first large grant and moving to financial viability for the project.
- Securing continuation of day care through the building programme.
- Working through and achieving solutions to legal and financial problems (e.g. negotiating the lease, VAT).
- Laying down the foundation for the new building.
- Opening of the Bell View Resource Centre.

The aims of this were to work towards:

1 maintenance and consolidation of the day care service

2 rebuilding of housing to extra care standards, providing shared and individual accommodation and facilities with 24-hour care support using trained personnel

3 providing accommodation for the administration and provision of respite care and community-based health and care services (Friends of Bell View, 1998).

Tremendous effort was devoted to fund raising to realise these aims. In the first year over £1,000 was raised and this achievement increased the momentum to raise further funding. The trustees, in turn, accepted the responsibility to lead the fund-raising endeavour, which included developing innovative schemes that captured the imagination of potential contributors. Some initiatives utilised the talents of the villagers (e.g. making and selling marmalade), some involved community events (e.g. coffee mornings, Victorian market) and others enhanced the villagers' sense of ownership in the Bell View project (e.g. the Stone Donor scheme where people paid £5 to sponsor a stone for the new building and £25 to sponsor a cornerstone). These activities ensured that Bell View was owned by the community that it served. The small community of Belford and the neighbouring districts, through local and individual donations, had raised over £30,000 by 2003, and in excess of £80,000 at the time of writing this report. It is anticipated that the community will continue to support the Centre after its opening.

As the project developed, the scale of work increased, and the trustees' application for funding enabled them to appoint a full-time project manager in 2001 to manage and co-ordinate building and development activities, identify service needs, secure partnerships with relevant agencies, promote Bell View services and activities, and secure further funding from external agencies. The fund-raising activities described above continued, and successful bids for capital and revenue grants have resulted in the generation of £1.4 million by 2004 – sufficient money to commence the building of a new Resource Centre and housing within Belford.

Negotiation, negotiation and more negotiation

The Bell View initiative involved negotiation with multiple stakeholders – service users, the village community, statutory agencies, architects and builders. Each stakeholder group had a view on what was feasible and what was achievable at Bell View within budgetary and legislative requirements. At times these views were

incompatible and the project team faced the difficult task of keeping everyone committed to the project and reaching a compromise that was acceptable across the board. It is beyond the scope of this discussion to report on every decision that the project team encountered. The following are included to highlight the difficulties that the team faced and the complex situations that they encountered.

Shifting the aims of the Bell View initiative from a protest about the closure of the Home to a major rebuilding programme involved negotiation with the village community to maintain their commitment to the project. Through extensive consultation the Bell View project team were able to ascertain the needs within the community and identify innovative approaches to meet those needs. Frequent newsletters and information-giving events were important elements of communication processes to keep everyone informed as well as committed to the project.

In parallel with the fund-raising efforts, complex negotiations were taking place with the County Council to secure the land that Bell View Home occupied for the rebuilding of extra care and Resource Centre facilities. The Bell View project team faced a steep learning curve as they negotiated the terms of the lease. The outcome was viewed as a success by everyone involved. For the County Council, obligations to the elders of Belford and surrounding districts were fulfilled as the contract specifications for service provision were agreed. The County Council agreed to a 999-year ‘peppercorn’ lease for the site.

As these decisions were made and the plans appeared to be set for the building programme to commence, the Bell View project team encountered another equally complex legal hurdle in relation to the VAT status of the capital project because of its multi-service focus. Having first been advised that the building would be zero-rated, the funding package was in place when HM Customs and Excise effectively revised its earlier decision. This sparked a lengthy series of negotiations and a claim for misdirection, which took over 13 months to resolve. This included enlisting support from the local MP and writing to the Minister for Rural Affairs, the Treasury Minister and the Government Rural Advocate to try to speed up the resolution because the time-limited funding package for the whole project was at risk. The team had to find additional funding for professional VAT advice and pro bono legal advice, which was an additional stress at such a crucial point in project development. Eventually, a negotiated settlement was agreed with HM Customs and Excise on an apportionment basis but this has resulted in restricted use of certain areas of the building on completion.

As the work on the building was about to commence, the services that were operating from Bell View Home had to be relocated otherwise vulnerable older people would be left with no day care or meals-on-wheels service in the village. While it was a difficult task for the Bell View project team to find suitable temporary accommodation, it was even more difficult to reassure service users that the temporary disruption would result in an improved service in the long term. Day care users, relatives and carers were anxious about the changes, particularly the demolition of a familiar building. To reduce their anxiety and to enhance their involvement in decisions about the services available in the new Resource Centre, the day care service users were included in decisions about the decor of the new facility, choice of furniture, choice of equipment and so on. Facilitating the involvement of service users and service providers in the minutia of decision making was given as much attention as the major negotiations that were required in the project.

At every stage, the team faced different types and levels of negotiation. These were different, but equally important, to the success of the project. The trustees faced many fraught moments when they felt that the project was doomed, yet their determination to succeed carried them through. During these times, brainstorming alternative ways to approach the situation highlighted a way forward. Sometimes this involved holding a community meeting and other times face-to-face discussion with councillors and other officials. The team’s resolve to succeed carried them through to the stage where they were able to negotiate with architects, builders and planners. The moment that the diggers moved onto the site, in 2003, was rewarding for those who had worked so hard and had showed such determination in the face of adversity.

The Bell View Resource Centre

The building work was completed in the summer of 2004 with the Resource Centre opening in November of the same year. As the building has multi-purpose facilities, what takes place in it will reflect the needs and interests of those who use it. The current building includes purpose-built facilities for day care (also bathing resources), a meals-on-wheels service, a coffee bar, a specially equipped kitchen, which can be used to assist people to maintain or regain kitchen skills following accident, illness or sensory loss, a sensory garden, activity rooms, meeting rooms, and office space for community organisations providing services to older people and their carers.

At the beginning of 2005, there were many partners who were working with the Bell View project team to provide and develop services.

1 *Partners who share the building and work with the Bell View team:*
- Hilary McGlynn, Bell View Day Care
- Age Concern Northumberland (has an office base at Bell View)
- Northumberland Rural Transport Partnership
- North Northumberland Carer Link Project.

2 *Working partnerships to provide and develop services:*
- Age Concern Northumberland (exercise classes, health development, information services and shared volunteer training)
- Alzheimer's Society (Dementia Outreach)
- Northumberland NHS Care Trust
- Voices of Experience Over 50s Forum
- Wendy Thompson (Extend Exercise Tutor)
- Belford Medical Practice
- Belford Community Pharmacist
- Belford Family Centre (intergenerational projects)
- Berwick Walking the Way to Health Initiative.

While a range of activities and services are now being provided from the Resource Centre, it is envisaged that they will change and develop in response to local need. Table 3 provides an overview of existing activities and services, and plans for future development.

Table 3 Activities and services provided in the Bell View Resource Centre (as at end of March 2005)

Activities/services	Description
Bell View direct service delivery and development	
Cafe project	A coffee bar and information service run by volunteers. Basic food hygiene training.
Carer Support Group	Relaunched on 1 March 2005. Extra books obtained from Care Trust for Carer Library. Carer Link project links established.
Community Car – pilot 'Dial and Go' service using NCT Citroen Berlingo	Funding bid submitted to North Northumberland Rural Transport Partnership (NNRTP) for start-up grant for pilot community transport project.
Walking for Health	Two walks each Monday.
Oral history project	New volunteers recruited to assist with next phase of development of workhouse history project.

(Continued)

Table 3 Activities and services provided in the Bell View Resource Centre (as at end of March 2005) (Continued)

Activities/services	Description
Partnership services	
Partnership Working Group	From initial inter-agency meetings to discuss community dementia services a Partnership Working Group has been established, which includes Bell View, Age Concern, Alzheimer's Society, Carer Link Project, St John Ambulance, NNRTP.
Bell View Day Care	Up to 18 people each day with different people attending (includes two new 'Rehab Day Care' places). Meals-on-wheels service.
Medication reviews/over 50s one-stop shop health days – one Health Fair held in November 2004 over 100 attendees	Interested partners to date: Age Concern, Berwick Handi-person service, Belford Medical Practice, Community Pharmacist, Health Development Team, Carer Link project, Northumberland County Blind Association (NCBA).
Chiropody	Needs assessment under way.
Care Trust Community Rehabilitation Team	Keen to arrange series of talks and equipment demonstrations for clients at Bell View.
Age Concern Northumberland	Falls prevention exercise classes every Friday. Joint volunteer training initiatives being explored. Ageing Well activities planned.
Care Trust Cardiac Rehab	Use centre every Tuesday and Thursday for assessment and exercise in eight-week blocks – moving onto other activities.
Carer Link Project – Alnwick and Berwick	Two part-time Carer Link workers based at Bell View, sharing office with NNRTP.
Voices of Experience – Over 50s Forum	Administrative support and use of IT and photocopier.
Age 3 Network – new Northumberland network for voluntary organisations working with older people	Project manager on the monthly Partnership Steering Group to develop constitution.
Berwick Handi-person Service Steering Group	Project manager helping to review and develop this service as part of a multi-agency steering group.
Berwick Sure Start	Possible intergenerational project links. Five-a-Day fruit day in June plus falls prevention and safe steps links could be developed.
Housing support/community warden services	Housing support needs survey completed 2002/03. Ongoing needs analysis and investigation of possible options and future funding streams.
Other activities and developments at Bell View	
Belford Art Club	Meeting every Wednesday.
Pilates	Classes every Tuesday.
Special interest talks	Tuesday afternoons. Topics include: Workhouse History, Bird Club.
Exercise classes	Extension of these classes.
Arts/crafts sessions	For example, rag rug wall-hanging project.
Bell View Therapy/Rehab Kitchen	To be installed by April 2005

The five extra-care bungalows were occupied in October 2004 by people who had care and housing needs. The management of the letting for these homes was a partnership between 'Jonnie' Johnson Housing, Belford Medical Practice, Northumberland Care Trust, Berwick Borough Council Housing Department and Bell View trustees. The initial allocations provided accommodation for eight people (three couples and two individuals).

The involvement of older people in Bell View

Introduction

In this section, the views of those who took part in the Bell View initiative are presented. The discussion focuses particularly on the different ways in which people were involved in the initiative and the strategies that supported their participation in decision making. The final part of the discussion highlights the key themes that emerged during the investigation of older people's involvement in Bell View.

Trustees' views of participating in Bell View (Belford) Ltd

Villagers were cross and then angry with the local authority's announcement that Bell View Home was to close. This led to a wave of support for the Home, which drew the community together in their concern about the reduction in the services that were essential to support older people to continue to live in their own homes. In response, individuals dedicated their time and energy to the initial protest against the Home's closure and later to the Bell View initiative because it was viewed as a 'worthwhile cause'.

Box 2 Concern for older people

> We don't want our elderly to have to go away to be looked after. We want them to be cared for in the context of their own community because their friends and their family are still there.

From the beginning, Bell View was a challenging project for all of the participants. In addition to the constantly changing goalposts, there were many obstacles to overcome. However, the cause that drew them together was perceived to be so important that they became determined to succeed.

Box 3 Determination to succeed

> The day that we were having problems with the lease and then we got hammered with the VAT, we were ready to start and we looked like we were going to lose the whole project and I can just remember being so angry about it and thinking I'm not going to let this beat us now, you know and you go in and you sit and have a coffee and you think there is no way we can give up on this now, no matter what it takes.

Indeed, their determination to find creative solutions to the problems that they encountered and persistence to work through endless negotiations with statutory authorities and funding bodies became the defining attributes of the project. While these qualities provided the energy within the project, it was fortuitous conditions, opportunities for different types and different levels of involvement, and innovative decision-making strategies that led to multiple achievements at different project milestones. Small successes led the trustees to grow in their confidence that they could fulfil the vision of securing the services that older people need to support them in their community. These were viewed as milestones within the project, which ultimately shaped Bell View into its current standing.

Box 4 Confidence grew through small successes

> That's what happened and they won and, since then, I think they've realised that if they can do that ... we had letters going to the Treasury, to the Minister of Rural Affairs and I think, once they realised how big that had gone and they had actually won that little battle, they realised that if they could do that they could do anything and I think from that point on they became more confident that Bell View was doable.

Fortuitous conditions

The decision to close Bell View Home was given to a small rural community that had faced many situations where they had been forced to fight to retain essential resources. Consequently, they had developed effective campaigning strategies, which they were able to draw on in this situation. There were also a number of individuals who were well informed regarding statutory and non-statutory agencies, and they were able to use their expertise for the benefit of the project. The combination of these groups of people led to the creation of a formidable team that took the project forward.

The team was committed to a central purpose but it was open to ideas about ways to fulfil that purpose. For example, they underwent training, listened to advice from consultants and, most significantly, followed their suggestions. It was generally agreed that, of all the advice they received, the suggestion that they should seek funding for and appoint a project manager had the most influence on the initiative.

Box 5 Expertise within the community

> There was a level of expertise within the small community, which enabled us to actually talk and enter a dialogue with professional carers and social services. Otherwise, professionally, we would have been lost and at a disadvantage.

It just happened that the right person, with the right skills and experience of working in statutory and voluntary sectors in health, social care and housing, was interested in the post. With the appointment of a dedicated worker, the energy within the project was harnessed and it moved onto a different level.

Undoubtedly, the people that contributed to Bell View have been the key to its success. They worked tirelessly as trustees, volunteers and fund raisers to support the project. In addition to these efforts they brought invaluable knowledge and wide-ranging networks to Bell View. This enhanced the resources within the initiative, but, more importantly, it optimised the likelihood of 'knowing about' what was available locally and nationally to 'get the job done'. Through their networks, Bell View activists identified funders who were likely to be supportive of the project, housing associations that they could work in partnership with and contractors that were willing to work within the project specifications.

Different types and levels of involvement

Those who took part in Bell View were supported to identify what they could contribute. As there were different ways for people to get involved, their talents and skills were matched with activity in the project (see Box 6). This was particularly pleasing to the older people who missed the opportunity to utilise their abilities in something that they felt made a meaningful contribution to their community.

Box 6 Everyone finds their niche

You've got to avoid tokenism at all cost, it's not enough to have two older people on a committee and say we are involving older people, but equally it's not appropriate to just open up your trustee meetings to everybody, you know, for instance, to anybody that wants to come in and chip in their twopenny's worth. So it's about having levels of involvement, layers, I suppose that's what we are trying to do so you can be involved with Bell View by just having information about the project, by sponsoring a stone, by coming along to a fund-raising event, by baking a cake, by being on a sub-committee, by helping to organise an event, by being a trustee ... so there's different levels and layers and ways in which people can be involved.

Throughout the project the workload was immense and demanding. There were a range of strategies that were adopted to sustain the high level of involvement the project enjoyed. Among these, effective communications and the inclusion of a social element to every aspect of the project were important. These issues are discussed later in the report.

Box 7 Work and social activities were equally important dimensions to Bell View

Have the social events and yeah a bit of a laugh about it, try and just enjoy it, enjoy it because I think people enjoying what they are doing are more likely to stay involved otherwise if it's all just about, you know, passionate anti-discrimination or whatever, after a while it's hard to be angry about something for ever ... I think that's one of the things we've tried to do is create a sense of enjoyment as well, so the bad times come with the good.

Innovative decision-making strategies

While everyone was involved in the project decision-making processes, the scale and type of involvement differed. Members of the trustee committee participated in the macro decisions (e.g. those that affected the planning processes and required some level of accountability), whereas fund raisers and volunteers were involved in micro decisions (e.g. those about day-to-day plans, selection of the furnishings and operationalisation of the service). Effective participation in macro and micro decision

making was derived from the opportunity to have ‘a chance to speak out’ and being well informed about the issue. With respect to the macro decisions the participants were kept informed through the project’s sub-committee structure and the weekly update (this took the form of an email, which bulleted key issues, events and incidences that had occurred during the week). These structures served a two-fold purpose – the provision of information and the opportunity to influence decisions as they were happening. At times so much happened so quickly that it was almost impossible to reach decisions through a process of consensus. In this sense shared decision making was sacrificed to ensure that decisions were timely.

The wider community was kept informed of developments in the project through newsletters and the monthly coffee mornings. Although the project team had been advised by experts to focus their efforts on securing large grants from funding bodies, the Bell View team were keen to maintain the sense of ownership of the Bell View initiative in the community. For this reason, they developed innovative ways to involve people in decisions – particularly micro-level decisions. One example of this was the way people were invited to take part in a session to decide on the size and shape of the rooms in the Resource Centre. In this situation people met in a large empty room with the architect and designed space for different purposes on the floor. The architect developed the interior of the new building from the ideas captured in this session.

In another situation, the day service users were asked to take part in the selection of furniture for the new facility. They looked through the catalogues that they were given and selected chairs that were similar to the ones they were familiar with. Later they took part in a demonstration where they selected different furniture. These outcomes highlighted the importance of creating innovative methods to enhance the extent to which people are informed and able to participate in the decisions that affect them.

Box 8 Being an active participant in decision-making processes

> I mean like the furniture choice … that was sort of was fairly typical where we had asked people from day care to choose furniture, and gave them lots and lots of catalogues, and at the end of it got one back from them with just one chair chosen, and it was exactly the same as the chairs they are sitting in now. So then arranging the demonstration and actually being able to give people the chance to look at a different range. And once they had tried the modern furniture, actually choose three completely different chairs … and having three different types for, you know … for different activities in different rooms.

Day care service users' views of participating in the Bell View initiative

The decision to close Bell View Home had a great impact on the older people who attended the day care service in the Home. This was a service that they valued, as it enabled them to continue to live independently in the community they had lived in for much of their adult life. The staff willingly attended to their needs and responded to their request for assistance. The opportunity 'to get out of the house' and socialise with others was particularly important to those who lived alone. The pending changes led to service users experiencing many conflicting feelings – anticipation that the changes would improve the services they already considered to be very good and anxiety that they would not be able to cope with the adjustments that would have to made in their lives (see Boxes 9 and 10).

Box 9 The importance of day care to those living in Belford and the surrounding areas

> The day centre – my husband came with me and he died two years ago, and it's been like being part of a family ... my son lives away and I have two granddaughters who also live away. So I am on my own up here and, as I say, Bell View is like having a family. It has helped a great deal.
> (Day service user)

Box 10 Coping with change

> But I don't know whether I will settle or not because it is going to be so different to what we have been used to.
> (Day service user)

The closure of the day care centre heralded change to the environment that they were familiar with. Many had watched the service develop and become part of their community. Now they stood by and watched the demolition of the building, which had housed the services that they so heavily relied on in their later years. While they were saddened by the loss that they had experienced with these changes, they were confident that the new centre would be as good if not better than the old one. Their confidence and hope for the future was based on the trust that they had in the day centre staff and the personnel involved with the Bell View initiative. From the first announcement signalling that the old day centre was to close they were informed of all the developments and, where possible, they were involved in decisions about

their future. This led them to feel reassured that decisions were being made in their best interests. They felt involved in and 'part of' the changes that would have a direct impact on their lives.

Although they were merely informed of some of the major decisions associated with the closure of Bell View Home and temporary relocation of services, they had a voice in decisions that affected the services they would use in the future. They were consulted about types of services they would like to be available to them in day care, such as bathing and hairdressing. They were aware that their choice was restricted by a range of statutory requirements that the Bell View team were obliged to comply with, such as fire regulations. Otherwise they were provided with a choice of what was available and affordable regarding the decision that had to be made.

The service users particularly enjoyed the opportunity to test out and select the decor and furnishings for the new centre. For example, as mentioned earlier, they were asked to participate in the selection of chairs. The project manager listened to their views and organised a trial of a range of chairs from a furnishing company. After the trial the service users opted for chairs they had previously been unaware of. Their decision created a sense of anticipation and excitement about the future when they would be able to sit in the chair they had put their 'name down for'.

Box 11 Active involvement in decision making

> Well it was a big van that came and I don't know where it came from, but we were allowed to go in and see all of the chairs and the dining tables and everything. And we could pick our chairs … I have got one something similar to this, but only higher where I can sit back. Even the dining chairs were available. They had arms where there were two pieces at the end where they were shaped so you could put your hands in, to raise yourself up. I thought that was great … I thought it was great going and trying them ourselves.
> (Day service user)

Being able to participate in the fund-raising efforts for Bell View was also important to service users. They were aware that large grants had been secured for the building project, yet they felt that their contribution was significant to its success. Many day service users had purchased a brick or a cornerstone and this had enhanced their feeling of 'being part of' the Bell View project. Through their purchase their names would be commemorated in a wall plaque and in this way they were securing their place in the future of Belford.

For the service users it was really important that they were able to participate in different types and levels of decisions about the development of Bell View. At a time of considerable change, opportunities were created to enable them to have their say in the things that affected them. Day care was an important part of their lives and, through their participation in decision-making processes, they were able to retain some control over the services that were available to them.

Fund raising for Bell View (Belford) Ltd

Since the beginning of the project considerable effort was devoted to raising funds for Bell View (for details see p. 19).

At first, fund raising was an enterprise that took place within the village and the surrounding districts. More recently, funds were generated from external sources such as the Lottery and charitable bodies, as well as the continuation of fund raising within the village. The efforts in the village have been co-ordinated in succession by a number of people who set themselves the objective of raising £10,000. These individuals worked with a dedicated team who used their talents and skills to make products in the village to sell during events that they organised in the village.

Box 12 Community donations were raised through a series of annual community events

The strawberry tea is one of the community events that has been held for two years.

During the event held in 2004, in excess of £900 was raised for Bell View. In part, the success of this event was attributed to the way in which the community was behind every part of this activity. People contributed the products to sell and they also attended as participants to buy the products:

> Not everyone can bake – some gave a couple of bags of flour, and others sent along sugar. We got so many bits and bobs and this all helped with the success of the day. It was so much fun, everyone getting together just having a good time.

There are many remarkable stories that illustrate the commitment of Belfordians to the Bell View project. In one situation ladies tirelessly devoted their time to preparing refreshments for the coffee mornings. These women worked in the kitchen where their efforts were largely invisible to the public, yet were greatly valued within the

project. Their work may not have been glamorous but it was an important fund-raising and information-giving activity.

In another situation one woman has generated in excess of £7,000 by making and selling marmalade, jams and chutneys. During the year she received donations of sugar, fruit and vegetables from local people and she volunteered her time to this activity, hence the profit margin was greatly increased when she sold these products within the community. Locally, she was highly regarded as the 'marmalade lady' and she prized the certificate that she was awarded by Bell View in recognition of her efforts.

The fund-raising activities within the project were diverse. Some efforts were community orientated whereas others focused on ways to capture the interest of individuals. Community events included the strawberry tea held in the summer and the Victorian market in December. Getting people together during these events maintained the interest in Bell View by the wider community in Belford. These events were publicised in local papers, which served the two-fold purpose of raising interest in Bell View in the locality and highlighting the need for community services for older people.

The stone donor initiative attracted donations by individuals. Stones could be sponsored for £5 and cornerstones for £25. People were motivated to participate in this initiative for different reasons. Some liked the idea of purchasing a brick as a gift to others or in commemoration of someone. Other people, who were unable to take part in fund-raising activities as a consequence of their disabilities, could participate in this activity. Their contribution was visible with the erection of the building and their name on the plaque that listed the contributors.

The efforts to raise funds within the community provided the basis to apply for larger grants from different funding bodies. The process of making a successful application to these agencies required specialist skills, and it was widely recognised that the project manager and the trustees made distinct and essential contributions that enabled Bell View to make the transition from a vision to a reality.

Many of the participants spoke of their concern about the future with respect to fund raising. Bell View required ongoing income generation to support its activities. While the local community had been very generous and supportive of Bell View it had been evident that the majority of support came from the same people:

> There's certain people in the village, they go to all of the coffee mornings and everything that is going on. It is the same ones that go to the events for Bell View, the Presbyterian church and the Methodist church. It is the same people.

Now that the building programme had been completed and the project was moving to a new phase there was a general feeling that local support was 'wearing a bit thin' with local people. There were other aspects of community life that had received little attention while the focus was on building Bell View and these were starting to claim their right for support in the village. The challenge for Bell View will be to live compatibly with other services in the village and to move to a place where financial support can be sustained.

Volunteers' views of participating in the Bell View initiative

Volunteers make a varied contribution to Bell View and this is equally valued within the project because it is recognised that different types of participation are necessary to bring the vision of developing services for older people in the village to fruition: 'Everyone pulls together to ensure that Bell View succeeds'.

The local community were united in their outrage by the decision to close Bell View Home, and this motivated a large number of people to dedicate their knowledge, skills and energies to the project. Volunteers were recruited in many ways. However, there is little doubt that personal invitations made through the village network effectively drew people to the Bell View initiative. This strategy led people to be aware that volunteers were needed: 'people aren't necessarily going to volunteer unless they are fairly sure that they are going to be useful and welcomed'. The work within the project was so varied that people were able to identify something that they could contribute to it, often with no further training (see Box 13).

Box 13 Contributing to a worthwhile project

She sort of said, 'well would you consider putting your efforts to helping out with the administration?'. That's really how I came on board because I was quite keen to help out with what was an extremely good cause. It was something I felt I could do without immediately taking on any other sort of training, which I didn't particularly at that time want to do in order to do it reasonably efficiently ... now I've got the office systems up and running it is quite rewarding actually. You want something we know where it is, we have a reference library to find out where things are, it is not finished by any means but it is getting there, particularly as the project is increased. I mean we went from one filing cabinet and half of a ropey one that was donated to five filing cabinets, which are full now. So there is a lot of work and a lot of paperwork and also to be involved in office systems because I never thought I would be asked for my opinion about how to set up the two new offices in the project but I have been and that is really nice.

In the village community there were individuals with specialist knowledge and skills, which had been acquired throughout their careers in services (such as social services, banking and local government) and other organisational roles (such as administration and policy development). They were willing to use their abilities to the benefit of the project. There were other people in the community who wanted to contribute in a practical way and were 'more hands on in what they liked to do'. Individuals were able to determine the types of contribution that they could make to the project and the extent to which they did this. Many of these people were retired and they wanted to continue to use abilities and knowledge they had acquired through their work on what they considered to be a worthwhile cause to benefit the community.

Box 14 Different levels and types of involvement

A member of the trustees had enormous skill and knowledge of social services. So I think that people who were involved with the establishment of the project and are on the committee are there because they have got skills and expertise … that is different from the people who get stuck in and offer all sorts of other contributions – not necessarily such high-powered professional contributions … I could not see myself doing a lot of the things that they struggle through on the committee … some people are much more hands on. They actually roll up their sleeves and get stuck in. That is just how they are.

As the project developed, the scale of work increased. This led to further demands on volunteers who had already given so much. Some of the volunteers who took part in this study stressed the importance of continual negotiation to determine the extent that individuals wanted to contribute to the initiative. Also, recruiting new volunteers to 'spread the load' was viewed as crucial to the future success of Bell View as it moved to its operational phase.

In addition to the positive impact that the volunteers' work had on the project, the volunteers experienced intrinsic benefits from their participation. They felt a sense of pride in being able to contribute to their community and pleasure was derived from a 'job well done'. Many spoke about the way that they got to know other people through the project and the enjoyment they experienced through their involvement. The volunteers' contribution to Bell View was acknowledged in many ways. There was public acknowledgement of their work during the annual general meeting, in newsletters and through the 'thank you' parties that were held. The public and personal recognition of their contribution was really important in enhancing their awareness of what they had achieved and in sustaining their involvement with Bell View.

Professionals' views of older people's involvement in Bell View (Belford) Ltd

Many different professionals, consultants and agencies have been involved with Bell View (Belford) Ltd throughout its life. Those who participated in this study attributed the success of the Bell View project to the passion and determination of everyone who was involved in it. From the initial protest until the present day, the project members maintained their resolve not to 'give in' to the many pressures that they encountered, with the aim of keeping the services that older people need within their community (see Box 15). These qualities attracted professionals to the project to work with the team to produce 'something that they could be proud of and something that was part of the community'.

Box 15 A committed group of people

The key thing for me was that they had such fantastic commitment to the project and such a vision of what they wanted to achieve. There were many barriers, yet they were determined and worked to overcome them.

Working with the Bell View team

The people who volunteered their time and energies to the Bell View project were respected by the professionals, who felt that they were 'very skilled and very competent people'.

By the time that most of the interviewees had come across the Bell View project the group had successfully organised the campaign against the closure of Bell View Home and were working tirelessly to generate funds for the refurbishment of the Home. These achievements bore testimony to their competence and ability to work together to fulfil the objectives that they set themselves.

The group were aware of the expertise required for their initiative and were all too ready to seek advice and assistance from appropriate consultants, agencies and professionals. One of the most significant decisions that affected the future of the project occurred when the architects presented the findings of the review of Bell View Home. The architects' conclusions clearly did not support the campaign that was directed at keeping the Home open and they were concerned that this had the potential to upset many people. They found that the team was disturbed by the findings but, more importantly, they were willing to examine all of the options that were available to fulfil their overriding aim of providing services for older people within the community. In doing this the team had to let go of their initial objective and work with a new and more demanding vision.

In another situation the group responded positively to the suggestion that they needed a project manager to harness their energy and ideas in a way that would move the project forward. All of the professionals indicated that the appointment of the project manager was a turning point in the history of the project. While she worked in partnership with the trustees, she had the capacity to act on the decisions that they made, and this led to successful applications for grants and working through complex negotiations with the projects' partners and with the statutory agencies.

In many situations, the team's openness and readiness to respond to the advice given by others led to professionals giving more than was asked of them. For example, the architects were willing to contribute their knowledge of the process for gaining charitable status, making applications for project funding and working with housing associations. The information and advice was warmly received by the project team who duly considered it. Hence decisions were made in collaboration with the project advisers who shaped the direction of the project.

Working through complex negotiations

As the project developed, the team encountered many complex situations that they had to 'work their way through'. This is clearly illustrated through the stories retold in Box 16 about working with the various departments of statutory agencies and unforeseen VAT requirements. These situations resulted in many setbacks and it was only the team's determination to fight through the battles that enabled them to find innovative solutions to their problems.

Box 16 Working through complex negotiations

> The Legal Department [of the authority] was tying us up in knots over the lease, the conditions of the sub-lease [there were parameters for activities within the proposed building and requirements for services] … I mean it was just unbelievable. The Legal Department had the ability to screw up what the Finance Department [of the same authority] was trying to make happen.

The design of the Bell View Resource Centre developed through active consultation with the community. At a very late stage it was decided that the attic space would be utilised as offices and meeting rooms. This decision led to a confrontation with the VAT authorities:

> At the very last minute when we were ready to appoint a contractor to start to work on the site, the arguments were still raging about whether we could have the upper floor or not. The upper floor was considered to be a commercial enterprise and therefore subject to VAT, and therefore going to cost 17.5 per cent more than it would have done if it was a community building. If we had to pay VAT the whole building programme would have been jeopardised.

The involvement of older people in the Bell View initiative

Bell View (Belford) Ltd was described as a 'community effort', where people from all age groups and different backgrounds participated. While this is the case it is also true that older people made a significant contribution to the project. As they were retired, they were able to devote time to the project in ways that other members of the community were unable to do. They worked alongside others as trustees, volunteers and fund raisers, which has been discussed previously. For some, this was an opportunity to use skills, talents and knowledge that had been redundant since their retirement (see Box 17). For others, it was an opportunity to do 'something meaningful in order to assist a worthwhile cause' and others were able to highlight the needs of older people from the perspective of older people.

Box 17 Getting involved in later life

> We became friends with Bell View and we went to one of the annual meetings and some kind soul who was *X* said 'I could put your name forward as a trustee' and I said 'yes' without very much thought. I realised since, I've probably been a workaholic all of my life and because I am retired I missed working. It is good being involved and it's an exciting thing to be involved with.

It was suggested that the active participation of a large proportion of older people shaped the strategies that were adopted in the initial protest and also later in the complex negotiations that were required in the building programme. The participants described how they had been eager to 'put up a fight' during their campaigning efforts of earlier years. With the wisdom acquired through age and experience they had reached the conclusion that building strategic alliances and entering into ongoing discussion with significant agencies and authorities were the campaigning strategies that were effective. They brought this knowledge to the project, thus influencing decision-making processes.

Box 18 Older people use discourse and negotiation as their selected tools for protesting

> One of the great things, I think as you get older, you're more likely to talk than to fight! It is very important. Just to talk and talk.

In a similar way, this group of participants drew on their experience of working with communities to develop approaches that effectively engaged local citizens in the initiative. They knew the local community and they were members of that community. While they were aware that the project required support from funders to realise its objectives, they recognised that it also needed ongoing support within the community. They believed that this could be achieved only if there was ongoing community participation in the project. In Box 19, one participant describes how this understanding of the Belford community led the Bell View team to ignore the advice of consultants/ experts at times and to act on the imperatives that were valued in the project.

Box 19 Drawing on wisdom gained through experience

> The experts told us what to do and what not to do. They told us not to run coffee mornings [and concentrate on securing large grants], but never mind we carried on with it. That's where you draw on the experience of older people. Older people knew what people would come to and contribute to so they stuck to their guns in spite of advice. That's where you draw on the experience of older people I think.

Overall, the participation of older people in Bell View made a considerable contribution to the human resources within the project, and significantly to shaping involvement strategies and decision-making processes. This ensured that the project was grounded in the perspective of older people in order to develop a service that was tailored to the needs of older people.

Key messages arising through the study

A worthy project

Bell View (Belford) Ltd was born out of a protest against the decision to close Bell View Home, which was a residential home that was highly valued within the Belford community. Although it became clear that the decision to close the Home was

appropriate, the work commissioned by the protest team highlighted the need for services within the village to support older people to live independently in their own homes. This spurred the campaigners on to change their direction, but not their resolve to support the overarching objective of providing services for older people within the village. Hence, the protesters became committed and enthusiastic to the cause they perceived to be truly deserving of their time and efforts.

A community-owned project

The Bell View project was more than a project that took place within the community. The local community developed and supported the project in real terms – through their voluntary work, their time and their money. Local citizens valued the project and they were determined for the project to succeed.

Effective leadership

Within the project there were a number of people who were instrumental in driving and shaping it. Their effective leadership enabled others to grasp the vision that later became a pioneering service for older people. They also led the project through many difficult times and used innovative problem-solving strategies to overcome obstacles that appeared to others to be insurmountable.

Everyone pulled together to bring the vision to fruition

The Bell View project moved from protest to creativity and, throughout this transition, those involved in the project were drawn together to support a worthy cause. The participants stuck to what they were good at, recognising that different contributions were needed for the success of the project. The cohesiveness and support between the project members were essential elements that motivated everyone to carry on and overcome all the obstacles that fell in their way of bringing the Bell View project to fruition.

Opportunities for everyone to get involved

The scope to make a contribution to Bell View was broad. From the outset different levels and layers of involvement were developed. This strategy ensured that

everyone could find a role where they could use their skills, knowledge and talents to the benefit of the project. Members carefully negotiated what they were committing themselves to. However, determining the parameters of involvement was difficult in an ever-changing project and with evolving roles. Although contributions differed, they were equally valued. There is no doubt that the recognition of people's activities and strategies to reward different contributions reinforced and sustained involvement.

Older people making a difference in their community

While Bell View was a community-based project, the contribution of older people was noteworthy. This group of people brought their experience of campaigning and professional expertise to the project. This made a significant difference to operational processes and the way that the project was conceptualised.

Balancing work with pleasure

Much hard work went into the development of Bell View and the subsequent building programme. This had the potential to drain people and to demotivate them when they encountered obstacles. The social programme that was built into the fund-raising activities and the 'thank you' parties counteracted the potential for the negative times to overshadow the achievements and the good work that was occurring in the project. The social events drew people together and strengthened the cohesion and support within the project.

Small successes led onto further confidence to work towards greater objectives with increased responsibilities

As Bell View members negotiated complex organisational structures and processes that resulted in successful outcomes, their confidence increased. They began to believe that they could secure funding and take on a building programme. With each achievement, their vision for the building programme grew. Hence, the small successes during the early stages of the Bell View initiative were important milestones that shaped the project and were crucial aspects of preparation for the participants to take on the substantial responsibilities in the project.

Effective communication

There were lengthy periods during the early years of the project when nothing appeared to happen. Keeping people informed of developments during this time was crucial to ensure that everyone stayed on board. As the momentum increased, up-to-date information was essential to enable people to participate in decision-making processes. Throughout the life of the project a multi-focused communication strategy evolved, ensuring that the community was aware of developments and decision makers had all the necessary information to enable them to fulfil an active role in the project.

Inclusive decision-making processes

Due to the complexity and scale of the project, decisions were required at multiple levels. Macro decisions (mainly concerning planning processes) were usually taken collectively by the trustees. As a group, they rose to the challenge of increasing accountability and responsibilities, which required careful deliberation. When the pace of the project increased, a balance had to be struck between inclusivity and getting the job done. In situations where a rapid decision had to be taken, the responsibility for decisions was devolved to the project manager.

Innovative decision-making strategies were adopted to involve a wider group of people in micro decisions (concerning detailed planning of the building and the service). Ensuring that the participants were fully aware of the choices that were available to them and the use of participatory approaches were key features of these strategies.

Ongoing challenges

In many senses the erection of the Resource Centre marked another beginning in the Bell View initiative. The project moved through many transitions: protest – to creativity – to community fund-raising efforts – to grant applications – to a building programme. Although each stage was different, there was one common thread that wove its way through this rich project – those involved with it rose to the challenges that they encountered. In this new phase project members face the demands of funding and providing a service to the community.

Summary

‘It has been a white-knuckle ride’, was the comment of members of the project team at a final meeting with researchers in the Bell View Resource Centre. This journey seemed so far removed from the situation witnessed at the completion of this report. Day centre users are enjoying their comfortable accommodation with chairs, colour schemes and equipment they had chosen themselves. Art groups, exercise sessions, voluntary organisations are using meeting and activity rooms, and the community cafe is open, providing refreshments for the Walking Group. The bungalows across the courtyard are all tenanted.

This study has aimed to trace the development of the Bell View project from a protest movement at the closure of a residential home to the development of a model of community care, which supports independent living for older people in their homes. This report has attempted to bring out the key messages from this process. We can see that, for the project team and the trustees, commitment, persistence, skills and experience have all been important factors in realising a vision. There has also been a balance between leadership and keeping everyone involved, with shared roles and responsibilities. Why was it a ‘white-knuckle ride?’ Systems of funding, regulations, constant changes in services all seem to put barriers in the way of innovatory developments rather than encourage them. In spite of all the odds, the Bell View project has succeeded in developing a model of care to meet the needs of the Belford community. However, the project does not end at this point. There are still further goals to work towards to promote healthy, independent living for older people.

The final question is whether a Bell View project could happen elsewhere, or is it special to a village like Belford? This study shows some of the features are special to Belford, but there are some lessons for any community.

Most important is that the Bell View model was developed with the community, by the community and for the community. There has also been involvement of older people at all stages and at all levels. So these must be the key messages for us all.

The DIY Citizens' Jury, Newcastle upon Tyne

Promoting public debate through Citizens' Juries

'Citizens' Jury' is a label given to a type of deliberative process – the exact methods and process of which can vary widely – which have been used both as research tools and for involving citizens in public policy decision making. The cornerstone of the legal jury from which Citizens' Juries draw their symbolism is that the deliberations of a small, representative sample from the population, once they have heard the evidence, can fairly represent the conscience and intelligence of the wider population. This draws on the tradition of representation and the right for trial by a jury of peers described in the Magna Carta in 1215.

Decision makers, from a range of policy sectors, have long examined how best to engage the public to participate. Involving citizens in the decisions that affect them is seen as important for ideological reasons (i.e. democratic process giving legitimacy, transparency and accountability) and pragmatic ones (e.g. getting popular support for unpopular decisions). In addition, older methods of consultation may not now be appropriate for a more educated and vocal population, or for the difficult and complex issues that need to be addressed. This view or need for an active, engaged citizenry in the UK derives partly from consumerist and customer-centred public sector thinking in the 1980s and 1990s, and also from a governance philosophy that highlights the reciprocal obligations between a government and people (Abelson *et al.*, 2003).

From this orientation, democracy involves informed, competent citizens making the decisions – not merely voting on an issue. Becoming informed requires deliberation; that is, collective problem-solving discussion, weighing different arguments and points of view, and coming to reasoned decisions. The Citizens' Jury – a process in which non-specialists are provided with information, are allowed to discuss and challenge it, and achieve consensus around priorities – is an attractive method for such democratic involvement. This informed, effective, legitimate public participation may be preferable to viewing the public as passive recipients of information and engaging in symbolic consultation such as may be achieved by other methods of engagement, e.g. questionnaire surveys.

Citizens' Juries have also been adapted for use as a method of participatory action research. Social science began by treating people who were the focus of research as 'subjects' rather than as participants or citizens (Wakeford, 2002). This view has changed radically over recent years and research is becoming much more

collaborative; however, methods such as focus groups are not seen to change the passive status of the people taking part – the participants are not necessarily involved in any change as a result. Citizens' Juries can be used as part of an alternative approach in which people scrutinise the evidence and interrogate witnesses, are given time to reflect and deliberate, and develop a set of conclusions (recommendations), which do not need to be unanimous. Sometimes the jurors are able to present their recommendations to policy makers in a face-to-face encounter. The Citizens' Jury can thus be a learning process for those involved and has potential to be a more rigorous research method than the opinion poll, which involves thousands of uninformed, instantaneous responses.

Development of Citizens' Juries

Citizens' Juries began in the United States (Crosby, 2003; Jefferson Center, 2004) and first came into the UK in 1994. Within four years, over 100 had taken place in a variety of fields, looking at different issues, and funded by local authorities, academics and non-government agencies.

In the mid 1990s, Citizens' Juries were utilised within the NHS for setting health care priorities and allocating resources. At the turn of the century, involvement of the public and service users in service design and delivery gained momentum with policy developments and later formal duties that required health care organisations to engage with representatives of user and community groups (Health and Social Care Act, 2001). This renewed the interest in Citizens' Juries as a way of examining health issues and related topics.

The utilisation of Citizens' Juries has changed in recent years. In some areas of public policy, their use has waned following earlier juries whose recommendations criticised government or funding bodies and were announced publicly; consequently, they became less attractive to policy makers. There is also concern that, in some cases, Citizens' Juries that were tokenistic have been used to give the appearance of open public consultation, and were biased, either by the way in which the topic question was set or through the prejudiced selection of witnesses and information presented.

Composition of a Citizens' Jury

The Jury Panel is made up of non-specialists who listen to evidence from a range of specialists with different perspectives and, after deliberative discussion, make recommendations that are fed back to decision makers and stakeholders to take forward. The fundamentals of the process are described elsewhere (Wakeford, 2002; PEALS, 2003a), and the details of the Newcastle Jury are given below. The Jury process involves several different groups of people each with particular roles. The exact composition of each group, as well as the minutiae of the process, will vary depending on the purpose of the Jury and the topic area chosen, and the groups and roles of individuals involved in the Newcastle Jury are shown in Table 4.

Table 4 Composition of the Newcastle DIY Citizens' Jury

Group	Description	Roles/activities	No. of participants
Steering Group	Organising group of those interested in topic. In Newcastle this group was made up of older people.	Co-ordinating and sustaining the Jury process; selecting the topic to be looked at; recruitment and oversight of the Jury and inviting the witnesses.	10
Oversight Panel	People who have a professional role or influence in the topic (relevant stakeholders), and those who value the involvement of ordinary people in getting policies improved.	Providing advice/sounding board to Steering Group; helping identify witnesses; ensuring a balance of evidence and witnesses; taking recommendations back to organisation and overseeing their implementation, advocating conclusions.	9
Jury Panel	Cross-section of population, randomly selected from electoral roll, symbolically representative (i.e. age, gender, race).	Listening to evidence; questioning witnesses; identifying further witnesses; reaching recommendations or conclusions and producing a report; publicising conclusions to decision makers and the public and pushing for their implementation.	13
Witnesses	Specialists in the topic area, preferably with a balanced mixture of views and variety of perspectives.	Presenting 'evidence'/information to the Jury; responding to questions.	8
Facilitators	In Newcastle paid workers from PEALS (Policy, Ethics and Life Sciences), Newcastle University.	Facilitating whole Jury process; organising initial launch meeting; helping identify the Oversight Panel; providing administrative support to Steering Group.	2

The Newcastle DIY Citizens' Jury

The Citizens' Jury held in Newcastle in 2002/03 was funded by the Joseph Rowntree Charitable Trust and was hosted by PEALS (Policy, Ethics and Life Sciences), Newcastle University, which employed two Facilitators with previous experience of running Citizens' Juries to co-ordinate the process. This was called a DIY Jury since members of the public (in this case older people) were involved in identifying the topic of enquiry for the Jury, rather than it being predetermined by the funding organisation (e.g. local authorities, drug companies), as has previously frequently been the case. To launch the initiative, older people were invited from a range of agencies and services working with older people from around Tyneside to the initial 'taster' meeting held at the Centre for Life in Newcastle upon Tyne. Around 60 older people attended this meeting to discuss issues of concern to older people, to learn about the Citizens' Jury method, and for interested persons to join the Steering Group. The different groups of people who took part in the Newcastle Citizens' Jury are shown in Table 4 above, along with the roles and activities they were involved in.

The Steering Group met over a period of several months to determine the topic for the Jury. The topic area affecting older people that was decided on concerned falls and the question posed was:

> How can new health technologies be designed and regulated such that the lives of older people are improved, not merely lengthened, particularly in relation to falls?

Concurrently with this, the Oversight Panel, which helped feed into these deliberations, was being recruited. Once the topic had been selected, further Oversight Panel members were recruited relevant to the topic area, and the identification of witnesses and the selection of the Jury itself commenced. Letters were sent to over 2,000 people (aged 18+) randomly selected from the Electoral Register from six wards within Newcastle. From these, 13 Jury Panel members were selected to take part.

Jury hearings were arranged and witnesses identified by the Oversight Panel were invited to provide brief presentations outlining their involvement with falls for the Jury Panel. At each session, the Jury first heard presentations from the witnesses and were then able to discuss the presentations and ask questions of the witnesses. During the hearings, the Jury Panel members were able to identify and call for further witnesses where they saw a need.

Throughout the hearings, and through discussion, the Jury Panel produced a series of recommendations around the topic of falls. When all the evidence had been heard, the Jury Panel agreed their verdict and produced a report outlining their recommendations. This report was widely publicised locally, beginning with a launch meeting to which relevant local stakeholders, including the Oversight Panel and witnesses, were invited. Jurors and members of the Steering Group presented their recommendations at national academic conferences. Members of the Oversight Panel were asked to take the recommendations back to their organisations and to push for their adoption. They were also asked to feed back to the Facilitators any resultant changes that had taken place; however, the degree to which this was done or was monitored is unclear.

Involvement of older people in the Newcastle DIY Citizens' Jury

Views of members of the Older Persons' Steering Group participating in the Citizens' Jury

How and why they joined the Steering Group

Older people from all walks of life accepted the invitation to participate in a meeting about the implementation of a Citizens' Jury in Newcastle. There was a lot of buzz during the 'taster' meeting, and people were inspired that they would have the opportunity to voice their opinion about things that mattered and about issues that affected the way they lived their lives. The event ended with many of the participants agreeing to become members of the Older Persons' Steering Group for the Citizens' Jury, Newcastle.

Following the 'taster' meeting, ten of the older people formed the Steering Group and were involved in the selection of the topic, jurors and witnesses, and in the dissemination of the recommendations from the Citizens' Jury process.

When asked about their reasons for devoting time to the Citizens' Jury, they spoke of the importance of ordinary citizens making a contribution to society. This was an innovative way to do this and had the potential to influence decision makers (see Box 20).

Box 20 Reasons given for participating in the Citizens' Jury Steering Group

I want to do things that help to make the world a better place.

To have a say about subjects that are important to the way that we live our lives.

Ordinary citizens were given the rare opportunity to discuss the issues with experts and professionals.

It is everyone's duty to get involved– we are all part of society and we have a responsibility to take part in the things that make that society a better place to live in.

The underlying thing that applies to all of us is that we are seeking social justice.

What helped or hindered them to fulfil their role?

The Steering Group that emerged after some weeks of commencing the project were highly committed to it. As a group, they had come to the realisation that this was a major project, which could be achieved only if they worked together. As they worked with each other they identified and came to value the knowledge, life experience and skills that every member brought with them. This led everyone to feel that they had something to offer and they were willing to do what they could to ensure the success of the project. They felt that there was an increased openness in professional and scientific communities to listen to the public and this made taking part in the Citizens' Jury worthwhile (see Box 21).

Box 21 Features of the Steering Group that helped participation

It was so interesting, listening to other people's views and what they had to say.

We all wanted to listen to each other and hear everyone's views. We know that we don't have the answers individually but we also knew that if we got our heads together it would be possible to improve things.

Everyone in the Steering Group got on with each other. There is great camaraderie in the group and over time we have grown to care for each other.

(Continued)

> We were paid all the costs of getting to the Jury. Also if you had an elderly relative that you were looking after that was funded. Whatever was necessary to enable people to take part was made available to you.

Most people felt that there was great camaraderie in the group. This was fostered by the skilled facilitation of the Citizens' Jury co-ordinators. During the working sessions and social events everyone was given the opportunity to air their views, which they felt were listened to.

Box 22 Being able to speak openly in later life

> Because I am an older person I have nothing to lose and given the information I am able to tell the truth. Others, such as scientists, work in a political situation and this may affect what they say. But I can tell it the way that it is.

The importance of providing the material resources that enabled people to take part cannot be underestimated. The Facilitators ensured that venues were accessible and people were provided with the support that they needed, such as loop systems for auditory assistance. Out-of-pocket expenses were reimbursed and funding was made available to pay for carer relief where that was necessary. The participants felt that these issues had often been overlooked when they were engaged previously in voluntary work and they were appreciative of this type of support.

While the Steering Group members spoke highly of their involvement with the Citizens' Jury they did encounter some difficulties. In the main, these problems were associated with changing personal circumstances. For example, one person spoke of the time that he had to reduce his input to the Jury because his wife's health had deteriorated and he wanted to provide more support for her. Another person spoke of her busy life as a member of many organisations and she had difficulty 'fitting the Jury' into her schedule.

Following the DIY Jury discussed here, a second Jury was run, funded by a drug company and focusing on the issue of GM foods. The Older Persons' Steering Group from the DIY Jury were encouraged to oversee this second jury process. The older people were concerned about the extent that they could influence the selection of the topic for the Jury deliberation (see Box 23). In the DIY Jury they felt that they were fully involved in the decision-making process, whereas they felt further removed from this process for the second Jury.

Box 23 Who is shaping the agenda for Citizens' Juries?

> The group largely drove the first Jury and it was a bottom-up process. In comparison, the second Jury was largely government driven. We had to do this quickly and I think that the second Jury was rushed through.

The final issue that the participants spoke about focused on the outcomes arising from the project. They were convinced that the Citizens' Jury was a very worthwhile initiative and that it did some good. They talked about the Jury process and the immediate products of it, such as the video recording, the guide to the setting up of DIY Juries and the reports from each Jury. However, they were less clear about the impact of the Juries. One person expressed his concerns in this way:

> It is extremely difficult to sit here and say what was it that we did achieve. There is not one thing that I can actually put my finger on, and of course I am not even sure that we know.

Evaluating the impact of any initiative that attempts to influence complex social situations is difficult. In this situation, the man quoted above continued to express his understandings of what occurred as a result of the Citizens' Jury by comparing the Jury 'verdict' to the ripple in a pond. As the ripple of water moves from the centre of the pond it gains momentum and increases in force by joining other elements in the pond. It is only by collective energy that change takes place. In a similar way he believed that the 'verdicts' in the format of Jury reports contribute to debates about policy and practice and, when the swell of opinion or evidence accumulates, change takes place. This is an important issue in its own right, but it has been discussed at this point because it influenced the way and the extent to which these older people participated in the Steering Group. They were convinced that their work mattered and that it made a difference.

What they valued about taking part in the Citizens' Jury

The following quotation epitomised the views of those who took part in the Steering Group:

> It gave us a sense of purpose and it was something that was entirely different. To me it was wonderful just going out and learning things and learning how other people felt. Different issues came out – all sorts of things, transport, things to do with the NHS … It was just so new to me. To me it was wonderful, just the feeling that you were being listened to. That most of all.

Being a member of this group was viewed as a great learning process. They were able to listen to experts talking about subjects that they were interested in but knew little about. It was also a situation where they developed the confidence and skills to articulate their ideas. During presentations of their work to parliamentary officers and to professionals in conferences they were able to talk to influential people in ways they had not considered possible. The participants felt that they were equal partners in the process and that all of their contributions were valued. They didn't have a chairperson, unlike other situations that they had experienced – this was important because no one's opinion appeared to be valued more than another's.

Box 24 How older people felt about their participation in the Steering Group

It gives you a voice and having that voice listened to is really satisfying. Through the Jury we are able to influence what happens.

Being part of the Citizens' Jury gave me the feeling of putting something back and taking something forward.

I get so much satisfaction doing things for the future to affect the future generation.

Prior to the Citizens' Jury I felt intimidated to talk to professional people but I don't feel like this any more.

I would never have thought that I would have been able to speak to people [those who attended the event in Cambridge] of that standing.

Throughout the entire process they had a real sense that their work was making a difference. They produced reports that had the potential to affect the lives of older people and, from the second Jury, their report was submitted to parliamentary officers and contributed to the national debate on GM crops.

In summary, taking part in the Steering Group was all of the above things but it was more – it was a life-changing experience.

Jury members' views of participating in the Newcastle DIY Citizens' Jury

When they were first approached to take part in the Citizens' Jury, they thought the term 'Jury' conjured up ideas of becoming involved with legal or court proceedings. The explanations given by the Facilitators quickly clarified this. Further information about the Jury process captured the imagination of those who were invited to take part as jurors. One participant recalled his initial thoughts of the Jury:

> I thought, 'Oh, this might be quite intriguing'. So it was curiosity more than anything else that kept me going back.

The idea of being able to question experts and decision makers about topics of public concern, and being able to contribute to a debate that had the potential to influence these people was greeted with enthusiasm. The majority of jurors had never had the opportunity to learn from leading experts, or to challenge their opinions. In this situation they found that they could listen to the witnesses but they were not passive recipients of the information. They were conscious that their contribution, considering and evaluating the evidence, had the potential to bring fresh insight to the debate. They felt that they were able to do this by drawing together the technical, professional knowledge of experts about falls and older people, and personal knowledge of older people who had fallen and/or subsequently used services.

Box 25 What the jurors enjoyed about taking part

Learning something new:

> Going every week you learnt different things. You got to speak to the people that were there and they were very good at answering your questions.

> I think the variety of witnesses was great … I would never have had the opportunity to hear the vast amount of work that is going on.

The jurors had control over the process:

> You could say to them, 'look you're straying away from what I want you to answer', so the Jury members were able to control the questions themselves.

> We felt that it was our group and it was us leading it.

Hearing the views of other people:

> They were very forthcoming with their ideas … I liked to listen to them because they could see it from their angle, from a different angle and that is why the Jury worked so well.

The personal development that occurred as a result of taking part in the Jury:

> It brought me out of my shell you know. I never thought I'd see the day I'd go to Cambridge University and sit there and others listen to my views. I didn't have the confidence because I had never been a speaker. [Now that has changed.] So I got a lot out of it.

Why did the jurors take part in the Citizens' Jury?

Curiosity and interest may have been the initial levers that attracted the jurors to the Citizens' Jury, but the possibility that they would be able to take part in something that 'made a difference' was the motivating factor that sustained their involvement.

What helped or hindered their involvement?

This was a new activity for everyone, therefore information and support was critical to enable them to take part. They found that the Facilitators were well organised and very skilled group co-ordinators. They instituted a number of processes that helped everyone to contribute to the discussion. One of the most welcome processes was the red card system – the jurors were given a red card and, when they felt that the discussion or the presentation from a witness required clarification or a change from jargon or technical language, all they had to do was raise this card. The jurors felt that this system promoted equal participation from everyone present and it gave them a degree of control over the events (see Box 26).

Box 26 Processes that helped the jurors to participate in the Citizens' Jury

> We were told that people will come into the Jury and we could speak to them about the topic that they were the expert in. We could ask them questions, they were learned people, academic people … When they came along what we were told to do was – obviously they were very clever in their environment, in their field. We were told that, if they started to speak in any jargon, we were to give them a red card. They were then asked to explain in words that we could understand … I found this really interesting and a real opportunity for me to see these people and to speak to them on real terms.
>
> [The minutes were] sent, or they email them to us for the following week, or we got them by post so we knew exactly what we covered the week before, so far. So we had a dossier right through the ten weeks … of what was covered on all the witnesses that came because, at the end, we wanted to go through all the witnesses and look at the best possible options so that information and the notes that were taken meant we had all that.
>
> A week gave you time to think about what you wanted to say because you knew beforehand who was going to be talking, who you could question, so it gave you a week to think to yourself, 'I'm going to ask this question'. If you wanted to you could look up information so you could ask them certain questions on their subject.

The Facilitators made minutes of each meeting and they ensured that the jurors received these prior to the following meeting. This was extremely helpful to the jurors, because it enabled them to take part in the discussions rather than focus on making their notes, and it provided a 'dossier' of all the topics and discussion that occurred during the ten-week session.

There was a gap of approximately one week between meetings. The jurors felt that this was important because it gave them the time to consider the evidence and, if they needed to, they were able to do further research on the topic prior to the following meeting. Other factors that supported their participation were: the opportunity to get to know the other jurors, provision of transport and payment of out-of-pocket expenses. These structures and processes enabled the jurors to develop the skills and confidence to participate in the activity. They would have welcomed the opportunity to take more time to discuss the issues raised by the witnesses with Steering Group members and they suggested that this should be considered in the future.

By the end of the Jury event, they were quite saddened that it was a time-limited situation and they would have liked the opportunity to take part in another Jury event. Some even felt that they 'had been plucked and they got what they wanted and then we were dropped' from the process, and they would have welcomed a way of sustaining their involvement, as they had enjoyed being part of the whole process.

Oversight Panel members' views of participating in the Newcastle Citizens' Jury

The Oversight Panel consisted of a range of stakeholders and interested professionals from statutory and voluntary, local and national organisations concerned with older people's issues generally, or specifically with falls. These individuals had a variety of roles in the process and cited different reasons for their becoming involved in the Jury. The Oversight Panel did not meet as a distinct group and, in some cases, did not clearly identify each other as members of the Oversight Panel – this was more of a 'virtual group', one member said.

Reasons for becoming involved in the Citizens' Jury

All members of the Oversight Panel were interested in the process of the Citizens' Jury and, for many, learning about the process and watching a Citizens' Jury being run was the major motivating factor for their involvement.

Box 27 Reasons for Panel members to be involved in the Citizens' Jury

Learning about the process:

> I was really interested because I'd heard of Citizens' Juries but I didn't know how they worked, so I was really interested to actually observe the process because I wanted to know what happened and how you did it.
>
> I think what we were doing really was adding to our store of knowledge as an organisation about the processes of involving older people.

Roles within the Oversight Panel

People identified various reasons as to why they were recruited to the Oversight Panel and described themselves as having differing roles within the Citizens' Jury process (see Box 28). Several people were asked to join the Oversight Panel mainly because of their perceived capacity to take the recommendations further. Other roles included providing contacts or links with networks of older people, identifying potential witnesses to the Jury and overseeing the 'fairness' of the Jury process.

Box 28 Roles within the Oversight Panel

Taking the recommendations forward:

> I was also involved in considering how, after the Jury had presented its findings, how we might put that into place in the Trust and I think I was seen as quite a key person because I work across several organisations.

Recruiting older people to the Steering Group:

> … what [the organiser] wanted to do was to get a group of older people together who would be involved in understanding the process and choosing the subject for the Jury. He particularly wanted that to be older people who weren't already involved in a lot of the things that we were doing through the Elders' Council and Better Government, etc. So we suggested a number of names and a number of sources and then he approached them.

Identifying possible witnesses:

> Well I knew I'd be on a sort of advisory panel and part of the job was either for me to think about who might be witnesses to the Jury or even to be a witness.

(Continued)

Overseeing the process/fairness:

> How it was explained to us was that we were there to make sure that the process of the Citizens' Jury was fair to the topic and that the outcome wasn't going to be influenced too much in one direction or another, and that there had been a balanced debate and that the whole thing had been done fairly and that the jurors had had the opportunity to look at the topic in enough detail to actually come to a decision.

Degree of involvement

A frequent theme among Oversight Panel members was that they felt that they had only minimal or peripheral involvement, at most attending two or three meetings. Generally, this was because of their own lack of time or because they were based a long distance away (for example, the main offices of a national organisation based in London). Three Oversight Panel members, however, said they had much more involvement and were closely involved in most or all stages of the Citizens' Jury.

Box 29 Degree of involvement

> I never met the other members – I mean I probably met some of them. I only really went to one big meeting at the start, which was before the Jury had had its first proper meeting as a Jury and there were lots of people from the Oversight Panel and it was a very broad discussion about what might happen. Having been to that, I didn't go to anything else and I didn't even attend any of the Jury sessions.
>
> I had quite a lot [of involvement] and I went to a lot of the meetings and I went to most of the Jury process, not all of it, but a good percentage of it. And I think that wasn't true for other members of the Oversight Panel who had, from what I saw, very little involvement. To the point that sometimes I would think, I wonder if these people realise that they're actually on the Oversight Panel, and what the Oversight Panel is meant to be?

Positives of the Citizens' Jury process

Overall, the Oversight Panel viewed the Citizens' Jury as having been a very positive process in terms of involving older people. They felt that the Steering Group, comprised of older people, had been closely involved and actively engaged throughout the process, from selecting the topic to running the Jury sessions. The

positive impact of the Jury process on the Steering Group members themselves was often flagged up, for example, in terms of increasing their confidence. The Oversight Panel were impressed by the way in which the Steering Group operated as an integrated, inclusive and effective group, and praised the high skills of the Facilitators for making this possible. Watching the process was also often a positive learning experience for the Oversight Panel members.

Implementing the recommendations – did it change practice?

Generally, the recommendations reached and distributed by the Jury were well received by Oversight Panel members and their organisations. However, they were not seen as providing new insights or ideas for solving the issues surrounding the topic of falls. The recommendations tended more to restate the problem areas and support the current initiatives and directions being taken by individuals, organisations and services providing falls-related services or initiatives (see Box 30). Oversight Panel members expressed both disappointment and reassurance about this. The Panel members found it difficult to identify changes in practice that had occurred as a direct result of the Citizens' Jury. This was, in part, due to the nature of the recommendations discussed above. There was a perceived lack of feedback about the Jury's impact and also an acknowledgement that assessing any such impact in complex systems – such as the NHS – is often impossible. The Jury's recommendations were frequently utilised by Oversight Panel members to reinforce their current practices and to add pressure to cases, such as funding applications, being made.

Box 30 Implementing the recommendations

> When we looked at the recommendations, there wasn't anything that wasn't being done. We didn't think, 'gosh, yes, we never thought of that'. So it was very helpful in that it reinforced what was already being done.
>
> As far as I was concerned I was able to take it back to our Action for Health group saying that they've recognised the value of what we do: we need to go on doing it. We wanted to bring it closer into what other people were doing; to the system shall we say. So we were encouraged by that.
>
> I think knowing that the Citizens' Jury felt things needed to be simplified is helping me remember that we need to keep things as simple as possible.

(Continued)

I suppose I was a bit disappointed that the members of the older people's group didn't want to follow it through. Maybe I would have liked to feel that there was more impact on the system.

In fact I think we will continue to look back at the recommendations from the Jury because we're still involved in Newcastle, so certainly we can look at that. But I think there really wasn't anything particularly new in the recommendations, you know, it was stuff that people knew already and in effect you're working on. Nor was there, I don't think, any particularly different emphasis 'gosh, yes we are doing that but we need to give it more priority'.

Reflections on the Citizens' Jury process

Overall, the Oversight Panel found the Citizens' Jury to be an interesting process and potentially useful for engaging non-specialists (in this case older people) in policy- and decision-making processes. They discussed the importance of: selecting a topic suitable for this type of process; ensuring that key stakeholders and those with power to act on the findings be involved and signed up for taking the recommendations forward; and ensuring a built-in follow-up component to oversee the recommendations being put into practice, and to monitor and provide feedback about any such impact. The process was seen as being of particular use in particular circumstances; marrying the process to a suitable situation was seen as important, especially since Juries can be relatively complicated, time-consuming and expensive to run compared with some other methods of engaging older people (or other community groups).

Box 31 Reflections on the Citizens' Jury process

Topic and impact:

I think to make it worthwhile you'd have to be careful about any topic that you chose. It needs to be something where the outcome could be a good impact on the system and needs to be timely as well. Something that's going to go on for some time, not just a one-off thing. But the other thing you'd have to build into it is to make sure that there will be those who can carry forward whatever the outcome is. That's perhaps the most difficult thing.

(Continued)

> I think it's really important that you have the key players there because, if you've just got people who can't really make decisions, then the whole process falls down.
>
> I felt, and I think I still feel, that, if you're trying to change a service or the way a service runs, that probably a process that is more about building partnership and more about working alongside people is more appropriate. I feel a Citizens' Jury, because of the way it's done, is probably suited to issues which are a bit more black and white and perhaps a bit more around ethical issues.

Not happening in isolation:

> I suppose the other thing I would say about it is, this sort of project needs to not happen in isolation to anything else that's going on in the city.

Fair debate:

> I think that's one of the good things about the Citizens' Jury, in my understanding of how it's supposed to work that combats that, the idea is that everybody gets a voice and that you have your witnesses for and against, so that you have a rounded debate, because it is easy for the stronger voice, the person who is confident to just dominate … so if you can create a process that stops that, and I think the Citizens' Jury does that to a certain extent because it does allow for different opinions to be heard, and then the Jury make their own mind up.

Complicated and time-consuming:

> It seemed to me quite a complex process because they had the older people's group and then the Jury and it's quite a complex and time-consuming and basically expensive process.

Facilitators' views of participating in the Newcastle Citizens' Jury

Setting up the Jury

This initiative was instigated by one of the Facilitators and a manager from the hosting organisation who submitted a bid to the JRF to fund a Citizens' Jury. They were particularly interested in running a Jury in which the topic was identified from grass-roots groups (bottom up) rather than local authorities or other commissioning bodies (top down), as had previously frequently been the case (see Box 32). At the outset they had not determined which community group might engage with the process, and one of the facilitators, who was new to Newcastle, was concerned with

making local community contacts and talking to people about the project. He describes this process and how the Jury came to centre on issues affecting older people:

> And so I tried to meet as many people in different areas of the community and people active in the community for the first sort of three or four months of the project, and the group that seemed like they'd be the best partners to work with, and there was a potential of impact on policy, were older people's groups.

Box 32 The DIY Citizens' Jury

> There have been, I think, getting on for 200 Citizens' Juries but they tend to be organised by some sort of decision-making body and their subject tends to already have been set. So we thought we would try a model where grass-roots groups rather than local authorities were engaged in deciding what the topic should be and actually managing the process. So that's why we call it the 'Do It Yourself Citizens' Jury'.

After identifying that older people and older people's issues were to be the focus of the DIY Jury, the Facilitators invited members from a range of older people's groups in the locality to a large meeting to launch the project. At this meeting, the concept and procedure of Citizens' Juries were outlined to attendees, potential topics of concern to older people were identified and those interested in becoming more involved were invited to form the Steering Group. The Steering Group was thus self-selected and was made up of people from a variety of backgrounds. The Facilitators attempted to keep membership as open as possible and to remove any barriers for people to be involved (see Box 33).

Box 33 Recruiting to the Steering Group

> I did go through a similar process here of saying, you know, 'what is the world of older people, of being over 50 and, you know, in a lunch club or people campaigning on health or pensions or something like that, what is their driving motivation to do this sort of work and what are the barriers to them becoming involved?' Again, in retrospect, I think involving more people with disabilities would have been good. I mean I think we did reasonably well but I think, you know, always the people with visual

(Continued)

> impairments, hearing impairments or mobility problems, it's going to be harder for them to come and, although I think we have quite a cross-section of different perspectives on the Steering Group, I think it could have been even wider than it was.

The Facilitators and the Steering Group met several times over the next three to four months. During this period they participated in an examination of strategies for (political) change and barriers to this; discovered about the Jury process; and honed down the topic for consideration. The Facilitators saw this part of the process as key:

> The heart of it for us was their decision about what it should be on … to actually work through what issue was important to them … where there is a maximum chance of them getting some positive change and to work to that with them making the decisions.

The topic had to be both important to and identified by older people, as well as being one that was timely and where policy could be open to influence or change.

Working with the Steering Group/older people

The Facilitator reflected on why the older people on the Steering Group engaged with the Citizens' Jury process and what they gained from being involved (see Box 34). He felt that, because the topic was identified by older people themselves and was of concern to them, this was an important factor in the Jury process. The fact that this was a deliberative process (rather than mere discussion), in which issues were deeply examined, the evidence weighed up and recommendations produced with a view to bringing about real and positive change, helped make the Jury process a unique and rewarding experience for the older people. The facilitator felt that having been involved throughout the Jury process, having 'ownership' of the output (i.e. the recommendations) and being able to press for change using material that they had helped to produce was also important to the Steering Group members.

Box 34 What the older people got out of the process

> [We tried] to just respect what they wanted to happen in the process … if one person out of the nine of them said 'well this is important' that we would actually respect that and discuss it. So I think the difference between this and other things they've been involved in is I think there

(Continued)

was, there was real discussion of the getting to the causes of things and deciding what to do about them in a structured way … this was actually saying 'what all this is about is getting positive change and that's why we're here and everything we do is sort of leading towards that'.

What did older people bring to the process?

The Facilitator had virtually no previous experience of working with older people or knowledge around issues affecting older people, thus his experiences of working with this group for the first time in a Citizens' Jury were elicited. The older people were seen by the Facilitators to bring with them a wealth of experience that was invaluable to the Jury process. These older people were able to draw on their own and others' lives, and often had much insight into the topic right from the outset (see Box 35). There also appeared to be an informality or social aspect to working with the older people's Steering Group that the Facilitators had not encountered working with previous Citizens' Juries made up of younger people (see Box 35).

Box 35 What did older people bring to the process?

Life experience:

> [We] both felt there was an awful lot of wisdom there that we were just tapping … they had a really good analysis even before the Jury happened of the issues … they had the confidence of thinking 'well I've lived through this, I've had brothers, nephews, aunts who've had falls and had experience of the NHS' and they were drawing in all that. So I guess that's the big difference between this one and ones that aren't involving older people.

Informality/social aspect:

> We learnt things like the Older People's Steering Group, it was important that they were feeling that the Jury sessions weren't just about these randomly chosen people from all ages and different parts of the city, but that the Steering Group could share, have some social interaction, even share some of their experiences with this Jury. Because, traditionally you would say, well the Jury are the public and the Steering Group are the sort of commissioning body, but actually here it was quite fuzzy.
>
> We had a couple of very informal get-togethers, meals … I think that made the process really enjoyable. That made the difference between this process for me and projects that have been much more mechanical.

Impact of the Jury

The Facilitator talked about the impact of the Jury; that is, getting the recommendations heard and acted on by stakeholders and those able to make changes within organisations dealing with falls (See Box 36). This requires organisations to have real 'buy-in' to the recommendations and the will to see them implemented. Thus, closely involving key people involved in the topic area of the Jury, those who have the power to make changes and act on the recommendations, is essential for this process to have impact and bring about change. There can be difficulties in assessing and identifying any effects of the Jury because of the complex nature of the systems (e.g. the NHS) that are concerned with the topic.

Box 36 Impact of the Jury

Getting the Jury recommendations heard:

> I think it's a real problem with any process like this, that is … sort of bottom up to the extent that it is planned from the grass roots, to then impact on policy. And, if it had been the commissioning body of the local authority whatever saying we want to consult and we will listen to the conclusion, they can, without sounding too cynical, they can shape how the Jury is reported to make it look like it changed something, whereas we don't have that luxury.

Increasing impact

The Facilitator felt that, with more time and resources for the Jury on falls, the recommendations could have been more widely disseminated, more strongly campaigned on (e.g. links made with national campaigns) and better taken forward. The Steering Group themselves did get involved with disseminating the recommendations to some extent. Increased funding would enable them to further propagate the findings, to push for their implementation, to chase up stakeholders and to monitor the uptake of the recommendations and thus see the impact of the Jury process through into the system. Lastly, the Facilitator highlighted the importance of disseminating the Jury recommendations among grass-roots older people's groups and networks. Again, this is time consuming (and thus expensive) and further resources for this would have been useful.

Box 37 Increasing the impact of the outcomes of the Jury process

Involving key stakeholders:

> I think that I'd turn the question around and say 'given that it's so hard to demonstrate what policies have changed, I think it's more trying to maximise the number of extra voices coming in'. Because you've got sort of Age Concern and Help the Aged and things like that, and I guess the jurors are saying 'this is an extra way in which we're saying this view is important and legitimate and needs to be acted on'. But partly it will always, unless the Newcastle Jury were to become a pressure group in itself, it's always going to be up to the stakeholders in that process to take it up.

Improving impact:

> Where I think we could improve the impact of future processes … is thinking 'who can we get such heavy buy-in to the conclusions that they will actually use it as a main plank of a campaign?'
>
> I think we would have been helped by having somebody's paid-for time to actually arrange meetings with all the different potential stakeholders, all the decision makers, people who might be able to influence.

Older people and impact:

> I think networking among older people's groups should be, I mean it's both necessary and important that there is lots of face-to-face interaction and I think that is quite labour intensive. So I think that's something that I wish we could have done more of but I think actually the Steering Group have done that as individuals in Newcastle and we were very lucky that a national project on reducing falls took some of our people to Blackpool for a national conference and to Harrogate for a project called 'Involving Consumers in the NHS'.

Key messages about involving older people in policy through the Citizens' Jury

The Citizens' Jury model can offer a rewarding and challenging method of engaging older people in policy and planning activities; however, the process requires consideration of several key issues.

Selection of the topic

Older people are more likely to want to become involved and find the process rewarding if the topic under review is one that is of interest and relevance to them. The DIY Jury process aided this, as the topic was selected by the older people themselves rather than it being imposed from outside (e.g. by the funding body). The choice of topic greatly impacts on the success and impact of the Jury. The topic needs to be one that is appropriate for the Citizens' Jury process and is timely, so allowing the Jury to give a voice in current public debate. The DIY process does give control to older people; however, guidance in selection of an appropriate topic or framing the topic appropriately may be required.

Process issues

The purpose of each Jury needs to be carefully considered beforehand; that is, whether the Jury is a means to an end (that is, will the recommendations impact on practice or policy?) or an end in itself (that is, a positive learning process for older people involved). The older people personally did gain much from being involved in the Jury process. However, they were also very keen for the Jury to have an impact on services, organisations and how falls are dealt with. If a Jury fails to have the expected impact (which could occur for many reasons including: the difficulty in monitoring related change; poor selection of topic; lack of support to carry recommendations forward; stakeholders not being involved or buying in to the process), once these expectations have been raised, the process may feel less rewarding for those older people involved.

Impact

The expected outcomes of Juries and the impact of their recommendations also need to be thought through. What is the impact that the Jury is expected to have? How will outcomes be measured? Who is in a position to act on the recommendations? The older people involved in the DIY Jury wanted the process to have an impact on society, to help change things for the better. Thus, the Jury process itself was important but it needed to have an impact/end outcome. There may be difficulties in assessing the longer-term impact, especially if complex social situations or organisations are involved. It may require additional funding for those involved to continue dissemination, drive the recommendations forward, and monitor and push for active change. Ensuring that key stakeholders and decision makers are

signed up to the Jury process and are willing to take recommendations forward is also essential. Without this buy-in, the process stands outside the system and is much more limited in the direct impact it can have, although the recommendations may be used as lobbying tools.

Organisational aspects

Adequate funding and a core infrastructure, including some administrative assistance (e.g. to arrange meetings, distribute written information, etc.), are needed to support and sustain the Jury process. As with any process seeking to involve older people, considering certain practical issues helps to make the process more enjoyable and available, e.g. ensuring venues are accessible, providing aids such as hearing loops, paying travel expenses, arranging travel, providing funds to cover for caring responsibilities, etc.

Facilitation

Skilled facilitators are needed to guide all aspects of the process, particularly when introducing the Citizens' Jury approach to new participants. In the Newcastle Jury, the Facilitators were seen as essential to making sure that all participants felt they had been heard, had been included, were able to participate and had contributed in an effective participatory event. The Facilitators helped to ensure that the older people (Steering Group) formed an effective group, and that their life experience and skills were valued and utilised, as well as helping them to develop new skills and confidence.

Personal benefits from involvement

The older people who were involved in the Newcastle Citizens' Juries gained much, personally, from the process. They identified that the Jury provided them with the opportunity to: be involved in effective group working; have a learning experience; increase their confidence; use their pre-existing skills and life experiences; develop new skills; voice opinions about issues that affected their lives; debate and ask questions of professionals; potentially influence decision makers; be involved in helping to positively change things and contribute to society.

Time commitment/sustaining the process

The amount of time that is required of older people involved in such projects, both in terms of day-to-day input as well as the duration, needs to be considered at the outset. As mentioned above, thought needs to be given to how the process is to be sustained; that is, how and by who the verdict is to be publicised, taken forward and implemented, and how and by who this will be monitored and encouraged. It may be that further funding is needed to support those who have been involved so that their learning, skills and enthusiasm can be harnessed.

Summary

Citizens' Juries provide an innovative and often exciting method for involving older people (and citizens in general) in deliberative decision making and policy and planning activities. This said, however, they may not be suitable for all situations; may require careful consideration of topic, skilled co-ordination and facilitation; and may be expensive to run. For the recommendations and verdict to have an impact on decision makers, key stakeholders need to be signed up to take them forward, and procedures need to be put in place to ensure that such impact is monitored, supported and encouraged.

Growing Older Living in Darlington (GOLD)

Citizen participation in all aspects of public life has been fostered and actively encouraged in recent years. This has led to the development of strategies and methods to enable two-way interaction between decision makers and citizens. Growing Older Living in Darlington (GOLD) has emerged within this national context as an approach whereby older people work in partnership with statutory and voluntary sector agencies to take forward older people's issues with the aim of improving the quality of life for older people in and around Darlington.

Prior to giving a description of GOLD and its development we turn to a brief discussion of the citizenry agenda, which was instrumental in changing the way that older members of the public have been perceived as consumers of services, and are now viewed as citizens who have the right and the duty to express their views of what they need to enable them to live active and rewarding lives.

Engaging older citizens in local democracy

At one time older people were thought to be a homogeneous rather than a diverse group of citizens. Service providers and policy makers believed they understood the needs and preferences of this group, whereas increasing knowledge of the differences that exist in this population has shaken that belief. The uncertainties that this situation created opened up the need for decision makers to listen to and consult with a group of people who had hitherto been marginalised, and sometimes excluded, from decision-making processes.

The momentum to engage with the older population was gaining ground in a context where many other changes were taking place across British society. A key driver promoting public participation and involvement came from being a member of the European Union, which placed a requirement on government bodies in 1992 to consult more widely with members of the public. This played out differently across the public sector. For example, in the NHS, the National Health Service and Community Care Act (1990) made consultation with service users a legislative duty for local authorities. Other government directives required active service user and carer participation in service development and its regulation. In response democratic initiatives (approaches that enable the public to influence and make decisions at a strategic level) and consumerist initiatives (approaches that facilitate consultation on an issue) developed. One consequence of this agenda has been the development of a public that is less deferential to policy makers and wants to have a say about the things that affect it.

The Government has supported specific initiatives directed at the involvement of older people in decision making. For example, in 1998, the Better Government for Older People programme (BGOP) was established. The evaluation study carried out by Warwick University (Hayden and Boaz, 2000a) indicated that integrated strategies for engagement with older people were developed in the 28 pilot projects led by local authorities in the programme. These initiatives provided a unique opportunity for older people to be heard by politicians, policy makers and service providers. There was great concern, however, by the older people associated with the programme about whether the work they had started would be sustained. Through the Older Person Advisory Group (OPAG) that emerged during the BGOP programme, older people continue to work in line with the Inter Ministerial Group for Older People.

The Government has not been alone in supporting the development of an informed citizenry. Other groups that campaign for and promote older people's issues have also focused their efforts on the involvement agenda. For example, the forums supported by Help the Aged and Age Concern (through the Debate of the Age) have worked towards giving older people a voice on the issues that affect their lives.

There is no doubt that these combined efforts have led to the engagement of older people in service planning and delivery processes, but success cannot be measured simply by the extent of engagement. What is also important to defining success is that older people have experienced positive changes in their lives – in the quality and appropriateness of the services they receive and in developing the confidence, skills and capacity to assume greater control in making their own life choices.

GOLD developed against this backdrop of service and policy development. Statutory agencies in Darlington were seeking innovative ways to engage older people, while older people themselves were seeking a voice.

Development of the Older People's Strategy in Darlington

Box 38 Demographic features of Darlington

Population statistics

Total population of Darlington = 97,888 (based on the mid-2002 Office of National Statistics estimates).

Resident population over retirement age = 19,212 (female 12,402 and male 6,810; retirement age female 60 years, male 65 years).

The proportion of retired people to the remainder of the population in Darlington is 19.62 per cent.

Housing statistics

Number of households (2003) = 42,300.

Pensioner households = 10,255 (25.5 per cent).

The work that led to the development of GOLD commenced in July 2000. Officers from Social Services, the NHS Primary Care Group and Housing in Darlington commissioned Peter Fletcher Associates to facilitate the development of an Integrated Strategy for Older People in Darlington and the surrounding areas. It was envisaged that this would be a long-term project that would establish structures for older people to be active citizens rather than users of services.

The project commenced with a service and agency agenda; however, this quickly changed. The focus on developing a strategy for the older population, which emphasised engaging with them to identify their priorities and what they needed to enable them to live full and rewarding lives, shifted the project towards an older person's agenda.

Box 39 Older people want to have their say about the things that affect their lives

> We are fed up just being asked to consult on other people's documents … actually we want to start with our issues really.

The initial stage of the project focused on the development of the Strategy document. Approximately 450 older people were consulted through postal and face-to-face surveys to explore their views of what it is like to grow older in Darlington, the issues and priorities important to older people, how services work and how they could work differently or better, and how older people can become involved in shaping the future. In addition, interviews were carried out with 50 members of staff from agencies that work with, or provide services for, older people.

The results of this work were presented in an open meeting in March 2001, which was attended by 120 people (later this group became known as the Growing Older in Darlington – GoiD group). During this event it became apparent that a number of forums existed to champion older people's issues but the activity from these groups was not co-ordinated. It was acknowledged that this energy had to be harnessed if the agenda was to move forward.

The event culminated with an invitation to older people to participate in the Steering Group to bring the Strategy to fruition. A meeting was convened for older people to select six representatives from those who put themselves forward for this purpose, which led to the formation of a Steering Group. The membership of this consisted of six older people and six professionals from statutory agencies. They worked with the wider group to produce the Strategy, which was ratified by Darlington Borough Council in January 2002. This document provided the framework for older people to work in partnership with agencies' staff (see Box 40).

Box 40 What is in the Darlington Strategy for Older People?

The Strategy had at its core a vision for the future: Darlington's older people, local authority and local health services, and other local organisations, having an open and honest understanding that they are equal and accountable partners, who are working together to:

1 improve the quality of life for older people in the Borough, and promote the benefits of doing so

(Continued)

2 ensure that older people are listened to, their views are acknowledged and respected, and their needs are met, irrespective of who they are, where they live and the services they may need

3 empower older people so they can make valid and informed choices, and have control over their own lives

4 provide opportunities for all older people to become involved with the improvement of services in Darlington, if they so wish

5 provide opportunities for all older people to have access to, and participate in, their community as useful and respected citizens, and to fully enjoy their social and leisure activities and interests.

This vision is underpinned by a set of underlying principles that enable older people to have a full and active role as citizens of Darlington and its surrounding areas.

Establishment and structures of GOLD

After the development of the Strategy document, the project moved onto the implementation phase, which is now ongoing. There was a gap between the development of the Strategy document and the establishment of GOLD, so the next phase really commenced with the appointment of staff to the integrated older people's team, later known as the GOLD team. The team included project management staff (one whole time equivalent [wte] Darlington Social Services and one wte Darlington Primary Care Trust manager), one community development worker (later increasing to two workers, with one on a temporary three-year contract) and an administrator dedicated to the team. Darlington Primary Care Trust (PCT) and Social Services provided the funding for staff costs and for the resources required for the initiative.

An early part of the work of this team was devoted to establishing a group of older people who were willing to take the Strategy forward and the structures to enable work to commence on older people's issues. First, they approached those older people who had taken part in the consultation activities to invite them to become members of Growing Older in Darlington (GOiD). A database of members was established and this now includes details of 385 people.

The people who agreed to join GOiD entered into much discussion about the acronym – GOiD. They did not like the images that were associated with 'GOiD'. So they suggested that 'GOLD' was more acceptable, as it gave a positive image to the initiative.

Following the establishment of the GOLD team there was a flurry of activity with the setting up of working groups known as 'GOLD task groups'. These groups and their work continuously change to reflect the priorities and issues of older people in Darlington. At the time of writing this report the following groups existed:

- Positive Images and Publicity
- Transport
- Rooting Out Age Discrimination
- Housing and Practical Support
- Information
- Active Ageing Reference Group.

Of the GOLD membership, approximately 10 per cent are actively engaged in the task groups, with some members participating in more than one group. The majority of the members take part in social events and consultation activities, and they receive information from GOLD through the quarterly newsletter.

GOLD is able to influence policy and service planning in Darlington through its relationship with statutory agencies. Older people are represented on the Local Implementation Team (LIT), the body that is responsible for implementing the National Service Framework (NSF) for Older People in Darlington. In addition older people engage with decision-making processes through their participation in the GOLD task groups and other groups that relate to the NSF milestones.

What has changed as a result of GOLD?

There is an abundance of literature describing what is now taking place under the auspices of GOLD. Members of the task groups work consistently to fulfil their objectives and this results in a range of outcomes. Here are just a few examples of the activities that have taken place in the last year:

- a survey on age discrimination in health services
- intergenerational work – GOLD members worked with schoolchildren to perform a play about attitudes to age and have worked on equality issues

- participation in the Darlington carnival
- GOLD anniversary events
- development of a bid and securing funds for an older people's nurse
- a programme of visits to residents of care homes is in development – the ReACT reminiscence equipment will be used in the programme to promote conversation and reminiscence between the resident and the visitor.

From the above list it is evident that the outputs from GOLD are varied.

The evaluation report produced by Peter Fletcher Associates (2002b) affirms that the Strategy has had a positive impact on the lives of older people.

> The work has raised the profile of older people, their needs, and their place as active citizens. The culture change that people hoped for has begun: attitudes are starting to change, so that what is considered is what older people require to lead full lives, rather than simply what services can do.
> (Peter Fletcher Associates, 2002b, p. 25)

This is a brief overview of the development of GOLD and the changes that have taken place, in order to give the reader an understanding of GOLD and the impact that it is having on the lives of older people. We now turn to a discussion about the involvement of older people in the GOLD initiative.

The involvement of older people in GOLD

Older people's views of their participation in GOLD

GOLD gave older people hope that things could change

The older citizens of Darlington wanted things to change and the overwhelming attendance at the initial consultation meeting bore testimony to this. There was a widely held belief that agency staff and the wider population of Darlington held negative and stereotyped views of older people (see Box 41). This limited the contribution that older people made to their community, and they wanted this to change.

Box 41 Negative images of older people

A lot of people think that once you get old you don't know anything, you are just a load of stupid people who they have got to put up with. Also there is no more use for you – you have lost your usefulness. Well we wanted to dispel some of these images.

Older people often become isolated because people think that there is no more usefulness in them. Some do have difficulties. They get arthritis and things like that. Some lose their sight and they become deaf … things happen to them and sometimes they have problems coping with life. We wanted to help these people by making it more possible for them to become integrated with the rest of the citizens of the town again.

With the development of Darlington Strategy for Older People and GOLD came the possibility that change could occur. A new vision slowly emerged – older citizens of Darlington could be instrumental in improving the lives of older people in their community through active participation in decision- and policy-making processes. This was pioneering and opened new possibilities for the way that people lived their later life in Darlington. When the people we interviewed spoke about this time, they highlighted the energy that older people brought to this project and their commitment to bring about change.

The first stage of the project focused on translating the vision that they held about creating a new and better future for the older citizens of Darlington into a strategy document. When the strategy document was developed it received a high-profile launch in the local media. This brought the creators of the Strategy into the public eye; for example, they were interviewed on radio. This was a new experience for many of the older people involved with this initiative and they enjoyed the acknowledgement that they received for their efforts. They were also pleased with the foundation they had established, which would make it possible to move the older people's agenda forward.

GOLD partnership or consultation

There was a real sense of partnership between older people and agency staff at the beginning of the project. Both parties felt that they had contributed something of value to the initiative. Their relationship had grown through working together on the Strategy and this was important to both parties, albeit for different reasons. The older people felt that they now had a platform that gave them a voice for older people's

issues and priorities, whereas agency staff felt that they had developed an approach for meaningful engagement with the public.

The equality and interdependence experienced by the older people appeared to change after the withdrawal of the consultants who had facilitated the development of the Strategy. The older people participants in the Strategy began to feel that they were being 'pushed to the background'. Slowly and increasingly they felt that they had less influence over decisions and the older person's agenda, though three of the six continued to be involved (see Box 42). They began to feel that they were being consulted rather than working in partnership with statutory agencies.

Box 42 Having involvement and limited influence

Older people were involved in the selection of the GOLD team. They asked questions of the applicants and took part in the final selection of the appointees; however, they had less influence over the final decision:

> If people are being invited to make a contribution it should have been on an equal footing with everyone else. In the question of votes everybody should have had the same votes. We [the older people on the panel] had one block vote and everyone else had individual votes. Either all social services should have been one, all PCT should have been one and we should have been one … what I am saying is, if you're going to have block votes, everyone should be block voting. And if you are going to have single votes everyone should be single voting. That is my point.

Transforming the vision to action

After the business of agreeing the Darlington Strategy for Older People and establishing the GOLD team, very little seemed to happen. Consequently, older people who had been involved in the Steering Group felt that momentum was lost and with this their zeal deteriorated. For the wider group of older people who had taken part in the initial consultation this had been their experience for some time. They had lost touch with GOLD.

All of this changed with the establishment of the GOLD task groups, with members being invited to take part. Those who were interested in the task groups quickly found that their work snowballed, particularly those who took part in more than one group and were involved with more than one organisation (see Box 43).

Box 43 Work all too easily snowballs and extensive commitments can get overwhelming

> One thing moves onto another and you get involved in the groups and then the coffee mornings and then the carnivals where you get involved in making things for that. It can turn into a full-time job.

Particularly when they are involved in a range of groups as well as GOLD:

> There was one day where I had three meetings in a day. One started at 4.00 p.m. and the other finished at 4.30 p.m. I had to leave one early and I had to make a rush of it. I was late for one and left the other early. Also I had to go out in the evening … But that doesn't happen very often.

GOLD had entered a new phase. This was an exciting time with so much happening at once; some of the concerns that had existed when nothing appeared to be happening about the future direction of GOLD were overshadowed by the wave of activity that brought a wider group of members into active participation in the working groups.

Why did older people get involved with GOLD?

People gave different reasons for their participation in GOLD (see Box 44). The overriding driver for many people was to use their time in ways that could improve Darlington and, in turn, could improve the lives of older people who lived in the town. This is best expressed in the words of one GOLD member:

> If you feel passionately about things you have a view and you get involved because you want things to be the best for everyone.

Box 44 Reasons given for taking part in GOLD

To improve the quality of life of older people living in Darlington:

> Wanting to make improvements to Darlington.
>
> To change the way the public perceived older people.
>
> Taking the opportunity to say what matters to older people.

(Continued)

To make a difference to the lives of older people:

> A desire to help other older people in less fortunate health and social circumstance, and in this way improving their circumstances.
>
> To help people to socialise – many older people are lonely and this is a big problem.

To do something meaningful in later life:

> For many personal reasons: to continue to use knowledge, skills and abilities post retirement, to increase social networks, to do something meaningful, to have fun.
>
> I wanted to join this particular group [Positive Images and Publicity Group]. It is not that I am vastly experienced, but I enjoy doing it … putting things together and just getting designs out and making up the designs.
>
> GOLD is an excellent forum for people who, all through their life, have not been part of a committee or in a position to make decisions. It is great to come into a situation where your views are listened to and they count.
>
> Getting out and meeting other people is really important to me – GOLD helps this to happen.

At a personal level, older people became GOLD members to provide opportunities for them to continue to use their skills, knowledge and abilities, and to develop them. They were supported to do this in a number of ways: for example, new members were asked to complete the expression of interest form, which asked for details of their interests and expertise. This information was used to direct members to relevant activities; also the GOLD newsletter included items about events and activities where members could take part.

The GOLD infrastructure was viewed as inclusive in the way that it enabled everyone to decide what and how much they would contribute to GOLD. For some this involved chairing a task group, whereas others used their skills such as carpentry to create the items for the GOLD float for the Darlington festival. Some were active participants in a range of activities, whereas others attended some of the annual celebratory events such as the Christmas party. Every contribution was valued, regardless of its type or scale. It was important to everyone to be able to ‘find a place’ where they felt they were able to participate within the committees and activities that existed under the auspices of GOLD.

Box 45 GOLD makes a difference to those who get involved

> It really just gives you the confidence to do other things. I think the fact that I enjoy being in GOLD is good, but it has given me the confidence to go and do other things.
>
> A lot of people withdraw into themselves when they retire and they don't want to go out. Becoming a member of GOLD stopped this happening to me.

Determining the scale of contribution to GOLD

While members determined the extent to which they were involved with GOLD, some felt that they were on the verge of being overwhelmed by their commitments (see Box 43 above). In contrast, others limited their participation to the social events. This led to tensions within the membership – some people felt they were doing too much while others seemed to make little or no contribution. The discussions that we had with active members led us to identify that, they were so enthusiastic and committed to GOLD, they required support to say 'no' at times.

The less active members also spoke about the issues that affected the scale of their involvement. They highlighted two key factors that determined this. First, they were heavily committed to other organisations or groups, yet they wanted to maintain their links with GOLD. They therefore continued their membership to enable them to be informed about what was happening. The other factor concerned their perception that they were too frail to make a very active contribution to the task groups but they continued to have a desire to participate in social activities that helped them to experience a sense of inclusion in their local community.

Box 46 Getting more people to become actively involved in the task groups is a thorny issue

> We want some more of those people to come but we don't know how to motivate them. We've tried various open days and meetings and writing to them … So we need more new people and possibly younger people to come and work with us.

What helps and what inhibits older people's involvement in GOLD?

Well this is why GOLD was formed – to let older people have a say in what they want and not having to be told 'this is for you'. We know what we want and that is why we get together to influence the running of the town in the way that we like it.

The idea expressed in the above quotation, that older people can have a say in the things that matter to them, was very influential in attracting people to GOLD and in sustaining their commitment to it. The structures of GOLD (the task groups and representation on the LIT) enabled members to communicate or meet with decision makers. This was a refreshing and empowering experience for people, particularly when they felt that their input had a direct impact on what was taking place in the town. The most satisfying experiences were those situations where GOLD members could see the immediate fruits of their labour. For example, older and younger people developed new understandings of each other when they worked together and this broke down some of the barriers that existed between these generations.

In contrast, the least satisfying experiences for GOLD members were the times when they felt that they were being ignored and even patronised. For example, members of the Transport Task Group spoke of their frustrations when they received no response from councillors after outlining their concerns (see Box 47).

Box 47 Having a voice that appears to be unheard is frustrating

I sometimes wonder about organisations – whether we're being patronised. They have to be seen to listen to groups in discussions about things but they have no intention of taking any notice. So you get a little bit despondent about it.

We've tried all the time. We're just wasting our time.

Well we have a council representative here, but all he can do is pass the information back up the line. It seems to go nowhere.

GOLD members felt that they were able to respond to agency-determined agendas and they were also able to set their own. In both these cases the GOLD team were found to be very helpful in providing support and resources to work towards each agenda. There was recognition that this was a developmental process and the members we spoke to felt that they were 'on the first rung of the ladder' and that, in the task groups, their 'ideas were beginning to gel'. In this respect some GOLD members experienced some lack of direction or uncertainty when they came up

against what they perceived to be blocks in the system. In these situations they would have welcomed greater direction from the GOLD team about appropriate or different approaches to influence agency-led agendas and agency-dominated decision-making processes.

The other feature of GOLD that has had a tremendous impact on the experience of members is the support, encouragement and fellowship that members give to each other. They are drawn to GOLD through their common interest, but it is the relationship-centred processes that help them to achieve their outcomes.

The GOLD team's view of working with older people

The team valued their work with the dedicated and enthusiastic members of GOLD. They found that it was refreshing to work with people who were committed to championing older people's issues and to working with statutory agencies to improve services. They witnessed the active GOLD members in the task groups tirelessly volunteering their time and effort to take the older person's agenda forward, and this was greatly respected.

There was a real sense of partnership working between the team and GOLD members. They valued the contribution that each party brought to GOLD – older people bringing their life experiences, skills and talents to all aspects of GOLD; and the team creating structures and processes to facilitate activities, and providing administrative support that enabled the groups to function. The bringing together of these different contributions led to many successes where members and the team could see that they were making a difference to their community through generating and implementing ideas from the grass roots.

Box 48 New ideas are always coming forward from members, ensuring that GOLD is continuously reshaped to reflect what older people want and what they need

A member mentioned that it would be good to have a gardening club, so we put in an application to get some funds and this was successful. Now the gardening project has started.

The team were also acutely aware that GOLD continued to encounter many blocks in its endeavours to influence policy and planning in Darlington; for instance, older people continued to be informed of decisions rather than being consulted in some

aspects of local government. The GOLD team were aware that things would have to change if older people were to 'realise the action side of GOLD' and increase their impact on the local community.

Developing new ways of working

To work effectively with older people team members felt that they needed to develop new practices. The key features of the team's approach to their work were being relationship centred and working in partnership with older people. This was quite a departure from the outcome-based or target-driven practices that dominated their work in statutory organisations. Being relationship centred required them to be very flexible and to engage in practices that were largely invisible to the organisation. For example, when the team described the way that GOLD members dropped into the office for a chat and the constant telephone calls, they highlighted the difficulty that they experienced in accounting for the use of their time. They had considered developing a pro forma to evidence their daily activities:

> We should monitor our time with members. I've drawn up a contact sheet but nobody uses them. But we should monitor what we're doing to help people, otherwise we can't prove what we are doing with all the time that we are spending with people.

Through getting side to side with members, the team felt that they were able to gain an insight to their issues and priorities. From this, they identified the most effective way of working in collaboration with members to achieve the outcome that they desired.

Box 49 Team members bring their knowledge of local organisations to GOLD, which enhances integrated working between GOLD and statutory agencies

> You need to have people on board who are working for the statutory bodies and authorities, and who understand the key issues of older people and the authorities. It is important to have someone who can run across the divide and that is what I think the team bring to GOLD.
>
> I understood the way that the council worked and I knew many other people in the council. I was able to get in touch with them when we were commencing a new project and this moved things along quickly … It is handy to know people; for example, when something cropped up, I was able to phone people and if they didn't know they gave me other names and that was really helpful.

Moving forward

GOLD had reached a transition in its development and was entering a phase where its members wanted their participation in local government to shift from involvement to having influence, particularly in those situations where they felt their voice was unheard or ignored. The team, in recognition of GOLD entering a new stage, identified four key areas where development was needed to move the agenda forward.

1 *Succession planning:* the membership of GOLD is ageing so one of the key factors that will affect its survival is its ability to attract others into membership. This should be as inclusive as possible to enable people with hearing or visual problems, ethnic communities and those living alternative life styles to participate. Past experience led the team to view recruitment as a 'slow and painful process'. The most successful strategies were relationship centred and the team have attempted to build upon this. Drawing new and existing members into active membership is also critical to GOLD's future, and this has been an aspect of GOLD that has troubled members and the team. Creating innovative strategies to get 'people on board and working in the task groups' requires investment at this point in GOLD's development.

2 *Capacity building:* GOLD members now have the confidence to attend meetings and speak on issues, but different developmental needs are emerging. If older people are to have an influence on decision-making processes through their participation they need: training to enable them to build a coherent argument, with a body of evidence to support their case; to acquire knowledge of the decision-making processes and decision makers in ever-changing statutory organisations; to develop skills to enable them to present their argument in ways that make the greatest impact.

3 *Shifting from a process-focused to an outcome-focused agenda:* the initial priorities for the team and members were process focused. When the processes were established some team members felt that 'GOLD had drifted' and 'GOLD had lost its way' because the direction of the project had not changed with the evolving situation. It was now time to become outcome focused. The overarching outcomes were set in the initial strategy document, which was a ten-year plan for the town. To reach that goal a business plan for GOLD and for each of the task groups could be developed, setting out the steps in incremental stages to fulfil the long-term objectives (see Box 50 below).

4 *Developing older-person as well as agency-led approaches:* GOLD members need to develop new and effective ways of engaging with agencies (see Box 51). Previously, key agency and local government personnel had stated that they would meet with members to discuss issues and they cancelled at the last minute. This gave the impression to GOLD and its members that their issues had low priority. To improve GOLD's effectiveness, its members and the team need to develop strategies to enhance agency commitment to enable them to realise outcomes from their efforts.

Box 50 Moving to an outcome-focused model of involvement

> I don't see a focus on outcomes here [GOLD]. I really struggle to come up with concrete achievements of what we've done. I don't want to undermine the work that we've done, but I came here wanting to make a difference … You need to know what you are aiming to achieve, and I think that the goal has to be specific … and that is where the business planning comes in.

In respect of being outcome orientated in the task groups:

> I think that they need to focus on the smaller aspects to get to the bigger picture of the problem. To get the bigger result they need to do one small thing at a time towards the final outcome … it has to be an incremental approach to things because they aren't going to get the big bang.

Box 51 Reaching commitment to achieve outcomes

> I would ask the statutory agencies what their top five things where they wanted to consult with older people, and when this was reached, I would then seek some written agreement with those people to commit them to attend meetings when the task groups invited them.

Another aspect of developing new strategies concerns the way that agencies and older people work together. In the main, consultation comes to GOLD rather than GOLD members and staff actively seeking ways to consult with external agencies. The involvement of older people in this way does not fully realise the citizenship approach that was embraced in the Darlington Strategy for Older People. If GOLD members identified the issues that were important to them and consulted with agencies about these issues then a citizen-based rather than a service-based agenda would permeate discussions between older people and agencies.

Stakeholders' views of older people's involvement through GOLD

Officers working in statutory agencies across Darlington and its neighbouring boroughs were keen to develop the consultative practices that they had used to fulfil their statutory duties to involve the public. In their work with older people they had been driven by a service strategy, hence they focused on engaging with the population of older people who were service users. Across statutory agencies there was a growing realisation that there was a need to 'spread their work to understand better the needs of the older population'. The emphasis on active ageing, among other issues in the National Service Framework, and the development of strategies to involve older people in local government, which were taking place in other localities reinforced this.

Hence, they sought ways to engage with the entire population of older citizens within the locality and this involved moving from a service-orientated to a citizen-based model of involvement (see Box 52).

Box 52 Moving to a citizen-based model to engage older people

> We wanted to move away from simply issues to do with the National Service Framework and service-orientated processes, and we moved to what we called in the Strategy a 'citizenship model'. This took in the whole population of older people as the starting point rather than that group of a small number of people who would need services at any one time, particularly social care or acute hospital care … So we took the decision to try and develop a strategy about what it was like to grow older and live in Darlington … This opened up the way to consider a whole range of other issues alongside all of the other things that we did within our organisations.

With the development of GOLD, the agencies had direct access to 'a fantastic body of consultation'. All of the agencies that were represented in the GOLD partnership were constantly engaged in a process of responding to requests for feedback on policy and guidance documents from government departments. Although this usually involved some form of consultation with the public, often, agency staff were given a short time frame to contribute to the process. This led to much dissatisfaction, as there was little time to organise meetings to give a considered response. GOLD provided an infrastructure for agency staff to approach and involve older people in one-off and ongoing consultation activities (see Box 53).

Box 53 Through GOLD older people have a presence that influences service development

> I think that GOLD has become embedded in the culture of Darlington … GOLD has moved from being single events where people came together and were presented with information, were involved in workshops, had an input and then they went away. The involvement now across the board is far more subtle and there's involvement from the community at all kinds of levels.

The shift in focus from service-oriented consultation processes was quite a major change for agency staff, which was both exciting and challenging. The excitement came from agency staff and older people establishing the agenda together with the possibility that they would collaborate to move issues forward. There was great willingness from everyone involved in the initiative to work in partnership with each other to change things for the better. Statutory organisations demonstrated their commitment through their financial support to GOLD, and agency staff gave their time and support to the initiative:

> I think that it has been very positive and altogether challenging … we have to keep the faith, this is about something that we started together with older people and we need to keep pushing it through.

Though agency staff and older people had moved with their vision of working in partnership to effect a new reality, the organisational structures around them had not changed to support new ways of working. This created tension for everyone involved. For example, agency staff felt that they had to respond to the imperatives of their organisation and, at times, this was incompatible with the priorities of older people (see Box 54). This led to a situation where they had to make hard choices concerning the priority to be given to the various activities in their role. They did this in the knowledge that the decision they made had the potential to undermine the partnership with older people, which they were trying so hard to develop.

Box 54 Incompatible agendas

> We don't get sacked if we don't do something that older people want us to do. We do get sacked if we don't reach our targets and fulfil our performance indicators. That's just a fact of life and I think that a lot of the early stage was about helping each other to understand our own respective agendas and to respect those agendas as legitimate.

Although these difficulties persist, everyone continues to be committed to move the public and patient involvement process away from being an end in itself, to realise outcomes that are valued by agencies and older people. This has been achieved in some areas and not in others. In housing, for example, partnership working has influenced specifications and standards for housing for older people (see Box 56 below). In contrast, there is a general perception that there has been little impact on transport policy.

Box 55 Organisational processes can influence the balance of power in partnerships between older people and agency staff

The older people on the initial steering group had worked successfully in partnership with officers to develop the strategy. The process of appointing staff to the GOLD team led the older people to reflect on their role and the influence that they really had:

> They felt that they had a real stake and power in what the posts were, what the job descriptions looked like, who made the decisions and appointments … and at the end of the day their role was advisory … they questioned who had the real power and what did it all mean.

Box 56 Working together on housing for older people

> It has changed the way that we think, right down to the little things … generally I think we are a lot more responsive in terms of how we consult within housing. We have got things we call like 'come for a chat' sessions … where what we found with older people in sheltered schemes is they don't necessarily want to come to a big public meeting or whatever. They like us to go out to their particular sheltered schemes and talk to them about the issues that relate specifically to them. And we are now getting much better feedback on the type of things that they want: better grounds maintenance, a lot more work in terms of adaptations in the home. They are not wanting baths, they want flat-floor showers. So we are changing specifications and standards and it has just taken off right across the board.

Generally, the stakeholders argued that their respective organisations were learning through GOLD how to work in partnership with grass-roots groups. This was a journey they had started but not completed. Along this journey the stakeholders had to overcome many hurdles, such as restructuring of their respective organisations and job reassignment. These changes were at the least disruptive and at the most had the potential to jeopardise GOLD.

They also argued that GOLD members had started the same journey and the development that was needed for them to reach their full potential was just emerging. To achieve this, the stakeholders made the following recommendations.

- *To build on practices that have proved to be effective:* there is much discussion of the benefits and limitations of GOLD being financially dependent on Social Services and the Primary Care Trust or becoming an independent organisation. The overriding view of the stakeholders is for GOLD to be supported to move to a position of interdependence, which will enable the organisation to enjoy the benefits of maintaining direct input to statutory organisations while members have the freedom to pursue an older person's agenda.

- *To extend the existing partnership:* the partnership does not have representation from all agencies and organisations that concern older people's issues. There is a notable lack of involvement from the voluntary sector and the Leisure Department within the council.

- *To enhance the capacity of GOLD to influence local policy and service planning:* the GOLD team and its members need to learn 'how to strike effectively'. Within Darlington GOLD has gained credibility as an organisation that has heightened awareness of and response to older people's issues. It is now time for the organisation to become more outcome focused, and to develop realistic and achievable objectives for the following and forthcoming years:

  > GOLD has found its place but it also needs to flex its muscles. I think that is our task for the next 12 months: to go from something that helped to create the Strategy, through an early transitional period, to something that then is able to be around to influence and implement bits of it itself.

The key messages about involving older people in local government through GOLD

Through their involvement older people want to make a difference

The members of GOLD volunteer their time, energy and expertise to this initiative. Members make different types of contribution to GOLD, which are valued equally – some members chair meetings and others contribute in practical ways. This is very enjoyable for most people, most of the time. When the work is demanding and at times frustrating, members continue to work in order to make a difference to their community.

Sustaining the involvement of older people

The active members of GOLD are extremely busy. They contribute to GOLD as well as many other community-based initiatives and older people's organisations. There is some concern that this level of activity cannot be sustained by such a small proportion of the membership. Attention needs to be given to encouraging and supporting new and existing members to make a full contribution to GOLD.

Older people and agencies value working in partnership with each other

Both older people and agency staff valued the opportunity to work together to make Darlington a better place to grow older in. This has led to outcomes that would not have come into being without GOLD.

GOLD is an effective model for the involvement of older people

With the development of GOLD came the opportunity to move away from a service to an older person's agenda. Those who were involved in developing the Strategy felt that this had been achieved. They were able to bring older people's issues to the attention of key decision makers without the need to negotiate organisational structures. The older citizens of Darlington felt that they now had a voice and were able to influence change.

Achieving a citizen- rather than a service-based agenda

The GOLD infrastructure provided a framework for an interdependent relationship to grow between the partners. It enabled older people to work inside the system as partners, giving their time and their knowledge to inform service development. While there was the opportunity for everyone to contribute something that was perceived to be of value by the other partners, the tendency to consult older people remains. Further development of the structure to enable older people to become equal partners rather than mere contributors to the process would enhance the effectiveness of this model.

Making the transition to an outcome-focused agenda

The early phase of GOLD has concentrated on establishing structures and processes. While many outcomes have been derived from these processes, these were largely by-products of successful processes. All the participants in the partnership indicated that the move to an outcome-based agenda would focus attention on those activities and those outcomes that have the potential to make an impact on the community. This transition needs to be accompanied with approaches that track the changes and outcomes arising from GOLD.

Pattern of involvement

During the implementation of Darlington's Older People's Strategy different patterns of participation emerged. Every contribution was valued equally. Where the older person's agenda was given priority, those involved controlled the activity. In other facets of GOLD the service agenda had priority and older people were involved in consultation activities. Tension occurred in situations where the participants had different understandings of the level of involvement and when their expectations of their influence in decision-making processes differed.

Effective leadership

The strong leadership from the original Steering Group and within the GOLD team has nurtured the older citizens of Darlington to contribute to decision-making processes within the town. Through effective leadership, GOLD has been sustained

amidst organisational changes that have occurred in statutory agencies. These changes, however, have impeded the development of GOLD because they have led to role change and redeployment of the agency staff managing GOLD. As the management team changed, this affected the operational processes within GOLD. A commitment to establishing long-term leadership, particularly within the middle-management level, would foster more effective community participation.

Capacity development

The partnership between older people and agency staff didn't 'just happen!'. Skilled facilitation with a degree of creativity led to the establishment of new working practices. GOLD's team and stakeholders learned from their experience of being GOLD members. Their capacity to work together has changed and developed. Hence, there is a need to support and nurture all parties in the relationship in order to continue to develop their capacity to make an impact on decision-making processes.

Summary

Through GOLD older people have a platform to raise the issues that are important to them and they have mechanisms to link their voice into existing structures. The innovative, interdependent way that older people and agencies are working together needs to be fostered and developed. The partnership organisations need to enhance their capacity to support the effective involvement of older people and members of GOLD need to develop their capacity to participate effectively.

Patterns of participation across the GOLD infrastructure vary. GOLD members are aware that they are participating in various ways. In some situations they are involved in consultation, which is controlled by decision makers and in other circumstances they have substantial control over all their activities. Hence, different types of influence and power exist within the same infrastructure. This is acceptable to older people, and appropriate if all parties within the partnership understand and agree to participate in this way, otherwise conflict and tension can result. By reviewing the purpose of the partnership, inconsistencies will come to light, particularly in situations where understandings differ, and, through negotiation, new ways of working based on a shared understanding of the agenda could be agreed.

GOLD is an ambitious project, which is still in the early stages of its development, and the report should be read and understood in this context. The overriding conclusion that can be drawn from this case study investigation is that GOLD has led to substantial change in the way that older people are involved in decision-making processes in Darlington.

The North Tyneside Handyperson Scheme

Development of the Scheme

The importance of good housing services – that is, repairs, maintenance, simple adaptations, gardening, decorating and so on – was highlighted through the following incident:

> One day I was out walking the dog and an elderly lady came out of her house and asked me if I could help her. I didn't know her, yet she drew me into her house. She said that she had had no lighting for a long time. The bulbs had gone, therefore I put a bulb in for her. She did not know me at all and was taking a risk! She did not want to ask the neighbours. (Member of the management committee)

This led the man who had been approached to reflect on the danger that this woman had placed herself in to make a minor, but necessary, repair to her home. This situation brought to his mind other circumstances where older people needed housing repairs and/or housing adaptations in their homes, yet were unable to identify someone to do the work for a price they could afford. Tradesmen were neither interested in undertaking these smaller jobs nor willing to accept a contract for such tasks. Even if a tradesman could be persuaded to do this type of work, the cost of the call-out charge was often prohibitive for older people to have the work done.

In response to these circumstances, the man explored different ways to meet these needs of older people, and concluded that a handyperson scheme would be appropriate:

> I contacted Social Services, to see what other schemes existed, and I went to see some of these. Following this, I got in touch with Age Concern about setting something up – that's exactly what we did. Formed a board and set up the Handyperson Scheme.

From this initial contact, Age Concern North Tyneside set up a Steering Group and the Scheme commenced in December 1998. Initial funding came from Tyne and Wear Health Action Zone and North Tyneside Council subsequently funded the Scheme for £20,000 per year.

The origin of this Scheme draws attention to the challenges of supporting older people to live independent lives in their own homes. As people age, one of the principal decisions they make is whether to stay put or move. This is a difficult decision because a house is often more than a mere building. It has become increasingly recognised that it is a place – a home – invested with meaning. For most people, home is at the heart of their personal/private life. It is a place where they can be themselves and a place that represents them. Munro and Leather (2000) in their investigations of owner-occupiers' accounts of why they chose to undertake particular work in their houses, found that they were strongly motivated by consumption values to do this. In other words, repairing or changing a home to make it a suitable focus for family and personal life, and a place that presents an image to the outside world that is acceptable to the inhabitants, is of greatest priority to occupants.

The importance of being able to modify a home in the service of personal needs does not change as people age, yet physical ability to do this does decline as age advances. In addition, the impoverished economic circumstances of older people, often resulting from inadequate pensions, prevent them from modernising and repairing their properties. For many people, how they will continue to maintain, repair and adapt their home is a source of unremitting, nagging anxiety throughout their later years (Harrison, 2000).

Box 57 Older people need assistance to do the things that they can no longer do

One older woman recalled a story that led her to seek support from Age Concern. The flat above her had flooded resulting in the need to decorate her flat. She contracted a decorator to do this. The decorator had taken her curtains down to paint and did not return to rehang them when the job was completed. She was unable to do this herself, so she contacted Age Concern for advice. The following statement gives an insight to her predicament:

> Oh goodness knows how I would have managed. I went five weeks without curtains up. One of my granddaughters tried to put the curtains up and the same day the whole lot came down. So I was five weeks

(Continued)

> without curtains and I just had newspapers up … you see the family don't live here and my daughter has had two big cancer operations in the last two years and she cannot get up on the ladders … I cannot get anyone in here to help.
> (User of the Handyperson Scheme)

British housing policy has attempted to respond to these issues by supporting projects such as 'Staying Put' and 'Care and Repair' (Anchor Housing Trust, 1984; Care and Repair Ltd, 1987). Such projects provide financial help, social services and advice and assistance on repairs for older people. While the demand for these services demonstrates that these are the services that older people want, there is also evidence of a great need for support to attend to small-scale jobs that are equally important to daily life, such as changing light bulbs, hanging curtains, decorating and bathing adaptations (see, for example, Cormie and Crichton, 1996; Clark *et al.*, 1998).

The situation in North Tyneside was a further example of this type of unmet need. The actions of local citizens led to the development of a service that was able to respond to people over 60 years of age and those under 60 who were in receipt of long-term disability benefit, and to assist them with housing adaptations, maintenance and repairs.

What services does the Scheme provide?

The volunteers provide the handyperson services in a friendly way and this is greatly appreciated by service users. There are three main areas of activity.

1 *Handyperson service:* this service provides small jobs that are required for maintenance and/or the repair of homes – for example, replacing washers on bathroom taps, supplying and installing smoke alarms, fitting carpet tiles, refitting towel rails, washing lampshades and fitting shelves in a cupboard. The range of activity does not include decorating, gardening, electrical and gas-fitting work.

2 *Home visit safety check:* this is a preventative and health promotion service. When new people contact the Scheme for assistance they are offered the opportunity to have a home visit safety check. During the visit the following are checked: smoke alarms, locks, kettles to ensure that the flex is curled, obstacles, lighting (bulbs are checked and replaced). The householder is also given advice about improvements that can be made to their home.

3 *Recommendation of tradespeople:* since the beginning of the Scheme, a list of recommended tradespeople has been developed. When individuals contact the Scheme, the list is made available to them.

The range of services within the above categories is continuously reviewed and developed in response to feedback from participants within the initiative.

Who can use the Handyperson Scheme?

The Scheme aims to target those people in greatest need. It is available to everyone over 60 and anyone under 60 on a long-term disability benefit. The vast majority of users are over 70 and almost a third over 80.

Service users are asked to meet the cost of equipment or appliances; however, labour is free.

Managerial and staffing arrangements

The Scheme is directed through a management committee, which is chaired by the person who initiated the project. The committee members include service users, the handyperson co-ordinator, handyperson volunteers, management committee volunteers, the Senior Development Officer of Age Concern North Tyneside and representatives from local agencies and organisations such as Churches Acting Together, Anchor Stay Put and (until recently) North Tyneside Council. Hence, the Scheme is networked to other local services through its committee membership.

The Scheme is co-ordinated by a part-time, paid worker, who is seconded from Age Concern North Tyneside. This employment arrangement is helpful because Age Concern North Tyneside addresses the employment issues, allowing the management committee to focus on the implementation and development of the Scheme. These arrangements provide security to the Scheme worker, who is responsible for the day-to-day management, which includes co-ordinating and allocating jobs to the volunteers, maintaining records and writing reports for funders.

There are 12 handyperson volunteers who work in the Scheme. The majority of the volunteers are recruited through Age Concern North Tyneside, which highlights the crucial role of this organisation in the implementation of the Scheme. The volunteers come from a broad cross-section of people who want to give something back to the

community. All of the volunteers are very 'people orientated' and they have an interest in DIY or have been skilled tradespeople.

Processes of involvement of older people in the Scheme

Types of involvement

In the previous discussion it was indicated that older people are involved with the Scheme in different ways. They use, provide and manage the Handyperson Scheme. However, we would not like to give the impression that these are exclusive categories. While some individuals restrict their involvement to use of the Scheme, others are both service users and members of the management committee.

When we asked participants about the type and extent of their involvement with the Scheme they indicated that it was important that they had the opportunity to take part in the Scheme in different ways. They were informed of the range of activities that they could take part in and were told about what this involved. Following this, they were supported to set their own parameters for their involvement with the Scheme.

What service users say about their involvement

All of the service users who took part in this study spoke highly of their experiences with the Scheme. We were left in no doubt that it was invaluable to them (see Box 58). Yet, the majority of service users preferred to restrict their involvement in the Scheme to that of user and they wanted to 'just leave it up to the others' to make management decisions.

Box 58 Quotations from service users about their experiences of the Handyperson Scheme

It was important:

> Knowing that there is someone there to do the things that you can't do for yourself.
>
> An efficient job.
>
> A reliable service.

(Continued)

A prompt service.

Having things done that were more than the task [e.g. a volunteer put linings on the curtains that she was hanging, although she was not asked to do this].

Being able to trust the volunteers.

Security:

It is good knowing that there is somebody there to do things.

A pleasant experience:

I thoroughly enjoyed it because [s]he was nice. [S]he was chatty. I don't get many people to talk to, as I say, most of my neighbours have died.

About the personal touch:

That [volunteer's name] is very nice and he asks you how you are.

This may suggest that the service users do not get involved in the way that the Scheme functions. This is far from true. They were concerned about the quality of service that they received and they wanted to be consulted about this. They did so by discussing the details of the job with the volunteer. There was evidence that these discussions influenced the way that the job was carried out, resulting in the service users feeling in control of what took place in their house (see Box 59). They also completed a customer satisfaction questionnaire to give their views about the work. In return for completed work they could give donations, and they promoted the Scheme by 'telling everybody about it'.

Box 59 Having a say in the service

I felt that I was listened to when a volunteer came to fix a clothes line and he wanted to do it another way. But I said that I want it this way so I can do it myself – so he listened to me and did it the way that I said.
(Service user)

Box 60 Reasons given for restricting involvement with the Scheme

I would not like to be on the management committee because that would involve travelling and I am not good at travelling now.

If I took part in the meetings I would need a taxi and that is expensive. I have to use a taxi to go to my doctor appointments.
(Service users)

A few service users exercised the opportunity to take part in the management committee and in the Annual General Meeting. They felt that it was important to 'have a vote in the way that the service changed', and to 'tell them [the management committee] from a personal point of view what the volunteers do – they are unable to do this only by feedback and I would be honest in what I said'. They felt that they were listened to and they were able to influence the decisions that were made about the development of the Scheme.

What volunteers say about their involvement

The volunteers came to this work via different routes. Some approached volunteer agencies or Age Concern North Tyneside and others came to the Scheme following a personal invitation from another volunteer. One of the main motivations to do this type of work was to help others. During the initial point of contact, they were asked about their interests, abilities and desires, and from this they were pointed in the direction of the Handyperson Scheme. Many of the volunteers indicated that taking part in the Scheme provided an opportunity to use skills and talents through providing services to those in need. As well as helping others they spoke of personal gains from taking part in this work, such as the satisfaction of being there for other people, experiencing a sense of achievement from a job well done and feeling part of something that was worthwhile. For those who were retired, the Scheme was a way of doing something that had a sense of purpose, which gave meaning to a phase in life when you 'can feel useless and ready for the scrap heap'.

Box 61 Volunteers' accounts of what they found satisfying and pleasing about their involvement with the Scheme

I am able to do jobs for people that they can't get tradespeople to do.

There is the satisfaction that you do a job that will help somebody.

I go there to help and when I do that, I feel great – that reinforces the feeling that I want to do more.

I feel very satisfied when I complete a job – this is well worth more than payment!

You have that flexibility to do what is needed within your capability and within the scope of the Scheme.

It is the look on their faces when I finish that I appreciate.

When they phoned the Scheme they asked for me. Well people don't forget and I enjoy that.

I am pleased when work comes because it gives me something to do when I am at a loose end.

I still want to feel important and do things that are recognised.

I have met some lovely people through the Scheme.

Box 62 Feeling satisfaction from a job well done

I was asked to shave a door because it was sticking and was difficult to open. When I got there I found that the doorframe was rotting. Someone had put fixing screws in to hold it together and, because the wood was rotting, the screws were coming out and were blocking the hinges … she didn't want me to do too much because she had heard that she could have her doors replaced by the council. I did what I could and when I left she could open and close the door. I was pleased that I was able to help in the way that she wanted it.
(Volunteer)

The participants were supported to determine the type and extent of involvement that they had with the Scheme. This was important because everyone felt they had a contribution to make, which should be acceptable to them (see Box 63). While some

volunteers were involved with aspects of the Scheme, such as the management committee, in addition to their handyperson work, they considered the various contributions to serve different functions yet to be of equal importance. The type of feedback that the volunteers received from service users and from the management committee reinforced this view.

Box 63 It is important to feel comfortable about the type of contribution that you make to the Scheme

For example, volunteers stated:

> I am happy with the way that things are. I am not one for meetings. I have little to say in meetings. I am a not a thinker but a doer.
>
> I have got involved in the Handyperson Scheme, because it is the type of activity that I like to do – it is just up my street.

There were many factors that helped the volunteers' participation in the Scheme.

- Using existing skills and abilities, and developing new ones.
- Personal qualities – they are interested in people and they are motivated to improve the lives of other people.
- It is an enjoyable activity.
- Being able to 'fit' the handyperson work into their lives – 'there is no pressure of time'.
- Personal benefits that are derived from involvement in the Scheme.
- Good support structures – if volunteers find that a job requires more specialist skills they can refer this back to the co-ordinator.
- Having the opportunity to meet other volunteers in social occasions to discuss their work.
- Strong leadership and good co-ordination of the Scheme by a person who is an effective manager and is concerned about the well-being of the volunteers – 'he is responsive to your personal needs … you look up to him'.

They did encounter and were aware of some difficulties.

- Potential change in personal circumstances – many of the volunteers indicated they were aiming to sustain their involvement with the Scheme. However, they acknowledged that this could be achieved only as long as they enjoyed good health.

- Setting parameters on how much time they devoted to a particular job.

- Using their own transport and equipment to do their work.

- Lack of detailed information – 'sometimes when I get to a job I find that what the co-ordinator has been told bears little resemblance to what is actually required. This may make the work more complicated or complex to complete.'

- Difficulties in defining what is or what is not a handyperson job – some jobs might appear to be minimal but, when the volunteer arrives at the house, they might find they require skills beyond their competence to do the job.

- Poor involvement of the volunteers in meetings where they could share experiences – 'The opportunities are there for us to meet up but this is not well supported'.

During the discussions the volunteers were keen to impress on the researchers the importance of this Scheme. It provides an opportunity for older and younger people to work in partnership in the service of their community.

Management committee members' views of the involvement of older people in the Handyperson Scheme

There was an overriding message from committee members – that they were committed to eliciting the views of the older people who used and worked in the Handyperson Scheme. The Scheme originated from the concerns of local older people and it functioned to serve this group of people. For this reason the contribution of older people has been actively encouraged and valued.

Box 64 Valuing the contribution of older people

The contribution of older people ensures that the way it works comes from the grass roots. They know and understand the problems that older people encounter and the best way of responding.
(Committee member)

Older people are aware of and they recognise those things that are important to older people. These may be missed or underplayed by younger people.
(Older person volunteer)

The management committee is a forum where service users, volunteers and paid workers discuss the Scheme and make decisions about its future development. Although the meetings are chaired, open discussion is encouraged and everyone is asked for his or her opinion. The members welcome the way that 'you are encouraged to give ideas and shout up', 'all opinions are accepted' and 'no one laughs at any suggestion'. Some people found this to be a refreshing experience and they felt that the group rather than particular individuals influenced the decisions that were made.

There were many examples where the involvement of older people had influenced decisions about the way that the Scheme ran. For example, a volunteer handyperson had struggled with situations where service users wanted to offer a donation to the Scheme. This was difficult because he did not want to accept cash when he was doing a job. He suggested that the volunteers could carry donation envelopes and, if service users wanted to give a donation, they could be supplied with an envelope. This is being considered. In another situation, the treasurer (a volunteer) had suggested changes to the invoicing arrangements and these were implemented. These examples illustrate the way in which the ideas and concerns of the older people associated with the Scheme are responded to.

The way that older people promote the Scheme is invaluable to its acceptance in the community. Many older people are anxious about letting a stranger into their home and promotion of services by word of mouth is the most effective way of reaching older people who are not known to statutory services, yet are in need of assistance to maintain their homes to enable them to live independent lives as long as possible.

Box 65 Acceptance of the Scheme by older people

> We used to meet in the Methodist hall for the management meetings. Older people also went there for luncheon clubs and to go out on trips. One of the ladies needed to have some work done. She was very reluctant for this to happen. The others persuaded and she agreed. You see, they look out for each other. It is important to get into these tight-knit communities to support them and you can only do this if they trust you. (Management committee member)

The above discussion indicates that older people have different levels and types of involvement with the Scheme. One of the major concerns of the management committee is how this can be sustained and increased. Although those currently involved with the Scheme have little intention of changing their commitment, it is acknowledged that the circumstances of the volunteers may change, therefore there is a need to continuously recruit new volunteers. This is not an easy task. Older people have many demands on their time and the Handyperson Scheme competes with other organisations to encourage these people to participate in its activities. One response to these issues has been the development of an infrastructure that is supportive to both service users and volunteers.

Processes that enable and sustain older people's participation in the Scheme

The above discussion highlighted the different ways that older people are involved with planning and shaping the Scheme. It is evident that everyone makes a contribution to decisions about what the Scheme aims to achieve and how it does this. For some, the contribution may be restricted to decisions that affect them directly. For example, service users take part in negotiating the way a job is carried out in their home and volunteers decide the type of work that they carry out within the Scheme. Others are extensively involved in making decisions about the ongoing management of the Scheme. It is important to note that every type of contribution, regardless of scale, is valued. This is communicated to service users, volunteers and management committee members when they are personally thanked for their contribution and when they see the outcomes of their efforts. The importance of being able to see a tangible outcome that is directly related to what they do cannot be underestimated. This both encourages people to become involved with the Scheme and sustains their contribution.

Other processes are in place to give feedback to those taking part in the Scheme. For example, written communication highlights the scope of the work and the positive impact that the Handyperson Scheme is having on the lives of older people who live in North Tyneside.

Older people are encouraged to make an active contribution to the Scheme by the Scheme co-ordinator and staff of Age Concern North Tyneside. They explore the talents, abilities and expertise of those who want to contribute to the Handyperson Scheme, and negotiate with individuals about what they would like to do, and how much and when they want to contribute. This is done in a way that enables the individual to feel they are in control of the situation and are able 'to fit their work in the Handyperson Scheme into their lives'.

In addition to the above processes, it was identified that effective co-ordination and minimal bureaucracy contributed to the successful way that the Scheme involved older people. In the words of one participant:

> It is a small, helpful and genuine organisation. The very fact that it is simple is why it works well. There is no bureaucracy. The Scheme is practical and meets the needs of older people in the way that they want their needs met.
> (Management Committee member)

Throughout the discussions we had with those involved with the Scheme it became clear that the processes that were effective were inherent in the umbrella organisation that the Scheme belonged to. This highlights the importance of building on existing processes that work and tailoring them to the unique features of other initiatives.

The future: reshaping older people's involvement with the Scheme

The involvement of older people in this Scheme ensures that the way it works is acceptable to and appropriate for older people. Although it has worked effectively in the way that has been described, it was suggested that different strategies were needed to encourage those who had minimal involvement in the Scheme to increase their contribution and to generate interest in new people to participate.

An overriding message that came through our discussions was the importance of maintaining diverse approaches for older people to take part in the Scheme. It was suggested that the future direction of the Scheme would be the development of a

membership organisation. To do this it would be important to build on what had been and was working. Some people may find that meetings are an acceptable way to do this, whereas others may prefer more practical activities. For example, one current service user suggested that 'having a coin box that she could continuously place coppers in' would be one practical way that she would want to contribute to the Scheme. This type of approach would benefit the Scheme and she felt that it would help her to feel that she was a member rather than merely a user of this service.

Summary

This is an initiative that is valued by the people who use and those who provide the Scheme. Involvement is:

- encouraged
- supported
- valued
- leads to outcomes that contribute to the well-being of older people who live in North Tyneside.

For those involved with the Scheme it:

- gives a sense of purpose in later life
- channels talents, abilities and expertise into something that is worthwhile
- provides opportunities to meet other people
- results in satisfying outcomes.

Older people's housing group in Newcastle

The many initiatives that have involved older people in housing issues in Newcastle have collectively been referred to as 'Older people's housing group' for the purposes of this report. While each initiative took place in response to particular concerns,

there are dominant themes evident throughout this work. First, housing is a central issue for older people because it can have a tremendous impact on quality of life and independence. As much of the housing that older people live in is inappropriate for their needs, there is an impetus to seek ways to develop and adapt housing that is fit for purpose. This has led to housing moving to centre stage of national and local policy, and to it becoming one of the dominant issues that older people campaign about. Hence, service users and service providers are committed to the same objective.

Second, there had been increasing understanding during the previous decade that service users and service providers might hold different views of the same thing. This knowledge underpinned the movement for 'public involvement' in policy and in the way that services are planned. Throughout the country service providers have been grappling with the best ways of engaging with the citizenry and, in Newcastle, various models have emerged for older people to become actively involved with agencies.

In this section of the report we explore the development of two innovative approaches that allowed for two-way interaction between the older people living in Newcastle and decision makers, and for public deliberation among the participants about housing. Before turning to this we will examine the context that these developments took place in.

Older people and housing in Newcastle

Demographic data from the 1996 Household Survey and the 2001 Census indicates that 18.3 per cent of the City's population is over retirement age (female = 60 and male = 65). The evidence suggests that the population of those over 75 will increase in the future. The City's older population live in a mixed tenure with:

- nearly half (49.8 per cent from the 1996 Household Survey) being owner-occupiers (this is expected to increase in the future)
- 36 per cent are local authority tenants
- 7.2 per cent are housing association tenants
- 5.6 per cent are private rented.

Of the older population:

- 90 per cent live in general housing stock
- 5 per cent live in sheltered housing
- 5 per cent live in residential care.

From these statistics it can be concluded that housing for older people is an important issue for a significant and growing proportion of Newcastle's population.

National and local housing policy

There are key agendas that have set the scene for specific policy development in Newcastle emerging nationally in housing policy. The Government's overall housing policy objective is to offer everyone the opportunity to have a decent, affordable and appropriate home, to promote social cohesion, well-being and self dependence. In addition there is a national commitment to bring all social housing up to the Decent Home Standard by 2010. While these objectives have been codified in a raft of policy documents, it is beyond this report to review them.

In the document *Quality and Choice for Older People's Housing* (Office of the Deputy Prime Minister, 2001), the plans for a strategic framework for local and national action to open up a wider range of housing, support and care options for older people were laid out. In this framework five key areas were identified for policy and service development:

1 diversity and choice

2 flexible service delivery

3 quality

4 joint working

5 information and advice.

The national policy is translated locally through Newcastle City's Housing Strategy and the Housing Business Plan. The City's Housing Strategy (2002) identified improved housing services for older people as a key agenda, and the plans to

achieve this were laid out in *Improving Quality and Choice – Newcastle's Housing Strategy for Older People (2003–2005)*. In this document two overarching objectives were identified:

1 to improve the quality and choice of older people's housing of all tenures across the city

2 to promote independence, and support opportunities to enable older people to stay at home within existing communities.

This is an onerous task, yet the availability of new funding opportunities and a commitment to programmes of urban regeneration by the Government provided the means to realise these goals. The programme for housing development that was set in place with this Strategy focused on the present and future needs of older people. Hence, there is a commitment to developing 'lifetimes homes' that can be readily adapted as the needs of the occupant change, and to rethink support and services by accessing the latest technology and housing adaptations.

The Housing Strategy was developed in consultation with older people through a Listening Event to ensure that the plans were based on what older people needed, and that they were appropriate and acceptable to them. This approach both embraced government policy, which promoted public involvement, and built on approaches that had been used successfully in the past. The commitment to involving older people in housing development was explicitly stated in the document *The Newcastle Plan – Towards a Community Strategy 2002–2010* (Newcastle City Partnership, 2002) and a key target was for policy makers and service planners to work with older people on homes for a better quality of life. This highlights the openness that existed for partnership working from the agencies in Newcastle but it tells only one side of the story.

Public engagement by the elders of Newcastle

The involvement of the older population in Newcastle in civic activities had developed during the previous decade. Although this appears to have had a somewhat chequered history there have been several key events that have influenced this. Perhaps the beginning of this story rests with the 'whole system event' that took place in 1995 with the work continuing until 1998. This event involved approximately 200 people from all walks of life (older people and professionals working in agencies) working together to explore the question: 'How can we improve the well-being of older people in Newcastle upon Tyne'. This led to

the establishment of a number of action groups, ranging from leisure, transport and health to housing.

Although older people were viewed as active partners in the activities that were carried out under the auspices of the 'whole systems' work, there was a transition during this time from a perception that older people were valued as equals to this becoming a reality. The maxim 'no elders – no meeting' became a working practice that became enshrined in all of the activities in which the elders participate in the City.

The completion of the 'whole system' programme saw the launch of the Better Government for Older People programme (BGOP) to develop the work further. Newcastle was successful in its bid to be one of 28 BGOP pilot sites. Essentially, this programme aimed to 'improve public services for older people by better meeting their needs, listening to their views and encouraging their contribution' (Hayden and Boaz, 2000b). During the two years of the programme the contribution of older people became further ingrained in the fabric of the City by building on and developing existing work.

Towards the end of the pilot phase of BGOP, the participation of older people moved into a new stage through the establishment of the Elders Council. This is an independent membership group of 294 older people and 52 organisation members who work to improve life for older people in the City by getting together with service providers to promote change. They make a unique contribution by drawing on their experience to highlight the issues and problems that older people experience in their day-to-day life. The philosophy that underpins their work with agencies is summed up in the following quotation from the Elders Council Chairman:

> Our way is to get together with service providers and say – 'right tell us what your problems are and we will tell you about ours – and then we will see if we can make progress'.

Throughout the previous decade older people have actively engaged with agencies and service providers. One of the priorities throughout this time has been to seek ways to improve housing for older people. As the way in which older people have contributed to public life in the City has changed, their approach to housing has reflected this and has also changed. A superficial glance at the various housing groups that have been established during this time may suggest that these groups were ad hoc developments in response to public agendas. It is only when the development of the housing groups is viewed against the changing horizon, which has been mapped out above, that it becomes apparent that the groups have

developed strategically to have the greatest influence on housing policy. Of these developments we will consider two – the House for Life initiative and the Housing Reference Group.

House for Life

The idea for the House for Life project was born at a time when the work on housing for older people in the City had reached a crossroads. Looking back, the various housing groups had successfully developed user-friendly documents that provided information to older people about the array of accommodation in the City. In addition, this work raised the awareness of those involved about many issues that had not been addressed, such as: the need to continue to develop approaches to facilitate elders' access to information about the services available to support them to live independently in their own homes; access to adaptations and support for older people who were owner-occupiers; and the need to encourage architects and housing planners to incorporate lifetime housing features into properties when changes were made (for example, level access, downstairs toilets). To bring about these types of changes the issue of housing for older people and the difficulties that they encountered would have to be raised across many agencies and across the public and private sector.

Looking forward, those involved in housing (through the Better Government for Older People housing group) were challenged about how they would realise such an imposing agenda, which involved many stakeholders with different and possibly incompatible priorities. Through discussion with others working nationally in the same field, the idea of adapting an existing property to act as a 'showcase of a House for Life', to older people and those working with older people, emerged.

Although those involved in the housing group thought that this would never come to fruition, and the enormity of the task was daunting, they did think that it was 'a rather good idea'. Hence, in 1999, they submitted a proposal for the House for Life project to Newcastle City Council's Community and Housing Directorate. When the Council agreed to this project in January 2000, it also committed a three-bedroomed property from the housing stock to this endeavour and resources for the adaptations that were to be made to the property.

Following this decision, a tidal wave of activity commenced. The Better Government for Older People housing group recruited a 'briefing group' of older people to advise on adaptations in the house. To assist them in their role they embarked on a programme of learning that included creative work such as 'Thinking about space',

practical information sessions including discussions about aids and adaptations, and site visits. Throughout, Better Life in Later Life co-ordinated the project. It made sure the briefing group sessions were timed to coincide with the key times at which decisions needed to be made and was responsible for liaising with city council officers and designers.

Together, older people and professionals worked to design a house to show how good design and adaptations, and support services such as Community Care Alarms, can allow older people to live independently in their own homes.

Box 66 House for Life 1 – a learning experience for everyone

We were limited in the type of alterations we would like to have done because of the type of property [typical council housing stock]. However, it was useful in the respect of, whatever we could do to this property, we could probably do to other council stock … We also tried to complete adaptations which would not cost a great deal of cash to convert back to fit future residents.

This scheme was as much about adapting a property for older residents than it was about assisting disabled people to live more comfortable lives. We felt that this was an opportunity to show the average person what could be done to help them as they get older and to reassure them that they did not have to accept the difficulties of growing older and becoming more infirm.

The insistence of the older people on the installation of patio doors was at first disapproved of but, once installed, the value of their existence was proven, because the room had very small windows, high up in the walls, and this made the room very dark and depressive, but once the patio doors were in place the whole vista was changed.

The key was to influence the funding body, the policy makers if you like. This was achieved when the show house was opened, and they were very impressed with many of the adjustments made and they talked about including these things in other developments.

What took place in the adaptation of House for Life 1 had a certain amount of influence on future thinking, especially on the housing officers who were involved and among other group … It was a learning curve for us all.

(Continued)

> Many of the adaptations of the house have become standard in the City because of the low cost of the renovations and the high value of them to the older person … this is a huge compliment to the people concerned. (Service provider)

The house opened as a showcase for public viewing for three weeks in September 2000. Immediately following this period a family that required housing specifically adapted for their needs moved in and the house returned to the general housing stock. In recognition of the value of this work the project was a finalist in the Sir Roy Griffiths Award for Housing and Community Care. Further details of the House for Life initiative are available in a full report (see Douglas, 2001).

Housing Reference Group

The House for Life initiative made a significant impact on the people and agencies that were involved. One of the important outcomes was the way that it raised awareness of the specific needs of older people with respect to housing across the City. It also highlighted the need for planners and policy makers to work in collaboration with older people to understand their needs, and to identify their expectations of the housing that they would occupy.

Some of the ideas that were inherent in House for Life found their way into Newcastle's Housing Strategy for Older People (2003–2005). For example, 'lifetime homes standard' became part of the vocabulary that was used to describe plans for the City, rather than resting as a theoretical idea in academic literature.

The older people who had been involved with this initiative wanted to do more. Initially, they had been involved in the development of the City's housing strategy for older people through the Listening Event that was mentioned previously. Following this they had hoped to work on House for Life 2. In this project they intended to develop an integer/smart technology scheme in partnership with the City Council and a housing association partner. One move towards this goal was the hosting in Newcastle of a seminar on smart technology, which brought together experts in the field from across the UK.

As time progressed, however, other priorities, such as the development of Extra Care in Newcastle, seemed to dominate the Council's agenda for housing for older people. This appeared to impede the work that the older people's housing group had

planned for House for Life 2. At the same time, the group were aware of the opportunities that were opening up for them to influence the developments that were taking place.

This appeared to be another crossroads where decisions had to be made about the focus of their work. A meeting was set up to reflect on the future. Through this they recognised that they had gained strength and confidence through House for Life 1, but it was important to position them to be able to influence and respond to agendas that were being set externally. This culminated in the emergence of the Housing Reference Group.

This group provides opportunities for members to learn about the latest developments in housing design and smart technology. Consequently, the group is well informed about what is available and what is possible to alter housing for older people. When consultation opportunities are presented to the group, they are then in a position to draw on their personal knowledge and their technical knowledge of housing.

Summary

In response to recent government policy that has promoted the involvement of the public in decision-making processes, the elders of Newcastle have embraced the opportunity to influence agendas that impact on the quality of life in later life. Housing is one of the issues that they have earnestly pursued. Older people want to have the choice to be able to stay in their own home or to move to care. Having choice is greatly valued by older people and, when they are able to exercise this in decisions about the way that they live their life, this produces a feeling of stability and self-control. The environment is equally important to older people. Being supported in an environment of their choice allows seniors to retain familiar contacts, not only in neighbours, but also in locations and services.

Through the older people's housing group and its various initiatives, older people have been able to highlight the importance of housing and community to their lives. They have been able to have their say about the type of support and care that they find acceptable and appropriate through innovative methods that have captured the imagination and the ear of professionals and policy makers. Consequently, they have been able to influence local housing policy and decision making to improve the lives of current and future generations of older people living in Newcastle.

The following section of the report shifts to examine the way that older people have been involved in House for Life 1 and the Housing Reference Group described above.

The involvement of older people in the housing strategy groups

Older people's views of participation in housing strategy groups

Older people from various backgrounds, living in different housing tenures (social housing, private rented and owner-occupiers) were members of the housing groups. They were drawn together by the importance that they attached to housing and their belief that older people want to be supported to remain in their own homes in ways that they find acceptable.

When asked about their reasons for committing time and energy to the project they highlighted many factors that influenced their decision to take part. First, they spoke of the need for older people to voice their opinions about housing, rather than being 'talked at' or 'told what is best for them'. Their personal experience of growing older had raised their awareness of the lack of understanding that existed about the problems that older people face in their daily life. By sharing personal stories and taking part in discussions about housing for older people they hoped they would be able to contribute to changes that would promote the well-being of other older people (see Box 67).

Box 67 Using experience and skills to improve the well-being of older people

I wanted to use my expertise and skills to help people in the future.

I live in an area that is being demolished. If they are going to build new housing for older people that they put them in a good location and include the ideas that we are discussing.

We need to develop housing and adaptations that are acceptable to older people. This will only be achieved by working from the experience of older people.

For some, participating in housing groups provided the opportunity to increase their knowledge of adaptations and equipment that they would find helpful (see Box 68). They were asked about their views of participating in two specific activities – House for Life 1 and the Housing Reference Group, and their responses are discussed in the following sections of the report.

Box 68 Developing knowledge through participation

I had an accident and I didn't believe that I could live on my own again. I wanted to find out about what is possible and how you can adapt your home to stay *put* and not move to sheltered housing.

I have a large garden that I find difficult to manage and from being involved in the housing group I want to see what I could do.

If only I could have seen an alternative to not managing my garden I would not have moved to sheltered housing.

I need to find out more information.

I needed to know more about what adaptations exist.

House for Life 1

Involvement in this project was exciting, yet difficult. When the team were informed that a house had been taken out of the housing stock to be developed as a show house, they became aware of the scale of the project and the responsibilities that they were to undertake. A budget was set aside for the project, which was managed by the City. The House for Life team were responsible for making recommendations for adaptations to the house and for negotiating these with the multi-agency housing group. Consequently, they were active participants throughout all decision-making processes.

They aimed to make adaptations to the house that would demonstrate what needed to be in place to enable older people to live independently in their own homes rather than move to sheltered accommodation. They hoped that the end product would be a prototype for the development of housing for older people in the City and in this way the project would have a lasting impact.

The timescale for the project was tight because the house could only be used for the project for a specified period of time and then it would be available for someone in need. Although this enhanced the value of the project for the team, with their efforts

contributing to the well-being of others, it imposed deadlines for decisions. When the project commenced, the urgency of the work was impressed on the team in the way that ‘five city officers descended upon us bearing plans and wanting to know what we wanted for the House for Life’. During their initial encounter with the multi-agency housing group they found that they had to establish working practices with the professionals who they were to work with. They wanted to make a real contribution to the project rather than merely be informed of developments (see Box 69).

Box 69 Establishing ground rules

A designer from the council addressed our meeting and told us of their intentions for the project. We objected to a lot of the proposals. He went away and had to revise his thinking to include the things that older people really wanted. He apparently thought that everything was cut and dried but he found that this wasn’t so. From this he redrafted the whole programme. He realised that consultation had to come first and not reporting when the deal had become a fait accompli. He was involved with the project throughout and he was great, really valuing the decisions made by the older people.

The work on the project was not easy. The group attended presentations on various subjects to increase their knowledge of possibilities for improving housing for older people. Following this, they held discussions with the design team about the technical improvements that could be made. They, however, constantly felt under pressure to make sure they were properly informed before making decisions. Often they felt that they were making decisions ‘on the hoof’.

Everyone around the table made compromises throughout the process. For example, the request for a patio door in the sitting room was at first denied, but, following careful deliberation of the points raised by the older members of the team about the small, high windows that made the room dark and gloomy for anyone seated in a wheelchair, it was agreed to fit the doors. On the other hand, the request to install a stair lift was not fulfilled because it was impracticable for the design of the staircase and it was agreed that a vertical through-floor lift would be more appropriate. The older people found there was very little opposition to the plans that they proposed and this was attributed to the way that they were ‘realistic and not too demanding’.

The participants enjoyed the process (see Box 70). They felt that it was a worthwhile project that had a real sense of purpose, and an end product that was tangible and could be seen. They were able to gain knowledge, and use this and their experience to influence decisions in a context that was relaxed and provided opportunities to work with others. Although the multi-agency housing group appeared, at first, to be the driving force behind the project, the older people were able to influence this and shape the way the house developed. By the end of the project the older people felt that their voice had been heard: 'It is satisfying knowing that older people are listened to – House for Life is proof of this', and 'It is nice to know that people in the Council are willing to listen'. Their determination, constant effort and hard work contributed to the success of the project.

Box 70 Older people's views of House for Life 1

Just the experience, when we first started out I hadn't a clue what was involved, meeting architects, engineers, I mean I'm just a housewife.

This was a learning curve for me, and to see the house finished was wonderful.

I could have lived there myself.

I liked the way that the garden was adapted, it was low maintenance.

We are doing something people want.

Seeing the dream come true was wonderful.

I was really proud of myself.

Everyone was listened to.

Future generations will benefit from us.

Well it was a miracle what we had been able to achieve.

It helped to show what can be done.

Having an actual house is proof of what can be done working with the Council.

To see that a House for Life can be achievable is rewarding.

Following the project older people feel that they were treated with credibility both locally and nationally. They felt that they had made the transition from a group that 'were not taken seriously' to one that was:

> We seem to be a very respected group, not a load of idiots.

Box 71 Older people's views of the changes in consultation practices that resulted from House for Life 1

> We are able to pass on snippets of information.
>
> We are able achieve greater understanding of people's needs and their problems.
>
> Being involved at the beginning of the planning and not consulted on someone else's plans.
>
> Being involved in every stage of the development.
>
> Being able to stimulate others in the building where I live.
>
> I would like to think that we would develop relationships with builders and planners and that they value the contribution of older people.

The Housing Reference Group

Participants of House for Life 1 left the project with the realisation that they have a voice that could influence what happened in the City. Collectively they felt that 'at last we are being heard' and they were confident they could address higher targets. Through the Housing Reference Group older people feel that they are acting in an advisory capacity to the City Council planners. They are also being consulted by housing associations when new developments are being planned.

The most important change that they believe has happened is that they are now invited to participate in the initial planning stage of new projects and not when everything is 'cut and dried'. They stress that this is a time of real opportunities for older people to influence housing policy and housing developments, to create something that is both appropriate and acceptable to older people. Older people should have real choices and there should be a mix of quality housing arrangements where they can live – including retirement villages, intergenerational housing, extra-care and mixed communities of owner-occupiers. Within such arrangements, new models of supportive housing need to be created to enable older people to live as

independently as possible. There is a willingness for policy makers to listen to service users and the resources available to make positive steps towards improving housing for this generation and future generations of older people.

Stakeholders' views of the involvement of older people in housing issues

Drivers to listen to older people's views of housing

While public services are driven by many policy agendas, public involvement and service integration have led to widespread changes in organisational structures and decision-making practices. As a consequence of these changes, housing, social services and health staff in Newcastle are working together to address common issues. One of these is identifying and developing ways to respond to the housing needs of an ageing population. As no western country had had experience of this type of demographic change until recent years, the participants argued that there was a need to base the development of housing for older people on the following factors:

- robust evidence
- local and national housing policy
- knowledge of the demographics of the city
- consultation with older people to develop an understanding of what they need and what they want with respect to housing – this is an ongoing process because individuals' expectations are continuously changing.

These factors contributed in Newcastle in the Housing Department to a culture that is open and willing to create innovative ways to consult with different groups in the population, and to listen to their views about housing and the environment that they live in. With respect to the older population, there was the impetus to do this in a systematic and structured way with other public services, such as Social Services, because older people use services that cut across organisational boundaries.

The cultural changes that were taking place in the statutory sector coincided with the emergence of groups of older people in Newcastle that were championing older people's issues, with housing being one of their central concerns. Hence, statutory agencies and older people were pursuing similar objectives and, when they were drawn together, they readily identified they had compatible objectives: to develop

housing that met the needs of older people; housing developments were to be grounded in the experiences of older people by consulting with them; both parties were interested in supporting older people to remain independent in their own homes; and supportive housing needed to develop in ways that were acceptable and appropriate to older people (see Box 72).

Box 72 The need to consult and the need to be consulted with came together at the same time

> Connections were made, so it was by good fortune that we came together that we were interested in finding out the issues that should be included in the housing strategy and they were interested in influencing that strategy.
> (Stakeholder)

Although both parties had similar objectives there were different considerations that they had to take into account. Older people needed time to acquire the knowledge to make informed decisions, whereas agency staff were required to work within specified timescales, and they were accountable for the use of public monies and public resources (see Box 73). These factors influenced when and how agency staff and older people worked together, yet this did not prevent House for Life 1 or the Housing Reference Group from coming to fruition. Both parties had great resolve to overcome these obstacles and, where necessary, they made compromises to develop partnership working.

Box 73 Obstacles to partnership working that were encountered

> There were two imperatives that influenced when things happened. One was that everything had to be done by September, yet the other was that they [the older people] wanted to discuss everything for ever more.
>
> It became a learning experience for all of us because we had to decide what was priority and although this was a really good educational experience, particularly for our technical team, we had to be mindful that we were aiming to produce a real product at the end.

Box 74 Developing the resolve to overcome obstacles

> It was quite a big decision to make to take a house out of the housing stock when demand was so high … we looked at this scheme and we thought that we could possibly do this and it would raise awareness of what can be done and it would be helpful in the long term. It might even alleviate some of the pressures on hard-pushed services … and I think we decided quite early on that we would do it but there was a lot of questions about where the house would be and who would live in it, but we were quite taken by the idea because we could see some of the benefits in doing it. It didn't take us long to see that we could do something with this house. It would be a showcase and at the same time we could tailor the house for someone's needs.

Now, stakeholders suggest they have moved to a different understanding of public consultation. There is recognition that both sides of the table – older people and agency staff – have something to offer. Previously, consultation largely involved telling others about plans that were in place, but now it involves seeking the views of the public at a time and in a way that influences the decision-making process (see Box 75).

Box 75 A meeting of horizons

> Everyone brings something to the table – our past experiences help us to understand the present-day needs of the elderly. Professionals aren't always right, but you have to listen to them and tenants. Owner-occupiers aren't always right either, but we have to listen to them.

House for Life 1

There is no doubt that everyone who took part in the House for Life 1 project found that it was an enjoyable and satisfying experience (see Box 76). This was attributed to a number of factors. First, it was a unique opportunity for people with different backgrounds and from different agencies to work together. Housing officers, older people, city designers, landscape gardeners, technical experts, occupational therapists and other professionals brought their skills, knowledge and experience to the project. Because they focused on the project and shared their expertise to complete it, the project became a very real learning experience.

Box 76 An enjoyable and satisfying learning experience

It was a most interesting project. We all felt it had a beginning, a middle and an end, and the enthusiasm of all involved was buoyant and enjoyable.

There was so much energy around – it provided something different for me.

We all learned a lot from each other and the project was successful. It was delivered on time and was thought to be a very worthwhile piece of work, whereas it could easily have been where we talked about everything but actually produced nothing. My big worry was that, at the end, we might not produce anything and then everybody would have been disappointed.

It was also an innovative project, which made it very different from the 'day job'. The process, itself, caused everyone to stop and think about what they were doing and this prompted much reflection on customary practices. From this, the project workers gained new insights of the needs and difficulties that older people experience with respect to housing (see Box 77). One of the most significant aspects of this concerned older people's need for low-level support to enable them to remain independent and to enjoy the quality of life that they desired. The change in thinking about housing for older people led some to rethink priorities in terms of budgetary planning and housing developments.

Box 77 Developing new insights

Yes, the House for Life 1 project has challenged thinking about housing and prompted professionals to rethink ideas of what older people want and what they require in terms of housing.

The work from House for Life has influenced people in housing to think more about prevention – one of the key things that came out of the project was that little things mean a lot and these can influence the quality of life of an older person. The little things tend to be inexpensive. Professionals tend to get hung up on the big jobs that tend to be expensive, so they may plan to do 100 big jobs and that will be the priority for one year, but it may have been better if they did 500 little jobs. Again it made us think again in terms of what was provided ... I don't think

(Continued)

that it is entirely coincidental that we are spending a lot of time thinking about ways to provide low-level services to support older people.

The house when it was open enabled people to see new possibilities and pushed people to think about housing in different ways – for example, it was typical that housing officers thought about the here and now and the constraints on their budgets. But the House for Life project caused them to change their focus and they began to think of the present as well as the future.

The work on a real house was very important to everyone involved in the project (see Box 78). At the beginning they were able to see, in a meaningful way, the scale of the work that had to be undertaken. And, at the end of the project, the impact on visitors to the show house, the new tenants and the influence of planning and policy of housing for older people in Newcastle was very evident.

Box 78 A tangible end product

Instead of just producing a report, we could say 'go and look at what we have done'.

There was so much energy around it and it provided something different for me, and the fact that at the end of the day there was a tangible product which could be seen and tested was an added bonus.

Seeing personally that the end product made a real difference to the lives of people – on many occasions when the house was open I overheard people saying 'Oh if only I knew about this, but now I will tell my neighbour … and that will help to sort out their problem'.

Finally, the project developed understanding of involvement of older people in public services and what they could offer. The concept of involvement of the public had traditionally culminated in meetings where consultation on various issues occurred. Following this project, and other activities in the City, agency staff now attempt to think laterally about the best way to involve the public to elicit their views about housing. One aspect of this is the effort that is given to developing ways for the consultees to be active participants in the process. During the House for Life 1 project the older people participants came to be viewed as committed, dedicated and keen – they were volunteers yet they attended every meeting. At the end of the process they were perceived as an informed group that were articulate and able to express their views about housing and adaptations in ways that influenced the entire process.

Box 79 The dedication of the older people to the project

When I think about the House for Life 1 project, people were volunteers. They gave up their time and they turned up at meetings, sometimes with little notice. They shared their experiences and they went to the house and so on. It was recognised but, when they told us about the 500 free hours that they contributed to this project, this highlighted the commitment of the older people to this project.

The enthusiasm of the older people who turned up at everything was quite amazing to behold, and it never altered.

House for Life 1 set the scene for the development of a new vision for partnership working.

On other schemes such as standard housing there would be an element of consultation with residents. But this was slightly different in the respect of the setting up of workshops, design discussions, and there was a working team of elderly people who told us what they wanted in the house. They pointed out areas of concern to them and this steered us into the direction of wanting to proceed with the design.

There are probably other factors that influenced people’s perceptions of their involvement in the project but the most significant were:

- it was an enjoyable and satisfying learning experience
- new insights to the needs and difficulties of older people with respect to housing were gained
- there was a tangible end product that had multiple outcomes for different people and organisations
- the contribution of older people to the process.

The benefits of the House for Life 1 project were identified as:

- it caused people to rethink what was happening
- it prompted the development of a new vision
- new working practices were developed

- it was a learning experience for those working in housing and associated professions
- it helped to reshape the agenda for housing in Newcastle from the here and now to thinking about the future (see Box 80).

Box 80 Thinking ahead

Every time you do something, i.e. put in a front path, then put in level access wherever possible and it is that kind of thinking ahead that is most important. It was very poignant in the private sector, where owner-occupiers put in patio doors but they don't think 'level access', so when their lives change and they may be wheelchair bound they then have to think about level access.

This part of the exercise has been good in the respect of making people think ahead to later life infirmities, which can be made easier to cope with.

Housing Reference Group

Although the House for Life 1 project demonstrated that older people and public service staff could work together to produce meaningful outcomes for a range of stakeholders, it also raised awareness that housing for older people was a broad agenda and that national interest in this subject was growing. This led those involved in the project to consider how they could best position themselves to grasp the opportunities that may emerge in the future. Housing officers and older people acknowledged that they had a different perspective about housing, and there was a need for an appreciation and awareness of both perspectives to inform policy (see Box 81). As the Council was receptive to any good practice and there was not a set view on how older people should or shouldn't be involved in local policy, this created the opportunity for older people to create a forum that was flexible and able to respond to changing agendas.

Box 81 The importance of listening to older people

Listening to the experiences of older people really opened the door and threw a fresh light on what people's expectations were.

(Continued)

The Reference Group provides a sounding board to raise awareness of the needs of particular individuals. For example, a member of Reference Group who is deaf highlighted certain issues and her views were taken on board with the development of the extra-care development.

By listening to the views of older people it became clear that older people do not want to live in sheltered housing, a form of bedsit, in their later years and new models of housing are being developed, such as extra-care schemes. These new initiatives are more flexible than the traditional models of sheltered housing and residential care.

It is much more dynamic to talk to real people with professionals supporting rather than talking with professionals alone. It has produced a completely different perspective on life and, if there is a debatable point, then it is better to have everyone present.

There is no doubt that regional housing policy is produced by a few people, maybe a consultant who hasn't got an axe to grind and they are quite capable of missing huge areas out, and I mean the regional housing policy was produced without anything on energy efficiency and fuel poverty in its first draft and in the end it's in there but only in about four words after the 'environments' (in brackets) saying 'including energy and efficiency', not really put to central stage, whereas in our 'Lifetime Homes' Strategy, Newcastle have it on central stage, which was included in our strategy of 1987/1988.

Those who took part in this study spoke of two different situations where they had had contact with the Housing Reference Group and they gave their views of these. The first was the Listening Event. Officers were invited to the Event to listen to people's real-life stories, which they found 'profound and deeply influential'. From these accounts the housing officers identified the key issues that they would respond to. Therefore, they argued that the contribution of older people to this event helped to reshape the priorities of the older people's housing strategy in Newcastle. The involvement of older people shifted the emphasis in the strategy to providing a better and diverse complete range of extra-care shelters. Also onto remodelling of the existing housing stock to improve services, so that older people could stay in their existing homes to maintain their independence if that was their choice.

Stakeholders also spoke of the extensive consultation exercises that are taking place between local services and government departments. They suggested that it is

important to respond, as this raises awareness of local issues or provides the opportunities for securing funding for local developments. Often there is a short timescale to give a response in these situations and there is normally a prerogative to involve the public in these exercises. This is demanding and only possible if established groups are willing and able to give an informed opinion on what are sometimes complex issues. The comments in Box 82 demonstrate the value that is attached to the Housing Reference Group by housing officers.

Box 82 Being able to respond to consultation exercises

It is important to have access to an established group of informed older people that can be consulted, sometimes at short notice.

By having access to the Housing Reference Group it is possible to consult with older people within what is sometimes a relatively short timescale. In the development of housing for older people there is a need to have the input of older people in the development of housing schemes. In one instance funding had been secured and the scheme took off – the plans had to be in place within a month of securing funding. This imposed a tight deadline on the extent of involvement of older people in the scheme. We set up discussions with older people through the Reference Group and the Elders Council fairly swiftly – this has been achieved. They gave feedback on how they perceived extra care and how extra care could be improved.

The benefits of the Housing Reference Group were identified as:

- being able to access different viewpoints
- having a group to share experiences of later life with housing officers
- being able to identify the priorities and concerns of older people
- being able to access a group of older people who are able to respond to consultation exercises quickly.

Supporting and developing the involvement of older people in housing issues

Now that older people have a voice in the housing strategy for older people and they have positioned themselves in a way that gives them flexibility to respond to local and national agendas that are changing, the stakeholders expressed the view that they should be supported to continue to champion housing for older people. To enable them to do this, stakeholders made suggestions for the development of participatory approaches to maintain and build on existing good practices in Newcastle. These are summarised below.

- *Use effective communication strategies:* there are many facets of this subject. Some of the key messages that were addressed in the interviews concerned language and feedback to those taking part. These issues are extremely important because they have the potential to promote or limit meaningful dialogue between older people and housing officers. For example, when engaging with older people, ensure that the language used is meaningful to all parties, as this will enable everyone to participate and to share ideas. Also, people need to be 'kept up to date with developments and the outcomes of their efforts', as this will enhance everyone's knowledge of events. The latter point is challenging for those working with Housing Reference Group because group membership is constantly changing as the circumstances of the members change.

- *Get the infrastructure right:* the participation of older people does not happen without support and the activity needs to be conducive to involvement. One stakeholder stated:

  > It is important to get the infrastructure right to optimise the possibility of successful outcomes. You need to make sure that there is always an infrastructure of professional support and an excellent technical officer with experience of special needs, because, if you get the wrong type of technical officer, he could be inclined to be completely deaf and will steamroll the project through according to his own agenda. You need good support workers who will help the project to flow without confrontation.

- *Provide training for those taking part:* older people bring a wealth of experience and knowledge of housing to the Housing Reference Group but this needs to be channelled appropriately for their message to have the greatest impact. They need to learn to ask the right questions of the right people, and to involve those people at the right time to be effective. One stakeholder highlighted these issues in the following way:

> I feel that there are major issues about educating older people about what questions ought to be asked to enable them to have a great impact and to move the agenda forward quickly. They need to ask the right questions but to do that requires an educational process to understand the questions that they should have answers to.

- *Seek new, innovative ways to involve older people:* knowledge of the most effective ways to involve older people in planning and policy processes is constantly growing. Therefore, those working in public services need to remain open to different approaches that may prove more effective than existing participatory strategies. This is illustrated in the following example. Until recently, housing officers met with the Elders Council housing group and the Housing Reference Group to provide up-do-date information on housing but they have now invited members of the housing group to attend the officers' meeting. This enables older people to have direct participation in decision-making processes rather than merely hearing of decisions that have been made.

The views of the housing co-ordinating team and Elders Council members about the involvement of older people in housing issues

Box 83 Older people – an asset to the community

> Housing is an important issue that affects the lives of older people, perhaps it is the most important issue in the ageing process.
>
> Older people have a lot to give and their opinions are born of experience.
>
> The potential of older people had been completely underestimated, but House for Life 1 was a real beginning … It was such a positive programme, ending with such a very visible and concrete piece of work. We gained a great deal of confidence and, since then, the City Council have developed an older people's housing strategy that many older people were involved with. The boundaries have now changed and we are being treated with credibility both locally and nationally.

The above quotations capture the resounding message that reverberated through these interviews – that housing is an important issue in later life and older people want opportunities to influence the development of housing for older people by older people. They want to be central to the decision-making processes and it has been through a number of influential events that they have developed approaches that influence policy makers.

House for Life 1

Since the early 1990s the elders of Newcastle had attempted to make a contribution to housing policy but their campaigning efforts bore little fruit. The House for Life 1 project changed this. Initially, housing officers appeared apprehensive about completing the project on time and the demands that might be made by the project team. This changed as the project progressed. The older people sought every opportunity to learn about ways to adapt housing to the needs of older people and to discuss the various possibilities for improvements, but they were mindful that decisions had to be made. This created a sense of urgency to be adequately prepared to make informed decisions at the required time.

While the project team aspired to tailor the home to the needs of an older person, they were mindful that there was a budget that they had to work within. Many of the alterations that they suggested were practical and required little cost, yet they made a significant difference to the quality of life of an older person. These types of adaptation demonstrated the impact of little things and these could easily be incorporated in housing across the City. Other adaptations, such as the fitting of patio windows, were expensive, and these were viewed as a luxury by housing officers. It was only the determination and the justification provided by the older people that led to the decision to include this alteration in the project. The end product was pleasing to everyone who witnessed the difference that it made to the house and this bore testimony to the insight of the group.

The project provided the opportunity for the older people to develop their negotiation skills. At times they made compromises and at other times they stood their ground, developing arguments to support the decisions that they had made. This was a major learning experience for the older people in the project team because many had little previous experience of undertaking this type of activity. Their success in influencing decisions, even the small decisions, caused the participants to grow in confidence and to recognise that they were an asset to decision makers. Following the project they were left with the impression that 'housing officers are now more inclined to listen to us'.

The House for Life project captured the imagination of everyone who took part. Perhaps this caused everyone to step outside of the box and think differently, or it may have been the enthusiasm, dedication, insight and willingness of the older people to share their opinions that caused policy makers to stand back and listen to their views in ways they had not done previously. It is impossible to extract cause and effect from this situation, but it is clear that the project changed the way that the elders were perceived by agency staff – they were now recognised as 'having something to offer'.

Box 84 Working towards achievable goals

Older people have been so central to it. The City Council officers were very apprehensive thinking that people were going to ask the earth, but the elders were realistic feeling the smaller things, rather than the big things, were more important in order to get it right.

People realise that we are being sensible and reasonable, and this is part of our success.

Our way is to get together with service providers and say, 'right, tell us what your problems are and we'll tell you about ours', and see if we can make some progress.

Box 85 The commitment of older people

It was striking that nobody stood to gain for themselves and people gave a huge amount of time and effort. They were willing to contribute so much for the greater good.

We recorded some 500 hours of work to the House for Life project so gaining respect within the council.

The Housing Reference Group

While the buzz that existed throughout the House for Life project dissipated when the show house closed, the elders wanted to pursue their interest in housing. They were aware that housing for older people was a key national priority and they wanted to maintain the momentum that they had developed during the project. At first there were plans for House for Life 2, which had technology as its central focus, and the older people were enthusiastic to engage with this project. However, the external scene was changing. The challenge for the group was how to respond to this situation.

They had learned through House for Life 1 that they could influence what was happening in Newcastle if they were addressing the same agenda as the Council and the local authority, albeit from a different perspective. Although House for Life 2 was mentioned in the housing strategy for Newcastle, there were other priorities and the group needed to be steered in the right direction to influence decision makers about these developments. The housing co-ordinating team prompted members of

the older people’s housing group to consider their objectives and to rethink the direction they were moving in. They decided that being more political in outlook and being positioned in a way that would enable them to respond flexibly to local and national agendas would enable them to have greater influence on decisions about housing. Thus, the Housing Reference Group was formed. The work of this group was more nebulous yet more responsive to ever-changing government agendas. It is watchful of opportunities to consult with statutory agencies and the Regional Housing Board to improve housing for older people.

Working with older people

The participants suggested that working with older people is stimulating because it is diverse and open-ended work. It is also challenging to work with a group that has been traditionally marginalised from decision-making processes.

Workers require personal qualities and skills to encourage older people to express their views in the most effective ways. The workers stressed the importance of being a people person and being able to get alongside the older person to find out their interests, talents and concerns. They have entered a time in their life when younger people primarily see them as a homogeneous group of older people, and this creates a situation where older people do not speak freely of their skills and knowledge. It takes sensitivity and willingness to ‘find the person’, and to support them to (re)gain the confidence to voice their opinion and challenge people who are perceived to be in influential positions. They need to be supported in emotional and practical ways to do this – an older person with hearing difficulties is unlikely to participate in a discussion if they are seated in a position where they are unable to follow the discourse.

It is a skilled activity to recruit older people to, and support them to actively participate in, the housing groups. The co-ordinators work quietly, supporting and co-ordinating the work of the older people. They provide information to the elders about recent developments in policy and housing, and offer suggestions about ways for the housing group to strategically address these issues. Furthermore, they work closely with the council and the local authority to ensure that the work of the housing group is directed to the ‘people of clout’. All of this is done in such a way that the members have ownership of the group and of the work that they agree to undertake.

Drawing on their experience of working with older people, the co-ordinators of the housing group and members of the Elders Council stated that the following factors contributed to the success of the housing groups in Newcastle:

- the active involvement of dedicated, enthusiastic members
- the respect given to every older person as an individual with talents, skills and knowledge to offer, and the valuing of the different contributions they make
- a clear understanding of the commitment, time, expectations and support needed when taking on a role
- knowing what questions to ask and who to ask them of
- openness and willingness of agency staff to listen to and act on the views of older people
- using the most appropriate method to involve older people in developing policy
- ensuring that the method used is stimulating, fun and effective
- seeking ways to develop products that influence change
- publicising the achievements of the housing group
- ensuring that new activities are linked into what already exists
- good communication throughout the entire project – regular updates to all members, newsletters are made available to those who cannot attend meetings and/or they are contacted by phone.

Box 86 Meanings attributed to working with older people

Working with older people and learning about their lives and needs, and knowing that what you do can have an effect on people's lives is a great responsibility.

It gives me a sense of freedom and also a real sense of purpose.

Being creative is important and the enthusiasm and support of older people keeps me going. The pleasure realised from being involved is enormous.

The emergence of a framework for sustainable involvement of older people in housing

From the analysis of the involvement of older people in housing issues in Newcastle, it was evident that three factors came together to enable older people to make a contribution to a housing agenda that was valued by housing officers and one where they were partners in the process. These were:

1 an infrastructure that existed across two organisations – the Elders Council of Newcastle and Better Life in Later Life – which facilitated involvement of older people in planning and policy activities

2 an established group of older people who were committed to the development of housing that met the needs of older people

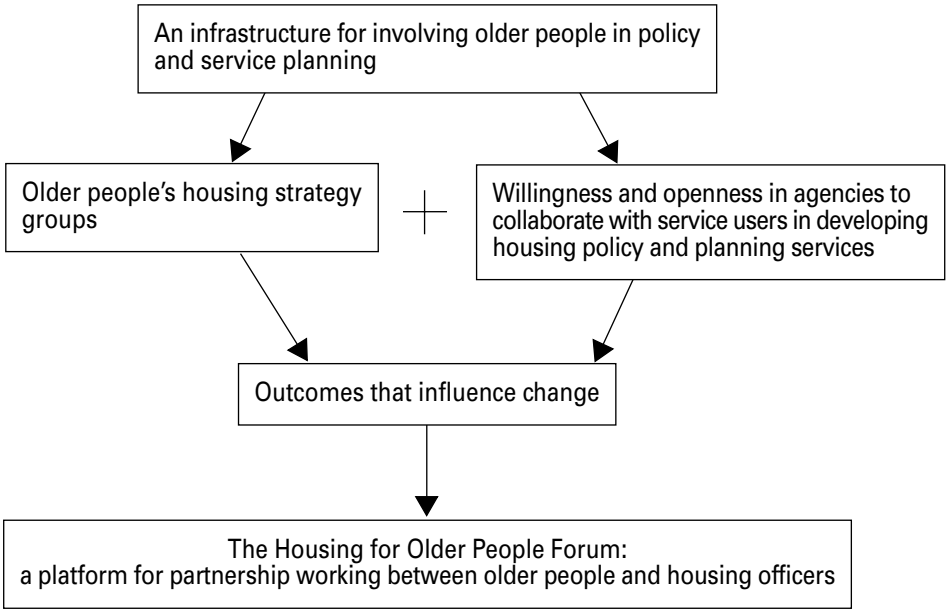
3 commitment to user involvement by housing agencies, which was supported by national housing, and health and social care policy.

The existence of groups seeking similar objectives and structures that brought them together provided the backdrop for partnership working in House for Life 1. Those who were involved heralded the completion of the project as a success, but it was more than an end in itself. The work on the house established older people as a credible resource that could inform the development of housing. They had entered within the circle of influence and had to develop ways to remain in that circle at the end of the project.

Through restructuring, the emergence of the Housing Reference Group has provided a way for older people to exist as a recognised body that agencies consult with. They are independent and the virtue of this is that they pursue the housing issues that they find important. While this situation enables them to campaign and represent the interests of older people, they may remain as a body that is consulted with, rather than one that is positioned to drive the agenda forward.

The interdependence of older people and agency staff in House for Life 1 had led to many mutual benefits for all participants. Perhaps building on the working practices that were established in that project, and seeking ways to create a housing forum where older people (members of the Housing Reference Group) and agency staff (housing officers and local authority housing managers) are stakeholders who consult and are consulted with, will build on past successes. (The framework for the involvement of older people in housing issues in Newcastle is illustrated in Figure 3.)

Figure 3 A framework for involving older people in housing issues



Summary

The elders of Newcastle, through the older people's housing strategy groups, have been able to influence housing developments in the City. Their work has raised awareness of what the older generation need in terms of housing to improve their quality of life. Consequently, their work has demonstrated that there are real benefits for planners, decision makers and service users when they use older people as a resource – a resource that had hitherto been untapped.

There was immense commitment from the elders of Newcastle and housing officers in the City to work together. Government policy promoting citizenry and agency collaboration had encouraged this, and local people responded in innovative ways to this agenda. Sustaining the partnership working that has been initiated through some of the housing projects is needed. The key suggestion arising from this report is the establishment of a Housing for Older People Forum, which is part of the formal structures of the City, to create a platform for partnership working between older people and housing officers.

3 Key messages from the study

The case study reports were read, along with the interview data, research notes, project group minutes and workshop records, by members of the research team. Through this process of analysis and discussion, a number of key themes were generated and a discussion of them follows. This discussion is a fairly traditional research report component, leaning towards the abstract and, as such, needs to be read rather differently from the case study reports that preceded it and the lists of questions that follow it. It seeks to describe and discuss broader themes that cut across cases, and, though illustrated with examples from the study, to paint a more general picture of the dimensions of the schemes investigated and the processes that were important. These themes do not fit neatly into the discussion of the cases, as we often found they demonstrated complex mixes of factors and developments – we could not easily classify a case as being, for example, top-down or grass-roots development, or displaying only one type of leadership. They were much more messy than this, perhaps reflecting their organic development in response to a number of factors.

This chapter, then, should be read in order to gain a sense of the overall themes the researchers identified in the data. It takes a step away from the more detailed discussion of the cases to look at patterns of involvement, in the hope that readers can apply the ideas across a range of schemes and projects they may be engaged in, or may come across in the future.

Top-down and grass-roots approaches to involvement

The groups and activities in the study varied according to whether they described themselves as having been established through a ‘top-down’ or a ‘grass-roots/ bottom-up’ approach. Some activities, such as the Citizens’ Jury, had strong organisational support and had developed in a ‘top-down’ way. In this example, the ideas were developed by a particular organisation, which set up processes to fund and manage the activity. This meant that there was a formal process of monitoring and evaluating the activity from the beginning. In addition, it was possible for the Jury to make use of the funder’s resources and networks in disseminating its work. Similarly, GOLD began with strong ‘top-down’ support from local agencies, which provided resources and facilities. Since this beginning GOLD has become more driven by grass-roots ways of working, but the initial help at the start of the scheme gave it a sound beginning.

In contrast, other projects had started off as grass-roots movements, for example with the Handyperson scheme, where individuals had identified a need or problem, and had developed ways of addressing it. Grass-roots movements had high credibility with older people, as they were seen to reflect issues that were important to them. However, while they might engender peer support, they could face difficulties in developing management systems and in working with other agencies, particularly those with statutory regulations.

While top-down activities could enjoy the benefits of existing systems and structures, and had credibility with other agencies because of this, they did run the risk of not having peer credibility. This was particularly the case if the activity was seen to be shaped by people, other than older people, who could be felt to have other interests and agendas at heart. These other agendas may also be felt to be too wide-ranging for a concentrated effort around older people's issues – the Citizen's Jury, for example, was one of many involving a number of different groups and issues.

Conversely, grass-roots movements were valued for their focus on older people's concerns, and older people in particular appreciated this. Problems could arise, however, when grass-roots movements tried to negotiate with agencies with a different remit and more formal structure. As governance issues came to the fore with these agencies, sometimes the ways of working in grass-roots agencies raised concerns. They did not always conform to norms of accounting or recoding and this could raise problems as the two types of organisation tried to work together. Grass-roots activities, therefore, ran the risk of being excluded from more mainstream activity, including funding streams.

Some activities, such as the Bell View project and the House for Life, combined top-down and bottom-up processes, managing to harness the advantages of both. This synthesis could happen in different ways and at different points, but much depended on the ability of the scheme participants to link up with sympathetic or receptive people in formal organisations who might provide resources, facilities or a platform for making views known. This could be a difficult process, with the potential for clashes between, or transience of, contacts but, if it could be done, it was an effective way of working.

Leadership

Another theme was the significance of leadership in the case study sites, where three types of leadership were identified. The first type rested with one or a few individuals, who had the vision, energy or skills to start the activity. This could create

some problems, as others could feel excluded, or if the founder(s) left the project. While this leadership was charismatic and energising, it was not always sustainable, and was vulnerable to change. It was also not always amenable to challenge or critique if the originator(s) did not welcome or facilitate this.

The second type of leadership could be termed ‘democratic’ leadership, where the direction of the group was determined by open debate and a formal or informal process of decision making. This form of leadership was flexible in the face of changing circumstances, where the skills needed by the leader could vary. The Bell View project, for example, needed people with an understanding of fund raising, planning, building and legal affairs to act as leaders at different points, and this involved a wide range of people. Democratic processes could arise naturally, but they needed careful review to ensure that they remained fair and open.

The third type of leadership identified was ‘external’ leadership, where direction came from outside the group, either through the mechanisms of funding where project leaders were formally appointed, or through the application of other agencies’ goals and procedures. This type of leadership could cause resentment if it was not felt to reflect the goals of older people, and was often reluctantly accepted as a necessary evil.

These three types of leadership were not mutually exclusive and had existed in different projects at different points in their development. Some projects, particularly grass-roots activities, had started off with charismatic leadership, where a small number of individuals had led a development. Over time, as more people had become involved and activity had become more complex, projects had moved towards democratic leadership. As projects became more involved with other agencies and their structures, activities became more led by external requirements and goals.

Supporting and facilitating participation

Another key theme throughout the case study work was the importance of supporting and facilitating participation. While the origins of an activity may have been top down or grass roots, after initial stages, where there was some degree of self-selection, increasing participation depended on careful thinking through of support issues, and the ability to engage with participants about their needs and strategies for meeting them.

Support could be practical, such as ensuring good access to meetings, which were held at convenient places and times. This practical support could also involve financial support and in particular an assurance that expenses would be paid promptly – important to people on a limited income. For people with sensory or motor difficulties, assurances that these had been planned for were important.

In addition, it was also reported that facilitating participation could involve strategies to increase the confidence of potential participants. This could involve encouragement to become aware of the skills and experience that they already had, or the provision of opportunities to gain new skills through training. These skills might be specific to the activity (for example, using office equipment) or more generic (for example, assertiveness or communication skills).

What was clear from the data was that encouraging participation was much more than simply making the opportunity available – schemes needed to be proactive. This did not necessarily mean they needed a formal advertising strategy, as existing networks and 'word of mouth' could do much to spread information. The next stage, from awareness to involvement, however, could depend on the efforts schemes had made to facilitate participation, and the information available about this. Some reported that potential participants did not like to ask about facilities because they did not want to discuss their needs, or assumed their needs disqualified them from participation, or they were not aware of the needs they had. Projects therefore had to do some forward planning and thinking, and disseminate their plans so that people did not have to ask about them.

Layers and levels of involvement

Looking at the accounts of involvement, it was apparent there were many different levels and layers, which sometimes increased as the project became more complex. While some activities remained relatively simple and roles remained static, such as in the Citizens' Jury, in other projects the range of activities increased. In Bell View, for example, people were involved in planning, design, publicity, lobbying and fund raising. This meant they could be involved in a relatively high-profile way, such as meeting council officials to make a case, or in other ways, such as making jam for fund raising.

The status that was accorded to each layer of activity was the same, in other words, everyone was valued for their contribution. The level or degree of contribution could vary, however, with some people devoting much of their time to the activity and

others simply ‘dipping in’ for short periods. Sometimes this depended on the stage of the project and what was needed, and at other times it depended on the capacity of participants, who could be involved in other activities or have other responsibilities.

This variability could lead to tensions, as workloads differed between participants and skills became redundant or in demand. Where these tensions arose, it was important for groups to retain a sense of ‘the bigger picture’, the overall purpose of the activity, to which individual egos were subservient. Tensions were also manageable where projects enabled individuals to see the impact of their contribution and to have it recognised by others.

Making and recognising impact

Some schemes enabled participants to see the impact of their participation more clearly than others. This could range from casual compliments to more formal recognition in newsletters, meetings, reports and displays. This provided information for those within and without the project, and was important, as much activity could be taken for granted or go unnoticed by participants, who were not always aware of what had been done by whom.

The process of recognising impact was aided by systems that set goals and timelines, and recorded and described change. If these were set too rigidly or with an inappropriate focus, they could be used to identify failures or shortcomings, while systems that were more flexible could also encompass achievements. Thus, if a project set goals too narrowly and failed to meet them, the whole project could be discounted, whereas, if the scope was more broad, members could identify a wider range of outcomes, including those that were desired but unexpected. As an example, one of the impacts reported for the House for Life project was an increase in the confidence of the members, but this would not have been formally recognised or intended by a scheme that focused on the development of plans for housing.

The importance of impact was reflected in many of the comments made in the case studies, where participants reiterated their motivation for taking part was to ‘make a difference’. If they could point to a difference that had been made – even if it was unexpected, then this validated past participation and encouraged future activity.

4 Working outside the system

One of the difficulties reported by some participants was the way in which they felt excluded or marginalised by mainstream services – 'the system'. This happened across all case studies and participants felt that they had done as much as they could, and went to legislative or funding bodies for support. This could mean that they made requests for more resources in order to take their work forward, or for changes in regulations or structures to allow developments to progress.

In either case, groups had to work with a variety of competing and changing agendas, which meant that any argument they had developed to fit one agenda might clash with another. This diversity across the system could emerge in different ways, as different sectors or departments thought differently, or existing policies were overturned by subsequent ones. In addition, interpretations of policies could differ between individuals and knowledge of current developments was not always shared widely.

In these circumstances, participants could feel frustrated when trying to negotiate with what seemed an incoherent and confusing system. On a positive note, some participants remarked that this had honed their political skills and developed their understanding of the system, which had moved beyond their rather naive assumption that 'the powers that be' had a unanimous and uniform position on policy matters. This sophistication, however, could also be a matter for regret, as participants felt dragged into 'turf wars' between individuals and organisations against their will.

Alongside this thematic discussion, another analytic process took place as part of the study. A workshop to which a range of older people from the wider group were invited was held. They included representatives from the projects explored in the research and the older people who had been researchers on the study.

Asking questions – older people

The findings from the case studies were presented to the audience and then they were asked to think of questions that they would advise people to ask if they were invited to become involved in any group or activity. These questions would help them decide to become involved in an activity or whether to continue with an activity. They are summarised as follows.

History

Participants stressed the importance of knowing the history of an activity. This would help people to understand why it had its current form, as groups could change considerably over time. This meant that it was sometimes difficult to work out the direction a group was taking, or what networks and connections it had. Finding out about the history of a group, therefore, could help a potential member clarify its goals and what it had achieved in the past. Participants therefore suggested the following questions about the group and about the invitation that had come from it.

1 Is the project because of another?

2 What is the background and track record?

3 Where has the involvement come from? (Is it led by an agency or by older people? Who initiated it?)

4 Who is funding it?

5 Is there a hidden agenda?

6 How will this link with other things I am involved with?

7 Am I sure that I’m not just a token participant, e.g. there as a token disabled person or as an older person?

Resources

Another set of questions were about the resources that the group and the individual had. These include material resources and others, such as enthusiasm, commitment and knowledge. Participants were encouraged to become involved if the invitation was made on the basis of recognition of their skills, experience or knowledge. This could be their individual abilities or, less significantly, their general experiences as older people. People were also encouraged to become involved if the activity was prestigious, had been well publicised, or had ‘clout’ (was taken seriously) with other agencies. Questions therefore included the following.

1 *Time*
- How much time will I be expected to devote to the project?
- Is it a time-limited project or a permanent commitment?
- How long will it go on for?
- Do I have the patience to see it through, particularly with constant changes in staff in agencies? (Advice: go to the top, to the people with the power – they change less frequently. Always go in person.)

2 *Interest*
- Is it of interest to me as an individual?
- Do I have the commitment, knowledge and experience to contribute?

3 *Funding and resources*
- Are there enough funds to complete the project or will they run out?
- Is the administrative structure properly supportive?
- Would personal costs be covered?
- Is there training available?
- Should involvement be paid? (How much/not out of pocket?)
- How are expenses reimbursed? (Does it meet with full real cost?)

4 *Membership and group dynamics*
- What sort of criteria are required to be a member?
- Will the group be representative?
- Will it be recognised that I have a constituency behind me?
- Is it meaningful enough for me to commit myself to it?
- Will it make a difference? Is it linked to people with authority/power?
- How many other older people are invited to the activity?
- Are they people I will enjoy working with? (Good company is important, but it's not everything!)
- Do I share the same vision of what this group is about and what it wants to achieve?

5 *Access*
- How will I get to the meeting and where will the meeting be held? (Accessibility: place of meeting/transport/disabled parking facilities.)
- Is it accessible? (Is it central?)

Process

There were also questions about the processes involved in taking part. Many of these were about the formal processes of information gathering, debating and decision making, but other questions, about group dynamics, were more difficult to answer before joining – they could be answered only once the activity got going.

Participants did not feel that activities should be problem free – they felt that there would always be some difficulties, but it was important they could assess them and decide whether to participate with these in mind.

They were encouraged to become involved if they felt that the process of involvement would be fair, open and supportive. This meant that they would be given opportunities to voice their opinions and knowledge, and this would be managed in a transparent and democratic way. An acceptable process would address issues of access, convenience and acceptability of activities. The following questions were suggested.

1 How much control will I have?

2 Will there be true involvement?

3 Are equal opportunities principles to be involved?

4 Is the group democratic in every way?

5 Is there a constant review of progress/membership/meeting and activity schedules?

6 Is there adherence to meeting procedures?

7 Is there efficient report writing?

8 How are people respected and equally valued?

9 Will there be professionals involved?
   - Look at how they respect others.
   - Need the same respect they would give to each other (partnership on both sides).

10 What accountability/responsibility will I have?

11 Will I be listened to and respected?

12 Will there be something sensible/relevant to listen to?

13 How much influence do we have?

14 What is set in stone already/what can't be changed?

15 Do everyone's ideas count? Are all options taken on board? Is there an atmosphere that encourages involvement (friendship, encouragement)?

16 Is effort made to check on people's abilities/disabilities (deafness, blindness, reading ability)?
- Don't draw attention to disability.
- Sensitivity – have sensitivity. Give people a quiet space to explore what they need to enable them to fully participate. Don't make an issue of it/form a friendship first (e.g. tape recording).
- Recognise the disability first and then create strategies to accommodate and respect it.

17 Is my ongoing commitment valued?

18 Are we approaching the decision makers in the most effective way?

19 Is it accepted that I have the right to refuse without feeling guilty?

20 Should there be a 'contract' of your involvement (might apply only to more formal groups)?

21 Is there intergenerational work?

22 Is work spread fairly?

23 Is it team work/real partnership?

Outcomes

Another category of questions was about the outcomes, either potential or actual, of the activity. While participants recognised that it was not always possible to ascertain these at the beginning of the activity, they realised they should keep them in mind

throughout. Although people could get great satisfaction simply by being part of a process of involvement, they felt that, without any outcomes, they would feel the activity had been a waste of time and effort.

Participants were encouraged to become involved if they thought this was likely to result in a clear outcome, which would make a difference to other people – not necessarily older people, but across the community. This could be changes in services or attitudes and knowledge. They therefore suggested that the questions below should be asked.

1 What is the anticipated achievement?

2 Is it cosmetic or planned?

3 Has it got a shelf life?

4 Who’s listening, what links are there to decision making?

5 What recognition is given to the activity?

6 Will it make a difference? (Look at the track record of the agency people inviting me to take part.)

7 How is the project going?

8 What progress have we made?

9 Are the agencies fulfilling their commitment?

10 Are we fulfilling our commitment?

11 Are the decision makers listening and responding with respect?

12 Who does it help?

13 How are we informed of achievements? (Progress report.)

14 What have been the disappointments?

15 Is anyone following up/acting on the group discussions?

Asking questions – agencies

These questions can be translated into questions that groups, agencies and organisations can ask themselves when they are requesting or encouraging participation. Again, these can be organised according to the headings used in the questions for potential participants.

History

1 Has the history of the group been explained?

2 Have relationships with other groups been explained?

3 Have changes over time been described?

4 Is it clear what the links are to other issues and developments?

Resources

1 How much time is required over what period?

2 What sorts of interests and skills will be engaged?

3 Has the funding for the activity been explained?

4 Is the availability of training clear?

5 Is the activity adequately staffed?

6 Will expenses or contributions be paid, and are the processes for making these payments clear?

7 What skills will members have or be able to access?

8 How has the membership been identified?

9 How will activities be managed and organised?

10 What interests will the activity appeal to?

11 How will access be guaranteed and supported? (Details of venues and facilities.)

12 How will different needs be accommodated?

Process

1 What are the processes for decision making in the group?

2 How can everyone’s voice be heard and reflected in activity?

3 What are the processes for monitoring and evaluating activity?

4 What are the links to other groups or organisations/agencies?

5 What responsibilities will each member have as an individual and collectively?

6 How much influence will the group have?

Outcomes

1 What outcomes are anticipated?

2 What impact will they have?

3 What recognition will there be?

4 What are the plans for disseminating and communicating outcomes?

5 Who will this help?

5 Conclusions

The questions generated by the study, along with the themes identified in the data, provide an overview of the processes and problems of older people's involvement. Clearly, participants were motivated by the desire to avoid tokenistic involvement and to be engaged in activities that really did 'get things done'. They were concerned that this study shared this ethos. The lists of questions, therefore, are an attempt develop something that might help to make a difference.

There are, however, other issues that arose in the study about the nature of partnership between academic researchers and older people. We found the academic traditions that we worked in – with particular notions of research rigour, validity and veracity – were not always compatible with the ideas of our partners. They took a utilitarian view of research – if it can be used, then it's valid. In other words they were more interested in outcomes than process, whereas we tended to focus on the process of design, analysis and reporting. Both positions have their strengths and weaknesses – the focus on outcome emphasises utility at the possible expense of rigour and the focus on process privileges this over usefulness. This looks like a choice between useful but 'messy' research, which has no academic credibility, or pristine research, which has no use and no credibility with users.

The challenge, therefore, is to develop ways of doing research that combine the strengths of both approaches, producing research that has a sound design and is useful. Hopefully, this study, by working in a collaborative way with involvement of older people at each stage, has gone some way to providing this.

Bibliography

Abbott, S., Fisk, M. and Forward, L. (2000) 'Social and democratic participation in residential settings for older people: realities and aspirations', *Ageing and Society*, Vol. 20, No. 3, pp. 327–40

Abelson, J., Forest, P.-G., Eyles, J., Smith, P., Martin, E. and Gauvin, F.-G. (2003) 'Deliberations about deliberative methods: issues in the design and evaluation of public participation processes', *Social Science and Medicine*, Vol. 57, No. 2, pp. 239–51

Abelson, J., Forest, P.-G., Eyles, J., Casebeer, A., Mackean, G. and the Effective Public Consultation Project team (2004) 'Will it make a difference if I show up and share? A citizens' perspective on improving public involvement processes for health system decision-making', *Journal of Health Service Research Policy*, Vol. 9, No. 4, pp. 205–12

Agich, G.J. (1993)*Autonomy and Long-term Care*. Oxford: Oxford University Press

Allen, J., Hogg, D. and Peace, S. (1992) *Elderly People: Choice, Participation and Satisfaction*. London: Policy Studies Institute

Anchor Housing Trust (1984) *Staying put: Help for Older Home Owners*. London: Age Concern

Andrews, J., Manthorpe, J. and Watson, R. (2004) 'Involving older people in intermediate care', *Journal of Advanced Nursing*, Vol. 46, No. 3, pp. 303–10

Arnstein, S. (1969) 'A ladder of citizen participation', *Journal of the American Institute of Planners*, Vol. 35, No. 4, pp. 216–24

Ashworth, P., Longmat, M. and Morrison, P. (1992) 'Patient participation: its meaning and significance in the context of caring', *Journal of Advanced Nursing*, Vol. 17, No. 5, pp. 1430–9

Barnes, M. and Bennett, G. (1998) 'Frail bodies courageous voices: older people influencing community care', *Health and Social Care in the Community*, Vol. 6, No. 2, pp. 102–11

Belford and District Local History Society (1995) *Local Council Role since Reorganisation*. Belford: Belford and District Local History Society

Bentley, J. (2003) 'Older people as health service consumers: disempowered or disinterested?', *British Journal of Community Nursing*, Vol. 8, No. 4, pp. 181–7

Biggs, S. (2001) 'Toward critical narrativity: stories of aging in contemporary social policy', *Journal of Aging Studies*, Vol. 15, No. 1, pp. 303–16

Blair, T. (1996) *New Britain: My Vision for a Young Country*. London: Fourth Estate

Blunden, R. (1998) 'Project points the way to giving older people real say in planning', *Working with Older People*, Vol. 2, No. 1, pp. 5–6

Blunden, R. and Ambache, J. (1998) 'Pairing up for meaningful consumer participation', *Working with Older People*, Vol. 2, No. 1, pp. 9–10

Boyle, D. (2002) 'Involving older people through time banks', *Working with Older People*, Vol. 6, No. 2, pp. 9–11

Brocklehurst, J. and Dickenson, E. (1996) 'Autonomy for older people in long-term care', *Age and Ageing*, Vol. 25, No. 4, pp. 329–32

Cahill, J. (1996) 'Patient participation: a concept analysis', *Journal of Advanced Nursing*, Vol. 24, pp. 561–71

Care and Repair Ltd (1987) *Care and Repair: A Guide to Setting up Care and Repair Agency Services for Elderly People*. London: Shelter/Housing Associations' Charitable Trust

Carr, S. (2004) *Has Service User Participation Made a Difference to Social Care Services?* Bristol: Social Care Institute for Excellence in conjunction with the Policy Press

Carter, T. and Beresford, P. (1999) *Models of Involvement of Older People*. York: YPS for the Joseph Rowntree Foundation

Carter, T. and Beresford, P. (2000) *Age and Change: Models of Involvement for Older People*. York: YPS for the Joseph Rowntree Foundation

Clark, H. and Dyer, S. (1998) 'Equipped for going home from hospital', *Health Care in Later Life*, Vol. 3, No. 1, pp. 35–45

Clark, H., Dyer, S. and Horwood, J. (1998) *'That Bit of Help': The High Value of Low Level Preventative Services for Older People*. Bristol: The Policy Press

Cormie, J. and Crichton, M. (1996) *Voices of Experience: Report to the Charity Projects 1992–95*. Kircaldy: Age Concern

Crawford, M.J., Rutter, D., Manley, C. and Weaver, T. *et al*. (2003) 'Systematic review of involving patients in the planning and development of health care', *British Medical Journal*, Vol. 325, No. 7375, pp. 1263–6

Crosby, N. (2003) *Healthy Democracy: Empowering a Clear and Informed Voice of the People*. Edina, MN: Beaver Pond Press

Darlington Borough Council (2003) *Darlington Strategy for Older People*. Darlington: Darlington Borough Council

Davies, S., Laker, S. and Ellis, L. (1997) 'Promoting autonomy and independence for older people within nursing practice: a literature review', *Journal of Advanced Nursing*, Vol. 26, No. 2, pp. 408–17

Department of Health (1989) *Caring for People: Community Care in the Next Decade and Beyond*. London: HMSO

Department of Health (1991) *Patients Charter*. London: HMSO

Department of Health (2000) *The NHS Plan – A Plan for Investment. A Plan for Reform*. Cm. 4818-1. London: The Stationery Office

Department of Health (2001a) *Involving Patients and the Public in Healthcare: A Discussion Document*. London: The Stationery Office

Department of Health (2001b) *The National Service Framework for Older People*. London: The Stationery Office

Department of Health (2001c) *The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century*. Available from: http://www.ohn.gov.uk/ohn/people/expert.htm

Department of Health (2003) *Patient and Public Involvement in the New NHS*. London: Department of Health

Department of Health (2004) *Patient and Public Involvement in Health: The Evidence for Policy Implementation*. *A Summary of the Results of the Health in Partnership Research Programme*. London: Department of Health

DETR (Department of the Environment, Transport and the Regions) (2000) *Preparing Community Strategies: Draft Guidance to Local Authorities*. London: DETR

Douglas, B. (2001) *House for Life Report 1999–2000. Better Life in Later Life*. Newcastle: Newcastle Healthy Cities Project

Douglas, B. and Everitt, A. (1997) 'It's the elephant they never forget', *Working with Older People*, July, pp. 18–21

Elman, C. (1995) 'An age-based mobilisation: the emergence of old age in American politics', *Ageing and Society*, Vol. 15, No. 2, pp. 299–324

Flower, J. (1993) 'Creating a forum', *Community Care*, Vol. 45, No. 9, pp. 20–1

Friends of Bell View (1998) Committee meeting minutes, unpublished

Hall, G. (2004) 'Promoting patient involvement', *Practice Nurse*, Vol. 27, No. 5, pp. 61–2, 64–7

Hardy, B. and Wistow, G. (1999) 'Dimensions of choice in the assessment and care management process: the views of older people, carers and care managers', *Health and Social Care in the Community*, Vol. 7, No. 6, p. 483

Harrison, L. (2000) 'Health begins at home: the housing–health interface for older people', *Reviews of Environmental Health*, Vol. 15, Nos 1/2, pp. 149–67

Harrison, S., Dowsell, G. and Milewa, T. (2002) 'Public and user involvement in the UK National Health Service', *Health and Social Care in the Community*, Vol. 10, No. 2, pp. 63–8

Hayden, C. and Boaz, A. (2000a) *Making a Difference BGOP Evaluation Report*. Warwick: University of Warwick

Hayden, C. and Boaz, A. (2000b) *All our Futures: The Reports of the Better Government for Older People Programme*. Warwick: Local Government Centre, University of Warwick

Health Advisory Service (2000) *Not because they are Old – An Independent Inquiry into the Care of Older People on Acute Wards in General Hospitals*. London: Health Advisory Service

Health and Social Care Act (2001) London: The Stationery Office. Available from http://www.legislation.hmso.gov.uk/acts/acts2001/20010015.htm

Help the Aged (2002) *Senior Citizens' Forums: A Voice for Older People*. London: Help the Aged

Hepinstall, D. (2001) 'The mutual benefits of involvement', *Working with Older People*, January, pp. 24–7

Hickey, G. and Kipping, C. (1998) 'Exploring the concept of user involvement in mental health through a participation continuum', *Journal of Clinical Nursing*, Vol. 7, No. 1, pp. 83–8

Huby, G., Stewart, J., Tierney, A. and Rogers, W. (2004) 'Planning older people's discharge from acute hospital care: linking risk management and patient participation in decision-making', *Health Risk Society*, Vol. 6, No. 2, pp. 115–32

Jefferson Center (2004) Website: http://www.jefferson-center.org

Jewell, S. (1994) 'Patient participation: what does it mean to nurses', *Journal of Advanced Nursing*, Vol. 19, No. 2, pp. 433–8

Jewell, S. (1996) 'Elderly patients' participation in discharge decision making', *British Journal of Nursing*, Vol. 5, No. 17, pp. 1065–71

Jones, K., Baggott, R. and Allsop, J. (2004) 'Influencing the national policy process: the role of health consumer groups', *Health Expectations*, Vol. 7, No. 1, pp. 18–28

Joseph Rowntree Foundation Older People's Steering Group (2004) *Older People Shaping Policy and Practice*. York: Joseph Rowntree Foundation

Joseph Rowntree Foundation Task Group on Housing, Money and Care for Older People (2004) *From Welfare to Well-being – Planning for an Ageing Society*. York: Joseph Rowntree Foundation

Kelly, M. (1998) Architects' report to Bell View Steering Committee, unpublished

Kirk, S. (1997) 'Involving communities in health service planning in primary care', *Health and Social Care in the Community*, Vol. 5, No. 6, pp. 398–407

McCloud Clark, J. and Latter, S. (1992) 'Working together', *Nursing Times*, Vol. 86, No. 48, pp. 28–31

McCormack, B. (1998) 'An exploration of the theoretical framework underpinning the autonomy of older people in hospital and its relationship to professional nursing practice', unpublished DPhil. thesis, Department of Educational Studies, University of Oxford

Maltby, T. and Walker, A. (1997) 'Release the talent of the third age', *Working with Older People*, July, pp. 10–11

Morris, J. and Lindow, V. (1993) *User Participation in Community Services Community Care Support Force*. Leeds: Department of Health

Munro, M. and Leather, P. (2000) 'Nest-building or investing in the future? Owner-occupiers' home improvement behaviour', *Policy and Politics*, Vol. 28, No. 4, pp. 511–26

Myers, F. (1996) 'Power to the people? Involving users and carers in needs assessments and core planning – views from the practitioner', *Health and Social Care in the Community*, Vol. 4, No. 2, pp. 86–95

Newcastle City Partnership (2002) *The Newcastle Plan – towards a Community Strategy 2002–2010*. Newcastle: Newcastle City Partnership

NHS Management Executive (1992) *Local Voices – The Views of Local People in Purchasing for Health*. London: NHSME

North Tyneside Handyperson Scheme (2003) *Annual Report April 2002–March 2003*. Newcastle: North Tyneside Handyperson Scheme

Office of the Deputy Prime Minister (2001) *Quality and Choice for Older People's Housing*. London: Office of the Deputy Prime Minister and the Department of Health

Office of the Deputy Prime Minister (2003) *Supporting People: A Guide to User Involvement for Organisations Providing Housing-related Support Services*. London: Office of the Deputy Prime Minister

PEALS (Policy, Ethics and Life Sciences) (2003a) *Teach yourself Citizens' Juries. A Manual for Planning, Implementing, and Campaigning with Jury Techniques*. Newcastle: University of Newcastle

PEALS (2003b) *Do-it-yourself Citizens' Jury Newcastle upon Tyne, Jury Verdict*. Newcastle: Newcastle University

Peter Fletcher Associates (2002a) *Growing Older Living in Darlington (GOLD) Integrated Strategy for Older People in Darlington*. Haydon Bridge: Peter Fletcher Associates on behalf of the Steering Group.

Peter Fletcher Associates (2002b) *Evaluation of Development of the Integrated Strategy for Older People in Darlington*. Haydon Bridge: Peter Fletcher Associates

Policy Innovation Unit (2000) *Winning the Generation Game*. London: Cabinet Office

Powell, J., Bray, J., Roberts, H., Goddard, A. and Smith, E. (2000) 'Goal negotiation with older people in three day care settings', *Health and Social Care in the Community*, Vol. 8, No. 6, pp. 380–9

Raynes, N.V. (1998) 'Involving residents in quality specification', *Ageing and Society*, Vol. 18, pp. 65–78

Reed, J. and Clarke, C. (1999) 'Nursing older people: constructing need and care', *Nursing Inquiry*, Vol. 6, pp .208–15

Reed, J., Cook, G. and Stanley, D. (1999) 'Promoting partnership with older people through quality assurance systems: issues arising in care homes', *Nursing Times Research*, Vol. 4, No. 5, pp. 353–63

Reed, J., Pearson, P., Douglas, B., Swinburne, S. and Wilding, H. (2002) 'Going home from hospital – an appreciative inquiry study', *Health and Social Care and the Community*, Vol. 10, No. 1, pp. 36–45

Reinhardy, J.R. (1995) 'Relocation to a new environment: decisional control and the move to a nursing home', *Health and Social Work*, Vol. 20, No. 1, pp. 31–8

Say, R.E. and Thomson, R. (2003) 'The importance of patient preferences in treatment decisions – challenges for doctors', *British Medical Journal*, Vol. 327, No. 7414, pp. 542–5

Social Care Institute for Excellence (2004) *Has Service User Participation Made a Difference to Social Care Services?* Bristol: The Policy Press for SCIE

Swingbridge Video (2003) *Video Handbook: How to Set up a Citizens' Jury*. Newcastle: Swingbridge Video

Wakeford, T. (2002) *Citizens' Juries: A Radical Alternative for Social Research*. Social Research Update 37. Guildford: University of Surrey. Available from: http://www.soc.surrey.ac.uk/sru/SRU37.html

Waterworth, S. and Luker, K. (1990) 'Reluctant collaborators: do patients want to be involved in decisions concerning care?', *Journal of Advanced Nursing*, Vol. 15, No. 4, pp. 971 –6

Wilber, K.H. (2001) 'Decision-making, dementia and the law: cross national perspectives', *Ageing and Mental Health*, Vol. 5, No. 4, pp. 309–11

Williamson, T. (2004) 'User involvement – a contemporary overview', *Mental Health Review*, Vol. 9, No. 1, pp. 6–12

Wistow, G. (2000) *The Modernised Personal Social Services: NHS Handmaidens or Partners in Citizenship*. Leeds: Nuffield Institute for Health

Wistow, G. (2001) 'Modernisation, the NHS Plan and healthy communities', *Journal of Management in Medicine*, Vol. 15, No. 5, pp. 334–51

Youll, P.J. and McCourt-Perring, C. (1993) *Raising Voices: Ensuring Quality in Residential Care*. London: HMSO

Appendix 1: Older people as co-researchers

This appendix has been included in the report to highlight the contribution of the co-researchers to the study and the significant influence they had on the way the study was carried out. Before we turn to this subject, a brief outline of the research design and the factors promoting the involvement of older people in research is given to provide a context for this discussion.

Research design

In this study, there were two parallel strands of investigation, which fed back into each other. The first examined the successful involvement of older people in planning and policy activities. The second concerned the involvement of older people as co-researchers in the project and discovering their experiences of this.

- *Strand one: the involvement of older people in service planning and policy activities*. There were two distinct phases to this strand of the study. The first was a workshop bringing together older people who were active in policy and service planning initiatives, to share their experiences about good practice. The second involved the in-depth investigation of five case study initiatives/projects in which older people had been successfully involved, to map infrastructure and processes across systems that affect the success of involvement strategies and initiatives.

- *Strand two: the involvement of older people as researchers in the study*. The aims of this strand of the project were to seek innovative ways of involving older people in the research process, and to promote and sustain the unique contribution they could make to the research. We also tried to capture the experiences of the older people co-researchers, the academic researchers and administrators who worked together on the project.

As one of the members of the research team was instrumental in defining the research agenda, developing the research proposal and commissioning the study, this gave impetus to sustain active and extensive involvement of older people throughout the entirety of the study.

Drivers promoting the involvement of older people in research

The impetus to involve older people in research gained momentum in recent years within a wider movement to involve service users and the public in research. In academic debate there has been examination of the (de)merits of conducting research on, rather than with, the study's subjects, and the proponents of participatory research have highlighted the way that research on subjects could be viewed as oppressive, disempowering, inadequate and inappropriate when that research attempts to explore people's views and subjective experiences of policy and service delivery in practice (Carter and Beresford, 1999). These negative outcomes are more likely to occur when the research involves those whose needs are more complex, such as older people and people with learning difficulties. Hence, there was growing recognition of the importance of accessing the different perspective that vulnerable populations and service users bring to research.

In addition, there has been a growing awareness in society of the service users' right to express their views and to contribute to decision making in public services and the generation of knowledge that supports practices in those services. However, older people, Biggs (2001) argues, have been systematically excluded from processes that would enable them to influence their lives and their communities. Blairite social policy actively sought to change this, as reflected in the following quotation:

> My vision is for a society in which older people are given more say in how services are run. We need to value and celebrate older people for the experience they bring and the active contribution they can make. They are an essential part of the Britain I want to build.
> (Blair, 1996)

In acknowledgement of these issues, policy makers and research funders have actively encouraged studies that consult with and involve service users and the public in an attempt to enhance the relevance, acceptability and utility of the outcome.

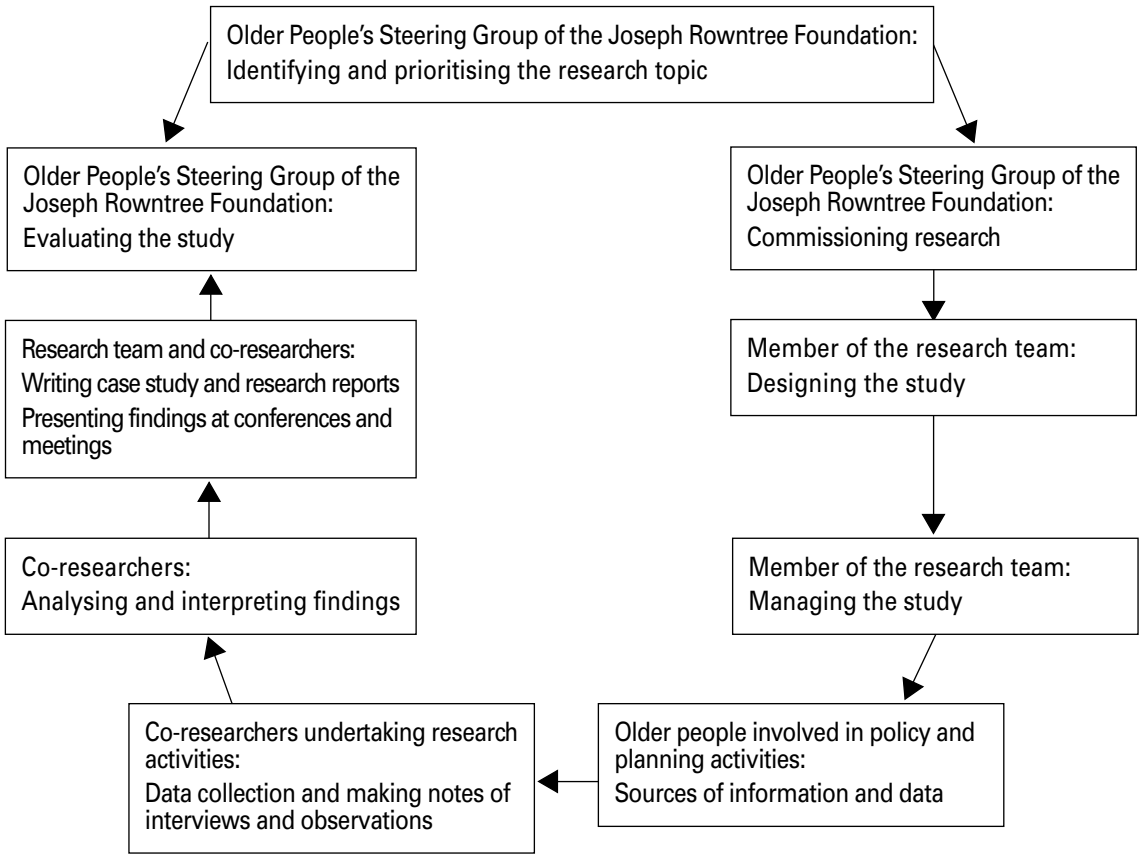
The movement to encourage and actively support the involvement of service users and the public in the creation of knowledge, either as collaborators in research or as independent researchers, has been evident in recent policy development in the UK. Within the NHS, this agenda has been supported by the creation in mid-1996 of the Standing Advisory Group on Consumer Involvement in the NHS R&D programme, which later evolved into Involve. This group is a sub-group of the Central R&D Committee, which advises the Director of R&D on research policy, priority setting and how funds should be spent. The group actively promotes service user and public involvement in health care research and supports initiatives that facilitate that involvement. Hence, an infrastructure now exists to support and move forward service user and public involvement in policy and health research.

Co-researcher involvement: what they did and what they thought of their experience

Type and level of involvement of older people in the study

Older people have been involved with every aspect of this study, from developing the initial idea to carrying out the investigation and writing the report. The process began with members of the Older People's Steering Group of the Joseph Rowntree Foundation prioritising and selecting the subject that was examined in this study. In response to the call for proposals to investigate older people's involvement in policy and planning, a research team was formed with the members being an older person, a community development worker and an academic researcher. Together, they designed a study, developed a successful bid and managed the study. As the project developed, older people were invited to participate in the research process, first as providers of data and then as co-researchers in the investigation. Figure A1.1 highlights all of the points in the study where older people have led and participated in the research process.

Figure A1.1 Roles and activities of older people co-researchers



For some, undertaking research was a new experience, which required the development of new abilities. They faced up to many challenges throughout the study, most noteworthy being the writing of the case study reports, developing research posters (see Appendix 5) and presenting the findings at national conferences. These achievements cannot be underestimated.

Recruitment of co-researchers

During the project workshop that was held in June 2003 to explore older people's experiences of taking part in policy and planning activities, the participants were invited to take part in the study as co-researchers in the investigation of the case study sites. They were informed they could negotiate the types of activities they felt able and wanted to do. This could include participation in data collection (visiting the case study sites, interviewing their peers, observing ongoing activity and collecting secondary data such as newspaper items and reports about the site), making notes following visits to the sites, data analysis and report writing.

Nine of the 37 workshop attendees responded to this invitation. All of the co-researchers were retired, and three were male and six female. Everyone had extensive commitments in a range of policy, planning and service provision activities. Two people had previous research experience (through postgraduate studies and participation in research) and two people were counsellors with well-developed interviewing skills. The main motivations for getting involved were to:

- get to know about other schemes/initiatives and how these schemes worked; for example, one of the co-researchers was particularly interested in finding out about the North Tyneside Handyperson Scheme because older people who live in Darlington have great difficulty in getting assistance to do small jobs around the house (e.g. changing light bulbs) – she wanted the information to take back to her own area to explore the feasibility of developing a similar scheme in her community

- expand existing networks that would be helpful to the initiatives the participants were engaged in

- use knowledge, skills and abilities, and develop new ones

- use and develop skills as social researchers.

Two co-researchers withdrew from the study during the first six months when their personal circumstances changed and they were no longer able to take part.

Preparing for the role of co-researcher

Following recruitment of the co-researchers to the study, a co-researcher meeting was organised to enable the co-researcher team to get to know each other and to find out more about the project and the five case study sites. After much discussion, the co-researchers selected the site – and in some cases the sites – that they wanted to work in. They also declared the type of research work that they wanted to do in each site (e.g. interviewing participants) and how much time they wanted to devote to the research project.

The second half of this meeting was dedicated to research training where the following topics were discussed: background and purpose of the study; research methods adopted in the study; setting up interviews; the practicalities of interviewing; carrying out interviews and using the interview schedule; making interview notes.

The real learning began when the co-researchers started to work in the case study sites. Although the project researcher made the initial contact with each case study site, there was much time devoted to getting to know the project/initiative and those involved with it in more detail at the beginning of data collection. This involved visits to the sites, getting to know the area, and occasionally observing meetings and activities that were taking place.

When the first interviews were arranged in each site, the researcher and co-researchers met to discuss the way they intended to conduct the interview and to practise their interview technique in an informal setting. For the first few interviews the researcher and co-researcher worked together, ensuring that there was time after each interview to reflect on the way it was managed, how questions were asked and alternative ways to do this, and consideration of the interviewees' responses. Hence, there were extensive on-the-job learning opportunities where research skills were assimilated. As data collection progressed the co-researchers took a lead role in interviewing and writing up the record of the interviews. It was a great relief to everyone that the interviewees were so enthusiastic about their initiatives that the 'interviews just flowed' and 'the interviews were really easy to conduct and it was great hearing about all the good things that are happening in our area'.

A tenet that underpinned the co-researcher aspect of the study was to promote and sustain the unique contribution that older people could make to the research. The project management team were concerned about the possibility that this team of co-researchers could have been trained in such a way that they participated in the study as professional researchers and this might have resulted in the loss of their unique contribution to the research process. This challenged the research team because the co-researchers required skills and the development of knowledge to actively participate in the study, yet this training process had the potential to change their contribution. This was a real paradox that the team struggled with throughout the study.

Recommendations from the co-researcher team for involving older people in research as researchers

- Make the project interesting and purposeful for those taking part – this may be achieved by promoting a desirable outcome (which may differ from academic interests), such as achieving outcomes that enhance the well-being of older people.
- Be clear about what is expected of researchers who are working on the project and be realistic about time commitment.
- Don't get too technical and avoid jargon.
- Enable everyone to take part and value each person's contribution – 'have different ways for people to take part', 'allow people to draw on their previous experience'.
- Provide opportunities for induction and ongoing training – this will differ at different points in the study.
- Be well prepared for the interviews, have clear written information for interviewees and an interview agenda.
- Practical organisation – issues around access, transport, expenses, etc. need to have been considered and resolved in advance.
- Administrative support – have someone responsible for organising interviews, providing equipment, planning the route, etc.
- Academic support – support people into the researcher role.

Supporting each other

While the research team supported the co-researchers by providing formal preparation for their role, on-the-job training, co-ordination of the process of data collection and working collaboratively throughout report writing, peer support emerged as a very important element of the study. Many of the co-researchers knew other people from the other activities or groups they were associated with. Knowing each other in different ways and having common interests created a bond within the team that would not otherwise have happened.

It quickly became evident that the co-researchers were supporting each other in their new roles. To build on this, co-researcher meetings were established as part of the project to enable the team to share their experiences of being co-researchers. They spoke about the ways in which they approached data collection, what worked well and didn’t work so well, and alternative ways of approaching the situation. The meetings were also used as opportunities to discuss the progress being made in each case study site and to explore the findings that were being generated as the study progressed. These meetings, therefore, combined formal and informal learning opportunities that enabled the team members to ‘develop new skills’ and ‘see the bigger picture’.

A key element of the co-researcher meetings was ‘having fun’. Achieving this was a learning curve for the academic researchers and the host organisation, which experienced laughter mixed with business in its corridors. As the project developed, the combination of work and pleasure resulted in outcomes that met both project and personal outcomes.

What did the co-researchers feel about the research process?

At first many were frightened and lacked confidence; however, they were reassured that they brought considerable knowledge and enthusiasm to the project. In reflection of their experience the co-researchers stated:

> It was terrifying at first.
>
> It was a definite learning curve.
>
> I didn’t know what was involved – I tend to say ‘yes’ before knowing what I’ll have to do!

Older people researchers

The following is a poem written by two co-researchers about their experiences of presenting a poster at the Involve Conference in Nottingham, 2004:

Off to Nottingham we set,
With some apprehension and regret.
With a poster under arm,
The audience we aimed to charm.
Co-researchers We!

To be involved was our intention,
Not quite sure what we should mention.
So Audrey and Mick spoke from their hearts,
Of experiences of taking part.
Co-researchers We!

The older persons' view we set.
Pleased with the reaction that we met.
Our contribution made at last,
Though the issues will never pass.
Older researchers are We!

Being supported and introduced slowly into the research process, feeling part of a team and the fact that the interviewees were generally keen to talk about the initiative they were involved with all helped the co-researchers successfully participate in the research process. The following factors helped them to engage with the project and their new roles:

> The moral support for us as new to this sort of thing was essential.

> Pulling us in slowly, that was a big help.

Taking part in the interviews was viewed as a positive personal experience; for example, when the interviewers heard what others had achieved, they felt encouraged that everyone can do remarkable things; also meeting older people in their late 80s/90s who continued to be actively involved in a range of activities promoted a positive image of advanced old age.

As a co-researcher they were able to draw from their life's experiences to make sense of the condition of other people's lives. Participation in the project, therefore, presented the opportunity to use skills, knowledge and experience in a different way,

which had the potential to make a meaningful impact on the work they were already engaged in. The positive impact of the role of researcher is captured in the following quotation:

> Being part of the project made us all realise that there is life after retirement.

What were the project outcomes that were of interest to the co-researchers?

There was much network building and sharing of experiences between the co-researchers and those they were interviewing. They were able to take information and lessons back to their own initiatives. This sharing within the project was much more immediate than it would have been through usual research routes, i.e. through reports and publications. The co-researchers stated:

> It was great to learn about initiatives in other places that are applicable to where I am.
>
> I found out about and saw for myself things that I had only heard about.
>
> I learnt about what older people need and should have available to them.

What the academic researchers learnt from this experience

Working with older people as co-researchers was both exciting and challenging. While the academic researchers quickly came to realise that the co-researchers were an enthusiastic group of people who brought a wealth of skills, knowledge and personal experiences that could be harnessed to enhance the project, they were also aware that new research practices and different ways of working were needed to elicit the added value of working together. A central principle that underpinned the practices that developed was respect for the unique contribution that everyone made to the project. There was no doubt that establishing close personal and social relationships between team members at the beginning of the project led to understanding and respect of the different perspectives of everyone. This might be time demanding but it was essential.

The co-researchers negotiated the type and level of their involvement (some visited case study sites and collected data, and others did this in addition to analysing the

data and writing reports), as well as the outcomes that they wanted to achieve from their involvement. This had to be constantly revisited as the co-researchers grew in skill and confidence, hence there had to be great flexibility to provide highly structured support where needed, or to allow people to develop and extend their responsibilities.

Though the co-researchers developed research skills and gained technical knowledge, it was a constant challenge to do this in ways that avoided turning them into (semi)professional researchers. At times this was difficult for the academic researchers who continued to work within organisational structures that had processes that were appropriate for traditional research practices with minimal service user involvement. In addition to the demands of the project the academic researchers found that they had to challenge university systems and develop innovative working practices to ensure that older people could be involved in the project in ways that were acceptable to them.

What might projects gain from involving older people as researchers?

In this project the interviewees (who were generally also older people) identified with the co-researchers in a way that they might not have with a younger researcher. The older people had a shared language (e.g. using ‘spouse’ rather than ‘partner’) and could build on shared experiences. It was felt that the contribution of older people as interviewers encouraged the participants to tell more of their story and in this way ‘richer’ data was elicited about the experiences of those taking part in the project.

Appendix 2: Involvement workshop agenda

OLDER PEOPLE'S INVOLVEMENT

in planning, policy and research

Involvement workshop
Gosforth Civic Hall, Newcastle upon Tyne
1 February 2005
10.30 a.m. – 3.00 p.m.

Programme

10.30 a.m. – 11.00 a.m.	Registration and coffee	
11.00 a.m. – 12.30 p.m.	Purpose, background and findings	
	Background and commissioning of the project	Vera Bolter
	Methodology and study design	Glenda Cook
	Reports from the case study sites:	
	North Tyneside Handyperson Scheme	Audrey Lax
	Housing for Life, Newcastle	Elsie Richardson
	Bell View (Belford) Ltd	Stella Swinburne and Vera Bolter
	Growing Older Living in Darlington	Judith Williams
	DIY Citizens' Jury, Newcastle	Anna Luce
12.30 p.m. – 1.15 p.m.	Lunch	
1.15 p.m. – 1.30 p.m.	Initial thoughts on factors encouraging involvement of older people in policy and planning	Professor Jan Reed
1.30 p.m. – 2.15 p.m.	Group activity: Working towards satisfying and effective involvement	Barbara Douglas
2.15 p.m. – 2.30 p.m.	Afternoon tea	
2.30 p.m. – 2.55 p.m.	Feedback, clarification and elaboration of group discussion	Professor Jan Reed
2.55 p.m.	Final remarks	Vera Bolter
3.00 p.m.	Finish	

Group activity: Working towards satisfying and effective involvement

If you were being invited to take part in a policy or planning activity, what questions should you ask?:

Before you agreed to be involved?:

At regular intervals during your participation?:

Appendix 3: Research workshop information handout

OLDER PEOPLE'S INVOLVEMENT

in planning, policy and research

Research workshop
Gosforth Civic Hall, Newcastle upon Tyne
12 June 2003
10.30 a.m.–3.30 p.m.

HANDOUT ONE

Project team
Vera Bolter (Elders Council of Newcastle)
Professor Jan Reed (Northumbria University)
Barbara Douglas (Better Life in Later Life)
Glenda Cook (Northumbria University)

The project has been funded by Joseph Rowntree Foundation

Programme

10.00 a.m.	Registration and coffee on arrival	
10.30 a.m.	Welcome and introduction to the workshop	Vera Bolter
10.40 a.m.	An overview of the research project	Jan Reed
10.50 a.m.	A guide to the older people's involvement workshop interviewing process	Jan Reed
11.00 a.m.	Sharing experiences – attendees are invited to work in pairs and then in larger groups to share their experiences of involvement in planning and policy activities	
12.30 p.m.	Lunch	
1.15 p.m.	Overview of the morning activities	Barbara Douglas
1.20 p.m.	Introduction to the second stage of the study. This involves investigation of five case studies, which are activities that workshop attendees suggest provide examples of good practice of the involvement of older people in policy and planning	Jan Reed

	What are the implications of being involved as a case study site?	Jan Reed
1.40 p.m.	Suggestions for case study sites	
2.15 p.m.	Coffee and ranking of case study sites	
2.45 p.m.	Feedback from the ranking process and decision on the sample of case study sites reached	Barbara Douglas
3.00 p.m.	Involvement as a researcher in the project	Glenda Cook
3.25 p.m.	Concluding remarks	Vera Bolter

Welcome to the workshop

Thank you for attending today.

Whilst we welcome your contribution to the project, we do hope that you find this an enjoyable and a beneficial experience.

What is the purpose of the workshop?

The workshop is the first stage of a project that has been established to develop an understanding of what helps and what hinders older people to become actively engaged in service planning, policy and research. This knowledge is important to future initiatives that aim to involve older people to ensure that this work is effective and satisfying from an older person's perspective.

The workshop gives participants the opportunity to share their experiences with others who have been involved in service planning and policy activities.

Sharing experiences of involvement in planning and policy

Welcome and introductions

Personal introductions

Take a couple of minutes each to introduce yourself to the other people on your table and to describe what planning and policy involvement activities you have participated in.

Following this, please divide into pairs to take part in the following activity.

Sharing our experience

Part one: One to one discussion

Working in pairs, take turns to be 'the interviewer' and the 'interviewee'. During your conversation, the interviewer is asked to note down the key points you make. In particular, we would like you to note down on a sheet of paper any 'quotable quotes', i.e. where someone says something in particularly striking ways. This will help us to retain some of the essence of the vibrant discussion that takes place during the workshop.

The conversation will begin by addressing the following topic:

Select one of the activities that you participate in and describe your involvement.

The interviewer will ask the following questions to promote discussion:

- What is the nature of your commitment to this activity? (For example, was it a 'one-off' or 'long-term' commitment?)
- What was pleasing or satisfying about your part in the process?
- What do you value about your situation that enabled you to be involved in this way?
- What were the outcomes of your involvement?

When both partners have taken turns at interviewing and being interviewed, then each person must select one key point about taking part in planning and policy activities from your discussion to present to those working on your table.

Part two: Small group discussion

The group first selects a reporter who will present their conclusions to the large group. Every attendee then presents the key issue that they have selected for further discussion by those working on their table. Throughout this stage of the workshop the reporter makes notes of the main points of the discussion that takes place to feed back to the large group.

This information will also be used to make a record of the event, so please make sure that the notes are clear and reasonably concise.

Putting forward suggestions for case study sites

As part of the research we are aiming to identify five different initiatives as case studies that illustrate different processes or aspects of participation by older people.

For each case study we will be seeking to do some in-depth work, which will include carrying out interviews with older people who have been involved in the initiative. This may also involve other types of data collection, such as observing a committee meeting.

We are looking for case studies that demonstrate different levels and types of involvement in all aspects of policy and planning. This may include older people's participation in organised committees, or those activities that older people have established and control.

Making a suggestion for a case study site

You may wish to work with others in the room who are involved in the initiative you wish to put forward as a case study. If you are the only person here today who knows about a particular initiative, you may prefer to work on your own.

You are invited to make a poster concerning your suggestion for a case study. If you would like to describe more than one initiative, please make a separate poster for each. The poster should include the following details:

- Name of the planning/policy involvement activity
- How the arrangements for involvement of older people were set up?
- What type of involvement older people have in the activity?
- What are the perceived strengths and weaknesses with respect to the involvement of older people in the activity?
- Why it would be interesting to use this example as a case study

Thank you for your participation in the workshop

We do hope that you have had an enjoyable day. We appreciate the effort that you have made to take part in the workshop.

Follow-up:

If you would like information about how the project is progressing, sign the newsletter receipt form on the registration desk. This will be available every six months throughout the project.

Prior to leaving:

Please do not forget to discuss reimbursement of out-of-pocket expenses with Glenda Cook.

Appendix 4: Case study information sheet

OLDER PEOPLE'S INVOLVEMENT

in planning, policy and research

Case study information sheet

This is an invitation to take part in the second stage of a project that has been commissioned by the Joseph Rowntree Foundation. This study seeks to develop knowledge of what helps and what hinders older people to become actively engaged in service planning, policy and research in order that future developments may build on those approaches that have proved to be effective. The study is being undertaken in the North East Region of England.

Background to the study

Recent policy developments have emphasised the importance of involving citizens in decision-making processes of public services, policy and research. This has resulted in more opportunities than ever before for this to occur. Whilst there is much written about the models that have developed to enable older people to become involved in these activities, there is little known about their experiences in the wake of these policy developments.

Models of involvement that have been developed indicate that there are different levels and types of involvement, ranging from the tokenistic presence of older people on committees, to older people establishing and controlling a group that has influence in their sphere of activity. To the outsider, or even those in the services who are working towards encouraging involvement, these differences are not always apparent. What may initially appear to be an ideal strategy for involvement could in practice be ineffective. Similarly, what may not look like an effective strategy may be productive and supportive. There may be a number of factors involved which determine the success or failure of a strategy and this study seeks to identify and explore them.

Aim of the study

To learn lessons about the processes of the effective involvement of older people in planning and policy.

Why have I been approached to take part in the study and what will it involve?

A workshop was held on the 12th June 2003, Newcastle upon Tyne. Older people from a range of agencies and groups attended this event and they shared their experiences of involvement in planning, policy and research. During the event the attendees were invited to suggest activities/projects to include as case study sites. Growing Old Living in Darlington was identified as one of these sites.

Key contacts from this scheme have been asked to identify the people and organisations that they felt were important in their efforts to promote the involvement of older people. You were identified during this consultation process.

If you agree to take part in the study this would involve participation in an interview that will be carried out in a place of your choice. During the interview the following topics will be explored: what helped and what hindered your involvement; mechanisms for feedback and accountability; what resources are required to support involvement; how is involvement sustained. The interview will last no longer than an hour and, if you agree, notes will be taken during the discussion or the interview will be tape-recorded. If the interview is recorded, at the end of the study the tape will be destroyed.

Will my taking part be confidential?

All information which is collected during the course of this study will be kept in a secure place and all personal details will be removed so that you cannot be recognised from it. Following completion of the study the tapes will be erased.

We intend to submit papers to professional and academic journals at the end of the study. Personal details will not be disclosed in any publication. Therefore, your contribution will be anonymous.

What are the possible benefits of taking part?

The findings of the research will be used to increase understanding of what older people value with respect to their participation in planning, policy and research. Knowledge of what processes are necessary for a valued experience to occur will be ascertained and this will provide the basis for good practice indicators to inform future developments.

Thank you for taking the time to read this information sheet.

More information about the study is available from:
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