

Older people shaping policy and practice

This publication can be provided in alternative formats, such as large print, Braille, audiotape and on disk. Please contact: Communications Department, Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP. Tel: 01904 615905. Email: info@jrf.org.uk

Older people shaping policy and practice

Older People's Steering Group



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

Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
Website: www.jrf.org.uk

© Joseph Rowntree Foundation 2004

First published 2004 by the Joseph Rowntree Foundation

All rights reserved. Reproduction of this report by photocopying or electronic means for non-commercial purposes is permitted. Otherwise, no part of this report may be reproduced, adapted, stored in a retrieval system or transmitted by any means, electronic, mechanical, photocopying, or otherwise without the prior written permission of the Joseph Rowntree Foundation.

ISBN 1 85935 244 8 (paperback)
1 85935 245 6 (pdf: available at www.jrf.org.uk)

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

Designed by Adkins Design (www.adkinsdesign.com)

This report is also available as a free pdf at www.jrf.org.uk. Further printed copies of this report, or any other JRF publication, can be obtained either from the JRF website (www.jrf.org.uk/bookshop) or from our distributor, York Publishing Services Ltd, 64 Hallfield Road, York YO31 7ZQ (tel: 01904 430033).

Contents

Foreword	7
Acknowledgements	9
Executive summary	11
Part I: Shaping the programme	18
1 Introduction	21
2 Developing the Older People's Research Programme: Origins, innovations, learning, challenges	23
Part II: Programme themes	27
3 Older people's own stories	29
4 Services supporting people	36
5 Community, family and citizenship	43
6 Involvement: Beyond tokenism	46
Part III: Programme messages	51
7 Key messages	53
Appendix: Key findings from the Older People's Research Programme	55
Bibliography	85

Foreword ■

When discussing the final draft of this report on the Steering Group, the older people present felt that we should contribute to the acknowledgements and the foreword. Firstly, we want to express our appreciation of the part played by officers and advisors to the programme. We hope that the programme is a significant addition to the research into being old and growing older. In particular, we thank Alex, our facilitator and summariser, for his care (in using his own words) in 'making sure I've got it right' when assessing what was being said.

With another nine research or development projects which follow on from the findings to date, the story is not yet complete. Yet at this stage we can say that doors have been opened wider, showing issues that have to be tackled.

The opening section of the report refers to the unequal partnership that generally exists between older people and professionals in shaping agendas. Within our Steering Group we have certainly been equal. We are pleased that our voices have been heard and that this has been reflected throughout the process – from setting the questions to shaping the outcome. Older people see this as so important.

The summary suggests a positive future arising from various initiatives concerned with improving the position of older people in modern society, emphasising their roles as contributors as well as receivers. The suggestion is made that a 'sea change' may be taking place. We think it is. But we also believe that more momentum and achievement is required if this change is to become the flow of the tide.

The older people in the group are glad to have had the chance to take part in this historical development through the Joseph Rowntree Foundation programme. It has been hard going at times, but the meetings have always been conducted in an atmosphere of mutual regard and respect. It has also been fun.

Stan Davison (Chair, Older People's Steering Group)

Vera Bolter

Imogene Martin

Nell McFadden

Pat McWeeny

Gloria Williams

Acknowledgements

This report is a programme overview of 17 funded projects within the Joseph Rowntree Foundation's Older People's Research Programme (2000–2004). The report is the product of discussions between officers and members of the Older People's Steering Group over the period from April 2003 to March 2004. The officers (Alex O'Neil and Melanie Henwood) initially discussed the findings coming out of the projects and these discussions helped frame a presentation to the Older People's Steering Group over a two-day period (12 and 13 May 2003) in York during which ideas for the report were hammered out. The 17 completed reports were each then sent out to one older person member and one officer for comments. These comments were incorporated into a draft final report, which was discussed at Steering Group meetings in July and September and at the Joseph Rowntree Foundation Social Care and Disability Committee. Following these discussions a fourth draft of the report was prepared and the summary findings rehearsed with the Older People's Steering Group in March 2004. In June 2004 the final document was circulated to some external readers and to members and officers of the Older People's Steering Group for comments. The final report represents the end of this process.

Members of the Older People's Steering Group said that, during its life of more than four years, the Group has held the whole programme together and, as such, represents both an eighteenth project and the most sustained discussion of the programme. This is reflected in the final report.

A further nine projects on the subject of 'bringing about change' are not due to report until 2005. This makes a total of 27 projects within the programme.

The members and officers/observers of the Steering Group have been:

Members

Stan Davison (Barnet Senior Citizens Forum and Steering Group Chair since September 2001)

Pat McWeeny (York Older People's Forum)

Nell McFadden (Inverclyde Older People's Forum)

Imogene Martin (Pepperpot Club, Kensington and Chelsea)

Gloria Williams (Pepperpot Club, Kensington and Chelsea)

Vera Bolter (Action for Health, Senior Citizens in Newcastle, from 2001)

plus:

Tony Carter (Greater London Forum, until 2003)

Tony Martin (York Older People's Forum, until 2002)

Jim Hammond (until 2002, died July 2002)

Brian Hodgson (Swindon, until 2002 and associate member since then)

Vera Ivers (Older Women's Network, until 2001)

Olive Morgan (Wiltshire and Swindon User Network, until 2001)

Betty Porter (Strathclyde Elderly Forum, until 2000)

Officers

Melanie Henwood (consultant/analyst, programme R&D adviser)

Martin Shreeve (member of JRF's Social Care and Disability Committee, since 2002)

Alex O'Neil (JRF research manager)

Helena Herklotts (Age Concern England, since 2002)

Elizabeth Sclater (Lewisham Borough Council, since 2002)

Tom Owen (Help the Aged, since 2003)

plus:

Tessa Harding (Help the Aged, programme adviser, to 2002)

Jim Kennedy (member of JRF's Social Care and Disability Committee, to 2003)

Paul Bedwell (Department of Health, to 2001)

Peter Fletcher (Peter Fletcher Associates, to 2000)

Louise Keeble (JRF administration support, to 2001)

With a total of 27 projects, as well as a great deal of formal and informal support, it is impossible to thank all those who contributed to the development of the programme. Thanks are due to Steering Group members and officers, the Joseph Rowntree Foundation, the Social Care and Disability Committee members and officers. Particular thanks are due to Robert Maxwell, JRF trustee and chair of the Social Care and Disability Committee, who gave support to the idea of a programme about older people being developed primarily by older people. Fundamentally, thanks are due to the older people and the researchers on the projects without whose efforts none of this would have been possible.

The facts and views expressed in this report have come through the above process and are not necessarily those of the Foundation.

Executive summary

The Joseph Rowntree Foundation's Older People's Research Programme was developed with and by older people themselves (in the Older People's Steering Group) working with officers, researchers and policy advisers. All too often there has been an unequal partnership between older people and professionals in shaping agendas. Rather than focusing on the views of professional researchers and planners about what needs to be done, the programme began with (and has persisted with) the priorities defined by older people. This has produced 18 completed projects (searching out issues) and a further nine ongoing projects (looking to bring about changes from the programme's findings). This report summarises the key themes from the 18 search projects.

There are two key strands within the projects and these are highlighted in the report. The first strand is the rich picture that comes through the 18 projects about older people's lives. The second is the story of the way the programme itself developed, and the central involvement of older people in shaping the programme.

From lives to strategies

At the early stage of the development of the programme it was sometimes assumed that the measure of the programme's success would be its expert commentary about very specific developments in current modernising strategies about older people.

In practice, however, the programme has always come back to a different starting place. There are ambitions that policy developments should start from a sound foundation, and real concerns that current mind-sets remain problematic at times despite the modernising language.

Start with older people's lives ...

The projects are rich with the voices of older people and this gives the impression of a companionable walk alongside people's lives.

Older people are a highly diverse population: there are different ages of growing older, different minority groups, different lifestyles and beliefs, and different attitudes and approaches to old age. Diversity must acknowledge the needs of black and minority ethnic older people, but it must not stop there. Often there are powerful examples of good practice among older people from within black and minority ethnic communities that others would do well to model. Equally, one must not see age or ethnicity as a problem to be solved.

Older people also share many common experiences. They are fully aware of the limitations of growing older but they also acknowledge that there are gains. There is a good deal of

frustration both about the services provided for them, and about the fact that society constantly frames their lives in terms of loss and 'risk management'. There are strengths and humour in old age which need to be acknowledged. Older people have a lifetime of experience to draw upon. They often have internal resources which need to be recognised rather than ignored by ageist assumptions. Growing older is a time of gain as well as loss, and there are sometimes rapid changes being negotiated.

In this context health is a much broader area than the need to treat illness. In age, being healthy is about being able to enjoy yourself, keep mentally active, do things which interest you, meet friends. The real supports (or services) that are valued are those that help negotiate ordinary things in life: relationships, learning, transport, housing, contact, being comfortable and secure.

To achieve all this, money is important and there is evidence both of pensioner poverty and of a lack of funding of services that older people value. This shortage of resources comes through clearly in the project work. However, the resources that older people need are much broader than money. Community, friendship and support – and the internal resources of the older person themselves – are crucially important in building a life worth living. There are important messages here for policy and practice relating to older people.

Older people also experience particular barriers. While ageism as a term is not commonly used by older people in the reports, there is strong evidence of its existence in a number of spheres. There are examples of the frustration caused by poor access to employment, both as a way of earning money and as a means of gaining meaningful activity. Poverty and the denial of opportunities in earlier life (particularly for the pre-1950s generation of women who were frequently denied education and careers) are also evident. Partly this is because the affluence and expectations that present-day working people gain through employment has not had the same impact on (and is not being enjoyed by) significant populations of older people.

Another obvious barrier is the way that older people are viewed by society. Current societal images of older people often show them as vulnerable (and needing care), aspirationally active (a Hollywood stereotype of the body beautiful), or comically grumpy. Many policy or practice assumptions still see older people as a burden, a problem to be solved, a group denied the ordinary things in life because of the processes of ageing.

The 'deficit model' of old age is still strong. In this model old age is seen an illness for which there is no cure, with the 'patient' losing rights because of the need to accept health or social care interventions to treat their ailments or to minimise risks caused by their illness. The modern challenge to the 'deficit model' is the 'heroic model'. In this model, older people only age successfully if they retain a capacity to compete with younger people in physically challenging activities. For the older people in our projects, of course, neither of these models works. They cast older people either in passive, submissive roles or they present aspirational messages (similar to teen or beauty magazines!) which do not reflect the ordinary negotiations in people's lives.

The reality of old age is a constant (and at times quite rapid and radical) negotiation between losses and gains. At present, few service models seem to have fully taken on board the nature of these negotiations.

The central point emerging from all the projects is that current policies, societal images of older people, services and strategies all struggle to break out of a pathologising or strongly deficit view of old age. Even where new developments are beginning to move towards a more holistic view of older people's lives, there is still a long tradition of seeing older people as 'vulnerable' and needing protection, as problematic and burdensome. Yet the projects also show that older people are not asking for much. They themselves are often the key actors who can make a difference to their own lives and to the lives of other older people. In order to do this they may only need more appropriate – not more – support than is on offer at present.

...then look at services

There are many reasons why most older people do not come within the umbrella of health services and, particularly, social care services. These include poor access to low-level support, the high eligibility criteria, a degree of stigma about accepting support, and the inflexibility or inappropriateness of practice in many respects.

On the negative side, there were strong messages in the projects about both a lack of resources and the reality of so-called 'person-centred services'. As previously mentioned, attitudes on the ground could be problematic, whatever the merits of the policy. There were real concerns that 'cost-effectiveness' concerns were more to do with 'cost savings'. And there were groups who were particularly on the margins in terms of receiving a service, or in terms of that service being appropriate.

There were, however, some positive messages, including a recognition of the need to start from older people's own ideas of what constituted a life worth living and some good examples of both workers and particular providers demonstrating flexibility and common-sense adaptability.

Essentially, it is important to recognise that even if conventional health or social care services were totally approachable, that sort of service support would only ever form a small part of what it takes for most people to live well in later life. While it is important that these services reflect what people want, it is also important that social services are not seen as the only actors who have a part to play. In fairness, it must be pointed out that it is often social services who are imaginative and in the vanguard of delivering this message to chief executives and other parts of local service delivery.

What comes through strongly in both the projects and discussions is the need to reframe service responses within several parameters. First, communities, community organisations and family, friends and community networks (often made up of older people themselves) are the major players in supporting older people. Second, there is a need for the quality of

service responses to be defined and driven more by older people. Third, services need to be more holistic and stop framing needs and services within tired and outdated models of delivery; they need to be responsive and adaptable to people's needs.

At present, despite a modernising façade, little seems to have changed in service delivery over the past few decades. Yet the consistent message coming through all the projects has been that approachable local services could make a substantial difference to people's lives.

Citizenship, community and family matter most

For many older people, 'community' still actually translates into 'isolation'. They live alone with no support or contact. While they may live in a residential or nursing home, their living room becomes a waiting room with different health or social care professionals briskly doing things to them and then moving on to the next appointment. This can be as isolating and disempowering as the stereotype of residential or nursing care. It is important to recognise this fact.

It is also important to recognise that older people are citizens who can play an active role as citizens. Not only are they often the hidden actors who provide support to other older people and invaluable child care within their families, but they may also have citizenship and community roles beyond these arenas.

There is a real need to address the negative images of old age and to recognise and value the contributions that older people have contributed, can contribute and will continue to contribute to community life. A great deal of knowledge and experience from older people is not valued or recognised.

In each of the projects there is a truth (or mythology) about supportive communities in previous generations. Even where these comments are made, one can actually observe informal networks of support. However, these networks are often hidden and tenuous. There are concerns expressed that 'younger older' people could do more in terms of volunteering to strengthen the hands of local communities.

Involving older people: The underpinning essential to good practice

This leads to the most crucial message to emerge from the programme as a whole from the projects, from the discussions at consultations and from within the Steering Group: now might be a crucial and exciting time for change. But the changes will only have impact if older people are meaningfully involved in designing and implementing the changes, and in defining the desired 'quality of life' outcomes.

Older people in our projects saw involvement being important both at a personal and a group level. They did not see involvement as being just about token representation on social services committees. Sadly, despite the rhetoric of involvement, in most cases the level of involvement of older people (personally in their own lives and collectively in local and in national initiatives) remains low, probably even lower than for disabled people.

It is possible that the initiatives of Better Government for Older People (BGOP), the Health and Older People's reference group (HOPE) to the National Services Framework for Older People, and the Older People's Advisory Groups (OPAGs) all represent a change in policies about older people. There are indeed signs, individually and collectively, that older people now have a stronger voice in framing initiatives about their lives. In this spirit the Foundation's Older People's Research Programme has been framed with and by older people.

Given the above initiatives, and the fact that older people have sustained a clear focus throughout four years of the programme, it does raise a question about why convincing levels of involvement of older people in programme development is not more usual.

It has been encouraging to note developments in other local and national strategies and the shift away from welfare and care agendas towards a more holistic, inclusive and 'rights-based' framing of older people as citizens. There is real recognition, often strongly promoted by directors of social services themselves, that policy and practice about older people needs to break out of health and social care. It has also been encouraging to see attempts to draw together different research disciplines to reflect the diversity of older people's lives.

On the other hand, it has also been very disappointing to note that despite current talk of holistic and rights-based approaches, many national and local stakeholders still see older people as the passive recipients of their services or of older people's or 'ageing' strategies.

Within the 18 projects in this programme, there are examples of how the involvement of older people has been developed (following Better Government for Older People). Sadly, the experience from the projects indicates that such initiatives have a precarious existence. In the four years of the programme it has also been a common experience to attend regional or national events where professional stakeholders have met to discuss 'joined-up' strategy about older people without there being a single older person on the platform or, often, in the audience. Older people have told us that this is quite a common experience. Discussions within the programme have highlighted that there is a glass ceiling at the level of consultation. Below that are the more common experiences of information giving or even (as they see it) manipulative strategies on involvement.

Meaningful involvement requires standards on:

- the numbers of older people involved;
- the stage of development when they are included;
- their ability to influence the outcomes;
- the resources to support them in becoming involved;
- their involvement throughout the whole process.

It is dispiriting that there are so few good examples of the meaningful involvement of older people either locally or nationally. Our experience shows that organisations developing older people's strategies or funding research and development programmes relating to older

people and the subject of ageing display doubtful standards when it comes to involving older people in defining questions, undertaking work and examining outcomes. Yet our findings have been that unless you involve older people in all these, it is unlikely that the policy or practice responses will robustly reflect what older people actually want.

If one message had to go out from this programme it is that unless programmes or strategies about older people have the fullest possible involvement of older people in their development, they are very unlikely to stand the test of time.

Involvement in practice: The programme development

The second theme from the programme has been about the process itself of involving older people in defining the programme. This is not intended, nor could it be presented, as a triumphalist example of good practice. There are many things within the programme that did not work, despite the best of intentions. There are things that could have been better negotiated. And there are instances of straightforward learning that had to be gone through on all sides in order to develop better practices. As a result, it is likely that this programme will be seen as a staging post towards a better involvement of older people in formulating strategies about their lives. Nevertheless, there is learning here which it is important to share.

Older people setting the agenda

Older people were involved right from the start in defining the programme. Preparatory work was undertaken with older people in consultation before any wider discussion involving other stakeholders. The older people themselves were pleased to note that they were invited in at this early stage. Throughout the wider discussion the focus remained on the agenda set by older people, and older people were present in sufficient numbers to ensure that their views were given priority.

Older people as commissioners of research and strategies

In the specific area of research about older people, this programme gives probably the most explicit example to date of older people as commissioners of research.

Questions about the involvement of older people in research are not new. There have been examples of older people as interviewers, in focus groups and as local researchers. It is important to build on such examples and also to look further afield and to see that the potential for involvement is wide.

The Steering Group has given a sustained example of older people as commissioners of research. Older people have been in the majority in the group but have worked in partnership with the Foundation's officers, external research and policy advisers to the programme and within the decision-making structures of the Foundation. This has often been a difficult but also humorous, affectionate and enjoyable road – for officers and older people alike.

Importantly, the programme showed that this approach is not only possible but that it produces richly valuable material. The ongoing testing of boundaries has made the process uncomfortable at times but has also fostered a spirit of openness and respect, allowing honest disagreements to be aired and, more often than not, amicably resolved. It has not been a perfect process, but there has been valuable learning on all sides.

The programme itself has demonstrated wider examples of involvement. In addition to older people acting as commissioners of research, they have contributed as researchers, co-researchers, interviewers, reference group members (to inform project development), peer reviewers (to comment on and scrutinise findings and conclusions), users of research findings and members of project advisory groups.

There are examples here to build upon, though it is also important to remember the need to support national and local capacity and development. There are also examples relating to standards and expectations of involvement which need to be developed more broadly. Of the nine projects still to be completed, three focus on learning, ideas and standards of involvement. These projects will report during 2005.

The structure of the report

The structure of the report reflects, and expands upon, the outline above.

- Part I gives a more in-depth presentation of the origins of the programme and the issues that emerged from a programme defined by older people.
- Part II presents the key themes about older people's lives that emerged from the projects and programme.
- Part III details the programme's key messages for different audiences.
- The Appendix describes each of the 18 completed projects in the programme.

Within the report, the phrase 'the programme' refers to the whole process and not simply the funded projects. The projects, the discussions within the Steering Group and events which were fed back to the Steering Group discussions all form part of the programme.

Some quotations have been anonymised or left in confidence. These might have been comments from individuals within events or from project teams.

The phrase 'that bit of help' is used throughout this report. It was originally quoted in the report *'That bit of help': The high value of low-level preventative services for older people* by Heather Clark, Sue Dyer and Jo Horwood (Clark et al. 1998). It is an expression also used by older people in general and the Older People's Steering Group in particular – partly to get away from the professional term 'low-level services'.

Part I

Shaping the programme

1 Introduction ■

There is a clear need for support which older people define ('what we want') rather than support which is service-led ('what they think we need and can have').

There was agreement among the group that any programme should reflect the breadth of issues which older people face and the joined-up nature of real and very different lives.

This consultation with older people is taking place before you've set the goal posts! This is so important. Usually we get invited in when politicians and professionals have made all the key decisions.

(From the original JRF consultation with older people)

The Joseph Rowntree Foundation's Older People's Research Programme has been developed with (and primarily by) older people, and is about older people's own lived experiences. It has dealt with the stage in people's lives when they need 'that bit of help'. It has not been possible to deal with all the issues and all the stages of being older. A number – an age – is not always helpful here. This is partly because people can reach the stage of needing some help at different ages, but mainly because the issues often start years before a service is given (or refused). Inevitably, since the issues develop long before people actually need the help, and since most older people do not come within the remit of 'services', the programme's primary focus has been on lives rather than services.

The programme has been defined by a Steering Group, which has met four times a year between 1999 and 2004. The Steering Group is made up of ten older people, working with officers and advisers. Jointly, the group have decided on the programme direction and reviewed it, responding to issues arising from the work that is being funded and from developments elsewhere. Thus, the initial review pieces about the involvement of older people made it clear that involvement isn't simply another topic on people's agendas. Rather, it is the fundamental, underlying issue, whether relating to the involvement of groups of older people or the involvement of the individual person. The group has also taken into account issues such as Care Direct and the National Services Framework for Older People.

The main perspective of the programme has been to look at what is needed and what is happening from the point of view of older people themselves.

The key areas the group has identified for action are:

- involving older people, both at organisational and at individual levels;

- addressing unmet needs;
- providing information, advice and advocacy;
- older people's definitions of quality; and
- the circumstances of older people from black and minority ethnic communities.

It also is looking at:

- older people and independence; and
- older people and money.

In terms of the National Services Framework it has looked at:

- older people's own views on intermediate care;
- person-centred services; and
- comfortable (rather than active) healthy ageing.

The aim of the programme has been to identify first the key issues and then the targets for change. This report is, therefore, written at a stage when the 'searching out' projects are completing and the 'bringing about change' projects have just started. The Steering Group and the Foundation have agreed that we do not want to produce knowledge simply for its own sake. Nor do we wish to publish reports that will gather dust on shelves. The test of the next phase will be the extent to which we can bring about changes.

2 Developing the Older People's Research Programme

Origins, innovations, learning, challenges

Origins

The Social Care and Disability Committee of the Joseph Rowntree Foundation considered the idea of an older people's programme in a review meeting at the end of 1998. The committee had a long track record of working with disabled people, service users and black groups. Work in these programmes contributed to ideas of user involvement, independent living, race equality, the social model of disability, supported living for people with learning difficulties, and the transitions of disabled children and young people into adulthood. However, apart from occasional projects, the committee had not undertaken a similar degree of work with or about older people. This was felt to be a significant gap and it was decided to apply approaches to do with involvement, which had permeated the other programmes in the committee, to older people.

Nationally there has been, and still is, a great deal of work going on in the areas of ageing and the provision of services for older people. The guidance from the committee was that this new programme should focus on and, crucially, be driven by the views of older people themselves. Several significant projects predated the programme:

- Margaret Coombs' report on the Oxfordshire Community Care Rights project (Coombs with Sedgwick 1998).
- Heather Clark's project on 'that bit of help' (Clark et al. 1998).
- Patricia Thornton's work on involving older people (Thornton et al. 1995; Tozer and Thornton 1995).
- Jacki Pritchard's reports on older women and abuse, and older men and abuse (Pritchard 2000, 2002).
- Norma Raynes' project on what older people wanted from the Home Care service (Raynes et al. 2001)
- Kam Yu's report on the care needs of Chinese older people (Kam Yu 2000).
- Kate Allan's research about listening to the views of people with dementia (Allan 2001).

Many of these existing reports were subsequently discussed within the Older People's Steering Group meetings. Older people from the Steering Group sometimes attended the launches of the above projects' final reports.

However, our story gets ahead of itself. Even before the Steering Group was formed, many of these reports informed the thinking about what our programme might look like. At first we thought that the focus of the programme might be on preventive or support services (such as intermediate care) which delayed the onset of ill-health or supported people to continue to live in their own homes. However, it became clear that, valuable as these supports can be, older people wanted to start with their lives, not with services.

Developing the programme

Programmes at the Joseph Rowntree Foundation are usually developed with the help of a programme adviser. This adviser is an expert in a particular area who helps the Foundation with matters relating to his or her field of expertise. However, the Social Care and Disability Committee was increasingly looking beyond this approach with the aim of placing a greater emphasis on getting agendas set by people with lived experience in a particular area. This is a similar approach to that adopted by Tessa Harding of Help the Aged and we decided to work with her to involve older people in helping to define the scope of the programme.

A consultation event involving 25 people (eight older people, eight with a policy and practice background and nine from research or consultancy) reviewed the field. Crucially, however, the eight older people had met JRF and Help the Aged officers the evening before to 'brainstorm' ideas about what older people would want from the programme. This was critical. As one older person on the day said with delight: "You invited us in before you set the goal posts!"

A number of themes emerged from this consultation, which overturned some of the initial expectations. Already the Steering Group were saying that prevention and independence were important issues, but a need to go back a step and begin with the lives, hopes and frustrations of older people themselves also became apparent. A number of core themes emerged:

- Involvement is an important issue. There needs to be more work on lessons to be learned.
- Services should start with older people's own definitions of quality.
- There is a great deal of unmet need out there, which is not being either monitored or measured.
- The needs of black and minority ethnic older people are not being met within mainstream services.
- Information, advice and advocacy are very important if we want to empower older people.

In addition to these five core themes, several key issues arose:

- Does money matter? For some, the important thing was to ensure a decent state pension while for others a good pension by itself would not solve particular problems such as the shortage of services and the problem of paying for long-term care.
- The question of independence. The language of independent living (which came from debates around disabilities) did not always sit easily for some older people. Was 'independence' the right word? Was an older person the same as young(er) disabled adult?

Although the programme adapted to, and was steered towards addressing, different circumstances including the National Services Framework for Older People, at heart it remained focused on the original core themes. The role of the Older People's Steering Group in maintaining this focus has been central.

The Older People's Steering Group

The adviser function for this programme was a new departure for JRF projects. Tessa Harding became the policy adviser while Melanie Henwood was the R&D adviser. In addition, rather than having a conventional adviser, the adviser role was focused within a new structure: the Older People's Steering Group. It was important that older people were in the majority in this group, in terms both of roles and of numbers. It was equally important that there should also be others present – researchers, analysts, people experienced in service provision – in a minority and advisory role.

The Steering Group was established with ten older people (based on the older people who had attended the initial consultation) and seven officers and observers. While, initially, the group was chaired by a JRF officer, it was agreed that it would be better if older people elected someone from their number to be chair. This was primarily so that the lines of accountability within the Steering Group were on a par with the lines of accountability within what became known as the parent Social Care and Disability Committee.

The Steering Group has met (on average) four times a year, and the minutes of the meetings reflect the debates that have ebbed and flowed among members (the ten older people) and between members and officers (the seven others). Each group has learned both from each other and throughout the life of the programme and these learnings include the following examples:

- The question of involvement started its life within the group as a topic to be addressed but it became an underlying principle for all the work.
- The idea of unmet need began as something to be measured but has now become something to be tackled.
- 'Independence' has been replaced by such concepts as 'interdependence', 'comfort' and 'a life worth living'.
- People who thought pensions were the priority are now worried about services. People who felt services were most important are now concerned about money.
- In the early days we talked about working for quick returns from our work but now there is recognition of the need to work towards more long-term results.

Relations with the Social Care and Disability Committee

The Steering Group was a new departure for the Foundation and, to some extent, we have all been learning as we go. It became obvious quite quickly that there was a tension between the roles of the Steering Group and the Committee. This was less to do with individuals and more to do with established roles within the JRF decision-making processes. JRF committees primarily scrutinise proposals, making recommendations to the trustees about priorities for

the Foundation's support. With hindsight, the creation of the Steering Group confused the process of taking the Older People's Research Programme forward. The position which has emerged since 2001 has been:

- Trustees define the overall priority for the Foundation, allocate resources and, ultimately, decide which proposals to support.
- The Older People's Steering Group define the programme and a subgroup comment on proposals received.
- The Social Care and Disability Committee scrutinise proposals, make recommendations to trustees about which proposals should be supported (this advice is normally followed) and comment on the shape of the programme (for information, to the Steering Group).

At one level, this summary may be of most value to people interested in the history of bureaucracies. However, it is also important from the point of view of involvement and decision-making: it shows the value of being very clear about what has been devolved to whom and what the meaning of 'involvement' is at each stage.

Programme, proposals, projects ... and progress

It was clear from the start of the programme that no one wanted more research for its own sake and, therefore, it was assumed that the programme would be action-orientated. In wishing to make tangible progress, we were probably too reluctant to admit that change takes time, that a discussion about the meaning of words was important and that at times projects would take unconventional paths, leaving Steering Group members (and JRF officers) feeling that nothing was happening.

In the early stages we funded a few think pieces, but it took time to develop concrete ideas of what the programme should do. The development of suitable proposals took time. At one stage, for all our ambitions, there seemed only to be a handful of projects in progress. Later, projects seemed to be happening all over the place, there were 27 projects on the go (including the Steering Group) and it was impossible to remember all of the detail of the programme.

Early in 2003 it seemed to Steering Group members that a lot of ideas had been discussed but there were no results coming back. And then, by May 2003, 17 projects started to report their findings and the JRF officers had prepared a draft review of the messages coming out from the programme. Suddenly there was a host of themes emerging and the pressing question was what to do with this knowledge.

At the time of writing JRF staff and the Steering Group are working on plans for 2004–5 to see how the work can be taken to older people's groups, policy makers and practitioners. The programme emphasis has shifted from 'finding out' to 'bringing about change'.

Part II

Programme themes

3 Older people's own stories

Many of the projects are rich with the voices of older people. The feeling is of a companionable walk alongside people's lives listening to them talk about how they have made sense of 'comfortable healthy ageing', how they view the importance of money, how they cope with the technicalities of intermediate care, how they interpret 'independence', and hearing their stories about the lives of black older people.

At one level there was frustration because one could not initially apply what we heard to current policies. And then we realised that this experiential knowledge is actually the bedrock of our work: the values that need to be understood fully before you start thinking about building services and policies on top of them. These aspects of the story are presented not with any immediate idea of how things might change (though there are things that could be done), but simply to tell the shared and different stories that come through the projects.

The ages of growing older

You cannot tell at 40 what life is going to be like at 60. And you can't tell at 60 what life is going to be like at 80.

(Older People's Steering Group member)

I had to retire at 60 and then the shop over the road asked if I'd go and work part-time and I said, "Yes, I'd love to." So I worked until I was nearly 65.

(Older woman, Godfrey et al. 2004)

It is very clear that old age isn't a single thing. The issues change as you get older. The struggle for purpose at retirement is very different from the need to maintain your quality of life as things become more difficult, for example, after an illness that changes horizons and boundaries. Old age brings great freedoms along with great limitations and one sub-theme that comes through in a number of reports is the blossoming of older women's lives in contrast to the narrowing of horizons of older men's lives. We might smile at the gender stereotypes, but both gains and losses raise important issues.

In developing a couple-centred lifestyle, a variety of solutions were arrived at within relationships, some negotiated, some reflecting a shifting balance of power. [Researchers' note in the margins: how do women come into their own at this time and men lose it?]

(Godfrey et al. 2004)

It is important to recognise that for many older people life in retirement is not simply about an individual's choices but is a constant negotiation between a couple. For many older women this has been a period of flowering and liberation that was previously denied to them because of a lack of formal education or a consistent career, and that is now possible because their family responsibilities have finally been thrown off. For many older men

retirement is both positive, in representing the end to exertion and struggle, and often negative too, in bringing a loss of purpose, status and role.

Problems with the 'deficit' and 'heroic' models of old age

The traditional model of old age is the 'deficit' or loss model. Broadly speaking this states that because there is no cure for old age it is acceptable to have low expectations of quality and choice. The counterbalance is the 'heroic model' which postulates the view that you only age well if you can still do all the things you did in your 30s and 40s. In reality, however, in many of the reports people were talking about how they negotiated their own balance of gains and losses.

In the medical models, with their emphasis on physiology and cure ... much research concentrates on losses and defines healthy ageing as avoiding or escaping them.

(Reed et al. 2003)

The positive 'heroic model' promotes the idea of old age as a positive experience. However this positive model focuses only on those older people who are able to retain full capacity and engage in rock-climbing and wind-surfing. (Incidentally, this model represents a commercial opportunity for companies wanting to make a profit out of anti-ageing drugs, cosmetic surgery and holidays.)

(Reed et al. 2003)

Neither model leaves any space for older people who experience the onset of limitations but nevertheless do not see these as defining their lives.

(Older People's Steering Group)

Older people in the consultation said that experiencing physical problems did not necessarily mean that the individual was unhealthy.

(Reed et al. 2003)

The best of times? The worst of times? Different times

Now you can't just believe it ... that you are your own boss ... that you can do what you want ... make your meals at your own time!

(Older woman, Godfrey et al. 2004)

We've got over the rough, unpleasant stuff ... You can't until you're old you see ... now it's the time to enjoy yourself.

(Older woman, Godfrey et al. 2004)

I don't trust myself going out any more ... the one or two friends I had picked up with just write now, they don't come to see me.

(Older person, Godfrey et al. 2004)

There were different views – even among older people – about whether old age represented the best or the worst of times. There was evidence that some older people (and not only professionals) were financially better off than when they were younger. In poor communities, older people said that they were better off than younger people who were unemployed or on low pay. We suspect, and this probably shouldn't surprise us, that there is the same divide of optimism and pessimism among older people as there is among people of other ages. Nevertheless, it seems true that in general the external environment – including societal images of older people, the barriers that exist, the limitations of access to money and services – still means that life gets worse rather than better for older people.

Integrated in (and disengaged from) the mainstream

There is a great deal to the idea that older people live in the same world as everyone else. But it is also true that the experiences of isolation (personal, familial, role and purpose) can be quite profound.

(Steering Group discussion)

Older people do not live in isolated ghettos. In the main, they live in the same streets as everyone else. Being an older person is only part of someone's identity. So it's not surprising that many of the issues and experiences raised have meaning beyond older people's lives. We had realised, for example, that many of the frustrations faced by black older people were very similar to those faced by older people in general. Similarly, many of the issues about moving through old age were equally true for younger people whose lives were in transition. And there is also a sense from older people that they should be integrated into the mainstream.

However, there is also disengagement. Older people certainly do live in the same streets, but they are often isolated. It's all very well to say that a Community Resource Centre should be for everyone rather than just older people but, if that were to become true, older people's views are unlikely to be the ones heard.

Strategies, strengths and humour

I have what I call my 'no' days, when you are not up to doing anything without planning. I try to plan each day so that I have no more than one thing to do and then I pace myself.

(Older person, Godfrey et al. 2004)

The picture that is often painted of older people is of being sad, frail, vulnerable and needy with few resources to draw on; a burden. In fact, the projects show the impressive range of strategies that older people develop in order to help them hold on to their idea of a good quality of life. Whether the project deals with information, advice and advocacy or direct payments, it becomes very clear that older people had a life before they became 'older' and that they retain skills, knowledge and experience that they can draw on. One older person is drawing on her past experience as a shop steward to manage a network of five personal assistants on direct payments. Another has become an expert information manager in order to deal with the complexities of health systems. In all of this, the humour comes through in

the focus groups and discussions: "When we were younger we managed all these things and made sure that things worked well for families and neighbours. What a remarkable generation we are [self-mocking laughter in the group]!" (group discussion, Godfrey et al. 2004).

Acknowledging limitations

The report's name is Growing old is not for cowards. Well you need to be courageous to get old because you do get aches and pains ... But to have that courage you need to interact with other people and that is very important.

(Reed et al. 2003)

One woman in her 80s lived independently at home and was a very active community visitor. She spoke of her wish that sometimes her family might recognise that she was getting older, though at the same time of a desire not to be seen as old.

(Godfrey et al. 2004)

Another woman said: "My daughter's comment was 'we don't want to think of you as not well because you are the one that organises everyone's lives'. Sometimes I would like to cry on someone's shoulder and I don't have permission."

(Godfrey et al. 2004)

This is a complex discussion which is played out in the report on comfortable healthy ageing but which is also evident throughout many of the projects. Older people acknowledge losses such as the loss of loved ones or a reduction in their own capacity to do things. But they still struggle to hold onto what they regard as a life worth living. They have to come to terms with their impairment, and a great deal of internal and external negotiation goes on to enable them to do this. They do not want to be defined by this impairment but, at the same time, they want others to acknowledge the implications of the impairment. It is a complicated dialogue.

Of course, the older person's limitation is only one part of the equation. Their own limitation exposes limitations elsewhere within the system: notably those of friends, family, society and services. Society talks about the frailty of older people but not about the frailty of its own responses.

Valuing diversity within and between communities

Older people from different minority communities said that they were fed up with the message that being Asian, Afro-Caribbean or black was to be 'a problem to be solved'. In fact, many of the day centres in different communities were very alive and active – much more so than some of the more boring day centres provided by the council.

(Butt and O'Neil 2004)

It remains a concern that older refugees still tend to remain excluded, isolated and unheard.

(Thornton 2000)

Diversity is seen as being entirely concerned with black and minority ethnic communities. It is clear that different minority communities have both very similar and very different needs. For example, older Chinese people often seek the comfortable familiarity of a Chinese culture which would, of course, be quite alien to an Asian or Afro-Caribbean older person. Each group, however, experiences the frustration of a well-meaning colour-blind approach – which only succeeds in creating a situation where everyone is equally offered roast beef. There is also much diversity within any community, be that black, working-class industrial, middle-class suburban, or whatever. For some older people religion is very important – sometimes evident in their attachment to the religious structures of Church, Mosque or other community organisation, sometimes in the spiritual way that they view the world. For others, a more secular or humanistic view of spirituality or belief is very important.

Images of older people

I could get lots of images of heroic and quite beautiful older people who looked as if they were competing with 40-year olds in sports competitions. And I could get even more images where service staff were being really kind to older people who were clearly in quite a submissive role. But a straightforward, equal, one-to-one discussion? This was as close as I could get. I don't know if I was having an off-day, or if this says something deeper about images of older people and involvement.

(Steering Group discussion)

We're fed up seeing 'grumpy old men' stereotypes on television. The Victor Meldrew character in One Foot in the Grave, you know ... it just makes me furious. Such a disservice as a presentation of older people!

(Steering Group member)

Older people felt that many of the images of older people reflected the ways that others wanted to see them, rather than their actual lives. These images had them as vulnerable and needing care, aspirationally active in a rather Hollywood treatment of the ageing body beautiful or just comically grumpy. Were these images a disservice? In Steering Group discussions there was a sense that they were problematic, if only because they cast older people rather simply in either passive or submissive roles or gave out unrealistic aspirational messages against which reality would fall short.

Steering Group members valued the fact that some of their peers could, and still wanted to, go snowboarding or bungee jumping. But that wasn't the main territory of negotiation between gains and losses for most older people and these extremes deflected discussions away from the more mundane and everyday circumstances around, for example, the bit of help that many older people needed and were happy to accept. In many of the projects, the humour among older people was far richer than the roles presented on television.

This does not mean, of course, that older people are all humorous, wise, patient and accommodating. Nor that they have no difficulty adjusting as they age.

He's comfortable? That's because he's looked after! You see disabled people nowadays going out and enjoying themselves. Not sitting in a corner doing nothing!

(Older woman, Godfrey et al. 2004)

With the exception of one key consideration, there is likely to be the same breadth of humour and irascibility among older people as in the population at large. The vital point to be made is that none of the prevalent images particularly belongs to or describes the actual lives of older people rather than any other group.

And the key consideration, of course, is that the onset of chronic pain, ill-health, dementia or similar issues has a very real effect on patience, humour, irascibility and relationships.

- There were examples within the reports of the evident strain on relationships as a consequence of these issues.
- There were also examples of bereavement, despite the pain of the loss of a loved one, representing at least in part a release for the surviving partner, friend or relative.

Older people and ageism

Language is important in either valuing or denigrating older people – for example, the use of phrases such as 'burden of pensions' or 'the increasing older population are a drain on resources' is to be avoided.

(Kerr and Kerr 2003)

Well I wouldn't have retired then but ... I mean you couldn't get a job at my age. I might have got one as a cleaner.

(Older person, Godfrey et al. 2004)

Older people do not always use the formal expression 'ageism', yet our programme produced strong evidence of its existence in a number of spheres. It is clear that health and social care service responses have much lower expectations of what constitutes a life worth living for older people than for the population as a whole. There are examples of frustration over poor access to employment both as a way of earning money and as a means of gaining meaningful activity. Poverty, and the consequences of a denial of opportunities in earlier life, particularly for the pre-1950s generation of women denied education and careers, are also evident.

Many of the physical ageing aspects of old age (which tend to be the topics of research and professional assessment) are seen by older people as a frustrating but entirely normal part of ageing. Defining their lives by these characteristics seems to be overly medical. The real challenges facing older people – within the losses that can be associated with old age – are to do with negotiating the ordinary things in life such as relationships, activity in later life, transport, 'that bit of help', contact, and being comfortable.

Old, older, oldest?

What's wrong with being called old? You talk about me as being an older person. Older than what?

(Steering Group discussion)

Question: When will you consider yourself to be old? Answer: Never!

(Steering Group response)

There are discussions, even among older people themselves, about the meaning of words: independence or interdependence, old or older. Some feel the word 'older' is a bit patronising and fails to accept the full implications of growing old(er). Others see the word as carrying too much baggage, as being too involved with limitations and failure. There is no resolution in the reports or in the discussions about the identities of growing older, but there is a complex discussion still to be unpicked about what it fully means to be old.

Older people and death

Oh yes, older people do talk about this. When we come back from a funeral we joke that we've survived another one! It's strange that the research didn't pick up more of this.

(Steering Group discussion)

There's not many old friends left. We just went to another funeral last week.

(Older person, Godfrey et al. 2004)

When issues about the end of life were raised in the projects they were usually about the mortality of others and the impact of these losses on older people's lives. There was little discussion about what the end of life meant. Yet members of the Steering Group said that older people do talk about this subject. The absence of this issue in the programme might mean that younger researchers were too uncomfortable to ask about it. Equally, it might indicate that older people felt it was too difficult or too personal a topic to address, or not positive enough to discuss with younger researchers.

■ 4 Services supporting people

Interestingly, older people were clear that they did not want their needs for services to dominate discussions about the quality of their lives.

(Quinn et al. 2003)

The previous section was very much about older people's lives as they really are, rather than about specific services. Older people do not define themselves by the services they receive and many do not receive any services. Nevertheless, approachable and valued services are important.

Challenges and barriers

It is important to recognise that although there are examples of good practice and valued services, many older people do feel that there are real barriers to useful and useable services.

Lack of resources

We're continually running pilots!

We haven't got the halls. Or, if they do exist, they are too expensive. There's nowhere we can meet!

(Quinn et al. 2003)

I know there are cutbacks in the NHS but at my age I might have popped my clogs before I get [a new hearing aid].

(Older person, Godfrey et al. 2004)

A common theme in many of the projects is a lack of resources. Sometimes this is about not being eligible to receive mainstream services. At other times it is about community groups not being able to access core funding. The problems about getting access to 'low level support' are important here. The insecurity of community groups is important for black and minority ethnic communities, but not only for them. As is clear from the programme's information, advice and advocacy reports, difficulties in getting support for older people's centres and difficulties in funding older people's organisations is widespread.

Barriers to person-centred services

[Direct payments] allow me to have my hair washed, but I can't have my toenails cut!

(Older person, Clark et al. 2004)

I can't do the cleaning. I can't do it and they don't do it. You know, looking around, that it

hasn't been done and you know you can't get up to do it. It is sitting there thinking about it that just gets on top of you.

(Older person)

There is a paradox of sorts in that older people may be offered a service they don't want while they cannot get access to a service that they do want. Sometimes the mismatch is in terms of agreeing or not agreeing with the assessment of need. But at other times it seems that resources are still locked up in services that don't do what older people want or in service practices that don't meet people's needs.

I asked the council for an assessment but they asked 'what type?' and I didn't know what to ask for.

(Older person, Quinn et al. 2003)

My wife had a slight stroke and it affected her waterworks and I had to change her bedding twice one night. The continence nurse sent me several free samples, which was helpful. But she didn't tell me I could get them free from the district nurse so I was paying £2 a day for them. Now I hear the council offers a laundry service for soiled linen. Why don't they tell you about this?

(Older person, Quinn et al. 2003)

Older people in acute wards are not routinely asked about their home circumstances or about how they will cope after discharge.

(Petch 2003)

Researcher: Has anyone explained to you what happens when you can no longer stay on the Crises Support Service Scheme?

Older person: I haven't a clue dear ... I'm putting all my trust in the system – whatever it is.

(Petch 2003)

The Herbert project on person-centred services makes the point that others have made in other programmes about service staff wanting to be allies to service users and older people but struggling with a system that they find perverse and inflexible (Herbert and Sawyer, forthcoming). The jargon-terms are about 'cost-shunting' and 'bed-blocking', whereby savings to one part of the system end up dumping costs on another part of the system. The Petch project on intermediate care, which backs up this finding, also questions whether the term 'intermediate care' really means anything, especially to older people.

Groups on the margin

The interviews show that many Chinese people are isolated from both the Chinese community and from mainstream society. The common causes of their detachment include language barriers, insufficient knowledge of public services and a lack of awareness of social rights. Nearly all (97 per cent) said they found it difficult to use social services.

(Discussion, Chau 2002)

It was an uncomfortable fact but, directly or indirectly, mainstream services and mainstream society were still seen by the older people in the groups [of Asian, Afro-Caribbean, Chinese and other minority groups] as being both ageist and racist. They said it was impossible to ignore this fact and it needed to be said.

(Butt and O'Neil 2004)

Our projects also highlight the other side of the coin. Practice remains problematic in terms of Chinese older people and older people from a number of black and minority ethnic communities when it comes to how the mainstream treats them. There are examples of good practice (including voluntary-based services within different communities). However, access to mainstream social care and health services remains comparatively poor and the idea of culturally appropriate support remains at an early stage of development.

There are other groups who remain on the margin. In addition to the previously mentioned group of older people who are isolated at home, there are those whose lives do not conform to the stereotypical norm: travellers, refugees and so on. People with communication problems, cognitive impairments (such as aphasia or dementia) and people struggling with depression are also on the margin.

Problematic values and attitudes

When I rang this lady and mentioned gardeners she said: "No, I'm assessing what needs your wife has." She added that gardening wasn't on the list but I said: "By golly but it has to be done." She said: "Gardening doesn't help your wife." So I said: "It certainly does". She said there was a firm line on this.

(Older man, Quinn et al. 2003)

"Do you like to have a cup of tea with your dinner?" the older man in the residential home asked me on my visit as a lay inspector. "Yes, thank you," I replied, grateful for the offer. The older man replied: "Well you can't! We are not allowed to have a cup of tea with our dinner here!"

(Bowers 2002)

They treat you as if you are simple. People look at you and explain like you could not understand.

(Older person, Godfrey et al. 2004)

It can be difficult to engage with services on some of the issues that arise. Often the service world is about managing long-established services within limited budgets and in the context of staffing and organisational difficulties. In all of this, the idea of what constitutes 'the real world' is often quite different to older people's definitions of their own real world. Although the service providers themselves can feel – and sometimes are – powerless, nevertheless the consensus emerging from the different projects seems to be that the balance of power between services and older people rests firmly with services. Services often still work within the 'deficit model' of old age, and still define ideas of outcomes (what people want) in terms

of medicalised or pathologised views of people's lives. There is a need to link the internal dialogue that older people themselves are having about managing the changes in their own lives, to the internal dialogue that public services are having about effectiveness and outcomes.

Valued services, or the managers' best value?

In fact, older people (usually) are not asking for the earth, and recognise that definitions of quality (and of what is possible) is necessarily a negotiation. We need to be clear (and honest) about who defines quality and to be clear (and honest) about what older people's role is and should be in this process.

(Steering Group discussion)

Direct payments is brilliant. It beats staying in an old people's home. But, you see, you'd be paying about £170 for an old people's home. Well, we couldn't afford it.

(Older person, Clark et al. 2004)

This leads on to a final point: that best value (and the government's idea of best value) is still being defined locally by policy makers and services in the same old mind-set of the lowest cost services. There is much to be commended in the government's approach to modernising services. However, the experiences of the older people and of the projects in our programme still show that the quality and the outcomes that older people want are still not central to the process – probably with the exception of Direct Payments where the link between best value and quality is clearest. In the main, if our projects are typical of experiences nationally, the modernising agenda still seems to be service centred rather than older people centred.

Building on strengths and promoting opportunities

It is important to address the problems of unmet need. But it is also important not simply to buy into a formulation of problematising services. Constructive messages have emerged from the projects and services, society and older people would benefit from listening to them.

Valuing older people's values

It is important – in terms of managing risks, in terms of a life worth living, in terms of the life histories and experiences of older people, in terms of what they value individually and collectively – that support should be there to really support and not to undermine the lives of older people.

(Steering Group discussion)

All too often, older people's experiences are not valued. Whether it is the value of having their dog walked, the need for a day at the seaside or help with their gardening, services still can be quite dismissive of what older people see as important in their lives. Older people don't seem to be asking for the earth: they understand resource limitations. But they want the issues that matter to them to be acknowledged in the way that support is given. The idea is 'give us what we value' rather than 'give us what you think we need'.

Older people's own strategies: Messages for others

If the situation is representative I think that it is very likely that within any grouping, faith, sports club, hobby, women's group or whatever there will be someone with the knowledge and experience to provide an answer to many problems.

(Kerr and Kerr 2003)

What became clear was that she ... had been successful in finding the information she needed and had managed to 'manage' it.

(Kerr and Kerr 2003)

Why have we included these personal experiences? Because it is about information, how it is gathered, how it is heard, what is done with it. Advocacy might sound like a very theoretical term, but in everyday life, a relative or a trusted friend can be a powerful and essential advocate.

(Steering Group discussion)

The programme brought to light many examples of older people developing their own strategies for living, whether those were techniques for managing the information issues on ill-health, examples of mutual self-help, or ways of negotiating with family members about support. But these self-help strategies are not always shared between older people. As a result older people may face problems on retirement or bereavement or ill-health on their own, with no examples of how to move forward.

It is also important for services to recognise that older people are not simply passive recipients of services. They are equal partners and central actors in deciding what a life worth living today looks like.

Services reflecting the breadth of people's lives

This committee does not 'do' money or transport but, at that first meeting, older people said: "You cannot clip our wings." You have to look beyond social services in looking at the lives of older people.

(Steering Group discussion)

What was seen as significant about Caring Together was the flexible and unbounded nature of its response, its base in mutuality and reciprocity, its attempts to engage older people on their own terms in decision-making and then to act on their ideas.

(Godrey et al. 2004)

Several of the projects have highlighted the fact that older people don't immediately talk very much about services, particularly health and social care services. Older people's lives are made up of so much more than these. That does not mean that services are valueless, rather that a valued service is simply a part of the overall fabric of people's lives. Home care isn't just about keeping people in their own homes; it is about helping people to link their lives at home to their lives outside their front door.

Respect, mutuality and human qualities

It was such a relief when she (the social worker) came, after all those leaflets.

(Older person, Quinn et al. 2003)

I thought if I could have Val to come it would be wonderful. Because I think she is a lovely person and I've always said if I have to have anybody I'd like it to be her.

(Older person, Godfrey et al. 2004)

It Pays Dividends is the title of the report about direct payments and it came from something a manager said. It gave staff a lot of job satisfaction to see people really empowered.

(Social worker in Clark et al. 2004)

As mentioned above, older people are fairly realistic about the limits to what is possible, especially with scarce resources. Often what matters as much as the services they are offered is the way they are talked to, and the human qualities of the staff they come into contact with. One senses a fear on the part of staff that older people might ask the impossible. In reality, if they really listened, they would understand that what older people are asking for are just the ordinary things in life – even if these do challenge the service stereotype.

In many of the reports, older people did not want to be seen as receiving at all. For them giving was important and many found it very difficult to accept support. Faced with the psychological issues that we all have when we value our own contribution and want to be seen as useful and valuable human beings, it is important that services at least start from a position of shared humanity.

Flexibility and common-sense adaptability

A service manager said that an older man felt the most important thing for him was that his dog got walked. The manager told him the service didn't do that and there weren't enough resources in the system to do it. The manager felt that the older man was being unreasonable.

I told the manager that it might be really important for the man and we couldn't judge 'reasonable' by service definitions. One of the other people present asked how I would have dealt with it.

"Well," I said, "did you discuss it with him?" I knew from work elsewhere that the way you say 'no' can be as constructive sometimes as actually saying 'yes'. As long as you discuss the reasons for decisions, most people will accept them.

In addition, if I'd been that older man, I'd have found it helpful if at least some thought had been given to how the issue could be addressed. Was there a volunteer or befriending scheme which might be able to give the old man some help? There might be possibilities,

and if there was a genuine acknowledgement that this was an important issue to me, I could at least have accepted it better.

(Project discussion)

It can be frustrating to see that the system cannot deal with the very ordinary and mundane things that older people ask for. When staff work with older people to make the impossible a possibility, everyone is cheered. The flip side of this is the very deep frustration when it becomes clear that a staff member has made the possible a real impossibility.

5 Community, family and citizenship

We need to see older people's lives in a wider context than services, and older people's roles in society as being much broader than mere passive recipients of care. Older people are not a problem to be solved.

Isolation

It is important to recognise that older people are citizens and family and community members in their own right. It is also important to recognise that, when it comes to offering support to older people, it is primarily older people themselves who provide that support. Having acknowledged this, however, it should also be recognised that many older people do not feel part of any community and are isolated from their family. The theme of loneliness and isolation is a strong one for many older people.

Exclusion from community includes older people in care homes, those with cognitive or communication difficulties, people who are completely isolated and those with reduced social networks.

(Steering Group discussion)

It's the evenings that are the worst. I lock all the doors and don't see anybody walking about.

(Older woman, Godfrey et al. 2004)

Isolation sometimes comes through bereavement or physical impairment, or simply through losing the networks that were there when people were in employment. Some older people go through a process of acceptance, which is an amalgam of adapting to the negative changes and a valuing, or revaluing, of some of the positive things in life.

Reciprocity: Giving and receiving

It was a self-help arrangement. She was housebound but her mind was still active. She would never have offered to do the ironing, perish the thought. But she had been a book-keeper and was happy to help people with the complex forms.

(Project Advisory Group discussion)

My son comes over and does quite a lot for me. He hates gardening, so I go over and cut his lawn.

(Older person, Godfrey et al. 2004)

I like giving as much as receiving. It's gracious to receive and my friends down the road grow veggies and leave carriers at the back door. When she wants something big I take her

shopping because they haven't a car.

(Older person, Godfrey et al. 2004)

It comes through in many of the projects that older people can and do give as well as receive. It is important for self-esteem that this reciprocity is acknowledged on all sides. Older people provide essential child-minding services in families and there are examples of older people collaborating in a self-help arrangement with others. This is not merely about volunteering to help make the system work, it is about providing useful services. It is of central importance to recognise that older people give to, as well as receive from, society.

Positive roles: Citizen, neighbour and family member

I'm a mentor to local primary school children. We've been matched up because their grandparents live a long way off, as do my grandchildren.

(Bowers 2002)

The Wing On Elderly Group is managed by volunteer Chinese older people for Chinese older people.

(Chau 2002)

In fact, we've never been busier – and our families depend upon us for childminding and other support.

(Steering Group discussion)

Older people are not a problem to be solved and they dislike seeing themselves as a burden. This is a complicated discussion. Many, perhaps most, older people will not need a specific (e.g. social) service. When they do need support, it is important to frame this within the overall contributions they have made throughout their lives to their families, neighbours and to society. Even when they do need support, that does not stop them from also being contributors in other ways.

People with rights and responsibilities

Older people are not a redundant part of society!

(Conference discussion)

Older people are taxpayers and contributors too. The services should be able to have the systems in place to work as efficiently as they can with what they get.

(Older person's comment)

People spoke of taking responsibility for dealing with litter or of attending local council meetings to raise neighbourhood issues.

(Godfrey et al. 2004)

It seems difficult to imagine society talking about older people having rights and responsibilities. The current debates are all couched in terms of 'the demographic time bomb'

and 'paying for long-term care'. The underlying theme is the fear that older people will simply be a burden on the rest of society. It is not clear that there is any shared understanding of the rights and responsibilities of older people in society.

We can't go back: The future of community and support

Older people here expressed strongly held values of mutuality, of 'looking out for each other' and of a neighbourliness that extended to those who were newcomers to the area.

(Godfrey et al. 2004)

One of the issues is about younger older people going off and having a great time. The load falls on a comparative few. I almost dread the phone call, knowing it means more work for me.

(Older man)

In many of the projects there were networks of support. Some were well rooted in communities; others were extended, stretched and at risk.

(Steering Group discussion)

Some of the projects demonstrate strong support networks. These are often dependent on place and the networks may consist of just a few people. There seems to be a widespread wish for a past age where communities really looked after each other. It may be an oversimplification, but it seems that the shared experiences of such events as the Depression of the 1930s, the Second World War and the economic recovery in the 1950s has created a generation that strongly believes in society and the common good. This may or may not be true but it is often the image older people have of their own generation.

It would be simplistic, and probably untrue, to say that people nowadays do not care about society or community. Often the life-stories in the different projects demonstrate quite complex support systems, not only among older people but also between generations. But it is also clear that we cannot go back to the culture of support of the 1930s and the war years. There is a need to think about future forms of community development and community support. How can we mobilise volunteering, for example, without it seeming to be 'do-gooding' or offering charity? We might wish that public services play a stronger role in people's lives but it is often families and friends who understand the stories of people's lives most clearly, no matter how willing services might be. Should services think more clearly about supporting the networks of support, rather than thinking about tidy solutions?

■ 6 Involvement

Beyond tokenism

The Older People's Steering Group has talked at some length about taking ideas of involvement, broadening them beyond a bit of consultation after the event, and about setting standards for what good involvement should look like. In discussions about involvement, Steering Group members said that there is a glass ceiling on consultation: involvement is most common below that theoretical line, not much goes on above it.

Older people speaking out?

If this had been a conference about disabled people or people with learning difficulties, they would be involved in it. With older people we are still catching up.

(Strategist at a conference)

Nothing about us without us. Nothing about me without me.

(Group discussion at conference workshop)

The quotations above come from two consultations. It is still possible to attend external consultations about older people where there are no older people either speaking or in the audience. This contrasts with experiences of disabled people or those with learning difficulties, where the strong expectation is that they will be partners in the consultation process. However, the evidence of the JRF programme is that the situation is changing for the better.

At another conference the disabled people's phrase 'nothing about us without us' was borrowed and amended to recognise the importance of the individual as well as in the collective. 'Nothing about us without us; nothing about me without me', was the confident outcome. For involvement to be real, it needs to be in place right at the start of any process, it needs to involve more than a few token older people, it needs time and resources, and it needs commitment.

Recognise both the individual and the collective

I'm not sure that older people like being 'organised'. That's why it's so important to have the whole spectrum of involvement. It's an individual thing as well as a political and collective thing. Having control over your life matters, even if you don't want to organise things on a larger scale.

(Older person, Carter and Beresford 2000)

Within the projects that make up the programme there are many examples of individual involvement whereby, for example, older people negotiate their own packages of support with direct payments. There are also good examples of individual involvement not happening, such as when services fail to engage with what older people judge as being of importance in their lives.

Involvement can also be collective. There are good examples of groups of older people who are already very experienced in involvement; such as the lessons from local services and strategies in Darlington, the work with older people from the Wiltshire and Swindon User Network and some local Age Concern groups. There are also good examples of older people starting to become involved; for example the Listening Events in Dorset. Sadly, there are also examples of very low standards of, and low expectations about, involvement. There are also groups struggling at the margin in terms of funds, energy and purpose.

Developing capacity and confidence

The themes of capacity and confidence – both for individuals and for groups – come through in many of the projects. Some of this is about lifelong learning, some of it is in drawing on the knowledge and experience that people already have. It comes through in the Godfrey project about older people growing in confidence as researchers and in the Kerr project [Kerr and Kerr 2003] on information, advice and advocacy. We should not underestimate the potential benefits of strengthening the hand of older people themselves.

(Steering Group discussion)

One of the strong themes to come from the programme generally is that of developing the processes of involvement. The Godfrey project, which involved older people in the research itself, is a good example (Godfrey et al. 2004). These processes are important and cannot be by-passed. They include developing the confidence to learn new skills. Such skills need to be grounded in the capacity of local groups to take up issues. This capacity may depend on the membership of the group, its sense of purpose, its links to helpful systems and even the health and energy of the members. Some of it is also about financial resources.

The need for capacity and confidence is also true of individual involvement. All too often the service menu seems very fixed and older people, who often do not want to ask for help, can then be unwilling to challenge the menu. So involvement isn't simply about developing local older people's forums, it is also about the individual support with information, advice and advocacy in order to challenge expectations.

Developing practice and expectations

The professionals still talked about being 'independent' only if you could do everything by yourself. They thought that involvement was about giving information about services or about some small consultation meetings. In this case, the barriers to involvement weren't about older people. The important 'training' that was needed was actually for the professionals!

(Comment at conference workshop)

It's like going into a restaurant without a menu. How do I know what I want if I don't know what is available?

(Quinn et al. 2003)

It is also important to address the other side of the coin, of course. Often it is the service

rather than the older person that most needs training about involvement. While the argument in favour of involvement is hard to deny, many services still feel the need to re-shape 'involvement' until they are comfortable, leading to something closer to either sketchy consultation or even just the provision of information.

Within the programme we have tried to ensure that older people are central and visible stakeholders when issues of importance to older people are being discussed. There is a question about the standards of involvement that should apply to other local and national policy discussions about ageing strategies and older people's programmes.

At the individual level, the same logic applies. Sometimes one senses that the service feels that it doesn't have any 'spare' resources and so it chooses to close down any discussion about other options. There is a need for honesty and flexibility in discussing individual lives.

In 'the daily routine' and in 'national policy'

Key issues on information, advice and advocacy from Norma Raynes' project:

- *Advice on how to level paths: make flags even so you don't trip.*
- *A list of agencies saying who does what and their phone numbers.*
- *How to get trees cut down.*
- *How to get information about the future of the residential warden.*
- *Getting information to deal with day-to-day worries, such as delays in getting boiler replaced.*
- *Getting information when you ask for it, not being told they will phone you back, or getting music and hanging on.*
- *How you can get first class information in the shortest time, for example about bath seats.*

This is very ordinary stuff. Let me contrast this with the project about intermediate care [Petch 2003]. One analyst identified a number of key issues:

- *A lack of awareness of roles and responsibilities in other services.*
- *The segregated nature of current professional education.*
- *A lack of coterminous boundaries between services.*
- *The difficulty of integrating small-scale winter pressures projects.*
- *Concern that the NHS and SSDs were using intermediate care money to make up for shortfalls in other services.*

The author herself notes: 'None of these, it will be observed, reflect the perspectives of older people.'

(Margiotta et al. 2003)

What seems to come through in the reports is that 'ordinariness' is not taken too seriously and that high level strategy is too important to involve older people in its deliberations. Whereas the messages that come through are that top-down and bottom-up issues are both

important – and older people need to be involved to make strategies meaningful.

(Steering Group discussion)

Involvement is still largely formulated along the lines of set piece discussions; in other words, meetings with minutes and resolutions. In fact, involvement starts at a very mundane level. Useful involvement should start with consultation about pavements or the fact that a house owner cannot get up her stairs. It should extend through the whole spectrum. Policy makers may feel that some subjects are too high level for older people to be involved but the sense that comes through some of the projects (and in discussions with Steering Group members) is that nothing should be so circumscribed. If something is intended to make a difference to older people, those people should be involved from the start. And if it isn't really intended to make a difference, then why is it being considered?

Moving beyond 'consultation' towards choice and control

There was evidence in some areas that the service providers and the project team themselves needed to challenge their own assumptions about involvement. I detected a sense that could be summed up as: 'It's the politically correct thing to do but we don't really believe in it.' Whereas, within the same project, there are service providers in another area who seem, on the face of it, to believe that they wouldn't and shouldn't get away with it if older people weren't strongly involved in service planning and monitoring.

(Project discussion)

It's always difficult to know whether local involvement is real, but at least some services realise that there is a ladder of involvement and they need to move up it. With the listening events there is at least some commitment to starting to move up the ladder. It will be interesting to see if mind-sets begin to change.

(Steering Group discussion)

This takes us to, what is for many, the core issue. As already noted, there seems to be a 'glass ceiling' to involvement on consultation. To tackle this, there is a real need to develop approaches that give older people more choice about, and control over, decisions relating to their lives. Sometimes the feeling has been that older people don't want to be involved in decisions. This may be true but what the programme shows clearly is that older people like to make their own decisions about what they do or don't want to do. The important part of this is that older people should be able to choose what they want to do and the relevant service should then respond appropriately.

For everyone ... as they wish, as they can

Many of the projects acknowledge the needs of older people with dementia, communication and sensory problems. However, this is a complicated area and one where we need to draw on projects that lie outside our programme.

Older people recognise the challenges that people with dementia face but, unsurprisingly, they find the subject unsettling and even frightening. They are unsure what to do about

dementia and they have a fear about it happening to them in the future. Such responses are not remarkable when it is considered that dementia transforms a familiar friend into someone who 'is not the same person' and 'who should be in a home, along with their own kind'.

Our wider learning about people with communication difficulties, dementia or learning difficulties – all very different conditions but experiencing similar exclusions – is that communication and involvement are still possible. Older people affected by these conditions are still able to express hopes, fears, affection and anger. The 'disruptive behaviour' they display often comes from frustration about not being understood.

We know from outside projects about older people with learning difficulties, aphasia and dementia, as well as from work about people with vision or sensory impairments, that people affected by these conditions are still able to exercise choices with support. It is important that services still recognise the person who exists behind the impairment. As one older woman with dementia said: "I like to use my own mind" (Allan 2001).

The officer's tale: Involving older people

It pays dividends.

(Care manager, Clark et al. 2004)

It's so easy to stay with the same old things, same old stuff.

(Social worker, Clark et al. 2004)

There's a massive sense of satisfaction.

(Social worker, Clark et al. 2004)

While the quotations above come from the report on older people and direct payments, they are equally applicable to a wider message about involvement at the collective level.

Many officers have said that they are frustrated that current practices deny people choice and control. All too often the involvement argument is framed as a moral or rights-based argument. A central truth – probably the one central truth which needs to be developed – is that greater involvement can lead to a real win-win situation with both older people and officers feeling the benefits. It is actually easier to frame policies within the realities of people's lives and it is certainly more rewarding for officers.

The wider learning from disabled people, service users, black communities, mental health users and people with learning difficulties has been that user involvement isn't just a matter of being the right thing to do. It actually leads to better decisions and better outcomes for everyone.

Part III

Programme messages

7 Key messages

The programme itself is summarised in the executive summary at the start of this report. This final section outlines a series of key messages which flow from the programme as a whole.

For service purchasers and providers

- Older people have told us that their lives are about more than health and social care. Transport, housing, leisure services, money, companionship and community are all important. While social services are often still seen as the leaders on older people's services, they could effectively work in alliance with older people locally to champion a wider approach to services for older people. This is primarily an area for chief executives and leaders of councils to give a lead.
- There is still an important place for the provision of appropriate services for those older people who do need health or social care support. However, health and social services need to break out of a dated, service-driven approach to such support. Sometimes they need to think about radically shaping new services. Sometimes it is more about shifting the balance of power within more conventional services in order to give older people more choice and control. Direct payments are one way of doing this, but it would be disappointing if conventional services were not able to respond to this challenge.
- There is a great deal of talk about holistic approaches; about moving away from a welfare view of older people as vulnerable and towards a rights-based approach which sees older people as citizens. Service planning and delivery needs to reflect this rhetoric.
- A key message from many of the projects is the importance of involving older people in the design, implementation and monitoring of services. Unless older people are involved in this way, it is unlikely that services and planning will reflect the detail of their lives.
- Involvement in older people's strategies requires some standards. Older people need to be involved right at the start. There need to be more than one or two token older people. There needs to be time, resources and commitment. It needs to be clear what is and is not on the table.

For central government policy makers

- A focus on key government targets has brought some gains for older people. Whether or not it is what was intended, this focus has led to services being so target-driven that they are less likely to be flexible and responsive to the specific needs of older people. There are examples in the programme of person-centred approaches being put to the back of the queue in the pursuit of star ratings.
- Government needs to find a way to encourage local services to be more person-centred without seeming to control the agenda from the centre. While there have been many national initiatives which older people have strongly welcomed, national policy itself needs to shift.

For funders of older people's strategies or research on ageing

- Unless older people are strongly present during the development of strategies or agendas, it is likely that programmes and strategies will remain in a welfare mode with older people being the passive objects of these initiatives.
- There are developing models showing ways of involving older people in all stages of agenda setting, implementation and review. Funders and strategists need to develop standards in their own practices in order to challenge themselves and to learn from good practice elsewhere.

For older people themselves

- Society's images may portray people as being vulnerable but older people have a lifetime of experience to draw on which is still relevant.
- Understanding bureaucracies. It would be nice if they were, but they tend not to be. And so the understanding needs to come from you.
- There is a need to speak out – individually, locally and nationally – about developing standards of involvement. Older people need to lead in developing these standards.
- The issues of ageism reach into all aspects of older people's lives. If services need to look beyond health and social care, then organisations of older people need to look beyond single issues like pensions.

Wider messages for everybody

- Stereotypes of grumpy old men fail to accurately describe the diversity, strength and humour of older people's lives. There is a need to recognise and develop more diverse, authentic, constructive and positive images of older people in families, neighbourhoods and the media.
- At present, images of older people either see them as vulnerable and passive receivers of care or as heroic and active rivals to younger people. There is a need to create a mind-set which recognises the rich opportunities that come with old age as well as the losses. Older people in our programme have told us that old age is a time of constant renegotiation when it is vital to retain the humanity of the person.
- Projects within the programme are capturing the lives and times of older people. For example, 'Reminiscence' projects with Afro-Caribbean older people record what it was like to come to the UK from the Caribbean for the first time. Such projects are a resource for communities and schools. There is a need to develop, respect and use these personal histories.

Appendix

Key findings from the Older People's Research Programme

This appendix includes the key findings of each research project:

Age and change: Models of involvement for older people	56
Older people speaking out: Developing opportunities for influence	58
Older people's definitions of quality services	59
Exploring unmet need: The challenge of a user-centred response	60
Unmet need and older people: Towards a synthesis of user and provider views	62
Living well in later life	63
Shared expectations, shared commitments	64
Older people's perspectives: Devising information, advice and advocacy services	65
Are you listening? Current practices in information, advice and advocacy services for older people	67
Intermediate care: What do we know about older people's experiences?	69
Getting old is not for cowards: Comfortable, healthy ageing	71
Older people doing it for themselves: Accessing information, advice and advocacy	73
Does money matter? Older people's views of their monetary resources	74
'It pays dividends': Direct payments and older people	76
'Let's move on': Black and minority ethnic older people's views on research findings	78
Building a good life for older people in local communities: The experience of ageing in time and place	80
Information, advice and advocacy for older people: Developing the thinking	82
Older People's Steering Group	84

Many reports, and Findings summaries, are available as a free pdf from the JRF website (www.jrf.org.uk/bookshop). Printed copies can be ordered online from the JRF website or from JRF's distributor, York Publishing Services Ltd, on 01904 430033. Contact details are given for publications not available from JRF or its distributor.

Age and change: Models of involvement for older people

Tony Carter and Peter Beresford

This study looked at ways of increasing the involvement of older people in organisations. It held discussions with older people's organisations, and drew on UK and international schemes and experience of involvement in a wide range of other fields. The final report gives a brief guide to different forms of participation so that older people and their organisations can:

- be as well-informed as possible about the strengths and weaknesses of different models and approaches;
- have a clearer idea of what they might be letting themselves in for when they get involved through any one of them; and
- choose the approach that best suits their requirements.

Key findings

The report noted that involvement wasn't simply about sitting in meetings with agendas and minutes. Involvement is important at an individual level, as well as being political and collective. Having control over your life is important even if you don't want to organise on a larger scale.

There are many forms for involvement – such as advocacy and information forums, user panels, consultation, user/pensioner groups, user/older-people led services, direct payments groups, networks, campaigning and direct action organisations.

Some forms of consultation were thought to be a waste of time. Useful questions to ask about consultation included: Who took the initiative? What is its purpose? Who is on the management committee? Who decides the work and priorities? How is the involvement funded? How are decisions put into practice? If the answers prompt real concerns, it may be that involvement is not worthwhile.

Access and support are essential to make involvement effective and inclusive. Access is only partly about whether or not a building is accessible: it is also about state of mind – making sure that older people can take part. This includes everything from arranging a convenient time to being listened to by decision-makers. Support includes financial support, training to develop skills and confidence, and support to allow older people to get together and work in groups.

There are two main approaches to consultation: the consumer approach and the democratic approach. Different forms of involvement have their own strengths and weaknesses. The approach has to be credible, well thought through, and clear about what older people should expect from it. There is a need for further work which looks at extending collective action to a wider number of older people. Black and minority ethnic older people, older disabled people and older people with mental health issues are particularly on the margins of involvement.

Age and change: Models of involvement for older people by Tony Carter and Peter Beresford is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published June 2000

Older people speaking out: Developing opportunities for influence

Patricia Thornton

This study reviews the opportunities older people have to influence their environment, the services that affect them and the society they live in.

Drawing extensively on published research and work in progress, it examines the limitations of 'top-down' initiatives in involving older people, and the dilemmas facing older people's organisations trying to have an influence. It reviews the issues in which older people are becoming involved and the methods of involvement. It asks which older people are missing out and considers how opportunities for them to have their say might be developed. An extensive bibliography references essential reading for practitioners, researchers and policy makers.

Key findings

The report noted that many 'top-down' initiatives are extending ideas of involvement for older people while 'bottom-up' approaches are also coming more to the fore.

The message from older people is that social care and health services, which are the traditional areas for consultation if not for involvement, are only part of a bigger picture of older people's lives. It is important that older people are part of the analysis, not simply contributors of information.

Older people are comparatively neglected in health-led initiatives and older people with specific issues such as dementia or mental health problems are often entirely overlooked.

The report notes that older women's groups are not widespread outside London. Equally, although older people from black and minority ethnic communities are researched, their voices are seldom heard. Older people in rural areas are often still at the margin and the ordinary voices of older people are hard to get to.

Traditional models of involvement do not always work for older people and many conventional methods are dull and unrewarding. However, a series of ordinary but innovative approaches – the use of telephones, letter-writing, visits and drama – offer the potential to reach a wider range of different people.

There is little information available about evaluation by older people of the involvement of older people.

Older people speaking out: Developing opportunities for influence by Patricia Thornton is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published June 2000

Older people's definitions of quality services

Hazel Qureshi and Melanie Henwood

This study looks at the meaning of quality and draws together existing literature about older people's definitions of quality services.

The authors discuss evidence about the impact of services on older people's quality of life, the changes that may be needed to improve this, and the effects of the way in which services are delivered. They discuss the implications for service delivery and for older people's involvement in quality assessment and quality assurance. Finally, they outline an agenda for possible future research. This report aims to fill gaps in our knowledge and to emphasise the centrality of older people's views in underpinning future developments in the area of quality.

Key findings

Quality of life outcomes identified by older people are mostly about achieving ordinary things in life: keeping clean and comfortable, enjoying a clean and orderly environment, being safe, having access to social contact and company, keeping active and alert, and having something interesting to do.

Different services can contribute in different ways to older people's quality of life by helping them live at home, by reducing the symptoms of ill-health, by improving communication, by regaining skills and confidence, and by improving income.

But the way that a service is delivered is as important to older people as a lists of tasks done. The way a service fits in with the person's life is as important as is whether or not the older person has control over the support. Is the older person treated with respect? All these are vital elements of service provision and achieving quality in these areas depends on staff reliability and continuity of support. It relies on the human qualities of staff members, their competence, knowledge and experience and their ability to be flexible.

This study showed that it is possible to assess and assure quality through a range of methods – some procedural and some more to do with talking to older people about their experiences. It also found that there has to be some recognition of the standards that people expect and a realisation that this might bring to the fore the need for changes in existing service provision. It decided that there is also likely to be a need to look at more robust tools, grounded in older people's definitions of quality, that can more closely define, assess and assure quality.

Older people's definitions of quality services by Hazel Qureshi and Melanie Henwood, is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published June 2000

Exploring unmet need: The challenge of a user-centred response

Mary Godfrey and Gill Callaghan

This briefing paper explores the meaning of unmet need from the perspective of policy makers, service providers and older people. Drawing on ideas of need in the literature, the paper takes as its starting point the view that need is socially constructed. It then examines existing research evidence in order to:

- make explicit the assumptions underpinning policy and service conceptions of need;
- review what is known about levels of unmet need within this relatively narrow framework;
- examine the difficulties many older people experience in translating 'felt' need into requests for help;
- consider how a user conception of need might be developed.

Key findings

A fundamental thrust of the community care revolution was to move away from a service-driven to a needs-led approach in assessment and service delivery.

The report notes that there have been some achievements in doing this, not least in some imaginative attempts to involve older people in a dialogue with professionals. On the other hand, many good intentions have been thwarted by scarcity of resources and by the increasing dominance of professional definitions of need.

The project notes a requirement to define or redefine need, taking the lived experiences of older people themselves as a starting point. Older people's own ideas about need are neither static nor formulaic.

Need (if that is the appropriate term) has to move beyond seeing older people as a burden or as passive bystanders in their own lives. It is a social construct that must be re-framed. A new reconstruction would acknowledge the importance of:

- intimate and social relationships based on ideas of giving and receiving;
- maintaining a sense of purpose, meaning and competence;
- retaining involvement in valued aspects of life;
- engagement in meaningful activities;
- retaining continuity with place and relationships;
- a sufficient income; and
- the provision of personal care in ways that ensure autonomy and sense of control.

This would involve a major reorientation of existing services and would involve:

- moving away from an individual or pathology concept of 'needy' which is based on a stigmatised notion of welfare;

- moving towards a model based on autonomy and self-determination (referred to elsewhere as a rights-based model);
- user involvement in determining what is acceptable risk; and
- accepting assessment as a process of facilitation and negotiation that begins with people's own experiences. (In practice this might suggest, for example, the care management role as being about working with older people, rather than doing things to or for them.)

Exploring unmet need: The challenge of a user-centred response by Mary Godfrey and Gill Callaghan is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published February 2001

Unmet need and older people: Towards a synthesis of user and provider views

Lis Cordingley, Jane Hughes and David Challis

This study of unmet need among older people provides a thematic review of the vast literature relating to this idea. It aims to establish common ground between user and provider views on what is a diverse and complex subject.

The authors cover two broad topics: areas of unmet need identified by older people, and the response of the formal sectors to the issue of unmet need.

The first section reviews commonly overlooked needs identified by older people and looks at the reasons older people resist support or help. In the second section, the authors describe studies which examine the ways social services departments identify and respond to the needs of older people. The final section suggests a number of alternative strategies for identifying unmet needs.

This study provides a useful summary of the issues associated with the nature of unmet need, agency processes associated with identifying need and ways in which user and provider perspectives could be brought closer together.

Key findings

The report noted that, in terms of older people's own lived experiences, 'need' is not the same as being 'needy' and older people shouldn't be seen as passive or dependent. Older people see many of the needs that the system ignores as legitimate and important, while many of the prioritised needs are overly medical and do not reflect older people's own priorities.

There were also found to be issues to do with access and assessment that policy and service provision should address. Eligibility criteria and assessment approaches must be both fair (among older people) and must achieve an equitable use of resources. This is not always the case at present.

Finally, the report highlights the gulf between current practice and the views of older people. There is a need to develop tools which are useable in policy and practice but which also reflect the views of older people. Nor should they reinforce professional or overly medicalised views of people's lives. Developments in the UK and abroad offer potentially valuable lessons in creating more sophisticated and sensitive tools.

Unmet need and older people: Towards a synthesis of user and provider views by Lis Cordingley, Jane Hughes and David Challis is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published February 2001

Living well in later life

Helen Bowers (with Penny Mendonca)

This conference with older people and other stakeholders reinforced what older people have said in many different projects.

Key findings

- Being active, staying healthy and continuing to contribute to society are crucial elements of a life worth living in older age.
- Older people continue to learn.
- Family and relationships are central to older people's lives, which have to be seen in the context of being valued and belonging.
- It is important to appreciate the differences between individuals, groups and different communities. Older people are a diverse group.
- Services have an important role to play and it is vital for local services to be approachable.
- Services should not limit older people's choices. Older people should be able to make their own choices and take their own risks.

From the event a series of recommendations was produced:

- It was important to work within local communities and services to formulate an agenda for local action.
- Bringing people together and working with their experiences was a valuable way of helping older people express their views. It was also a way of recognising that fun and social contact had an important part to play in serious business.
- When devising support programmes, the following design tips would help ensure the successful participation of older people:
 - overall clarity of purpose, aims and objectives;
 - thorough preparation;
 - strong design;
 - adequate support;
 - a clear process;
 - good facilitation;
 - sound organisation;
 - guaranteed follow-up; and
 - shared ownership and accountability.

Shared expectations, shared commitments

Ruby Chau

This report was the result of a conference of 150 people that was funded by the JRF Older People's Research Programme. There were 95 Chinese older people, 23 Chinese organisations and 14 mainstream organisations attending. The conference developed out of a previous JRF project about the social care needs of Chinese older people which had highlighted the exclusions faced by Chinese older people in UK. However, the different stakeholders in the research were not content simply to state the problems. They wanted to move to some consensus about what Chinese people wanted and needed in order to enjoy a comfortable old age. The intention was to identify the next steps that local and national organisations needed to take to address the issues.

Key findings

Six key areas for improvement were highlighted:

- health and social care;
- housing and transport;
- pensions, welfare and living standards;
- older women and their caring role;
- social contacts and leisure time; and
- social rights and participation.

The groups identified five key expectations for older people under each of these headings. A new project has been supported within the Older People's Research Programme to see if change can be brought about in practice. The new project will hope to refine the expectations developed at the conference and see how local strategies and services can act on these expectations.

Shared expectations, shared commitments by Ruby Chau is available in English and Chinese versions from Ruby Chau, University of Sheffield, Department of Sociological Studies, Elmfield, Northumberland Rd, Sheffield S10 2TU.

Published 2002

Older people's perspectives: Devising information, advice and advocacy services

Ann Quinn, Angela Snowling and Pam Denicolo

This study reviews a project exploring the needs and problems of older people in relation to information, advice and advocacy. The researchers worked with the Slough Older People's Forum, which represents the diverse communities of older people, and with service providers. They examined:

- The barriers older people face in getting information, advice and advocacy, particularly the problems they face in finding out about services which could help them.
- Older people's views on what information services they want and their key priorities.
- How older people perceive the service providers' distinctions between information, advice and advocacy.
- The challenges faced by current services in attempting to give accurate and comprehensive information to older people.

The report also considers the resource limitations on providing new services and highlights possible solutions to some of the problems.

Key findings

The study found that older people experienced barriers at three stages. First, it was difficult to discover that there was information, advice or advocacy that could help them. Second, it was hard to gain access to the appropriate services. Third, there were problems in receiving practical help to act on the situation and reach a solution.

Older people used information, advice and advocacy without necessarily knowing the difference. Instead they saw these concepts as cyclical and inter-linked. Older people from black and minority ethnic communities were especially excluded.

Older people wanted information that is centred on their lives rather than based on agency definitions. Different older people had very different strategies for finding relevant support. Continuity of contact was important. Information about leisure was as important for older people as information about social care or health services. Most people would have preferred an information bank or information centre.

Among the range of findings it became clear that there was no single solution to the problem. There was, however, general agreement that:

- Information should be centred on the needs of people, not on descriptions of the provision of services.
- Leisure activities were crucial for older people and information needed to reflect this.
- It was important to maintain information systems in a way that older people would find useful.

- Services should work together to provide common material.
- While advocacy and advice can be difficult to define and achieve, older people saw information as being valueless if it did not lead to concrete change. When developing services and support, there is a need to reflect this holistic and sophisticated understanding of information, advice and advocacy.

Several ideas came out of this project which might be employed in a local strategy. These included an older person's jury, barter schemes, a social business register, and an older people's information centre.

Older people's perspectives: Devising information, advice and advocacy services by Ann Quinn, Angela Snowling and Pam Denicolo is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published June 2003

Are you listening? Current practice in information, advice and advocacy services for older people

Pat Margiotta, Norma Raynes, Dimitri Pagidas, John Lawson and Bogusia Temple

Central to much government policy is the view that clear and timely information, advice and advocacy should be available for older people. This study reports on a critical review of current practice in services designed to provide information, advice and advocacy for older people. The information is derived from a literature search, a search of the websites of local authority and major voluntary organisations, and the input of three focus groups involving older people living in sheltered housing and elsewhere in the community. Examples of good practice are highlighted and some recommendations are made for future action.

Key findings

The overarching conclusions were:

- It is crucial to involve older people in all stages of design, implementation and monitoring (DIM).
- Older people need to be truly central in all provision and all schemes.
- Face-to-face communication is very important for many older people.

When providing information and advice, the report concluded:

- There need to be different products (for example, both books and audio-tapes).
- Producing written material in a minority language may be of little use. There is a need to acknowledge that some older people will find written material in their own language almost as inaccessible as written English. Instead, more should be done to recognise the value of existing information networks in different communities, and work with them.
- A proportion of older people use (or are willing to learn) about the internet. There needs to be support for this, and material on the internet needs to be regularly updated.
- Before more material is produced, it is important to do a little work to find out what actually works.

In the field of advocacy, the main findings were:

- Older people should be involved at all levels in planning, organising and supporting advocacy schemes.
- Volunteers should be drawn from as diverse a population as possible.
- Advocacy should be centred on and driven by the needs of the older person.
- Advocacy schemes should be well publicised and easily accessed.
- They need to be funded in a way that maintains their independence, and this should be the cornerstone of national standards and codes of practice for recruitment, training and supervision of volunteers.
- Health and social care practitioners need training about the role of advocacy.

Are you listening? Current practice in information, advice and advocacy services for older people by Pat Margiotta, Norma Raynes, Dimitri Pagidas, John Lawson and Bogusia Temple is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published August 2003

Intermediate care: What do we know about older people's experiences?

Alison Petch

The NHS Plan provided major investment for intermediate care, which now features as one of the eight core standards of the National Service Framework for Older People in England. This report combines a literature review and discussions with members of the West of Scotland Senior Citizen's Forum to provide an overview of recent evidence on intermediate care.

Against a backdrop of a wide range of definitions the author considers what is actually meant by intermediate care and considers recent government policy in this field. She explores what sort of care services older people themselves want, and their views on the outcomes of their care. She also considers admission to hospital, the discharge process and schemes to avoid admission or promote early discharge.

The study outlines areas needing further research and exploration, and concludes by highlighting the need to take older people's views into account when planning the future of intermediate care.

Key findings

In looking at what is covered by the term intermediate care – including intensive support at home and 'hospital at home' schemes, along with hospital discharge, 'step up' and 'step down' services – it became clear that although it is a topical term the concept is vague and unproven.

Most worryingly, the study found that the language, early consultation and goals of intermediate care have all been framed in terms of making services more efficient. Current debates still focus on the issues for services: such as the lack of coterminous boundaries between services, the segregated nature of current professional education, or the use of intermediate care money by the NHS and Social Services to make up for shortfalls in other services. None of these concerns reflect the perspectives of older people and it is only very recently that the voices of older people have begun to play any part in deciding what is or is not a valued service.

The report notes, in particular:

- It is essential to monitor and supervise home care staff to ensure that older people are confident about returning home.
- The 'not my job' culture in domiciliary care has affected older people's confidence in the systems.
- There is a real concern that intermediate care is simply a cosmetic term to justify emptying hospital beds.
- The availability of convalescence or halfway house support was seen as a key indicator that the idea of intermediate care was being taken seriously.

- There was a diversity of circumstances and, consequently, needs among older people (including older people with dementia or needing higher levels of support). The systems should be designed to give people confidence.
- The insertion of additional elements of intermediate care may actually work against a whole systems approach.

Intermediate care: What do we know about older people's experiences? by Alison Petch is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published September 2003

Getting old is not for cowards: Comfortable, healthy ageing

Jan Reed, Glenda Cook, Susan Childs and Amanda Hall

This literature review explores different ideas about what constitutes 'comfortable, healthy ageing'. Discussion groups and interviews with older people revealed their own definitions of good health and these formed the search terms for the study. However, the team faced difficulties using older people's own terms as the basis for their literature search, probably because much literature on older people is not based on older people's own priorities.

The study discusses the prevalent medical model of ageing, which sees it as a time of inevitable decline and loss and defines healthy ageing as avoiding or escaping this. It also reviews the 'heroic model', which promotes the idea of growing older as a positive experience. Both of these views have their limitations and the authors suggest that a new concept of older age may be needed. They conclude by highlighting areas for further research and study.

Key findings

The study found that expectations of active healthy ageing came from policy makers, researchers and services planners. Older people preferred the idea of comfortable healthy ageing.

Of the two models of growing older to emerge from the literature, the more passive, 'deficit model' is the basis for most decisions about how to treat old age in our society. Decline is seen as inevitable and pessimistic assumptions are made about ideas of choice and control, quality of life and risk management.

The 'heroic model' sees ageing as an enemy to be fought, and views 'giving in' to the effects of time as a defeat and a failure. The 'heroic model' celebrates wellness but leaves no room for the physical decline that older people recognise as a normal and healthy part of ageing.

Neither model allowed older people to age positively and successfully. This contrasted with the lived experiences of older people in the reference group. They reflected the wider message from the programme as a whole that old age was, in essence, a negotiation between gains and losses.

For older people, health was less about a focus on specific, often inevitable, impairments and more about living well by continuing to enjoy friendships and take pleasure in everyday activities. As a result, resources to enable older people to live well were only partly about material resources (such as money, transport, facilities). Social and psychological resources (such as friendship and support, information and advice) were also important.

The study highlighted the need to understand and take into account the diversity of personal outlooks held by older people in terms of their expectations, values and attitudes. It also showed how vital it is to ask older people about their own ideas and models of health in order to move beyond the models found in research and the media.

Getting old is not for cowards: Comfortable, healthy ageing by Jan Reed, Glenda Cook, Susan Childs and Amanda Hall is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published September 2003

Older people doing it for themselves: Accessing information, advice and advocacy

Laurie Kerr and Vivien Kerr

Written and researched by two older people, this report looks at the diversity and breadth of information, advice and advocacy available to older people. It also examines how and whether older people can find out about and manage these services.

The authors reviewed existing literature and mapped current provision in the London Borough of Barnet. Laurie Kerr met organisations providing services and working with and for older people and also researched good practice initiatives where older people were advocates or the main resource for information and advice.

Through discussions with individuals and groups of older people, the authors investigated older people's approaches to getting information. They found a vast amount of information available to older people which older people themselves were unaware of.

Key findings

- In almost all instances, the information needed exists in some form and is out there for the finding.
- Older people have a vast amount of experience. They can employ this for themselves and they can also be a resource for their peers.
- Advocacy is personal as well as professional. It is important not to become confused by jargon – the need for advocacy is real and of an 'everyday' nature.
- It is important not to 'problematise' older people nor to use the sort of language that denigrates them.
- Older people are very diverse and stereotypical images of them are unhelpful.
- Older people are equal citizens and should not be seen as a marginal or separate part of the population.
- Each older person needs to be his or her own 'strategy manager'. There is a need to develop individual strategies to find out what you need to know.
- There are models of good practice that services can draw upon in developing local strategies.

Older people doing it for themselves: Accessing information, advice and advocacy by Laurie Kerr and Vivien Kerr is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published November 2003

Does money matter? Older people's views of their monetary resources

Glenda Cook, Jan Reed, Susan Childs and Amanda Hall

This report summarises key points in the literature on older people and their money. It also includes reflections of a group of experts – older people and others – about how older people view their financial circumstances, how they use their money, and what needs they feel should be met.

It reviews the process of identifying themes and sources. This process began with discussions with experts, individual interviews and focus groups. Some of the sources were 'grey literature' that carried information which the experts felt was particularly useful. Other material used was research literature.

The report includes a full literature review, highlighting areas of concern to the older people involved in this project that were not reflected in the literature. The overriding conclusion was that the value of money for older people rests in what it enables them to do, and in the sense of control over personal circumstances that it gives.

Key findings

- For some, living on a meagre income reflects their life experience. Some feel that they may be better off now than before. Others feel that old age represents a substantial decline in income.
- For most older people, the real value of low incomes decreases more rapidly over time.
- There were groups of significant rich and significant poor among the older population – the former being most likely to be recently retired and the latter among the oldest pensioners.
- Some of the key informants lived in housing estates distant from convenient and lower-cost supermarkets.
- Setting aside money 'for a rainy day' was difficult because the timing and scale of that rainy day was more unpredictable than at earlier stages of life and because there was little opportunity to save up to replace reserves.
- There was a generally poor take-up of benefits, particularly with images of 'spongers' and 'scroungers' affecting the pride of many older people.
- The system seemed to treat harshly those who were just above the benefit line or who had saved money for their retirement.
- Even a moderately 'good' pension might be insufficient to meet the costs of growing older associated with ill-health and impairment. Direct payments could address some of these costs but the eligibility criteria were often too high and the take-up too low. In addition, support for older people on these schemes were still quite limited.
- Older people are still seen as a burden. This ignores the fact that in the past they contributed significantly to the wealth society enjoys today.
- Much of the support for older people came from older people.

Does money matter? Older people's views of their monetary resources by Glenda Cook, Jan Reed, Susan Childs and Amanda Hall is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published January 2004

'It pays dividends': Direct payments and older people

Heather Clark, Helen Gough and Ann Macfarlane

Although older people have been entitled to use direct payments since 2000, take-up remains low. Drawing on interviews with older people, local authority care managers and direct payments support service workers, this report looks at how older people use direct payments and how they make them work. It considers the role of direct payments support services and local authority care managers in making direct payments a real option for older people.

Key issues discussed include:

- The benefits of direct payments for older people.
- The experiences of a group of minority ethnic older people.
- The perspectives of care managers.
- The role of direct payments support services.
- Local authority funding of support services.

This project followed on from an earlier JRF study which looked at what older people wanted from direct payments and similar types of support. It studied how older people were using direct payments in a number of areas, including a black and minority ethnic community within a northern local authority.

Key findings

- For older people the benefits included an improved quality of life, greater motivation and feeling happier. In other words, there was a positive impact on social, emotional and physical health.
- Most older people used their direct payments to employ personal assistants.
- Some older people used personal assistants to enjoy social and leisure activities or to develop alternatives to institutional respite care. Such activities were rarely included in care plans and older people met the extra costs themselves.
- Good, accessible information about direct payments was crucial, as was the need for support services.
- The funding of direct payment support services depended on historical precedents and budgetary constraints rather than strategic decision-making. The absence of government guidelines meant wide local variations with knock-on effects for the viability of direct payments.
- There were no instances where health authorities contributed to a direct payments package and so older people were unable to purchase, for example, chiropody or physiotherapy. Older people found these restrictions absurd.
- Direct payments were rarely part of the culture of care management teams. Care managers need educating about direct payments, the support of their line managers, time to think and work creatively, and a clear understanding of the role of direct payment support services.

- Care managers faced tensions between sticking to eligible needs and ensuring flexibility to allow users to meet their priority needs. Nevertheless care managers who had successfully worked in this way remarked on improved job satisfaction.
- Direct payments enabled some black and minority ethnic older people to secure support relevant to their needs. However, they also had language and literacy barriers in using direct payments and they also needed support with financial and administrative requirements.

'It pays dividends': Direct payments and older people by Heather Clark, Helen Gough and Ann Macfarlane is published by the Policy Press in association with JRF. It is not available in pdf format but can be ordered from JRF's distributors (see page 55).

A Findings summary, **'Making direct payments work for older people'** (ref. no. 234), can be downloaded from the JRF website (www.jrf.org.uk).

Published February 2004

'Let's move on': Black and minority ethnic older people's views on research findings

Jabeer Butt and Alex O'Neil

This report asks what contribution research can make in transforming the experiences of black and minority ethnic older people.

Over 100 older people from black and minority ethnic communities were involved in three separate consultation events that took place in Leeds, London and Bristol. At these events, supported by interpreters and facilitators, older people were presented with a summary of research findings about older people from black and minority ethnic communities.

The authors explore the value of mainstream and community services in meeting the needs of these older people, including the impact of funding. They go on to consider money in the lives of older people, continuity and change in family and community relationships, and the need to involve black and minority ethnic older people in future research.

Key findings

- The rapid growth in numbers of black older people was evident.
- Language, communication and a lack of useable information were problems for all groups.
- Poverty in all its forms was a problem among many minority communities and especially among older people. Poor access to pensions and benefits compounded this.
- Changing family roles and cultural norms were causing problems among these communities, including elder abuse.
- Many were experiencing poor housing conditions and a lack of social housing options.
- In many groups, health was poorer than the average for their age group in UK. Access to healthcare was poor, partly because of a shortage of interpreters but also because of a lack of awareness of cultural norms.
- There was a perceived need to address mental health issues, often caused by the isolation many felt.

The study identified gaps in the present services.

- The work of interpreters needs to be backed up by better facilitation and advocacy.
- There needs to be better education about cultural matters among health and social care professionals.
- Black and ethnic minority community groups needed more, and more secure, funding, especially in light of the fact that mainstream services were often failing such communities.

The study found many differences between different communities. (For instance: interpreters were more important for Chinese older people, but access to pensions advice was more important for Afro-Caribbean groups.) There were also differences between black groups and

their white counterparts in terms of experiences of racism and an insensitivity to cultural norms.

There was a deep frustration that mainstream society saw black and minority ethnic older people as problematic while failing to recognise their strengths or value their diversity. (Some minority community day-care services had important lessons for mainstream services.)

There were also many common causes between black and minority older people and the main body of older people in many of the needs and frustrations.

'Let's move on': Black and minority ethnic older people's views on research findings by Jabeer Butt and Alex O'Neil is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published May 2004

Building a good life for older people in local communities: The experience of ageing in time and place

Mary Godfrey, Jean Townsend and Tracy Denby

This detailed project has been working with older people in Leeds and Hartlepool, looking at what older people mean by 'well-being' and 'quality of life'. Older people were involved in researching the issues, in discussing the findings and in shaping the conclusions. It is an engaging report that is full of humour, the texture of people's lives and the practicalities of how older people negotiate the changes in their own lives.

Key findings

The project noted:

- Old age offers new experiences and opportunities but it also requires adjustments in order to successfully manage the losses that accompany ageing.
- Older people were continually confronted with attitudes and behaviour that devalued ageing. Older people often internalised these.
- Older people's physical, emotional, social and financial circumstances are the result of a lifetime of living but these change as people grow older – sometimes providing networks of support and sometimes leaving people isolated.

It also found that older people face different types of obstacles and challenges:

- Big events such as bereavement or acute, life-threatening illness fundamentally change the rhythm and pattern of daily life and might require support of a psychological, emotional or practical nature.
- Age can bring both the disruption of valued social relationships and the reduction of social activities. If older people's horizons are not to be irrevocably narrowed, action is required to replace the losses.
- Smaller scale, day-to-day problems can be as frequent a source of stress and frustration as chronic ill-health and impairment.
- The physical and social environments in which people live – such things as fear of crime, inaccessible shops, poor transport and inappropriate housing – can create obstacles for older people.
- The gap between the negative stereotype of old age contrasted sharply with the experiences of older people as they constructed – often with great humour and friendships – a meaningful and productive life over the whole of the age span.

For the individual, the services and support which sustain 'healthy' ageing are those which open up opportunities for self expression and engagement in social relationships and activities; provide practical, social and emotional support in coming to terms with changes; and offer assistance with the daily problems that constrain people's lives.

At the neighbourhood or community level, healthy ageing requires the existence of

environments that are safe, secure, easily negotiated and which fully integrate older people.

At the societal level it is about action to reduce inequalities and to encourage the proper valuing of older people.

At all of these levels, older people's own resources and energies are crucial. They are also often overlooked and devalued. Old age is less about 'a problem to be solved' and more about supporting older people in devising their own solutions.

Building a good life for older people in local communities: The experience of ageing in time and place by Mary Godfrey, Jean Townsend and Tracy Denby is available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Published September 2004

Information, advice and advocacy for older people: Developing the thinking

Andrew Dunning

This report is a wide-ranging literature review and briefing paper on the subject of information, advice and advocacy for older people. It draws on literature definitions of these terms and looks at current and developing policies and practice, nationally and locally.

Key findings

The basis of the report is that there is a need to understand the definitions, principles and different forms of information, advice and advocacy. It is important to be clear that the terms overlap, but also that people often jump from one to the other as the need dictates.

Accessibility is crucial if these definitional issues are not to remain dry desk-based discussions. Making them real for older people means addressing availability. In matters of availability, the appropriateness of the approach is crucial. Different approaches range from 'improving the impersonal' to 'making the impersonal personal'. An example of the former would be providing better written formats while 'one stop' help shops would be an example of the latter.

Generic schemes can have advantages, in that they treat the whole system and avoid duplication. They can have disadvantages too. Older people may find it harder to identify them as a resource aimed at them, or the specific needs of older people may be diluted or lost.

Specialist schemes – those focused on older people specifically – can be more easily focused on otherwise 'hard to reach' groups and can raise the profile of older people's issues. Unfortunately, they can also end up duplicating work done by other groups and competing for the same resources.

The report found that, generally, a scheme's effectiveness depends both on its independence and the involvement of older people.

The report highlights the need, expressed both by the project and by older people themselves, for a more strategic approach in policy, planning and provision around the topic of information, advice and advocacy. It looks at initiatives such as Better Government for Older People (and the practice within local areas such as Rhondda Cynon Taff), the Patients Advice and Liaison Service (PALS), the Information Complaints Advocacy Service (ICAS), Care Direct, and activities within the Department of Work and Pensions. It also specifically examines the potential for national standards in relation to advocacy, especially using ideas such as independence, involvement, accessibility and strategy.

Developing the thinking on information, advice and advocacy for older people by Andrew Dunning will be published in 2005, when it will be available as a free pdf at www.jrf.org.uk/bookshop or from JRF's distributor (see page 55).

Forthcoming 2005

Older People's Steering Group

This 'project' has been an advisory-cum-steering group to the programme as a whole.

Strictly speaking the group has comprised ten older people and seven officers (the latter being a JRF officer, a research consultant, two JRF committee members, an officer from local government and officers from Help the Aged and Age Concern). Over its lifetime, membership has been fluid but throughout there has been a core of six older people and four officers.

Working alongside the Older People's Steering Group has been a more informal and fluid group of black and minority ethnic older people. This has met through consultation events, planning meetings and project advisory groups.

Key findings

The original meetings helped to set the agenda for the programme as a whole and, essentially, the group has been the commissioning body for the programme.

Subsequent meetings discussed the meaning of terms such as 'independence', and have helped to reshape approaches as new initiatives such as the National Services Framework came on board. The group has also promoted ideas, such as the unmet need project and the enquiry into low-level support.

Most recently, the group has been looking at ideas of involvement with the aim of beginning to set some standards for national adoption. It has also received and discussed the findings of the 17 projects described above, and these discussions have shaped the final programme report.

This publication – which represents the final report to the search phase of the programme – has been developed out of discussions with the group at several meetings throughout 2003 and 2004.

Bibliography

Allan, K. (2001) *Communication and consultation: Exploring ways for staff to involve people with dementia in developing services*, Bristol: The Policy Press/Joseph Rowntree Foundation.

Butt, J. and O'Neil, A. (2004) *'Let's move on': Black and minority ethnic older people's views on research findings*, York: Joseph Rowntree Foundation.

Carter, T. and Beresford, P. (2000) *Age and change: Models of involvement for older people*, York: Joseph Rowntree Foundation.

Chau, R. (2002) *Shared expectations, shared commitments*, Sheffield: University of Sheffield, Department of Sociological Studies.

Clark, H., Dyer, S. and Horwood, J. (1998) *'That bit of help': The high value of low level preventative services for older people*, Bristol: The Policy Press/Joseph Rowntree Foundation/*Community Care* magazine.

Clark, H., Gough, H. and Macfarlane, A. (2004) *'It pays dividends': Direct payments and older people*, Bristol: The Policy Press/Joseph Rowntree Foundation.

Cook, G., Reed, J., Childs, S. and Hall, A. (2004) *Does money matter? Older people's views of their monetary resources*, York: Joseph Rowntree Foundation.

Coombs, M. with Sedgwick, A. (1998) *Right to challenge: The Oxfordshire community care rights project*, Bristol: The Policy Press/Joseph Rowntree Foundation/*Community Care* magazine.

Cordingley, L., Hughes, J. and Challis, D. (2001) *Unmet need and older people: Towards a synthesis of user and provider views*, York: Joseph Rowntree Foundation.

Dunning, A. (forthcoming 2004) *Developing the thinking on information, advice and advocacy for older people*, York: Joseph Rowntree Foundation.

Godfrey, M. and Callaghan, G. (2001) *Exploring unmet need: The challenge of a user-centred response*, York: Joseph Rowntree Foundation.

Godfrey, M., Townsend, J. and Denby, T. (2004) *Building a good life for older people in local communities: The experience of ageing in time and place*, York: Joseph Rowntree Foundation.

Herbert, G. and Sawyer, L. (forthcoming) *New approaches to support older people at home*, York: Joseph Rowntree Foundation.

- Kam Yu, Wai (2000) *Chinese older people: A need for social inclusion in two communities*, Bristol: The Policy Press/Joseph Rowntree Foundation.
- Kerr, L. and Kerr, V. (2003) *Older people doing it for themselves: Accessing information, advice and advocacy*, York: Joseph Rowntree Foundation.
- Margiotta, P., Raynes, N., Pagidas, D., Lawson, J. and Temple, B. (2003) *Are you listening? Current practice in information, advice and advocacy services for older people*, York: Joseph Rowntree Foundation.
- Petch, A. (2003) *Intermediate care: What do we know about older people's experiences?* York: Joseph Rowntree Foundation.
- Pritchard, J. (2000) *The needs of older women: Services for victims of elder abuse and other abuse*, Bristol: The Policy Press/Joseph Rowntree Foundation.
- Pritchard, J. (2002) *Male victims of elder abuse: Their experiences and needs*, London: Jessica Kingsley Publishers.
- Quinn, A., Snowling, A. and Denicolo, P. (2003) *Older people's perspectives: Devising information, advice and advocacy services*, York: Joseph Rowntree Foundation.
- Qureshi, H. and Henwood, M. (2000) *Older people's definitions of quality services*, York: Joseph Rowntree Foundation.
- Raynes, N., Temple, B., Glenister, C. and Coulthard, L. (2001) *Quality at home for older people: Involving service users in defining home care specifications*, Bristol: The Policy Press/Joseph Rowntree Foundation.
- Reed, J., Cook, G., Childs, S. and Hall, A. (2003) *Getting old is not for cowards: Comfortable, healthy ageing*, York: Joseph Rowntree Foundation.
- Thornton, P. (2000) *Older people speaking out: Developing opportunities for influence*, York: Joseph Rowntree Foundation.
- Thornton, P. and Tozer, R. (1995) *Having a say in change: Older people and community care*, York: Joseph Rowntree Foundation.
- Tozer, R. and Thornton, P. (1995) *A meeting of minds: Older people as research advisers*, York: York University, Social Policy Research Unit (SPRU).

