

Involving Older Age: The route to twenty-first century well-being

Shaping our Age



Final Report
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Cover images: Carers and people with dementia enjoyed working together as a group, Person-centred conversation in practice, Learning digital photography and Some members of the Older People's Reference Group in conference.

Involving older people in improving their well-being Shaping our Age



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Foreword

David McCullough, Chief Executive, Royal Voluntary Service

Sometimes in our working lives we're lucky to see something that is simple and yet profound. I've been privileged to join the Royal Voluntary Service (nee WRVS) a little while after the *Shaping our Age* project began and have watched the initial findings turned into reality in the local projects.

I use the word profound carefully because while this project hasn't been about investing in shiny new things or making technology the answer to all our challenges, it has thankfully been about new ways of doing familiar things – with remarkable results.

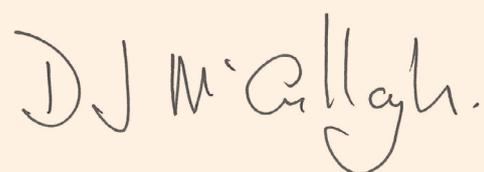
The project has taught us to listen carefully to older people when they tell us what they want from their lives, to work with them to help create the right results and, although this shouldn't be a surprise, it has allowed us to experience the enormous difference that results from being involved in shaping your own world.

One of the most resonant things I've heard in my time at the Royal Voluntary Service was from someone involved in *Shaping our Age* who simply told me: "young man, I've spent too much time with people telling me what I need rather than listening to what I want".

Surely getting older shouldn't mean that people with a lifetime's experience of building homes and families; of raising and educating children; of working in and for their communities are by virtue of their age less able to express what they want, to make choices and to continue to make a real contribution to society?

This is exciting and innovative research but most importantly it's a catalogue of wonderful rich human stories that lie at the heart of *Shaping our Age*. I know that the findings in this report will shape the thinking of our organisation for many years to come; I hope you will read it and feel that way too.

My sincere thanks to all those who have contributed, funded and guided *Shaping our Age*, but my biggest thanks goes to those who have stopped to listen carefully and acted on what they have heard.



DJ McCullough.



Summary

Introduction

Shaping our Age was a three year research and development project supported by the Big Lottery Research Programme and a unique partnership between WRVS (now Royal Voluntary Service); the Centre for Citizen Participation at Brunel University and the Centre for Social Action at De Montfort University. The project aimed to connect and interweave two key concerns: improving older people's well-being and increasing their involvement while providing new insights into emerging issues around ageing by:

- Exploring how older people understand and define their well-being
- Selecting five WRVS services to participate in action and development projects
- Developing participatory ways through local activities in which older people could help each other to achieve well-being
- Providing the learning that could help to enable and support older people to improve their and other people's well-being.

Context

Two fundamental changes in relation to ageing are currently taking place. The first is demographic. The numbers and proportions of older people have grown and will continue to grow significantly. The debate surrounding this tends to portray older people as a problem at a time when cuts in public spending are imposing financial constraints on systems of care and adding to what is seen as 'the cost burden of a decreasing proportion of taxpayers'. The second change is in the recent political and public interest in 'well-being'.

Shaping our Age challenged negative perceptions of ageing by seeking to recognise the valuable economic, political, social and cultural contributions to UK society made by older people. It also sought to move older people from the margins to the centre of debates surrounding their well-being by supporting their active contributions to society.

This report presents a summary of the seven key findings from the project. These have come from older people involved in the national well-being consultations and in the five local action projects carried out as part of the project.

Key Finding 1: Participants defined well-being in personal terms

Well-being was described by participants as feeling healthy and free from pain; being happy, contented, satisfied, fulfilled, 'loving life', having peace of mind, comfort, enjoyment, self-worth, self-confidence, safety, dignity, security, a sense of belonging, being needed and having a sense of achievement.

Participants went on to identify a complex mix of factors that shaped their well-being: good physical and mental health; achieving and accomplishing; leading an independent life; living in a comfortable, safe home and community; having sufficient personal finances and the comforts arising from faith, belief and spirituality.

They also highlighted the importance of keeping active: getting out; having a range of interests, hobbies and activities whether in the home or in the community; keeping busy and keeping fit. Many of these activities involved being with other people. This leads to the second of our seven Key Findings from the project as a whole:

Key Finding 2: Social connectedness was by far the most strongly voiced and frequently mentioned aspect shaping well-being

Relationships and social contacts with family, friends and within communities were highlighted as essential to well-being. As well as offering practical support, these connections bring a sense of belonging and feeling valued to older people. They also offer the well-being benefits gained from fun, good conversation and laughter. The contribution of groups and clubs to well-being was frequently mentioned along with volunteering and supporting others.

Key Finding 3: The 'doing to' approach - traditional approaches to working with older people, while meeting important needs, are not necessarily conducive to improving their well-being

We found that traditional older people's services, whilst addressing important practical needs, can also encourage passivity and dependence. We observed these approaches in a number of different contexts and describe them for explanation only as 'doing to' approaches, the main elements of which are:

- Doing things *for* older people: rather than working *with* or alongside them and responding to expressed preferences which older people are supported to think through, identify and choose.
- Already doing it: There was a strong belief among many staff and volunteers that they were already 'doing involvement'. This was interpreted as older people being consulted and volunteers and staff delivering to them.
- Workers reinforcing lack of engagement and involvement: Offering choices or asking older people to take on more responsibility was often considered by staff as too challenging for older people.
- Disempowerment and negative perceptions of ageing: Although older people were generally grateful, there were some who criticised the way existing services were delivered. They complained about being patronised and not being sufficiently involved or valued. We also heard from people outside the services who did not want to be associated with what they saw as traditional and stereotypical models of delivery or with services specifically targeting older people.
- Not meeting diverse needs: Traditional older people's services and groups were often not fully accessible and inclusive for people with visual or hearing impairments, older disabled people, wheelchair users, older people with learning difficulties and older mental health users.

There was other important learning about the 'doing to' approach:

- Perceiving the staff/volunteer role as 'helping' older people rather than 'listening, talking and working *with* them' and unaware of how to do it any other way
- A focus mainly on practical tasks and on meeting physical and other needs rather than building relationships and well-being outcomes
- Having programmed activities *for* older people rather than facilitating a process *with* and/or between people to identify activities
- The worker decides, does most of the work and older people are directed in what to do

- A focus on outputs and measures rather than the quality of the experience for the service-user
- Perceiving older people as a homogeneous group.

Key Finding 4: An involvement-led approach to working with older people helps to create and sustain a humanistic process that can enhance social and personal well-being

This approach has three elements: values, methods and actions/activities. We consider each of these elements in turn.

1. Key values to underpin involvement

A fundamental value is to start with the older person or with the group; what is important and relevant to them; believing in their knowledge, skills and experience; acknowledging that everyone is different. It also involves believing that regardless of age and impairment, older people have the potential and motivation to grow and develop their capacities and make a valuable contribution to others. It is necessary to spend time with older people and to be committed to this way of working.

2. Methods for involvement

The Involvement Workers, who were recruited to work with older people in our five local projects, used a number of important methods:

- a. Small groups which helped to build a sense of belonging, friendship, mutual respect and support and a sense of achievement arising from successful group outcomes.
- b. The creation of an appropriate environment for involvement with contacts and meetings arranged at times to suit older people; in accessible, welcoming venues and with effective and accessible communication to keep older people informed and updated.
- c. Facilitation or being 'alongside' participants was the most appropriate way of working and we learnt about the skill-set required to create the dynamics for involvement. This included listening, probing and encouraging older people to get to know one another, uncovering what was important to people, building rapport and trust, giving praise, encouragement and personal attention and supporting older people to take on roles and responsibilities.
- d. Meaningful conversations: Participants valued having conversations with people who showed an interest in them. Being in company, talking, socialising, being treated equally and having a laugh, all enhanced involvement and well-being.

- e. Engaging Diversity: The national consultations revealed that barriers exist to well-being for specific groups of older people. We discussed ways to address these barriers with black and minority ethnic communities and identified a need for direct contact and outreach in their environment, to build partnerships and to engage these communities in meaningful consultations. We also explored methods for engaging older disabled people and found success when using an approach that focused on the individual, their capabilities and interests. When working with people with dementia we found value in meaningful conversations, creative activities and games and valuing the person as an individual.

3. Action and activities for involvement

Participants engaged in wide-ranging actions and activities across the five sites including a survey, photo-films, planning and presenting at events, dementia equality outreach, healthy walks, taster activity sessions, group discussions, physical games, learning to choose and use digital cameras, computer training, poetry, baking, knitting and painting. These activities provided a focus and framework for involvement especially when the interest and motivation for the activity arose from the participants themselves. Creative activities, like collage or poetry, were therapeutic, useful to stimulate discussion, build confidence and encourage mutual support. What was important was not the activity, but what older people wanted to do.

Key Finding 5: Involvement in a process of personal development and small group interactions contributed most to social and personal well-being

Participants told us that the involvement process created the space for people to have a voice, to be motivated and gain confidence, to develop their interests, to have fun, to be open, energised and creative. Both social and personal well-being benefits were highlighted.

Social well-being benefits arose from being part of a group and doing things together. Participants said that they had formed trusting and helping friendships, gained a sense of belonging and companionship and built self confidence and achievement through positive group outcomes. They also gained benefits from feeling useful and valued by others.

Personal well-being benefits included self-confidence; learning about diverse topics including poetry, computing and dementia equality; enjoyment and contentment and personal autonomy.

Participants and local staff acknowledged that the Involvement Workers had been

instrumental in enabling and supporting involvement. They identified the qualities required to work with older people as being open, friendly, caring, interested, patient and a good listener. Skills considered to be particularly valuable were being able to forge group bonding; giving people the opportunity to talk; working at the pace of the participants; encouraging, rather than leading and making participants aware of their own skills and abilities.

The Involvement Workers also made a positive impact on staff and volunteers who, having witnessed at first hand the benefits from working within an involvement-led approach, took this approach into their own practice. In particular, they learnt to hand responsibility to older people rather than doing everything themselves. They also learnt how important it is to listen to older people.

Key Finding 6: Education and training are required for an involvement-led approach to working with older people

A question to emerge was to what extent it would be possible to enhance existing practice through education and training. This question arose from our observations that some volunteers were not confident in sustaining conversations with older people. We, therefore, developed a pilot training course on communication, person centeredness and equality.

Attendees evaluated the training very positively, saying that it was highly relevant and they recommended it for staff and volunteer induction to the host organisation. They particularly commended the course for being tailored specifically to their roles and for bringing together staff and volunteers from other locations to share professional practice and experiences.

Key Finding 7: There are significant barriers to involving older people in improving well-being

A number of barriers to well-being and involvement were identified by participants.

- The main barriers to well-being were poor physical health, particularly when mobility is affected; mental health problems; hearing and sight impairments; the ill health or impairments of close relatives and pressures associated with being a carer; financial pressures and discrimination owing to race, impairments, sexual orientation, dementia and old age. Being isolated was considered by many to be the biggest barrier to well-being in old age, caused by a range of factors including all of those above. All of these barriers need to be addressed as effectively as possible. Older people's well-being cannot be conceived of or treated in isolation.

- The main barriers to involvement included negative perceptions and labelling of older people; traditional services which are off-putting to many older people, particularly people who do not wish to be identified as old or who prefer to mix with all ages. A lack of practical support for involvement was also mentioned as a barrier in relation to transport, staff, community centres and venues, funding and information. Other barriers to involvement were identified as:
 - Low self-confidence/self-esteem: linked to bereavement, retirement, low educational attainment and living in areas of deprivation.
 - For older people from black and minority ethnic communities, barriers included: having a low profile within some third sector organisations, a lack of confidence in accessing services outside of their communities, language barriers and the lack of provision to take account of cultural requirements.
 - Older men can be less involved than older women and on retirement tend to have fewer local social connections. Missing the company of other men is a particular issue and there are few men only clubs or activities to address this.
 - The resistance of some older people to group involvement: their negative stereotypes and expectations of existing provision; preferring to socialise at an individual level; feeling their lives are busy enough or being too tired.
 - Older people reluctant to take on leadership or other responsible roles which they associate with 'doing things together' and traditional organised activities.

Conclusion

There are two overriding messages arising from the findings:

1. Social connectedness and positive relationships are central to older people's well-being.
2. Older people have important insights to contribute to the well-being debate.

These messages have a number of implications:

- Older people's involvement in all aspects of *Shaping our Age* reveals the potential that exists for their greater contribution. This requires a shift in mindset away from notions of personal 'deficit' (what people cannot do) to one which focuses on people's collective and individual capacities to shape their own well-being. The findings from this project support an **involvement-led approach** that values the potential of older people, their aspirations and strengths.
- Major barriers exist to well-being for specific groups of older people. However, an involvement-led approach offers new possibilities for tackling these barriers and issues of exclusion.

- The creation of a more involving approach will require changes in worker/volunteer education, training and roles.

In a period of austerity, it is especially important to reevaluate traditional ways of working and to consider issues of sustainability and prevention. It is also timely to value the resources of older people and their potential contribution. We have found that a new generation of older people do not necessarily want to be associated with traditional models of service. If 'Darby and Joan' clubs were a helpful traditional response to older people's longstanding need for social connectedness, it is now time to take forward their twenty-first century equivalent and this is likely to be a participatory one. In this likely future scenario, the traditional 'doing to' model will have increasing limitations. The involvement-led approach is not a panacea to address all the challenges of ageing. However, as part of a range of initiatives, we believe it can make a significant contribution to older people's well being and may have knock-on effects for other social care and health services.

We hope that the findings and recommendations from this study can inform current policy and practice debates and future provision, as we believe they fit well with health and well-being agendas and wider policy initiatives.

The Next Steps: Informing Change

A supportive framework is necessary to release the contribution, experiences and energies of older people. Such a framework needs to promote cultural, policy, organisational and practice changes.

Recommendations - A Framework for Involvement and Well-being

Here we offer some practical recommendations for taking the findings forward drawn from the ideas and suggestions from older people, partner organisations and others involved with *Shaping our Age*. These are intended for practical implementation, ongoing discussion and further research within the sector.

- 1. Promote a new culture of ageing** by challenging negative perceptions of ageing and acknowledging the collective and individual capacities of older people and the value and diversity of their experiences and opinions in improving well-being.
- 2. Introduce, promote and monitor policies that facilitate and enable** the involvement of older people to shape policies and strategies at all levels of government that affect their well-being. Also, adopt ageing policies and practices that embrace all aspects of their lives and not just those concerned with health and social care issues.
- 3. Commit to changing to organisational cultures** which demonstrate the principles of involvement and inclusion of older people at the highest level within

organisations in governance, planning, delivery and evaluation of services. This would include an organisational policy on involvement with commitment from leadership and staff at all levels and dissemination of these principles throughout the organisation especially in relation to management, staff and volunteer supervision and support.

4. **Promote involvement-led approaches** to working with older people which value human interaction, communication and inclusivity and support older people to develop individual and collective self-help around their well-being. This would require organisations to recruit and support staff and volunteers with the values and skills for this approach and training, supervision and support with a focus on the benefits and potential of ageing rather than only on the deficits. This would include experiential training in an involvement-led approach and person-centred communication. Education/training would also need to address issues of diversity and equality, ageism, dementia and disability.
5. **Implement systems to support involvement** to include ensuring accessible venues, transport and information, IT support and the funding in support of these and other expenses including training, personal assistance, respite care and activities.
6. **Build partnerships between organisations** that maximise funding opportunities across the third and statutory sectors, including user-led and black and minority ethnic organisations, particularly at local level, to encourage and support more generic work around older people's well-being, joint training for staff across organisations, intergenerational activity and community cohesion.
7. We recommend that **further research** is needed to support the *Shaping our Age* model:
 - Apply the involvement-led model to a specific service/location/group over a longer timeframe to further explore the impact of this approach on older people's well-being.
 - Undertake participatory/action research to address the barriers to well-being and involvement for black and minority ethnic older people, older men, older people in residential care and lesbian, gay, bisexual and transgendered/ing people.
 - Involve older people in rolling out involvement-led approaches more broadly. Further research is required to support older people to shape policy issues across the UK and beyond. Such research could build on the learning from *Shaping our Age* in relation to the mechanisms required to facilitate this work, involving older people in the process.



1: Introduction

This is the story of *Shaping our Age*, a project which grew out of big changes affecting older people and ageing in Britain and many other countries. *Shaping our Age* was about involving older people in improving their well-being and the well-being of others.

All kinds of changes; medical, scientific, social, cultural, economic and environmental, mean that people are living longer, particularly in western societies. This is happening at a time when there is a sense that there is less public money to spend on looking after people if they need help in their older age, not least because of such changes in the population's age distribution.

At a time of particular economic uncertainty, so far what this has mainly meant is pressure for cuts in traditional services and increasing calls that people should do more to look after each other. This is easier said than done, in a context of rising unemployment, people in work working longer hours, increased geographic mobility, people being expected to work longer in their lives and uncertainties about pensions and social care.

Much of the political and public discussion about older people seems to be tied to old assumptions and short-term thinking, often with the subtext that older people are a 'burden' and their growing numbers a problem rather than a boon. One interesting departure has been the growing interest in broader ideas of 'well-being' to counter-act traditional preoccupations with morbidity and illness. Another has been the increasing and widespread interest in listening to what people on the receiving end of policy and services have to say, instead of just relying on old-style 'experts'.

These were the starting points for *Shaping our Age*. It aimed to connect and inter-weave these two key concerns. First, what does their 'well-being' mean to older

people themselves – as yet not enough attention had been paid to their take on the subject. Second, given that traditional responses to their rights and needs were increasingly being ruled out as anachronistic and too costly, how did they think their well-being could be improved in difficult times and what part did they feel they could play in making this happen.

So *Shaping our Age* began with some challenging aims and ambitions. Instead of seeing older people as perhaps worthy and deserving, but essentially passive and dependent, it prioritised them as a crucial but neglected source of ideas and with a central role to play in finding solutions.

Thus *Shaping our Age* was designed to provide new ideas and insights to the new and emerging issues around ageing. The project aimed to connect and interweave two key concerns. We made a direct link between these two concerns - older people's well-being and their involvement - because of the repeated failure to support and enable older people to be meaningfully involved in issues affecting their lives. This was important given the increasing numbers of older people and ever tighter resources for state support. It was a unique partnership project between WRVS (now Royal Voluntary Service) the Centre for Citizen Participation at Brunel University and the Centre for Social Action at De Montfort University. These three organisations share a commitment to involving older people in improving their well-being.

Shaping our Age was a participatory research and development project and was funded by the Big Lottery Research Programme for three years from 2010 to 2013. Its objectives were to:

- Explore how older people understand and define their well-being
- Explore and develop with older people participatory ways individually and collectively in which they can improve their well-being
- Provide the learning that can help to enable and support older people to improve their own well-being and the evidence base and tools for providers, commissioners and policy makers to transform the way they support older people's well-being.

The project was carried out in four phases:

- Phase One: A national consultation on well-being with a diverse range of older people across the UK
- Phase Two: Defining well-being indicators and the selection of five WRVS services to participate in five action research projects
- Phase Three: Undertaking local activities and action research in the five sites
- Phase Four: Dissemination and action

Right from the start, even before we got funding for and began work on *Shaping our Age*, we were finding out that older people had something particular to say. As a prelude to the project and to ensure that it was really informed by older people themselves, we organised two national discussion groups of older people. On both occasions, there was talk of, '70 being the new 50'. Participants identified different terminology which they thought was less stigmatising than 'old' or 'pensioner', terms like 'seniors' and 'elders'. It became clear that however policymakers and service providers might think, they were largely reluctant to be included in the category of old or older people. They didn't identify with 'older people' and while it might seem natural to others to lump them together, they certainly didn't see themselves or their lives as bounded by such an identity or necessarily want to spend their time with other 'older' people. This flies in the face of much policy and provision and was an early warning that if the project was going to involve older people on equal terms and listen seriously to and act on what they had to say, then many conventional wisdoms were likely to come under challenge.

The purpose of this report is to present the findings from *Shaping our Age* to provide a resource for older people, policy makers and service providers working with older people. Our particular focus has been on the older people involved in our study, their opinions, concerns and perspectives, drawing principally upon the evidence from these sources to produce our findings and recommendations.

Following this Introduction, Chapter Two sets the policy, research and demographic context for the project and explains the rationale for the research aims and methodology. Chapter Three outlines the four phase methodology. The overall findings from the key research and development phases of the project are presented in Chapter Four. This makes up the main part of the report. Chapter Five sets out the conclusions from the project and Chapter Six brings together ideas for next steps and recommendations. A reference section is followed by two appendices. Appendix One provides biographies of the *Shaping our Age* research team and Appendix Two offers a more detailed account of the project's methods and methodology for those who are interested.



2: The Context

Two fundamental changes in relation to ageing are currently taking place. These changes provide the background for *Shaping our Age* and are the rationale for the project. The first of these changes is **demographic**. The numbers and proportion of older people in UK society have grown and will continue to grow significantly. People are now living much longer. This will inevitably present challenges for wider society and particularly for employment markets, pensions and health and social care services, which need to catch up with such major change. However, the debate surrounding population ageing has been conducted in largely negative terms. Older people are frequently portrayed as a burden and as a passive and dependent group with spiralling needs (Brindle, 2011; WRVS, 2011). At the same time, our capacity to pay for these increased needs is seen to diminish at a time of shrinking budgets and with a lower proportion of working taxpayers to meet the greatly increased 'cost burden'.

This negative portrayal reveals important insights into how we continue to view older people. Historically older people were seen to be in need of 'care' and 'service' and this has tended to foster notions of dependency (Oliver, 2001). The continuing use of patronising language in the media and the public domain helps perpetuate this view. Negative perceptions of ageing ignore the gains of living longer, the contribution of older people and make unevidenced assumptions about the health risks of extended age.

In contrast, these demographic changes can also be seen as an opportunity. The pre and post war generation has made a valuable economic, political, social and cultural contribution to UK society and many continue to do so in both paid and voluntary capacities. In doing so, they help to build and sustain personal relationships, intergenerational solidarity and social capital (WRVS, 2011; WRVS, 2008; United Nations, 2002). As one older person who advises *Shaping our Age* stated:

There's only about 5% of older people who require to be in care. The rest of us are getting on with our lives and contributing big time.

Most older people live independently and maintain close relationships with family and friends. In addition, older carers provide practical and emotional support to partners, families and friends.

The second change is the recent political and public interest in the idea of '**well-being**'. In relation to older people, the well-being debate presents a welcome opportunity to shift away from policy approaches that see ageing as a problem, to one in which the role of services is about facilitating people to improve their own well-being within society. Traditional ideas of service delivery have largely shaped the nature of services provided *for* older people. The problems of ageing are still largely seen within deficit notions of decline and 'care' (Sharif et al, 2012; Joseph Rowntree Foundation, 2004). Solutions are still largely framed in terms of individual adjustment and continue to emphasise medical, biological and psychological interventions to address the dysfunctionality of ageing (Phillipson, 2013). In addition, older people are still largely viewed as passive recipients of such interventions with the balance of power resting firmly with providers (Reed, 2007; Joseph Rowntree Foundation 2004). Such practices remain stuck in traditional service-based models of support, which ignore the key part that policies and practice based on seeing, valuing, and responding to the whole person can play in maintaining confidence, capacity, and contribution (Audit Commission, 2004). Older people's well-being is not just about health, social care and services. It is also about older people who are part of families, networks and communities, who are already engaged across all aspects of society (IDeA, 2010).

An important issue in relation to this debate is to how well-being is defined, as there is no consensus about its meaning. In the past, the debate largely centred on its philosophical, economic, medical and psychological components. In recent times, this has widened to embrace wider dimensions such as the social, the environmental and the political (NEF, 2009). Essentially, this debate seeks to determine to what extent 'well-being' constitutes an internal state (within the body and mind) and to what degree it is determined by external forces (by others, society, economics, and so on). Or, indeed, to what extent it comprises a complex interplay of person and society. To date, objective factors figure more prominently than subjective perceptions in most existing measures and not a great deal of attention appears to be given to individual and collective experiences. It is helpful to note that the UK government accepts that it is important to assess people's 'subjective well-being' in considering social and economic progress and evaluating the impact of policies and services (Waldron, 2010).

The debate around services in relation to older people has mainly been medicalised and confined to academics, professionals and policy makers (Jordan, 2007). A key question is how the voices of older people can be heard within this debate. This is

especially important given the growth of political and policy interest in hearing the voice of the service user. In recent times, important work has been conducted which explores the potential and contribution of older people to service development (Ward et al, 2012; Wistow et al 2011; Tanner, 2010; Dewar et al, 2004; Joseph Rowntree Foundation, 2004). There has also been a range of different approaches to involvement which seek to involve older people within state and third sector initiatives (Carter and Beresford, 2000). However, older people and their carers often remain on the margins of this debate and there are significant barriers that prevent them from offering their perspectives on well-being (Blood, 2010; Walker, 2007).

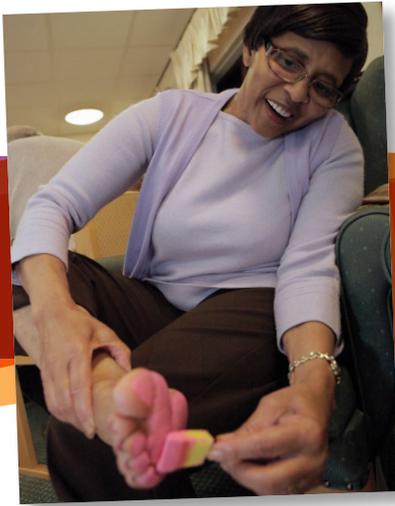
The relationship between well-being and inequalities is also crucial. Older people cannot be abstracted from wider social forces that have largely determined their life chances and continue to impact on the resources at their disposal and the choices they make (Bond and Corner, 2004). Both diversity and inequality highlight the importance of hearing a range of voices and particularly those older people who are most excluded (Begum, 2006). The term 'older people' embraces diverse and complex experiences of people who have changing needs and aspirations. It extends to a wide age range. It includes those with a high sense of agency who live healthy, active lives and share positive experiences of growing old. At the same time, a significant number of older people may not achieve this and can experience isolation, poor health and ageism. These diverse voices, when combined with the often low expectations of older people, are a vital link missing in discussions of well-being.

Shaping our Age wanted to move away from long-established and stereotypical perceptions of older people as merely a drain on welfare, on families and communities. We believe that a cultural shift is needed in how we view older people. In taking this view, we are building on the work of previous initiatives and studies (Beresford and Carr, 2012; Beresford et al, 2011; Scottish government, 2011; Doyle et al, 2010; Blair and Minkler, 2009) and are informed by the social model of disability and the associated philosophy of independent living (Fleming et al, 2011; Barnes and Mercer, 2006). None of this is to deny the values of medical and caring interventions that clearly benefit older people and particularly those with high support needs. However, we argue that much could be gained from a shift in thinking to a position where ageing is seen as a societal resource and reality rather than a problem where older people are only to be understood in terms of need. Most importantly, we need to explore how older people themselves can contribute to improve their own lives and those of others. This would mean that older people would be involved in defining their own sense of well-being and shaping the quality of services and support that would meet their aspirations.

Shaping our Age is thus located within a well-being framework. We define involvement as both a collective and individual process that can enable older people to improve their own lives and those of others. Without denying the difficulties older

people may face, our primary focus is on the capabilities, strengths, knowledge, skills and experience of older people. Older people's involvement is a crucial starting point and essential if negative perceptions of ageing and notions of dependency are to be challenged. We seek to create opportunities for those voices to be heard and to shape their own visions of what constitutes a better life for them and others like them. In doing so, we plan to listen to what older people have to say about their well-being and to explore how their collective capacities can best be nurtured. We also hope to learn with them how best to involve older people in improving their own well-being and that of others.

WRVS/Royal Voluntary Service has committed itself to incorporating the lessons learned from this initiative in its own future operation. The project is running at a time of exciting change within Royal Voluntary Service with its new Service Delivery Strategy system based on a person-centred approach. Royal Voluntary Service is developing a network of service hubs throughout Britain, which will provide an integrated range of services. *Shaping our Age* intends to bring new learning and insights to enhance this new approach to service delivery. It thus provides a test ground for this new approach, which can lead to improvements in older people's well-being and which potentially has wider relevance to services and policies.



3: Methodology

This section briefly describes the research approaches and methods used in all phases of the project. It also outlines the organisational structure of the project team. There were aspects of communication and dissemination during all four phases and an action-reflection-action cycle throughout. A more detailed discussion is available in Appendix Two.

Principles of Participatory Research

Shaping our Age adopted a participatory approach to research, seeking to involve older people in all aspects and stages of the work and underpinned by the following principles which were identified in our research proposal to the Big Lottery Research Programme:

- An equal, non-hierarchical relationship between researchers and participants, recognising that everyone has an equal and different contribution to make to the research process
- Commitment to the empowerment of participants
- Starting with the ideas and understanding of the people involved
- The researcher working as the facilitator of a process of learning, development and change
- The researcher setting in motion processes of participation to shape agendas, make decisions and effect outcomes
- The approach involving movement from understanding and knowledge generation into action for change

- Acceptance of the responsibility not to leave participants unsupported at the end of the process.

Organisational Structure

Shaping our Age was a collaborative project. The three main Partner organisations were WRVS (now Royal Voluntary Service), the Centre for Citizen Participation at Brunel University and The Centre for Social Action at De Montfort University. The universities were represented by Professor Peter Beresford and Jennie Fleming respectively, both experts in participatory research with specialist interests in emancipatory disability research (Beresford, 2002) and Social Action Research (Fleming and Ward, 2004).

A **Research Team** was responsible for undertaking and managing all aspects of the research and administration and comprised Project Worker (shared role) and Research Manager roles, assigned to Martin Hoban and Vicki James. Peter Beresford and Jennie Fleming acted as academic research advisers on the Research Team. The Research Team authored this report and represents the 'we' referred to throughout. Short biographies are presented in Appendix One.

A **Project Group**, composed of the Research Team members along with Executive Directors and Managers from WRVS/Royal Voluntary Service, was responsible for the strategic direction of the project and overseeing the work of the Research Team. This Group was chaired by WRVS/Royal Voluntary Service and met quarterly. Latterly it was chaired by the Chief Executive of WRVS/Royal Voluntary Service, a symbol of the organisation's commitment to the project's findings.

An **Older People's Reference Group** was recruited within the first few months of the project through a transparent application and interview process. The group, which comprised 15 older people, advised the Research Team throughout and was also responsible for dissemination of the findings. They were actively involved in all the project's activities, from providing guidance on the original national consultation with older people, to interpreting and reviewing the overall findings. All members were active volunteers in WRVS/Royal Voluntary Service or other local and national organisations, well networked and were drawn from locations throughout the UK including Northern Ireland, where WRVS/Royal Voluntary Service does not have a presence. Four Older People's Reference Group workshops were held over the three years and members were paid a fee and expenses to attend. The group participated in the project in other ways; for instance, participation at Partner conferences, recruitment of Involvement Workers and selection of WRVS services for the five local projects. Their feedback on the research approach and emerging findings was ongoing throughout and invaluable to the project.

A **Partners Group** included about 20 representatives of government departments and other public, private and voluntary sector organisations throughout the UK with

a concern with ageing and older people. Recruited by invitation, this group acted as advisers to the research particularly in regard to networking and dissemination of the findings. Three partners' conferences were held over the life of the project.

Both of these groups and staff within WRVS/Royal Voluntary Service were sent regular project updates by the Research Team.

Involvement Workers were recruited to facilitate projects in the five localities identified for the development phase of the project (see later).

Phase One: National Consultations on Well-being

A UK wide consultation programme involving a diverse range of 163 older people (aged 65+) in focus groups and qualitative individual interviews was undertaken during the spring of 2011. The consultation took place both within WRVS and within partner organisations and the aim was for older people to define what well-being meant to them; their interpretations of what shaped well-being; how the services they received affected their well-being; the barriers to achieving well-being in their lives and their suggestions for change to improve the well-being of older people.

The methodology and results are presented in an interim project report, *Voices on Well-being* (Hoban et al, 2011) and available to download at royalvoluntaryservice.org.uk/shapingourage. The results are also presented briefly in Chapter Four of this report. Participants identified a complex range of factors that affected their well-being. While issues such as health, finances and faith featured prominently, the overriding finding was that social connectedness was highly important to well-being. This finding heavily influenced the selection of the five WRVS services and the local *Shaping our Age* activities in those sites. The method for selecting the services is presented in Appendix Two.

The five sites, based on the services provided by WRVS in autumn 2011, were:

Chesham House Community Centre, Lancing, West Sussex: Lancing is a small coastal town located on the main route between Brighton and Worthing. At the time, Chesham House offered a range of services and activities including a lunch club, computer lessons, exercise class, transport service, cribbage group, reminiscence group, information and signposting.

Kirklees Good Neighbours Service: Kirklees is a West Yorkshire District of old mill towns and county villages. The main settlements are Huddersfield, Holmfirth, Dewsbury and Batley. The WRVS service offered befriending services, telephone befriending, health awareness, lunch clubs and a home from hospital service.

Thanet Good Neighbours Service, Kent: Thanet District Council encompasses the coastal towns of Margate, Broadstairs and Ramsgate. The WRVS service operated from an office base in Ramsgate and offered a range of services to meet individual

needs: befriending, shopping, dog walking and trips.

Scottish Borders Social Centres: Social Centres newly opened and in development offering services to frail older people through referral for one or two days a week. *Shaping our Age* was based in Centres located in the small towns of Jedburgh and Kelso situated in the rural Border area. The Centres provided breakfast, lunch, crafts, exercise, healthy eating, socialising, information and trips.

Sheffield Northern General Hospital: A pilot on-ward WRVS volunteer service was underway on an orthopaedic ward in this hospital. The service offered personalised support to patients – principally to those with dementia – which included encouragement to eat and drink, small practical tasks, pastoral support and conversation. At the same time Sheffield Hallam University was conducting an evaluation of this service for the hospital and WRVS.

The Involvement Workers

Once the five sites were confirmed the Involvement Workers were recruited. Their role was to engage with and facilitate the involvement of older people within the research project.

We selected four highly experienced people who understood and supported the key values of participation and involvement. They worked for 13 months from February 2012, for two days a week at each site, until the end of March 2013. One of the Workers was based in the two Yorkshire sites; the other three Workers were based in one site each.

The Workers were managed remotely from WRVS Cardiff by the Project Worker and Research Manager. The Involvement Workers gave presentations on their work in the local sites to the Older People's Reference Group (November 2012); a Partners' conference (January 2013) and a WRVS Heads of Service meeting (March 2013). They were also involved in the production of five short photo-films which present their approach and local outcomes. These can be seen at royalvoluntaryservice.org.uk/shapingourage.

Phase Three: The Five Local Projects

The main aims of this phase of the project:

- Engage with, and facilitate the involvement within each project of older people in the research
- Work with older people to consider and decide upon ways of maximising their well-being and that of other older people

- Develop with older people exploratory activities which would allow the research team and participants to learn from them, identify any barriers encountered, and begin to find ways to improve and overcome them.

Involvement and Research – a Five Stage Process

The Involvement Workers were guided by a five stage process set out in more detail in Appendix Two. Based on a community development model of practice, it was designed as a guide for the Involvement Workers. The five stages were:

1. Compiling a profile of local services and policies affecting older people
2. Starting to establish relationships with local older people and organisational contacts
3. Bringing together a group of people or individuals to work with the Involvement Worker
4. Involving the older people in developing existing services or shaping new ones
5. Preparing an exit or succession strategy and evaluating the well-being benefits for older people involved in the project.

The projects varied in process and execution depending on local circumstances and project aims. It is not feasible to present each project in detail within this report. However, each one is summarised in an accompanying report (James et al, 2013) which is available at royalvoluntaryservice.org.uk/shapingourage. The approach of each worker was guided by the principles of participatory research; the five stage process and the indicators of well-being from the national consultations.

Working with groups and individual older people

We were interested in older people's involvement and well-being individually and collectively. To address the collective approach, we developed a process based on forming small groups of up to a dozen people and working with them over extended periods.

We also wanted to work with individual older people. In practice, the distinction between group and individual work was by no means clear. Even where groups were formed, working with individuals within those groups was found to be important to the process. In two projects it was not feasible to form groups and individual work predominated there. Our aim was to fulfil the requirement of the original bid which identified that about ten participants should be closely involved in each project. Also social connectedness had been identified from the national consultation phase of the project as the main driver of well-being and we wanted to explore this further with groups and individuals.

Simply put, the Involvement Workers' approaches in the five projects are presented below. Further information on the local projects is presented in an accompanying report (James et al, 2013).

Borders Social Centres: The Worker built trusting communications with individual participants through meaningful conversation, facilitation and small group work. Activities centred mainly on discussion, memory work and games. The key outcomes were learning to inform practice and policy, a pilot training course for Centre staff and volunteers in person-centred communication, an accompanying report and photo-film. A capacity building team funded by the Change Fund will carry forward the small group work started by the Involvement Worker, exploring the potential for a community drop in centre in Kelso.

Kirklees: The Involvement Worker was based within the WRVS Good Neighbours Service for the first eight months. During this time she engaged with older people and volunteers in the WRVS befriending services, good neighbours, lunch clubs, volunteer led social clubs and volunteer coffee mornings. She also made contact with a variety of small voluntary organisations and church groups within the Kirklees area and conducted outreach work with black and minority ethnic communities. For the remaining four months the Worker was based outside the WRVS service working with three groups of older people; two of them in sheltered housing complexes and one with carers and past carers. She worked with them to define their interests and to establish appropriate activities.

Chesham House Community Centre, Lancing: The Involvement Worker facilitated a process leading to a group of older people taking an active role in developing and promoting social activities based on mutual support. This group developed a role as advisers to the Centre with potential to have an input on the development of Royal Voluntary Service services more widely in the area. The Worker helped the group to develop their skills and confidence to build autonomy. The group identified their own terms of reference and called themselves, the 'Friends of Chesham House'.

Thanet: The Involvement Worker formed a small group of established volunteers from a number of local voluntary organisations including WRVS. They came together to develop their role as local 'influencers' and identified the need for an up to date local information directory for older people. Working with other local statutory and voluntary organisations, the group was influential in helping to secure funding for this directory. The directory will be used as a resource for befrienders and for on-line access. The group undertook a survey of information needs to inform further applications for grant funding.

Sheffield: The Involvement Worker's time in Sheffield was divided between two stages. For the first five months she consulted patients and carers about their experiences of being in hospital and contributed to an evaluation of the WRVS on-ward volunteer service by Sheffield Hallam University. For the following nine

months she worked outside of WRVS with a local dementia support group to develop a 'toolkit' of group activities for dementia equality outreach. She also worked to build capacity within the group to enable them to deliver outreach workshops within the community.

In all five locations, workers raised awareness of well-being and involvement with older people, staff and volunteers within WRVS and in the wider communities.

The contexts were all different (Table 1). Also, each Involvement Worker had different skills, interests and ways of working and this was a significant factor in creating five very distinct projects. Two of the projects were based entirely within WRVS for the whole time; one was entirely outside of WRVS and the two Yorkshire projects both started within WRVS and then moved to community settings. There was also a mix of group and individual working amongst the projects.

Table 1: The Five Projects

Project	Context	WRVS Service		Working principally with:	
		Within	Outside	Group/s	Individuals
Borders	2 Social Centres	✓		✓	✓
Lancing	Community Centre	✓		✓	
Kirklees	A Good Neighbour Service	✓		✓	✓
	B Sheltered housing; carers group		✓	✓	
Sheffield	A Hospital	✓			✓
	B Community Support Group for people with dementia and carers		✓	✓	
Thanet	Volunteers from wider community of voluntary organisations		✓	✓	

The Participants

The profiles of participants in each of the five projects varied quite widely by age, gender and disability and we were able to build upon the diversity of participants included at the national consultation phase, particularly by involving more carers, frail people and people with dementia in the local projects. We also involved a diversity of participants by class, urban/rural location and ethnicity. Appendix Two includes a summary of the range of participants included in the whole project.

This diversity gave the project particular strength and value by allowing us to work in an empowering way with a wide range of people. Some participants were able to become very actively involved; for example, participants in the Sheffield dementia equality project and in the Thanet 'influencers' group were relatively energetic and willing to take on active and responsible roles. On the other hand, some participants were very old and frail and their level of involvement was limited. This was the case in the Borders and in two of the Kirklees activity groups. Nevertheless, in all projects, and for all participants, regardless of impairment, the Involvement Workers challenged them to be active and to take on responsibility for their own well-being appropriate to their capabilities.

Evaluation

Evaluation was built into this phase of the project. Each worker undertook evaluation interviews in early 2013 which aimed to identify the extent to which participants had gained well-being benefits from their involvement in *Shaping our Age*. A qualitative script or schedule was developed to guide the interviews and group discussions including questions around the following topics:

- The extent to which individuals took on responsibility for the group/others
- What participants got out of the project and whether it had changed anything about them
- What hindered involvement
- Not so good things about the project and what could have been better
- The impact of the project on well-being
- The contribution of the Involvement Worker.

The evaluation interviews were recorded, transcribed and analysed by the local Project Worker and Research Manager. Participants also completed evaluation questionnaires about the impact of the project on a range of well-being indicators including enjoyment, independence, learning, making friends and socialising, self-confidence, achievement, feeling useful and being valued.

Local stakeholders familiar with the five local projects were contacted by the Research Manager for evaluation interviews and, where possible, these were conducted, mostly by telephone. They covered the same topics as for the participant interviews and group sessions but also included questions about the influence of the project on their own learning and practice. The evaluation findings are reported in Chapter Four.

Succession Strategy

A key concern of the Older People's Reference Group was that the learning from *Shaping our Age* should have a continuing influence and not die with the end of the formal period of the project. We had a responsibility to ensure that the local participants were supported beyond the life of the project. At the outset and throughout, the Involvement Workers informed them that the local projects were time-limited. They also worked alongside participants in ways that encouraged self-direction, ownership, skill building, self-confidence and independence. As with any ending, there were feelings of loss on both sides and in each project the workers managed the parting with sensitivity and marked the ending with informal events.

At the same time the Workers made efforts to find other local organisations to take on support for the groups and by and large, were successful in organising successful exit strategies which are summarised in an accompanying report (James et al, 2013).

Data Sources and Analysis

Throughout all stages the Workers made extensive notes of their interactions with contacts including WRVS staff and volunteers, community organisations and older people. They also reflected on their own practice and made notes of these reflections. They audio-recorded their group sessions and interviews with their participants to ensure processes, outputs and outcomes were captured. Audio recordings and worker notes were analysed by the Research Project Worker and Research Manager, using grounded theory and thematic analysis (Charmaz, 2006; Glaser and Strauss, 1967).

As the findings emerged, we presented them to separate meetings with WRVS staff; the Older People's Reference Group and the Partners' Group and feedback from these sessions also informed analysis and the relative priority given to each of the key themes. The Research Team also met regularly throughout the life of the project to discuss and review the emerging findings. The diagram below (Figure 1) summarises the process of discussion and review that took place with people outside of the research team during the final stages of the local projects phase.

Figure 1: Timeline of analysis process based on presentation of early and interim findings, final report and dissemination



As with any research project, *Shaping our Age* had its limitations. It operated with finite resources over a fixed period, in just five local sites, with a limited number of older people. These limitations are presented in Appendix Two. At the same time the project was able to include and work collaboratively with a diverse range of older people in varied settings exploring issues about well-being and involvement which until now had not been examined in detail with older people.



4: Findings

Introduction

In this chapter we present main findings from the national consultations with older people and the action research with older people within the five local projects, the two key phases of the project.

We start with a summary of the main findings from the national well-being consultations. These are also available in full in *Voices on Well-being* (Hoban et al, 2011). In this consultation, the following questions were explored:

- How do older people define their well-being?
- How is well-being shaped in their lives?
- How do services impact on their well-being?
- What barriers are faced by older people in achieving well-being?

The learning from the national consultations led us to identify the indicators of well-being and principles to guide the selection of the five local WRVS services (See Appendix Two). The findings also laid the foundations for the work of the Involvement Workers and older people at each of those sites.

The Involvement Workers also subsequently undertook consultations locally around well-being and these revealed similar definitions and drivers of well-being as identified in the national consultations. This congruence lends strength and validity to the results overall during a process of building our understandings around older people's well-being throughout the project's life.

This chapter moves on to findings arising from the work in the five local sites, encompassing key learning around an involvement-led approach and barriers to involvement. The well-being outcomes from this participatory work from the sites are then presented.

We identified seven key findings from the research overall and we present each in turn:

Key Finding 1: Older people defined well-being in personal terms.

Key Finding 2: Social connectedness was by far the most strongly voiced and frequently mentioned issue shaping well-being.

Key Finding 3: Traditional approaches to providing services for older people, while meeting important needs, are not always conducive to improving their well-being.

Key Finding 4: An 'involvement-led' approach to working with older people helps to create and sustain a humanistic process that can enhance social and personal well-being.

Key Finding 5: Involvement in a process of personal development and small group interactions contributes most to social and personal well-being.

Key Finding 6: Education and training are required for an involvement-led approach to working with older people.

Key Finding 7: Participants identified barriers to involving older people in improving their well-being.

Defining Well-being

Key Finding 1: Participants defined well-being in personal terms

Well-being was described by participants as feeling healthy and free from pain and was associated with feelings of happiness, contentment, satisfaction, fulfilment, loving life, peace of mind, comfort, enjoyment, self-worth, self-confidence, safety, dignity, security, a sense of belonging, being needed and having a sense of achievement. The following comments about how well-being feels to them highlight this:

Feeling healthy is a good basis for well-being.

I'm quite happy with what I've got I accept what I've got and I'm quite happy at the moment.

If you don't have peace of mind you can't be happy and contented.

Participants identified a complex mix of factors that shape well-being

Beyond the basic needs of shelter, food and warmth, well-being was strongly associated with a range of interrelated issues: being healthy, both physically and mentally; having control; achieving and accomplishing and leading an independent

life. The benefits of being self-motivated, positive and resilient and being able to adapt to changing circumstances were also highlighted. So too were the benefits of a comfortable and safe home and community; a clean and attractive environment; having sufficient personal finances to live in comfort and free from worry, and faith, belief and spirituality:

Well-being is being able to do what you want to do, when you want to do it and you still have the ability to do it.

I mean, I'm quite happy in my own home. I've got a nice comfortable home.

She reads her Koran and says her daily prayers. She says it gives her like a sense of serenity in her life.

Participants also mentioned the importance of keeping active: getting out; having a range of interests, hobbies and activities whether in the home or in the community; having pets; keeping busy and keeping fit:

If you're confined in the house, any worries you have seem to multiply. Getting out allows you to put them in perspective and you don't feel like the only person on the planet.

Since I lost my husband I've taken up Bridge which I love. And I've bought a laptop which is taxing me to the absolute extreme.

Every Thursday morning, there's Keep Fit for over 50s. That's good for socialising too.

As highlighted in the last comment, many of these activities involved being with other people. This leads to the second of our seven Key Findings.

Social Connectedness and Well-being

Key Finding 2: Social connectedness was by far the most strongly voiced and frequently mentioned aspect shaping well-being

Relationships and social contacts, especially with family, friends and within communities were highlighted as essential to well-being by most participants. Aside from the practical support derived from these connections mentioned by some, participants appreciated knowing that people cared about them and valued them. The importance of having fun, good conversation, laughter and the sense of belonging gained from being with other people were also highlighted:

I think it's a sense of belonging and being needed, you know

Togetherness is the point

I have such lovely neighbours who come in and have a laugh. I have a little fund of stories I tell them and we have a laugh then.

Groups and clubs were identified as important to well-being by many participants:

We have friends here that we can talk to and we have a good laugh by having games and a day to look forward to.

For some participants volunteering and supporting others was important:

I feel fulfilled and meeting other people on a daily basis keeps my mind active and outward focused ... remaining focused on others keeps me from wallowing in self-pity.

This theme of keeping minds focused away from troubles and concerns and on to more positive subjects was a frequently mentioned benefit of being socially connected.

Moving to the Five Local Projects

In these early consultations, older people identified a strong link between their well-being and being involved whether informally with friends and family and through hobbies, or more formally by using services like lunch or social clubs or through lobbying or volunteering.

These understandings, along with the other findings from the consultations, shaped our thinking about the approach to the following phases of the project. They informed the principles for selecting the five service sites. They also led us to conclude that we needed to bring people together to facilitate social interaction in our local projects. We decided that forming local small groups of older people would be one way to achieve this aim.

The local projects explored the practicalities of working with older people to enhance well-being through further involvement. The processes undertaken, the learning arising and the well-being outcomes from the initiatives developed are presented in the following sections of this chapter.

The 'Doing to' Approach

Key Finding 3: Traditional approaches to providing services for older people, while meeting important needs, are not always conducive to improving their well-being.

We have seen at first hand the work undertaken by organisations that provide services to older people. Committed staff and volunteers on the ground provide vital and practical services that meet a range of individual needs. However, we found that these approaches may not always be conducive to well-being and can put off many older people from availing themselves of help and support. There also seems to be a danger that traditional approaches to working with older people can reinforce passivity and dependency. We observed these approaches in a number of different contexts and we describe them here for explanation only as a **'doing to'** approach. We found that the primary focus of this approach was on tasks, achieving outputs and delivering activities. Based on feedback from older people and our own observations, we outline some of the key elements of this approach.

Already doing it

We heard early on in the project that there was a strong belief among many staff and volunteers who work with older people that they are already 'doing involvement'. Older people are asked what activities they want and if possible these are provided by the staff or volunteers. As one Involvement Worker observed:

Older people are consulted about what activities they would like ... and action is taken to try to provide these but the older people are not necessarily involved.

Workers reinforce lack of involvement

Offering choices or asking older people to take on more responsibility was seen as too challenging as these comments from staff and volunteers illustrate:

But people don't want to get involved, they don't want the responsibility. They don't want to talk, they don't want any speakers. They want to play bingo, have a cup of tea and do the raffle.

Helpful but paternalistic

The helpful but paternalistic and defensive nature of this approach was also evident at times. As one Involvement Worker observed when she tried to ask a group of older people for their ideas about possible new activities:

When ideas came up from the new participants, the coordinator [worker] tended to jump in defensively to say that these things already happened which didn't help to open up the discussion.

Patronising and disrespectful attitudes

An example of this was observed by one of the Involvement Workers when she invited staff from a particular organisation to meet with a group of older people to discuss ongoing support. In this instance their attention was not focused on the older people they had come to meet:

I noticed ... continuous ringing of and answering mobile phones, not being able to stay long due to other priorities ... having their own planning / catch up conversations.

Pressures on staff

An important contribution to this approach was pressure on existing staff. This was noticeable particularly in terms of limited time to spend with older people, heavy workloads and having to achieve organisational and funding targets. This sometimes meant that staff tended to take responsibility for doing things for older people as they felt it would be easier and quicker than involving them.

Disempowerment and negative perceptions of ageing

We found that older people on the receiving end of this approach were often grateful and accepting for what was given to them. Indeed, many participants felt they benefitted from existing services and expressed appreciation of staff and volunteers. Older people were seen to have respect for authority figures, were used to being directed and were reluctant to challenge or make personal demands on the services they received. Often, we found that when older people were asked what they would like to do, they tended to plump for something they did regularly and knew about rather than thinking up new ideas or taking on some responsibility themselves:

Older people accept what is given to them.

You get to an age where you are happy to let people do things for you.

I just want to be led.

Paid workers in the area can run these things for us.

Others, however, had mixed experiences and voiced criticisms of the way existing services were delivered. We heard from participants, particularly outside the services, that many did not want to be associated with what they saw as traditional and stereotypical models of delivery. One person described it as not wanting to be, *shuffled into a building and then have to be taken back home in mini-buses*. Some had negative perceptions of ageing and did not want to be associated with these approaches as these comments reveal:

I don't want to come to your older people's crèche.

I'm not going to sit with a bunch of old fogeys – even if I am one.

I don't associate myself with older groups.

I don't want to be isolated from the rest of the population as it keeps you from getting into an old age mind set.

Many services for older people are very much 'for old people' and many people I know, even in their 80s and 90s don't want to be treated like old people!

There were strong views from some people that they were being patronised within existing services. These people felt they were not sufficiently involved and thought that service providers did not value their experiences. Involvement was often at a very basic level. As one member of an older people's group stated, *[we were] not asked what biscuits we like*.

Others felt resentful, frustrated and excluded from not being able to influence decisions or otherwise contribute to the services they received. The following comments reflect some older people's strong feelings:

They're patronising and don't treat members as equals.

When you get to a certain age people stop involving you.

The lack of engagement by the authorities with older people is shocking.

The people that go to ... all these organisations, the people who are in charge, I don't know that they mean it but it's probably because they do it all the time, they tend to treat everybody the same and it's like you come here, you are now an old lady or an old man and it's 'hello dear, are you alright... can you manage...?' Some people then will just knuckle down and say, 'oh well you know yeah probably they're right, that is exactly what I am now', you know.

They're not looking to be told that they're old or that they need looking after or that they need someone to tell them what time of day it is or to escort them to the toilet. Alright some people do need that help but, you know, not everybody does and it's wrong because it's not the way to treat people; it's disrespectful.

Decision makers yes, I mean they have been very arrogant in that they haven't been asking us what we want and whatever structures you have, physical or social, it's just as well to get the views of the people who are going to be using it or looking at it and they haven't bothered, you know it's like we were nothing.

Decision makers don't use the experience of older people to shape services.

We may be concerned that those who care for old people think of them as 'losing their minds, inactive, boring, no fun to be with', and treat them with lack of respect, dignity, lack of individuality – almost as though they are invisible. We don't want them to treat us like that.

Not meeting diverse needs

Traditional older people's services and groups, as presently organised, are often not very accessible and inclusive for older disabled people, wheelchair users, people with hearing or visual impairments, with learning difficulties and mental health users. As an example, one of the Involvement Workers attended a lunch club where people with hearing impairments were not able to join in the Bingo with the others because there was no hearing loop. As these participants explained:

People think we are stupid because we cannot hear.

Bingo is difficult when you have a visual impairment / hearing impairment.

I wouldn't want to go to tea dances, that would only remind me of things I can't do any more.

Some older disabled people stressed that existing services do not give sufficient attention to their particular requirements and that they are often perceived to be incapable of contributing to shaping services. This experience of exclusion was reflected in a comment from a member of the Older People's Reference Group:

I feel older people with physical impairments are often thought of as incapable of any input ... as they are old and have a physical impairment their life experience is perceived to be worthless.

Little interaction

We found that when people gather together it is not always the case that they interact with one another. Although people could see each other weekly they did not seem to engage in conversation. An Involvement Worker recalls how she

became aware of this during a session when older people were being interviewed by volunteers about their employment histories:

I was quite surprised to learn that the older people had little idea about what each other had done for employment in the past despite the fact that they have all been attending the Centre for a long time... the older people said to me that there were some people using the Centre every week that they had never spoken to.

This revealed to us that the human interaction was very much between individual older people and the staff/volunteers and not with other older people. Often people were isolated even though they were in a formal group setting. Early on, the Involvement Worker identified that this could be a barrier to mutual support and the possibilities for users to develop their own ideas and activities.

'Doing to' culture in a hospital setting

Being in hospital brings particular challenges to well-being and creates anxieties for older people. Consultations in the early part of *Shaping our Age* and in the local project phase (James et al, 2012) revealed concerns for in-patients that went beyond illness, treatment, recovery and boredom. The attitude of some staff was criticised: not giving proper explanations; talking over patients and making them feel as if they were a nuisance. Also incidents of neglect were revealed; for instance forgetting to return to a patient on a bed pan, rough treatment when washing and getting dressed and lack of care at meal times.

Some patients recalled their experiences of being on the receiving end of 'doing to' practices which were also felt to be lacking in respect:

I'll tell you what I don't like ... When I'm in here, getting washed, getting dressed ... 'Oh, I went to the barbeque last night ... did you enjoy yourself?' ... I can't be doing with it. I'm not just a piece of meat! They talk over me. That, I do not like.

I felt that the doctors didn't listen to patients properly; you know they sort of look at you with a blank expression on their face and make a note on paper ... But I don't think they really took in what you were saying.

I know you have to lose dignity when in hospital, but not to be pushed to one side as if you don't exist.

For people living with dementia being in hospital and away from familiar environments could be particularly distressing and carers recalled treatment in hospital which they regarded as lacking care, respect and dignity:

She didn't even know she was in hospital. All she knew was that some strangers came up to her and started shoving her around ... It was as if they didn't know how to handle people with dementia.

He was in the (hospital) for quite a long time and in that time he was spoke to so little that he couldn't actually speak when he was discharged because he never used the muscle of his voice box. He had to learn to speak when he got home.

They weren't feeding her at all so I had to go up at mealtimes – they just used to put her tray on the bed, you know. She didn't know what it was.

Further elements of the 'doing to' approach

There seem to be a constellation of characteristics associated with the 'doing to' approach. Other important learning about these characteristics can be listed as follows:

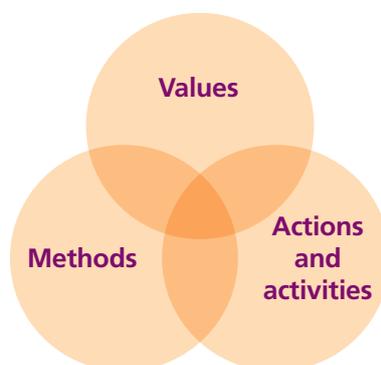
- Common perceptions that older people are in deficit rather than capable of making a contribution to their own well-being and that of others
- Perceiving the staff/volunteer role as 'helping' older people rather than 'listening, talking and working with them' and lack of awareness of how to do it any other way
- A focus mainly on practical tasks and on meeting physical and other needs rather than building relationships and well-being outcomes
- 'Having programmed activities' for older people, in which the worker decides and does most of the work with the older people being directed in what to do
- The focus on outputs and measures rather than the quality of the experience for older people
- Not asking older people for their opinions for fear of raising expectations that cannot be met
- Perceiving older people simplistically as a homogeneous group
- Imposing service-led approaches on older people; for example, going in with 'a jolly approach', the underlying assumption being that older people need to be jollied along and organised.

Involvement-led Approach

Key Finding 4: An involvement-led approach to working with older people helps to create and sustain a humanistic process that can enhance social and personal well-being

Three key elements, **values, methods and action/activities**, are central to this approach (see Figure 2). These emerged from the practice, analysis and reflections within the research team, in consultation with the Older People's Reference Group and from discussions with Partner organisations. We will consider each of these elements in turn.

Figure 2: The three elements of an involvement-led process



1. Key values to underpin involvement

The **first key element** of an involvement-led approach to working with older people is that it needs to be grounded in a set of shared values which include the following:

- Starting the process of engagement with the lived experiences of older people and seeking to understand older people within the context of their own lives
- Acknowledging different starting points and backgrounds, understandings, abilities, experiences and personal histories
- A belief that older people have knowledge, skills and experience to improve their own well-being and that of their communities
- A belief that older people, regardless of age and impairment, have an innate potential and motivation to grow and to develop their capacities and agency as human beings and make a valuable contribution to others
- Seeing older people in all their diversity
- Recognition that working with older people in an involving way takes time, commitment and energy.

Throughout the project, we found that these values resonated very strongly with

older people involved with *Shaping our Age*. A common thread through the discussions was the need to see older people less as a homogeneous group with needs and problems and more as people capable of contributing to their own well-being and that of others. A recurring theme from discussions with the Older People's Reference Group was the need for a change of mindset:

I think it is vital not to treat older people as 'older people'! They are just people like us, with a wide range of needs, experiences, ideas and ways of doing things, who just happen to have been around a long time.

There were similar messages from older people across the research sites. In particular, there was a strong message that people did not want to conform to the expectations of others. Most people wanted to engage in interesting and stimulating activities within their capacity and together with others:

I don't want to conform to what others think I want, or what they think I can or can't do.

We're just not here to look at the sea.

2. Methods for involvement

The **second key element** of the involvement approach is the methods we used to engage with older people. As part of the research, Involvement Workers used a number of important methods that were underpinned by the values outlined above; the main ones being:

- Small groups
- The creation of an appropriate environment
- Facilitation
- Meaningful conversations
- Engaging diversity.

Small groups

Our national consultations highlighted the well-being benefits for many of getting together with others sharing similar interests in forums, clubs and social activity groups. For this reason we decided to use small group development to create opportunities for a process of involvement to emerge, allowing us to study in some detail the process in a range of different contexts. Some examples of our learning from this method of intervention are outlined below:

- Small groups helped to build a sense of togetherness, mutual respect, belonging, trust and support based on a sense of commitment to a shared process and a common goal
- Small groups helped establish strong friendships; people felt relaxed and confident enough with one another to share their emotions including excitement, fear, concern and laughter. This was particularly important to people living alone or who had lost close friends through bereavement.
- Group members felt a sense of achievement, pride and satisfaction arising from group outcomes. For example, in Thanet, when funding was secured for an information directory and in Sheffield where a successful launch of the outreach group involved each member speaking to an audience of more than 50 delegates.
- Groups helped to build confidence based on acquiring new skills (for example, in facilitation and presentation) and gaining knowledge. In one of the groups, the involvement of participants with dementia contributed to increased understanding of the condition.

A participant with dementia highlighted the benefits to her of being part of a group comprising carers, past carers and people living with dementia:

I like that (the group) because I like to listen to different people about their opinions and you know and what happens and it's nice to know that other people have the same goings on, shall we say, as I do.

Other participants mentioned additional benefits:

I think it's a relaxing type of meeting this for ourselves ... you can come here and relax and listen to what's going on ...

Well as I flash past in my buggy I'm a nobody; nobody knows anything about me; nobody knows who I am - just somebody going past. But being one of the group I'm somebody because ... you work with other people and you've made a mark on life instead of just being somebody that nobody knows anything about.

Friendship and companionship ... which of course you don't get when you go home, not if you live alone. That's it, you come in the front door, you shut the door and that's you. But here, of course, you interact with everybody.

The creation of an appropriate environment

A key factor was the way things were organised to create a supportive and welcoming environment for the process of involvement to emerge between the worker and participants. An important first step was to create settings whereby people could meet with others to share and discuss. The learning points below relate to the practical tasks needed for meetings.

- Timing of meetings, activities, events to suit participants
- Familiar, accessible venues, easy to access by public transport or on foot, comfortable, pleasant layout, welcoming, with refreshments
- Comfortable chairs arranged so that participants can all see each other. As one Involvement Worker stated:

Everyone, including myself and the volunteers, sitting on the same height of chairs in a circle so everyone could see everyone else and no one seemed more important than the others.

- Transport provided if required
- Communication with the group: keeping members informed and reminding them of meeting dates by word of mouth, email or post, notes, posters or newsletters (Hinchliffe and Vagnarelli, 2013).

Facilitation for Involvement

We found that a facilitative style of engagement, 'being alongside' participants was the most appropriate way of working. The principle of starting with individual people was important, while at the same time seeing them as part of a group or community. This created the conditions in which people could interact with each other. When people met up in small groups, we sought to facilitate quality relationships and interpersonal communication. As part of this, we learnt about the skill-set required to create the dynamics for involvement. Examples of this learning are outlined below.

Groups needed time to find their common interests, build mutual respect and identify common goals. As one Involvement Worker put it:

I allowed people to take their time in thinking about things.

One of the participants clearly acknowledged the value of having sufficient time for discussion within the group before they were ready to decide on a particular course of action:

We started by spending time talking about what was not happening and how we would like it to be; in other words, verbalising our VISION for a better future. Only afterwards did the DOING emerge. I do really think that this seemingly elementary stage of Verbalising the Vision is what has made the difference for me and other members of the group... Time, patience, and teasing out what we were thinking... and I think in our fast-paced electronic world we have slipped into the habit of skipping essential first stages in any given process.

It was necessary to probe interests, prompt and share. A pre-prepared schedule of open questions was useful as a guide. One Involvement Worker cited the benefits of open questioning:

I found that probing was necessary to elicit information... Much deeper questioning is needed to get a meaningful response.

Gentle encouragement of some of the less vocal participants is also needed as this Involvement Worker states:

I encouraged the quieter service users to join in by gently asking if they had a view on the topic.

Other key learning points about facilitation:

- *Facilitating is listening, observing and learning*
- Encouraging older people to talk to and get to know each other through sharing life stories, achievements and aspirations. This helps to build bonds and empathy.
- At times, particularly in the early stages, it may be necessary for group facilitators to temporarily take on a more leading role to keep up interest and pace.
- Allowing time to sit, listen and hear what is being said and not said. Finding out what is important to people, their favourite topics of conversation and what they like to do.
- Allowing time for both sad and happy emotions to be felt, acknowledged and expressed
- Using humour and getting people to relax into conversations
- Building trust, giving praise and personal attention
- Sensitive challenging when helpful
- Allowing people's interests to emerge from group interaction and providing the starting point for action and taking on roles and responsibilities
- Standing back and encouraging older people to take on roles and responsibilities.

Meaningful conversations for involvement

Another important method emerged from the research which we describe as meaningful conversations. Having the time really to engage an older person in topics which interest them is important. This method was used with both individuals and groups. Not surprisingly, participants valued having conversations with people who

showed an interest in them. Being in company, talking, socialising, being treated equally and having a laugh, all enhanced involvement. We also found that older people were pleased when we listened to their opinions and concerns, especially when they thought that we were taking them seriously and that they would input into our reporting.

We found that starting conversations around people's lived experience and following up with open questions such as 'why?', 'what?', and 'how?', allowed people to identify their own issues and offer possible solutions to problems they were experiencing. Many people found these conversations helpful:

I've really enjoyed our conversation and don't want to leave now. Will you be coming back?

These chats with you make my day.

The importance of coming together for informal conversations was mentioned by an Involvement Worker:

Chatting over tea and cakes, feeling socially and emotionally supported, is equally as valid for individuals as is participating in an activity.

In the hospital setting, patients and carers highlighted the benefits of company and conversation in diverting patients from thinking about their problems and pain, breaking the daily routine and alleviating boredom (James et al, 2012). We found this particularly beneficial for people with dementia. These were some of the comments made by patients:

I do appreciate you talking to me. I wanted you to cheer me up because I were feeling so down. I were feeling so miserable ... Oh I'm so happy to talk to you – just anybody.

Thank you for listening to me. It does an old man good to get things off his chest sometimes.

Methods for engaging diversity

Black and minority ethnic communities

One of the main findings to emerge from the national consultations was that particular barriers exist to well-being for specific groups of older people. In seeking to address these barriers, we explored ways to build partnerships with communities. For instance, we wanted to engage with older people from black and minority

ethnic communities in Kirklees and explore with them how these barriers could be addressed. We found that people we consulted had little or no prior knowledge of services. As the Involvement Worker stated:

The profile of WRVS in black and minority ethnic communities is limited / absent and, therefore, a potential barrier to get involved as they are unaware of the service.

This didn't just apply to WRVS. The worker identified the following main learning points from her conversations with older men and women within these communities:

- Additional knowledge and the use of particular methods may be required to work with specific groups of older people. However it is the underlying values and practice of the involvement-led approach which are crucial to effective working with any communities.
- Build direct contact with black and minority ethnic communities via outreach. As reported by the Involvement Worker, one older community representative felt that, *it is important to meet and consult with the community in their environment. He felt that language barriers can be addressed by utilising volunteers in the group acting as interpreters.*
- Make direct personal contact to establish relationships and partnerships.
- Challenge often false assumptions that black and minority ethnic communities have support from extended families and, therefore, do not require support from external organisations.
- Learn about other cultural experiences; for example, the need for women's only services within Muslim communities.
- People want real, not tokenistic, involvement.
- Recruit volunteers from within black and minority ethnic communities.

Older disabled people

We were very much aware that there is an interface between disability and ageing (Priestley and Rabiee, 2001). Many people age with physical and mental impairments and others acquire these as part of the ageing process. However, this should not mean that they are excluded from having a say about the services they need. As one member of the Older People's Reference Group argued:

Many old people are not particularly fit and/or healthy and yet manage not to be dependent and passive. Even if they become dependent, they can still have active minds and take part in shaping their own lives and the services they need.

The national consultations identified a number of barriers to older disabled people's involvement (see later under Barriers) and in the local projects we explored how these could be addressed on a practical level. What follows are a few examples of how one Involvement Worker sought to engage older disabled people and older blind and visually impaired people:

- An older woman with a visual impairment was unable to play table-top games. This acted as a barrier to her being part of the group. With the Worker's support, three members of the group designed and created a large scale snakes and ladders game. This removed the barrier and enabled the woman to join in with others as she wanted to.
- The Involvement Worker supported an older woman living in a sheltered housing complex, who is a wheelchair-user, to attend meetings and be part of the group. She also identified a teaching role for her in the group allowing her to contribute and thus helping her to feel more confident and involved.
- The Involvement Worker engaged creatively with older blind and visually impaired people, using the senses of hearing, smell and touch to explore feelings and thoughts on well-being. A poem was created during the sessions with words shared by participants around an activity on well-being (see Appendix in James et al, 2013).

Important learning also arose from our work with people with dementia in both hospital and community settings. These include:

- Spend time to get to know the individual and encourage them to make an appropriate contribution. In the Darnall Dementia Awareness Group, people with dementia educated other members about dementia. As stated by the Clinical Manager of the support group:

The inputs might be different and if you've got somebody with a fairly severe dementia, it might be only very small, but it doesn't mean that their involvement is any less, and sense of ownership of that.

- See the individual and not the condition. One participant with dementia was made to feel useful by being part of a group:

Well I think if you can be useful ... I think that means a lot just to be ... useful anyway.

- The importance of sustained supportive relationships
- Flexibility is essential
- The need for volunteers with the aptitude and who are skilled enough to engage with older people
- Support for volunteers and training in the use of meaningful conversations, creative activities/games and communication techniques.

3. Action and activities for involvement

Having considered the first two elements of an involvement-led practice, we now go on to present the third key element: action and activities. Participants engaged in wide-ranging actions and activities across all the sites. These included being involved in a survey, photo-films, planning and presenting at events, dementia equality outreach, healthy walks, taster sessions, memory work, sharing personal stories, involving each other in conversation, discussions on current issues, storytelling, social history, physical games, themed activities, birthday celebrations, group lunches, photography, learning to choose and use digital cameras, computer/internet training, poetry, cookery/ favourite recipes, baking, gentle exercise, knitting, crochet and painting. Furthermore, participants achieved a wide range of tangible outcomes as part of this (see James et al, 2013 and photo-films at royalvoluntaryservice.org.uk/shapingourage). The key learning in relation to actions and activities can be listed as follows:

- Action and activities provide a focus and framework for involvement.
- Involvement requires people to identify with, have an interest in and be motivated by, an action or activity in order to take on a role within a group.
- Participants value activities that are shared with others.
- They also appreciate having the option of moving on to new activities when their interest or enthusiasm for an activity has waned.
- Activities need to reflect diversity of experiences and be wide ranging, meaningful and relevant to the lives of participants. We found that not everyone attends for the same reason or wants the same out of attending. Some people prefer activities for the mind; some prefer physical activity and all seem to enjoy both small and large group conversations:

Everyone wants different things, and those things change over time.

Older people want to try something new – something different, which is stimulating.

- Using creative activities was a particular interest of one of the Involvement Workers and central to her approach. We found that these activities provided a relaxed environment, were therapeutic, useful to stimulate discussion, to share concerns, increase involvement, build confidence and encourage mutual support. Creative and participative activities are key elements in the dementia awareness toolkit developed by the Darnall Dementia Awareness Group.

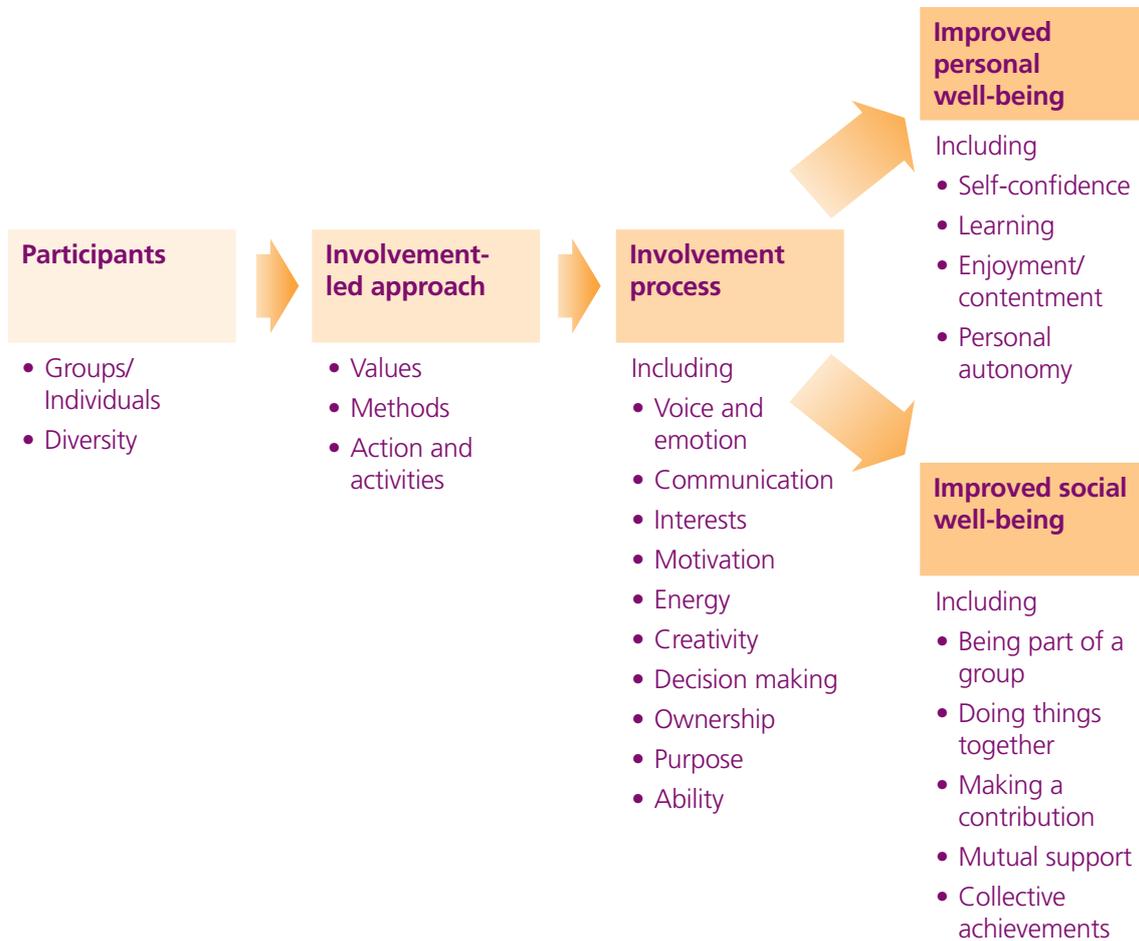
Linking Involvement and Well-being

Key Finding 5: Involvement in a process of personal development and small group interactions contributes most to social and personal well-being

This study set out to explore how older people could be more involved in improving their own well-being and that of others. Therefore, a key question for us was the extent to which the interventions in the five sites impacted on the well-being of the participants. We needed to evaluate participants' experiences of their involvement and the contribution of the Involvement Workers to this process.

The evaluation revealed that the overall response to *Shaping our Age* was very positive. Participants greatly valued the actions and activities they had generated and the tangible outcomes they had been supported to achieve. However, the most significant finding to emerge was that personal development and small group interactions contributed most to social and personal well-being. The involvement process created the space for people to have a voice, to be motivated, to build confidence, to develop their interests, to have fun, to be open, energised and creative; in other words, to be the agents of their own well-being and to contribute to the well-being of others. Thus we started with an interest in two separate issues; older people's well-being and their involvement, and sought to explore their well-being in a participatory way, and the project showed that these two issues are closely inter-related. Involvement supports and improves people's well-being. This is illustrated by Figure 3.

Figure 3: The Shaping our Age model – linking involvement with well-being



In this section, we present the key findings from the evaluation of the *Shaping our Age* process. These are divided into social and personal well-being benefits. These results resonate with the indicators of well-being arising from the national consultations (see Appendix Two).

1. Social well-being

The main elements of social well-being can be categorised as follows:

- Being part of a group
- The value of doing things together
- Making a contribution to others
- Mutual support
- Collective achievements

Being part of a group

Most participants identified benefits from being part of a group and being connected with others; in particular the value of company and friendships, the sense of belonging that being part of a close group can bring and, for some, a way of overcoming isolation:

People are the best tonic.

People want to belong.

I'd be on my own whereas there are people around me and I feel more content within a group. I am not sitting there on me own dropping off to sleep.

It's amazing how we've all come together. Well we are all in it together and it isn't just down to carers, it's the people with dementia and everybody and we're all in it and we're all enjoying doing it; we're getting so much out of it; it's unbelievable.

A group of older visually impaired people shared similar positive experiences. An Involvement Worker engaged this group in creative activities and afterwards, participants shared the benefits of group interaction and meeting others:

The group came up with very interesting questions.

I enjoyed everything about it.

Exploring what well-being is really all about... we looked at the senses... and how that affects well-being. It's been very interesting to see what's come out of it.

(I enjoyed) meeting other people; hearing their views.

Doing things together

Many participants appreciated doing things together with others:

Everyone gets involved. That's the whole point of it.

Getting together and talking about different things.

We can all sing from the same song sheet.

I enjoy just coming to the Centre but I enjoy it even more when we are all doing something together. Hearing what other people say is interesting and encourages me to have my say too.

Making a contribution to others

They also stressed the importance of contributing to support others:

Glad to make a contribution.

Each person - even the ones who only came to one meeting - contributed something that helped to complete the picture of what we could achieve.

I think most of us feel we're contributing to helping other people really in real terms, rather than helping ourselves.

You know, if you're doing something for somebody else you do feel better.

Everyone is enthusiastic about doing something for their community.

Mutual support

For many participants, the value of mutual support and building trusting, helping relationships with others emerged as very important:

And I just listened to your voice and it was so controlled and calm and delivered at the right level and as I listened to it I thought, I know you're nervous, probably as nervous as I am, but I thought, well, if M can deliver it like that, I can. So your confidence gave me confidence really.

And it wouldn't have mattered if one of us had stumbled or something because one of us would have took over ... We would have been there to help one another ... because we knew we could rely on each other.

It's good to help each other. Helping makes you feel better. It makes you feel you are still here.

I see it as putting back into society. I've been ill with cancer in the past and people helped me, so now I want to help others.

Collective achievements

A number of participants felt a sense of achievement, pride and satisfaction arising from positive group outcomes:

It feels good. It feels as though we've achieved something really good. Because I don't think we ever thought we would did we?

We have achieved an awful lot.

I don't know how we all got together but it has worked. I don't see why it wouldn't work in the future with different people.

Well I think it's just been such a build up for weeks on end and we never thought we'd get there and suddenly it's here, we've done it and we can sit back and think well we did a good job there.

These positive quotes from groups resonated strongly with similar comments throughout the project. Participants seemed to gain a great deal from their experience of small groups in *Shaping our Age*. The interesting aspect to this is that such positives do not necessarily emerge from traditional formal and bureaucratic group structures. This is a significant issue emerging from the project. Work with older people has often been tied to a narrow formal and bureaucratic understanding of being in a group or doing things together. In fact, such groups often present barriers to involvement (see Barriers), apparently off-putting many older people. This feedback is important because it reveals the value of people working together and encourages us to reconceive group work and define it in different ways.

Feedback from staff outside *Shaping our Age*

As part of the evaluation, we welcomed feedback from staff who were familiar with the work of the Involvement Workers on the ground. A housing Co-ordinator, who worked with older people, endorsed the benefits of the group to residents in the housing complex. She said that this model of group development was positive, contributed to *beating the isolation* they faced and to *building relationships*. She also observed that residents *felt respected and listened to* and that it had *built their confidence*.

Another scheme Co-ordinator supported this. She observed both individual and group development, with participants enjoying the process, having a purpose and people helping and learning from each other. She commented that, *there is a glow there and, from little acorns bigger oaks are growing*.

2. Personal well-being

The benefits to personal well-being from people's involvement, emerging in the project, can be categorised as follows:

- Self-confidence
- Learning
- Enjoyment and contentment
- Personal autonomy

We will consider the impact of *Shaping our Age* on each in turn.

Self-confidence

A recurring theme raised by participants was that they felt more confident and assertive as a result of their involvement and achievements:

I feel more confident in myself.

It was because you saw people blossom didn't you? They just came out of their shells and people that you didn't think would have opened their mouths - and suddenly they were in the middle of it all.

... being one of the group I'm somebody because other people know you're there, you work with other people and you've made a mark on life instead of just being somebody that nobody knows anything about.

An Involvement Worker said:

One lady in the group shared how she had talked more in the group than ever before. She perceives herself to be a quiet person usually – just listening.

The importance of staff also feeling a sense of well-being from the process created by the Involvement Workers and its impacts on the participants was highlighted in this comment:

The fact that you're working with people who are so full of enthusiasm and you can see their confidence growing, for me that well-being, my well-being is increased and that will last for a while and it keeps me coming back every week.

Learning

Another common theme was the learning from being involved in the project that older people felt they had achieved. This included learning about such diverse topics as poetry, computers and dementia equality:

I enjoyed poetry, ... I'm enjoying this... playing on [a] computer... I don't know what I'm doing like... but... I think I could get interested in it. I've considered buying one for a while...

I've learned things I didn't know – Google Earth – didn't know you could go back to see how it used to be... so that's something I'll do – look to see if there's anything before the houses that we lived in were built.

Well at first I didn't really know whether I was going to take to it to be honest but every week I do come; you learn a little bit more, enjoy it, there's, you know, painting and everything, there's always something going on ...

So it does make you more aware of it (dementia) more so than before when I didn't understand it at all. So yes it has helped me quite a lot.

Also wider learning went on and particularly from activities and discussions with other group members:

I've become someone that gets in and listens to other people.

It's surprising what you can do when you put your mind to it.

To have a discussion like this is very stimulating for the brain.

It's just sort of as we talk we've learnt about each other quite a lot haven't we really.

When we did the cookery class, it wasn't a class as such, it was a gathering of people with lots of experience. You didn't teach them how to cook; they already knew how to cook but they were able to exchange ideas and recipes...

Enjoyment and contentment

Most participants clearly identified the importance of enjoyment, fun, laughter and humour:

I fair enjoy these discussions with everyone joining in.

So it were nothing that I would even have dreamt of doing, as I say painting my hands and feet ... so that's where I've enjoyed it ... and I think you need a little bit of lightness as well because it (caring) can be too serious, it can be too serious.

We have worked hard but we've enjoyed it haven't we.

Cried a few times as well but we've had a good laugh.

Personal autonomy

A number of participants stressed the link between being involved and the sense of personal autonomy gained:

We feel we can change the world.

It's made me do something that I thought that I would never ever do - is to come to a group like this and get involved.

It's an effort at my age to take care about my personal appearance but coming to the Centre to meet others motivates me to make an effort to look smart.

Involvement Workers' contributions

Participants acknowledged that the Involvement Workers had been instrumental in enabling and supporting them to become involved. These were some of the comments made about the Involvement Workers by the older people at the local projects:

You're the anchor; you're the one that keeps us all together ... I just think that the thought that we knew you were there, if we needed backup we would have... could have found it straight away.

And she'll sit there and she'll go 'so what do you think should happen now? How do you think we should do that?' You know and you can feel yourself being pulled into this web you know, get on with it sort of thing.

Didn't offer to do things for the group. She says it's up to us and, you know, have a go and encouraged us and said we can do it.

When asked about the qualities required to work with older people, participants used the following words to describe the Involvement Workers: friendly, open, patient and understanding. They also made the following observations:

Willing to come to them where they are

Someone to sit and talk to

Interested

Feedback from local practitioners

Feedback from staff working in local services also acknowledged the contribution of the Involvement Workers to enabling involvement. They highlighted that Involvement Workers:

- Gave older people a voice
- Created a real group bond
- Genuinely cared about the older people
- Gave everyone the opportunity to talk
- Put no pressure on the older people
- Worked to the pace of the group to grow activities organically.

One staff member worked closely with an Involvement Worker and described the value of commitment, listening and responding to feedback:

[The Involvement Worker] has bonded very well and people are committed to her. She listens to people and understands them. She connects well with people and they know that she cares. She is very good at involving them and getting feedback and she took the feedback on board.

She went on to say that the Involvement Worker:

Made them aware that they're good at things – it definitely makes a difference to their confidence and happier I would say. It makes them happier and able to do other things.

When staff were asked about the qualities required to work with older people, they felt that *listening, having the right attitude, and calmness* were important. In addition they mentioned being *sensitive to disability, looking at the whole person, going at a pace determined by the older person and encouraging* rather than leading people.

Influence of *Shaping our Age* on local practitioners

In several of our projects our Workers made a positive impact on staff and volunteers who, having witnessed the involvement-led approach at first hand, adopted the techniques in their own practice. In particular, they learnt to hand responsibility over to older people rather than doing everything themselves. They also learnt how important it is to engage with older people, to listen to them, to uncover their real wants and interests:

I now wait for people to offer - rather than jumping in and doing everything.

(Involvement Worker) has definitely left a legacy – I thought I knew how to work with older people, but I have learnt a better way of doing that.

It has enormously reduced my stress. Oh yes, because I carried the weight of what I'm trying to do on my shoulders alone until now because, you know, although I've got a committee they don't do anything. And yesterday I actually ... wanted decisions off them ... it's no longer just me doing it. Oh yes, it's made a lot of difference. working in a different way with the senior citizens.

I think definitely (Involvement Worker) has made us more aware of the fact that listening to people is much more productive and should be more deeply ingrained. Listen to what they need rather than just telling them what we can offer ... now I'm much more inclined to talk to them first. I approach it in a different way to find out what their needs are. I definitely learnt that from (Involvement Worker). You have to wait for them to make the suggestions.

Education and Training

Key Finding 6: Education and training are required for an involvement-led approach to working with older people

A question that was raised at the Borders site, was to what extent it would be possible to enhance the existing practice of staff and volunteers through education and training to inform a more involving approach. The Involvement Worker in this context had observed that some volunteers were not clear about their roles, preferred task focussed work and were not able to spend much time with older people. Also when they engaged service users in conversation, some of them were not confident in sustaining conversations beyond a few minutes. At the same time, the Involvement Worker was aware that staff and volunteers were committed to and interested in exploring working in more involving ways:

I really felt it would be beneficial for them all if they could do some training in person-centred communication and it would make things easier for them in the Centre and make the older people feel much better because, without doubt, they feel good when someone really engages with them.

The wider issue of how paid staff and volunteers communicate with older people also arose in discussions with the Older People's Reference Group. One member defined the nature of the problem in this way:

I think staff and volunteers can be good at making tea, helping people to move from one place to another, but there can be a real lack of those basic human qualities: listening and talking with people, not just talking at people.

This led the Involvement Worker, in consultation with the research team, to develop a pilot training course on communication, person-centredness and equality. Working with an external trainer, the Involvement Worker organised a pilot course that was supported by local management who agreed to pay the staff to attend the training. The aim of the training was to enable more involvement-led approaches to practice by promoting more active engagement between older people and staff/volunteers.

Principles underpinning the training

A series of principles underpinned this training. These were:

- The person is the worker's starting point. The trainer put it this way:

One of the key principles is that the person is the expert on themselves. Any work with them has to start from that basis and you then add on to that core conditions which are about empathy, trust, being non-judgemental, being accepting and actually seeing the world from the perspective of the person you are trying to talk to or communicate with. How do they see the world and how do you get that understanding - and if you have those together then your communication is going to be solidly grounded and trust is going to build.

- People have an innate motivation to grow and to develop their capacities as human beings.
- The workers' value position is about listening, valuing, believing in and trusting people.
- The worker creates the conditions for facilitation by adopting a non-directive, non-judgemental, accepting, warm and caring stance.
- The worker does not impose opinions, biases or their values on another and their life outlook (McCall, 2013).

Organisation of the training

The first half-day session was organised for staff and experienced volunteers and a second session followed a few weeks later, allowing delegates to try out some techniques in the workplace in the intervening period. Twelve people in total enrolled for the course: three volunteers, the Service Manager and eight Deputy Service Managers.

Key learning from the training

This training was evaluated very positively by training delegates. They thought it was relevant and they wished it had been offered at induction to their work in the Social Centres. They particularly thought that the course was beneficial because it had been tailored to fit the Social Centres. The opportunity to network and share concerns and best practice with other staff and volunteers was also greatly valued. These are some of the comments from those who participated:

I came away changed from the training – it served as a reminder - I want to improve on what I'm doing.

People really connected with it because they understood the relevance and it didn't matter if you had done various sessions before. It was relevant, it was current and it made sense.

I thought it was excellent... it should definitely be continued regularly. More hours involved. Being able to engage people a lot more often.

I have to say that it was excellent as it was very specific to the job that we perform.

[We] intend to roll out the training... [There's] potential to do this for new Centres coming on stream.

Support to encourage involvement and well-being

Aside from the time, training and support required for staff and volunteers to work with older people in an involving way, a number of additional elements emerged that need to be in place. These include:

- **Transport:** community transport by volunteer drivers or convenient, accessible public transport. We saw how vitally important supported transport is for people to attend the Social Centres in the Borders and to ensure that disabled people were included in the dementia users and carers group in Sheffield. We also spoke to people in other areas who took full advantage of their free bus passes.
- **Fully accessible community venues and centres** support older people to connect with others. The lack of an accessible community venue in Ramsgate was a barrier to involvement. In Lancing, on the other hand, Centre users of Chesham House considered the welcome and activities provided there contributed significantly to their well-being and especially so for people living alone. We also saw for ourselves the importance of ensuring that venues were fully accessible. When looking for venues in central London for the *Shaping our Age* conferences, we were challenged to find venues with the high access standards that we expected. Too often we encountered arrangements which, although legal, or described as accessible, were in practice, awkward and inadequate.
- **Easily accessible information** about a wide range of services and advice and in a range of formats to suit diverse preferences, whether on-line, in newsletters, leaflets or by word of mouth. Account must also be taken of the information needs of people using minority languages and people with hearing or sight impairments, or who don't communicate verbally for other reasons.
- **Funds** are required to pay for all of these requirements and to subsidise activities like, for example, keep fit, craft and computer instructors and to purchase materials for activities and crafts. Involvement can cost money and require a budget. *Shaping our Age* events which older people organised and ran locally required significant funding. For instance, a group of participants organised

a public event in Sheffield and funds were provided by *Shaping our Age* and sponsors for design and print, a minibus, hire of digital equipment and venue, buffet lunch and other costs.

Barriers to Involving Older People in Improving Well-being

Key Finding 7: Participants identified many barriers to well-being and involvement

Participants in the national consultations and in the local projects highlighted a wide range of barriers. A member of the Older People's Reference Group said:

The barriers can seem like mountains.

We have split the barriers here into those identified by participants as barriers to (a) well-being and (b) involvement, although there is overlap between the two.

a. Barriers to Well-being

- **Poor physical health and impairments**, especially severe and chronic pain, which may limit mobility and the ability to lead the same active and social life as before:

If you're continually ill or feeling unwell your quality of life is not very good.

- **The ill health or impairments of others** – particularly close relatives. Family 'carers' mentioned particularly how this impacted on their own well-being:

He was an invalid and he couldn't go out ... he used to get very depressed ... and it was very hard for me as well.

- **Mental health problems** are often closely associated with physical health difficulties and impacted on older people's well-being. Depression and dementia were especially highlighted:

It's very easy to go into a negative state ... you know if you get a twinge or a spasm in your back ... so you can easily trigger off some depressive thoughts.

My mind doesn't seem to want to do things that I want it to do ... me words are coming out different to what I'm trying to say. It's a horrible feeling.

- **Sensory impairments** can be associated with feelings of detachment from others:

Because of my eyes, as well, I can't see my friends until they're up close and I feel like I've lost my friends because of that.

- **Being isolated** was considered by many to be the biggest problem in old age; linked to bereavement, marriage break-up, being a full-time carer, restricted mobility, sensory impairments, poor physical and mental health, sexual orientation, language barriers, fragmentation of families, unsupportive communities and the tendency towards remote and depersonalised services:

Being 94 is awful. Well, it is because all your friends have died ... I haven't got a friend left. So nobody can come to see me cos they've all gone.

Very lonely because I am a widow ... All my children are grown up. They all have their own family to look after and care for.

Well, the post office has gone and there's not much opportunity to socialise in the village any more.

- **Financial pressures** cause anxiety especially for older people struggling to pay for the basic essentials like food and heating:

The pension we get means that we have to think whether we can afford to buy things. That shouldn't come into it, but it does.

- **Discrimination** owing to ethnicity, disability, dementia and sexual orientation but most frequently mentioned against older people, ageism: being treated disrespectfully, being patronised, and being labelled as a burden on society:

A lot of the elderly feel that they don't get the respect.

b. Barriers to Involvement

The 'doing to' approach has already been discussed, but a number of other barriers to involvement were identified by participants across our five local projects; by members of the Older People's Reference Group during our workshops and in on-line discussions with them and from our project Partners. Many of these barriers reflect broader structural issues and exclusions in society, sometimes internalised by older people themselves and often by others.

- **Negative perceptions of older people** in the media and in society in general can lead to older people resisting being identified with what they see as a negative identity and oppressed group and as a consequence avoiding being involved in older people's services and groups. This could have a doubly damaging effect, distancing older people from what help and support there might be. There was a feeling that being 'old' was synonymous with being seen as having little to offer and holding no opinions that count. These negative opinions were considered by participants to be disrespectful but also a waste of valuable experience:

As soon as you retire you find a label is hung on your neck. We have a wealth of knowledge and experience – yet we are rendered useless and a burden on society.

Participants felt that younger people did not always appreciate or understand older people; that inappropriate labels were applied to a diverse group of people who are linked only by their ages. The reluctance to be associated with such labels that first emerged in the initial consultations preceding the project re-emerged strongly:

I don't believe anyone in our group (Older People's Reference Group) thinks of themselves as old. The problem may partly be that the media are dominated by younger people who don't believe they will ever age themselves and so regard 'old' as a derogatory term.

How can you give a single 'label' to an 11 million plus, very diverse group of people?

How we get over to the youngsters that we are not 'brain dead' – yes, difficult ... we can only try to get people to understand old age is something we all want and we hope youngsters and others realise that life and activity don't stop at 30, 40 or 70!!

We look around at our friends and find that, well, yes, some are getting a tiny bit forgetful and some can't walk very fast, but they are definitely not boring – they are fascinating to talk to – and great fun to be with.

- **Traditional and inappropriate services** were associated with a 'doing to' culture; where, in the case of social clubs and groups, the focus was upon providing 'entertainment', practical tasks and timetabling rather than actively involving the service users. We encountered resistance amongst some participants to being associated with such services because they identified them with negative stereotypes of being old; because they perceived them not to be meeting their needs or because they preferred to mix with a wider range of age groups. Some participants felt that these services tended to stereotype older people:

Many services for older people are very much ‘for old people’ and many people I know, even in their 80s and 90s don’t want to be treated like old people!

- **A lack of practical support** can constrain a process of involvement; for instance, the shortage of accessible and affordable transport; support staff and resources for staff and volunteer training and expense systems to support activities and initiatives. Also we encountered staff in a range of services for older people who were time-pressed and under pressure, trying to juggle with competing priorities and to achieve their targets and outputs. Involving older people takes time and patience and this was not always perceived as of high priority.
- **Resistance to group involvement and to taking on roles and responsibilities.** Some older people are not ‘group’ people and prefer to socialise at an individual level; others feel their lives are busy enough and have no time. Tiredness is another barrier particularly for the very old and people who are caring for relatives and spouses:

No, I’m not keen on joining large groups. I prefer to do things at my own pace. I can’t do the small talk thing. I prefer linking with individuals rather than groups. Definitely not keen on committee roles – I’ve got enough in my life.

For those that do join groups it appears they are increasingly reluctant to take on leadership or other active roles to keep the groups running. A number of reasons were identified:

- Feeling they have little to offer; lacking self-esteem and self-confidence
- Fearing responsibility and the legalities associated with formal roles
- Being put off by dominant personalities
- Feeling too old and tired; they have enough to do; believing that younger people should be taking on roles (but that younger older people are not joining groups targeting the old):

If they’re 55-60 they don’t want to join in, they do other things, they go to shows or to the theatre.

- Reluctance to commit or be tied down; enjoying the freedom and spontaneity that retirement brings; saying they have done their bit during their working lives:

...you’re retired, you don’t want to commit, you’ve had a whole working life of commitment. You want to do things when you feel like it. It’s part of being retired. You’ve got choice and you’ve worked hard towards it!

Thus many older people do not want to be 'organised' or regimented and that is their expectation or experience of much of the provision for older people that is available to them.

- **Low self-confidence/self-esteem** can limit involvement and is linked to bereavement and retirement:

They are reluctant to go out to new groups because they don't know who'll be there and familiarity is important to them.

When you retire you lose confidence. Then the less you do, the less you think you can do.

Negative life experiences can also knock the confidence and assertiveness out of people:

I think we've all been so down in our lives with the caring haven't we?

Low educational attainment and living in areas of deprivation were also seen to be factors in low self-confidence and limited involvement:

Thanet is a parochial area. There's lots of deprivation both social and economic for the young and the old. People are so used to things being done for them. They think they should be there to be served. It's a service user's mentality: they owe me.

- **Increasing isolation of older people within communities.** This is a complex issue, also identified as a barrier to well-being in our national consultations. Participants believed that older people were isolated for a wide range of reasons, including inadequate responses to ill health, restricted mobility and bereavement:

Many older people are suffering from bereavement (even if it was many years earlier) and struggle with going out on their own.

He feels that transport is a big issue in the area and people may be experiencing social isolation if they could not access the bus links.

Participants said that not everyone experienced isolation in the same way. Some preferred to do things alone, were quite content to be alone and did not want to socialise. However, for others isolation was an unwelcome state, causing or aggravating illness and leading to loneliness and loss of confidence. Some of our Older People's Reference Group members encourage isolated people

to get out and become involved with social groups and had witnessed at first hand the well-being benefits that arose. However, they said that this work is resource intensive requiring persistence, persuasion, support and trust-building over extended periods:

Even when I have befriended people and said, 'I'm going, it will be good, come with me,' they still won't come because they have got into the habit of not going out socially and this is, in some cases, proving impossible to break.

You have to work with them. It just doesn't happen overnight. It takes weeks maybe to get somebody out of a flat and its hard, like, at times.

The importance of being sensitive to individual preferences was highlighted:

We have to respect some people choose to be isolated. They choose to be behind their doors and they may be emotionally well. Others aren't. They go on a downward spiral, so it's a matter of being sensitive to the needs of certain people ... we've tried to get people out of doors to day care centres and lunch clubs and it's not for them. We have to respect that.

Barriers to involving diverse groups

- **People living with dementia and carers.** We found that there is insufficient support in place for the involvement of people with dementia, for instance a lack of care and stimulation while in hospital. A nursing professional working with people with dementia highlighted the challenges:

If a person has a mental disability it's very, very difficult to get them to participate. You have a lot deeper to go to get them into that.

It was felt that people living with dementia and their carers were all too often written off and their opinions not sought. Carers made the following comments:

Do they ever come out to a group like this and find out what people want? They don't seem to do they?

They should speak to people who are trying to cope rather than being in a little cocoon of not being affected themselves.

Carers living with people with dementia experienced social isolation, lack of support and difficulties in accessing information:

I found it very stressful because I was with him 24 hours a day.

You don't get to hear about services anyway. I mean when my husband was diagnosed, I never had a support worker or CPN (Community Psychiatric Nurse) or a Social Worker or anything. A good eight, nine years. And it wasn't till I kicked up a fuss and said I think we need some help round here, that I eventually got a CPN.

They should put you in contact with the right people. I mean, luckily they put me in contact with Darnall Dementia but it took years to get what you wanted or any really good help you needed. It took far too long.

- **Ill health, impairments and restricted mobility** act as barriers to involvement unless suitable support and confidence-building are available. Lack of confidence in physical mobility, fear of falling, loss of memory and generally feeling unsafe or vulnerable can prevent people from going out:

As we get older, most of us find it harder to do the things we used to do easily and with increasing physical and mental problems it can seem too much like hard work to go out.

It is not always possible to overcome barriers to involvement caused by impairments, as observed by a Social Centre Manager:

Poor hearing is the main one - buzzing in the ears – trying to get tuned in – yeah, hearing pure and simple and it's difficult to overcome that. They do want to get involved and it must be annoying and they don't want to be a nuisance.

- **Black and minority ethnic communities** were considered to have a low profile within some third sector organisations. Our Involvement Worker in Kirklees approached some support groups within the Asian community to identify barriers to involvement in services. The groups welcomed the personal contact with our Worker; were pleased to be involved in *Shaping our Age* and were keen to develop partnership working. They considered that face to face contact was essential to *learning more about each other*.

However, these consultations highlighted specific barriers for this community:

- Limited awareness within the community of services offered by the voluntary sector
- The level of charges can limit access to services
- Restricted funding for support groups limits the range of activities on offer

- A lack of confidence within the community in accessing social opportunities outside of their cultural groups
- Language barriers and the need for interpretation
- A need for women's only groups to support the involvement of women from minority cultures.
- **Older men** can be more isolated than women, especially following retirement or bereavement, because they tend to have fewer local social connections and networks. Two members of the Older People's Reference Group made the following comments:

So, when they retire, most of them don't have ready-made social groupings, whereas most women have a circle of female friends.

I asked the men who come to our bereavement cafe in the nearby town - and it is mostly men who come - most have been bereaved for some time and got over the shock, but are just very lonely. They don't have many friends ("everyone was our friend and I don't see much of them now she's died"), don't have many interests, just don't know how to get out and spend time with other people.

It seems that missing the company of other men is a particular issue and there are few men only clubs or activities to address this:

Men, especially, are not well catered for.

Ladies have plenty of groups to join and the men don't.

It's mostly females that I meet and so one of the reasons I play golf is because I meet men.

We also found that there seems to be a gender divide in how older men and women prefer to socialise and spend their time and a difference in the volunteering roles preferred by men, which tend to be more task oriented:

Men's company is far different than women's company, you talk about different things.

Old single men don't go to Age Concern. They go to the United Reform Club.

I think that men like to focus on a thing ... I find that women are much more interested in how do we get everybody to be involved; how is this family going to get along ... Men are interested in, oh, I see a problem. I'm going to deal with it ... I haven't got time to talk to all these people, you know. I'm just going to fix what I'm going to fix.

- **Other barriers to involvement** identified in this study were less commonly mentioned but, nonetheless, important in the sites where they were raised:
 - A confusing array of local organisations, structural changes in services and high staff turnover leading to confusion for workers and service users alike.
 - A competition culture within the third sector. Although there are many examples of third sector organisations working in successful partnerships, some participants felt there was an increasingly competitive culture that acts as a barrier to sharing resources. The formation of effective local funding or working partnerships was considered to be restricted by red tape.
 - Inadequate or confusing information about services for older people and low computer literacy which inhibits access to information.
 - Regulations designed to protect service users can limit involvement: *You're afraid to provide meals. Well you can't if you haven't got a health and hygiene certificate. Sometimes you worry about taking someone out because of 'health and safety'.*
 - Supported housing complexes seem to instil dependency in many of the older residents. As a Housing Coordinator said: *When they move in here they tend to treat it more like an old folk's home sometimes, and they leave their independence on the outside of the door.*



5: Conclusion

In conclusion, we will set out our interpretation of the main messages from this study and consider their wider implications.

As we have seen, **the first main message is that social connectedness and positive relationships are central to older people's well-being.** This highlights an important aspect of well-being in that for many older people it is best achieved in conjunction with others at the levels of family, friends, neighbourhood and community. This message from the national consultations was confirmed in the local projects when the link between involvement and well-being emerged in more detail. We found that older people, through their active involvement with others, really could improve their own well-being. This finding is consistent with studies which have found that well-being is not simply a state of mind or body that we either possess or not as individuals, but is something that emerges from what we create with others through our actions. When we act on things that are important to us, we engage in positive social relations that can enhance well-being (Ward et al, 2012; Letcher and Perlow, 2009; White, 2008).

The second main message is that older people have important insights to contribute to the well-being debate. This study, albeit on a small scale, opens the door to new learning about this important concept. At the consultation phase, we learned that older people shared complex understandings of the term, which mirror the wider debate. They also identified the factors that shape well-being and how it can be improved. At the local project phase, we learned that when given opportunities and with the necessary support, older people welcomed the freedom to engage in action and activities that were relevant to their lives. In addition, their reflections on their collective and individual experiences within *Shaping our Age* offered valuable insights to inform our understandings of well-being and involvement. The crucial learning from *Shaping our Age* is the value of these accumulated life experiences and the diversity of opinions that older people brought to this study. This learning adds to findings from other studies which argue for the

subjective voices of older people to be central to services, policy and research (Blair and Winkler, 2009; Walker, 2007; Social Care Institute for Excellence, 2007; United Nations, 2002).

These two key messages have a number of implications. To start with, older people's involvement in all aspects of *Shaping our Age* reveals the potential that exists for their greater contribution. To realise this potential it would be necessary to embrace the challenges of an ageing population, tap into their abilities and bring their voices, ideas and experiences to the centre of services and policy. This would require a shift in mindset away from notions of personal 'deficit' (what people cannot do) to one which focuses on people's collective and individual capacities to shape their own well-being. This should also not be confused with 'leaving older people to do it themselves', but instead with funding, policy and practice geared to involving older people in helpful, tried and trusted and innovative ways to be agents in their own and other people's well-being.

One of the ways to achieve this involvement, as demonstrated successfully in this project, is to promote collective and individual models that challenge notions of older people as passive recipients of welfare (Bowers et al; 2007; Nolan et al 2001). This would mean starting with their own interests and motivations and supporting their involvement in a variety of actions and activities. Key to this is how we choose to work with older people. It implies a rejection of traditional approaches which this study suggests limit the potential for involvement, social connectedness and, hence, well-being.

The findings from this project support such an **involvement-led approach** that values the potential of older people, their aspirations and strengths. It is an approach to working with older people which emphasises, 'What do you want to do? And how can I help you to do it?' rather than 'I can do it for you', 'You'd like to do this, wouldn't you?' or 'This is what we do here'. It is important to stress that an involvement-led approach is not a collection of techniques but a value-led process with human interaction at its core. It is the quality of the communication and the underlying values that are the crucial factors. It is not just about providing diversionary activities, keeping people amused or meeting basic needs (although vitally important for some). It is about providing opportunities for involvement and the creation of new collective and personal experiences that can lead to greater well-being.

A further implication emerging from the national consultations and from the local project phase was that major barriers exist to well-being for *specific* groups of older people. *Shaping our Age* was a relatively small scale project. However, we did test out particular methods for involving black and minority ethnic older people, older disabled people and people with dementia (see Findings and James et al, 2012). The important learning here is that given its underlying value base and its emphasis on creative methods of involvement, an involvement-led approach offers new

possibilities for tackling issues of exclusion. However, this approach does require additional time and resources and development work, as well as further research.

The creation of a more involving approach will require changes in worker/volunteer education and training. An essential element of this approach is the nature of the working relationship between the worker/volunteer and the older person/service user. We found that older people want and welcome interventions that provide the necessary support to enable them to achieve what they think is important in their lives. It is a process that needs to be supported throughout organisations working with older people at all levels. It also takes time and resources and is grounded in the values, knowledge and skills of a person who facilitates this interaction. It is crucial that the worker/volunteer believes that the adoption of this approach will bring more satisfaction and meaningful outcomes to their own practice. Our fieldwork revealed that an involving approach is not familiar or comfortable for all staff and volunteers on the ground who have been socialised into a much more traditional approach. This would raise issues for recruitment, supervision and education/training and particularly the incorporation of equality and diversity issues into work with older people (Branfield and Beresford, 2010; Help the Aged, 2008; Age Concern, 2007; Godfrey and Callaghan, 2000). It requires systematic change throughout organisations in support of involvement-led practices.

The value of social connectedness and involvement on older people's well-being are not particularly surprising, given most people's expectations of everyday life. It is, however, surprising that these have not been given greater prominence in policy and practice developments. Therefore, it is hoped that the findings from *Shaping our Age* can also inform current policy and practice debates. Certainly they are likely to fit with health and well-being agendas and wider policy initiatives to enable the involvement and active engagement of citizens. This is particularly true of the proposals for The Future of Adult Care and Support in Northern Ireland; the Strategy for Older People and the Social Services and Well-being Bill in Wales; Reshaping Care For Older People in Scotland and the Vision for Social Care in England. It is also important to consider the wider relevance of these findings for community development with older people and its links with Big Society ideas as well as prevention and sustainability initiatives.

Clearly, recruitment, provision of education/training, support and supervision will have resource implications particularly in terms of funding and time. In a period of recession and austerity, it is a good time to reevaluate traditional ways of working and to consider issues of sustainability and prevention. It is also a good time to value the resources of older people and their potential contribution to this approach. Evidence from *Shaping our Age* reveals that a new generation of older people do not want to be associated with traditional models of service. The 'Darby and Joan' club was a helpful response to the importance of social connectedness for older people in another age. This project has pointed to the importance of advancing its equivalent

to meet the same enduring need in the twenty-first century. In this likely future scenario, the limitations of the traditional 'doing to' model are likely to become increasingly apparent, particularly in seeking to address issues of social isolation, loneliness and exclusion. The involvement-led approach is not a panacea to address all the challenges of ageing. However, as part of a range of innovative approaches, it can make a significant contribution to older people's well-being and is likely to have knock-on effects for other groups and other social care and health services.



6: Next Steps: Informing Change

Taking Things Forward

There are two main findings from *Shaping our Age*:

- Social connectedness is central to older people's well-being.
- Given the opportunities and the necessary supportive conditions, older people can shape their own well-being through a process of meaningful involvement.

These raise a number of challenges for improving older people's well-being. A key challenge is how older people can be helped to sustain and create meaningful social connections with others that can improve well-being within their own lives and communities. For this to happen, it is necessary to consider more enabling and involving approaches to working with older people. New forms of practice, as we have seen, demand a fundamental change in mindsets - in the way everyone thinks about older people. It requires the shift we have highlighted from a 'doing to' culture of service provision to one which has a focus on people's capabilities and potential to shape their own lives and their communities. A member of the Older People's Reference Group clearly states the attitudinal change required:

I'm sure we all know what needs to change – those responsible at every level for fulfilling the needs of older people need to have a different attitude towards older people. Instead of having things done to them, older people need to be encouraged to say what they want, to make choices about every aspect of their lives, and to do as much as they can and want to do.

In arguing for such a shift in mindsets, we are not underestimating the challenges this would pose, particularly in a time of recession and with ever-increasing needs. The issue is not necessarily about finding more financial resources but more about how these can be better used and looking at different ways to provide support and services. Most importantly, it involves thinking about the way we work with older

people and their potential contribution not just to their own lives but also to the communities in which they live and the lives of others.

Recommendations – A Framework for Involvement and Well-being

A supportive framework is necessary to release the contribution, experiences and energies of older people. Such a framework needs to promote cultural, policy, organisational and practice changes. Below, we offer some practical recommendations for taking the research findings forward. In doing so, we draw on the many ideas and suggestions shared by older people, partner organisations and others involved with *Shaping our Age*. These are intended for practical implementation, ongoing discussion and further research within the sector.

1. Promote a new culture of ageing

- Acknowledge the connection between social and individual well-being and the centrality of positive relationships on older people's lives within families, friendships and communities
- Encourage an involving and positive culture of ageing which has a focus on older people's collective and individual capacities to shape their own lives within communities
- Challenge and change the negative perceptions of ageing within society, within organisations and amongst older people themselves
- Acknowledge the value and diversity of older people's experiences and opinions in improving the well-being of communities.

2. Advance policies that facilitate and enable

- Adopt national and local policies and strategies that nurture, facilitate and support the involvement of older people rather than seeking to mould and limit their contributions by setting pre-determined outputs
- Adopt policies and practices in relation to ageing that embrace all aspects of older people's lives and not just those concerned with health and social care issues
- Facilitate and support older people to shape policies and strategies at all levels of government that affect their well-being
- Consider how existing service relationships within health and social care provision can be made more humanistic and more closely tied to how older people may define their own well-being.

3. Change organisational cultures

- A critical starting point is commitment to and demonstration of the principles of older people's involvement and inclusion at the highest strategic level within organisations
- Change the 'doing to' model to ensure that older people are not just given a service but are actively involved in deciding what they want to do and how they can be involved in achieving objectives that will bring positive improvements to themselves and others
- Develop an organisational policy on involvement that supports and encourages commitment from staff at all levels
- Encourage leadership championing the principles of involvement across the organisation
- Advance education and dissemination of these principles throughout the organisation especially in relation to management, staff and volunteer supervision and support
- Support older people's involvement in governance structures, in planning and in the delivery of services. As a member of the Older People's Reference Group said:

The structures don't exist to include us.

- Embed service user well-being self-defined outcome measures in service evaluations
- Engage with and ensure representation of older people from diverse communities within organisations at all levels.

4. Promote involvement-led approaches to working with older people

- Facilitate and support older people to develop individual and collective self-help around their interests to improve their well-being
- Adopt involvement-led approaches to practice which value humanistic interaction, communication and inclusivity
- Recruit and support staff and volunteers with the appropriate values and skills for this approach. Older people should be actively involved in the recruitment process
- Provide mandatory education and training for fieldwork staff and volunteers with a focus more on the benefits and potential of ageing and less on the deficits. This would include experiential education/training in an involvement-led approach and person-centred communication for individual and group work. Education/training would also need to address issues of diversity and

equality, ageism, dementia and disability. Provide support for older people to be fully involved in the development and delivery of this training

- Use positive language in branding and other publicity to reflect the positive contribution of older people.

5. Systems to support involvement

These need to include:

- A specific budget to support involvement. This could be used for vital support such as travel, expenses, activities, accommodation, training, personal assistance, administrative support and room hire
- Physical and communication access: A member of the Older People's Reference Group stated:

Venues need to be barrier-free; there needs to be a good sound system, induction loops, refreshments.

- Support the availability of accessible and affordable transport and particularly for those living in rural and dispersed communities. As a member of the Older People's Reference Group stated:

Transport (free or cheap) would take older people to the places where they could be more involved and active.

- IT support to facilitate communication between people and to source information
- The provision of information that is relevant, brief, up-to-date, jargon free and accessible. Many participants involved with *Shaping our Age* questioned the use of technology to meet the information requirements of all older people. This participant argued for more face-to-face contact to tailor information to the preferences of individuals:

Older people like face-to-face contact because they haven't grown up with technology like this generation.

Information providers also need to take into account the particular communication needs of groups such as older people from black and minority ethnic communities, those with sensory impairments or who for other reasons communicate differently or non-verbally.

6. Partnerships between organisations

A member of the Older People's Reference Group highlighted that:

Greater co-ordination is required between all local community groups to encourage the elderly population to more readily participate.

- Build partnerships and maximise funding opportunities across the third and

statutory sectors, particularly at local level, to encourage and support more generic work around older people's well-being, joint training for staff across organisations, intergenerational activity and community cohesion.

7. Further Research

Further research is needed to refine and build on the *Shaping our Age* model. This model certainly seems to have gains to offer and work taking it forward generally is likely to be helpful. In addition, some areas particularly seem worth exploring. These include:

- Applying the involvement-led approach emerging from the project to a specific service/location/group over a longer timeframe to explore further the impact of this approach on older people's well-being
- Exploring barriers. An important finding is that certain groups of older people confront significant barriers to their involvement and thus experience social isolation and exclusion. Further participatory/action research is needed to address these barriers particularly in relation to black and minority ethnic older people, older men, older people in residential/nursing care and lesbian, gay, bisexual and transgendered/ing people
- Involving older people in rolling out involvement-led approaches more broadly. Further research is required to support older people to shape policy issues across the UK and beyond. Such research could build on the learning from *Shaping our Age* in relation to the mechanisms required to facilitate this work, involving older people in the process.



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Person-centred training in Jedburgh and Kelso. Shaping our Age 2013.

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The following unpublished report was also produced:

James, V., Hinchliffe, D., Hoban, M., Fleming, J., Beresford, P. (2012) *Shaping our Age, Local Report Sheffield. Consultations with Service Users and Carers*. unpublished report. Cardiff: WRVS.

Appendix 1: Biographies of the Shaping our Age Research Team

Martin Hoban was a part-time Research Project Worker for *Shaping our Age*. Prior to joining the project, Martin worked as a community worker in the South Wales Valleys, the North East of England and in Ireland. He has a background in the Disability Movement and has considerable experience of involving service users as a development worker, educator and researcher.

Vicki James was WRVS Research Manager and also shared the *Shaping our Age* Project Worker post for two days a week with Martin Hoban. Vicki has worked as a researcher and consultant in a variety of roles within the public, private and University sectors over the last 30 years. Before joining WRVS in 2010 she worked in a social research agency and before that as a consultant in an international tourism consultancy. She is now a Freelance Researcher and Independent Consultant.

Peter Beresford OBE is Professor of Social Policy and Director of the Centre for Citizen Participation at Brunel University. He is also a long-term user of mental health services and Chair of Shaping Our Lives, the national independent service user controlled organisation and network. He has a longstanding involvement in issues of participation and empowerment as writer, researcher, educator, service user and campaigner. He is a member of the Ministerial Leadership Development Forum for Social Care, a Trustee of the National Skills Academy for Social Care and a regular contributor to the Guardian.

Jennie Fleming is Reader in Participatory Research and Social Action Director of Centre for Social Action at De Montfort University. Before coming to De Montfort University she had many years professional work experience as a community worker and social worker and is professionally qualified in both disciplines. Jennie is committed to working in a participative and empowering way; whilst being at the Centre she has been active in the development of participative research methodologies working with community members and service users ensuring their input and contribution to research projects that affect them.

Appendix 2: The Methodology – Further Details

This Appendix is intended to be read in association with material in Chapter Three explaining how we carried out the *Shaping our Age* project. It provides more detail for those who are interested.

Initiating the Project

Peter Beresford was approached by the then Chief Executive of WRVS to see whether he would be interested in undertaking a research project in association with the organisation. He made two suggestions which were agreed: (1) To involve Jennie Fleming of the Centre for Social Action at De Montfort University who could bring valuable additional skills and experience and (2) that from the beginning the project should involve older people themselves.

Given increasing political and policy interest in ideas of ‘well-being’ and the as yet limited involvement of older people themselves in discussions and definitions of well-being, this was seen as an area that might be a valuable and useful subject for further work. To ensure that a possible project was informed right from the beginning by older people’s views and ideas, two small national consultation focus group meetings were organised with a range of older people with links with WRVS and an interest in policy, practice and research. They reinforced the view that this was an important area to investigate and helped define the focus of the project that was proposed to the Big Lottery Research Programme and which was successful in gaining a grant of £500,000.00, covering a period of three years.

The Research Methodology

The project was described as a three year action-research project, which included a research and a development phase. The methodology adopted to undertake the project was a participatory one. The aim was to involve older people within the tried and tested research approaches of social action research and emancipatory disability research. The research was underpinned by these two complementary approaches which had been used and developed by Jennie Fleming (Fleming and Ward, 2004) and Peter Beresford (Beresford, 2002 and *Shaping Our Lives*, 2013) respectively, in national and international contexts and with a diverse range of people.

Emancipatory disability research, developed by the disabled people’s movement,

grew out of the sense that mainstream research was damaging and disempowering to disabled people. Informed by the values of the social model of disability and the philosophy of independent living (Barnes and Mercer, 1997), it is concerned with equalising the power relationship between researchers and participants and undertaking research committed to the empowerment of disabled people and broader social change in line with the achievement of their rights and needs. Social action research starts from the ideas and understanding of the people involved – those who are experiencing the issue. It involves a realisation that research is a process of learning, development and change and the researcher is the facilitator of that process.

Social action researchers set in motion processes of participation to shape agendas, make decisions and affect outcomes; they have non-hierarchical relationships with participants, recognising everybody has an equal but different contribution to make to the research process. Data analysis and dissemination are undertaken jointly, and there is a responsibility not to leave the participants unsupported at the end of the process. The approach involves moving from understanding and knowledge into action. Neither approach has developed their own specific research methods, but employs methods consistent with their participatory and egalitarian philosophies.

An initial stage of desk research made it possible to ground the project in existing knowledge about the well-being of older people and its 'measurement' as well as integrating original work exploring the views and perceptions of older people within the project.

Involvement in the research

A number of processes of involvement to ensure the meaningful participation of older participants in the project were adopted. These included their involvement in:

- staff recruitment
- setting the parameters of the research
- selecting the local projects
- designing the research
- developing the local projects
- information collection
- analysis of findings
- evaluating findings
- reporting, communicating and disseminating.

The National Consultation with Older People

This was the first phase of the project and was carried out through a series of focus groups and individual and paired interviews in the four UK countries.

The Participants

Table A.1: Participant Profiles: National Consultations on Well-being

Number of participants	163 in total 125 in 16 focus groups 38 in 30 individual or paired interviews
Age	65-69: 24% 70s: 43% 80s: 29% 90s: 4%
Gender	48 Men (29%) 115 Women (71%)
Ethnic Origin	23% Black and minority ethnic communities 77% White British
Location	Urban: 60% Rural: 40%
Day to day activities limited because of a health problem or disability which has lasted or is expected to last at least 12 months	No: 37% A little: 36% A lot: 27%

Profiling data were self-defined by participants

The Development Phase of the Project

1. Selecting the Five WRVS Services

This phase, undertaken during the summer of 2011, involved selecting five services within WRVS suitable for the development phase of the project. Some background to WRVS is included here to set the context.

WRVS, now Royal Voluntary Service, is a national charity with a network of staff and volunteers throughout England, Scotland and Wales running support services for older people (www.royalvoluntaryservice.org.uk) It grew out of a national organisation developed during the second world war, offering help and assistance to deal with the effects of the war on the home front, including the dislocation, destruction and loss of life created by mass bombing.

At the time of selection there were over 400 premises from which at least one or more of a range of WRVS services were provided including community transport, onward services, hospital shops, meals on wheels, befriending, lunch clubs, community centres and social clubs, good neighbours services, home from hospital and hospital to home services.

During the course of the *Shaping our Age* project, WRVS underwent a transformation in the way in which it was managed and run. Moving from individual local services, WRVS instituted a process for establishing a network of area based service hubs where a mix of complementary services was provided to older people. Central to the transformation was placing the service user at the centre and tailoring service plans to their individual needs.

Our local project work required a close working relationship with older people, basing our local projects within five WRVS services and appointing Involvement Workers to facilitate initiatives at each site. The project aimed to explore ways that older people could take an active part in improving their well-being and the well-being of others through their involvement in developing new or existing services, activities or projects.

The findings from the national consultations and discussions with the Older People's Reference Group identified a range of indicators of well-being and some underlying principles for the selection of the services. The indicators are presented in Table A.2 below.

Table A.2: Indicators of Well-being

Main Theme	Sub-theme
Feelings of well-being	<ul style="list-style-type: none"> Belonging Confidence Comfort Contentment Enjoyment Feeling useful Feeling valued Happiness Peace of mind Satisfaction Self-esteem
Positive relationships and social contacts	<ul style="list-style-type: none"> Family Friends, company, neighbours Groups and clubs Interests and activities Going out Places of worship Volunteering, supporting others and campaigning

Main Theme	Sub-theme
Good Health	Physical health Mental health
Having a sense of independence	Control of daily life Regaining independence after illness, disability, bereavement
Place and environment	Belonging to a supportive community Being comfortable and happy at home Safety and security A good social life Pleasure in the outdoors Attractive natural environment Pets
Positive attitude to life	Self-motivation Taking responsibility for self Positive memories Accomplishments
Faith, religion and spirituality	Personal beliefs and meaning Prayer Spiritual experience
Finances	For comfort, security and contentment

The principles for selecting the services were as follows:

- Older people to be actively involved in service development and delivery. This could be at varying levels of involvement, as determined by older people themselves.
- Older people to have improved opportunities for social interaction; social isolation to be tackled.
- Older people to be actively involved with and connected to the wider community.
- Older people to be encouraged/supported to maintain independent control of their own lives.

Other principles of research approach and practice:

- Importance of one-to-one interaction/support
- Treat older people with respect and dignity
- Work with individuals and/or groups
- Acknowledge that there are different attitudes to ageing
- Build resilience and self-esteem
- Importance of advice, information, education

- Recognise and embrace diversity
- Local staff and volunteers are committed to the research.

The indicators of well-being and principles were circulated, to national, regional and local level staff within WRVS. Eight local service sites were shortlisted and telephone interviews undertaken with the Heads of Region and local staff in each. Notes of these interviews were circulated within the research team and to members of the Older People's Reference Group and we provisionally selected five sites based on the potential they offered to involve older people. We also aimed to choose a range of sites by type of service provided.

We subsequently visited each of the five sites to discuss the principles and logistics of working together; to confirm commitment from local WRVS staff and to begin arrangements for working together. Once the sites were confirmed, Draft Working Agreements were sent to local WRVS managers responsible for each service. These agreements were intended to guide understanding and good working relationships.

2. The Five Local Projects

A Practical Five Stage Process

The five stages were based on a community development model of practice, developed by the research team, based on previous experience and designed to guide workers and participants over the relatively short timescale of 13 months for two days a week at each site. We were conscious that practical initiatives had to be selected and the constraint of time to a large extent determined what was possible. Whilst giving some direction, pace and purpose to their work, the five stage process did not constrain the detailed aims, approach and methods used at each site; there were no pre-set agendas and no outputs or outcomes defined at the outset. Also, it is important to note that the process of involvement and the learning arising from it were considered to be as important as the final outputs.

Participants in the Five Local Projects

In the **Borders** project, *Shaping our Age* had weekly contact with approximately 35 participants in two WRVS Social Centres in Kelso and Jedburgh over 11 months. Almost all were in their late eighties and early nineties and were physically disabled or in the early stages of dementia. Most lived alone, had high support needs, limited mobility and memory issues. About a third of them were men and all would identify as Scottish and/or white British.

Kirklees: When based within the WRVS service, the worker engaged with a wide range of older people in guest speaker events and attending clubs and groups: older people, older volunteers, older men and women from the Asian Muslim and Sikh communities. These were ad hoc or one off interactions over six months, not

Figure A.3: Local Projects - A Five Stage Process

generally sustained over more than a few occasions. On leaving the service, she formed three small groups – two in sheltered housing complexes and a carers’ group. She met with these groups weekly: at one of the sheltered housing groups for two months; the other sheltered housing group for three months and the carers group for five months. She also ran a one-off focus group with a group of people with sight impairments:

- Small group of residents in Batley sheltered housing complex. Four regular members of the group were women aged between 74 and 91. One of the women used a wheelchair and was physically disabled owing to a stroke. From time to time other women and men joined in to socialise. All identified as white British.

- Small friendship group in Huddersfield sheltered housing complex. Made up of varying numbers week to week, but with a core group of two men and three women aged between 74 and 90 years; two of them with multiple impairments (visual, hearing, depression, restricted mobility, diabetes). All identified as white British.
- Former carers and bereaved carers group in Huddersfield. There were five regular members of the group; three men and two women aged between late 60s to 80s. One of the men was living with dementia and was cared for by his wife who also attended. All, apart from one, identified as white British; one identified as white Irish.
- Blind and visually impaired people. This was a one-off small group session that the Worker facilitated in addition to the three groups outlined above. This comprised eight people, six of them older people; three men and three women aged between 69 and 92.

The **Lancing** group consisted of five women and seven men ranging in age between 73 and 86: seven in their 80s and five in their 70s. Three of them had restricted mobility (using walking frames/mobility buggies) and four were people with diabetes. All but four of them were living alone; one cared for her husband who was also a member of the group. All identified as white British. The worker engaged with this group over 11 months.

For the **Sheffield hospital** consultations, the worker conducted interviews with 32 patients and 11 carers for two days a week over four months. All patients were in hospital owing to hip fractures caused by falls. All but six of the patients were women and most were in their 80s or 90s. Nine of the patients had varying degrees of dementia. Patients stayed on the ward for an average of 20 nights. The Worker also conducted three focus group consultations in the community with six bereaved carers of people with dementia; five current carers and three women and one man with dementia.

Sheffield Dementia Awareness Group: The core group of people who stayed with the process throughout was made up of six women, aged between 62 and 92; other members dropped out for reasons of ill health. The Involvement Worker was with this group for eight months under *Shaping our Age*, and at the time of writing was still involved in supporting their outreach work. One of the group cared for their spouse who was living with dementia and four of them were bereaved carers. The oldest member of the group had Alzheimer's disease. The Clinical Manager of Darnall Dementia Group, attended all *Shaping our Age* meetings and, on occasions, students of health care studies also attended. All but one identified as white British. One identified as African Caribbean.

Thanet: The participants who stayed with the process throughout, over a period of 11 months, included seven women, all of them already active in volunteering roles

for a range of local voluntary organisations. These included an intergenerational project, a heritage project, groups in support of people living with dementia, the Thanet Senior Citizens group (Chair and other members), The Children's Society; WRVS (dog walker) and Church based organisation (befriender). Ages of the participants ranged between 63 and 80. One of them was visually impaired and another had restricted mobility. All but one identified as white British. One identified as white American.

Ethical Considerations

Ethical approval was awarded to the project by the Research Ethics Committee of the Department of Health and Life Sciences at De Montfort University: in December 2010 for the national consultations and in January 2012 for the local project work. Ethical approval was also granted by Sheffield Teaching Hospitals NHS Foundation Trust for our evaluation work with patients. The Involvement Workers passed enhanced CRB checks.

Whilst networking with older people and local organisations, our Involvement Workers distributed information about the project. Potential participants were then able to give their informed consent to be involved based on this information. Participants were asked to sign consent forms for taking part; for audio recording and for anonymous quotations and materials to be used in reports and academic papers. This information assured participants that their comments would be treated in confidence and that they would not be identified in any reports of the findings. Written consent was also requested for photographs and film.

We were careful to ensure that no-one was excluded from taking part for reasons of equality. Involvement Workers were sensitive to the needs of individual participants and, where necessary, travel was provided for participants and appropriate, accessible venues were provided and paid for.

Limitations of the Research

Like all research projects, *Shaping our Age* had limitations. Thus its findings have to be read with a degree of caution and can't and don't claim to be definitive. We do, however, feel that they offer some important insights that should helpfully be followed up and developed. Potential limitations include the issues identified below.

Participatory Research

We started off with qualitative consultations with people selected through purposive sampling and then moved on to action research projects in five sites. We included a diverse range of older people in both stages of the project and, therefore, believe

our findings reflect the viewpoints and opinions of older people in general. However, as is typical with qualitative participatory research, we are not able to prove this, as the participants were not selected by random selection.

The Barriers to Involvement

Although we met some people who were disengaged from older people's groups and activities, we were not able to estimate the proportion of all older people that they represented. Neither was this an aim of the project. Our findings do suggest, however, that services that adopt involvement-led approaches might lead to more people being encouraged to use them. This is because the people we met repeatedly reported that they were put off by traditional services that adopt a 'doing to' approach.

The advantages and disadvantages of being located within an organisation

Being located within an organisation had both advantages and disadvantages. On the plus side, it provided a base, contact with staff and volunteers and, in three projects, easy access to service users. We also gained valuable insight into working practices and the impact of changes within an organisation. Perhaps most important, it meant that there was a real possibility of the work of a time-limited project being taken forward in the ongoing work of the organisation. This was a commitment made from the inception of the project.

However, working within an organisation on a separate project that was exploratory and which to some degree challenged current working practices was not always easy for either side. This led to some tensions and misunderstandings and in two projects we had to move outside of the organisation to fulfil our brief. Our workers were made aware from the outset that difficulties might arise, were encouraged to be sensitive and to be prepared to adapt to changing circumstances. We had hoped that our selection process for the services and the Working Agreements would avoid any issues with the host organisation. However, the project was never easy to explain owing to its unpredictability. In the end, however, we brought five projects to successful conclusions and the collaboration was successfully fulfilled.

Reaching isolated people

At the outset of the project, we had hoped to involve some people who were isolated. However, in spite of efforts through networking with local organisations, we realised that this would involve more time than was available to us. However, we did gain some learning from members of the Older People's Reference Group and local professionals undertaking outreach with isolated people. This is a pointer to us of the importance of developing such work with very isolated older people.

Geographic spread of the project

The five projects were widely dispersed and so too were the members of the Older

People's Reference Group. Whilst this offered diversity, it also created practical difficulties caused by distance and separation, including supporting 15 older people to travel sometimes long distances for meetings and the need for the remote supervision of Involvement Workers.

Five Small Local Projects

Our detailed findings on involvement-led practice arose mainly from five local research projects. We worked with groups of older people in those projects for varying periods of time depending on local circumstances; from two to 11 months. This project was small scale and time limited and because of this, as has been said, caution needs to be taken in drawing hard and fast conclusions. Nevertheless, it is reassuring that similar findings arose from each of the separate projects – located both within and outside WRVS - and that similar practices were seen to work towards well-being.

Inevitably, because there were five participant-led projects, not all possible issues could be explored. For example, there were no intergenerational projects and none of the projects focused specifically on any of the equality strands, omissions we would like to see rectified in future work.

Training

The Involvement Workers were expected to combine research with a community development approach when working with older people. In retrospect, we believe that formal training in qualitative research and community development would have been beneficial as part of the induction to the project since the two do require different as well as complementary skills.

Time and Resources

This project was complex and demanding for the researchers. There were several groups of interested parties that needed to be managed through the process, not the least of them being the Involvement Workers and participants in the local projects and the Older People's Reference Group. There was a requirement for the researchers to undertake a wide range of duties all of which required considerable time: a lot of it on administration. We strongly suggest that any project of this type in the future should ideally have at least two full time researchers and an administrator as part of a team and in a shared base. This would help to improve communication and allow researchers more time for thinking, review and analysis.

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Involving older people in improving their well-being

Shaping our Age

