

foundations

Analysis informing change

www.jrf.org.uk | October 2004



Older people shaping policy and practice

Since 2000, the Joseph Rowntree Foundation has been supporting a programme of research about the lives of older people.

The programme was developed by and with older people themselves, working in a steering group with officers, researchers and policy advisers. Rather than focusing on the views of professional researchers and service planners, the programme examined the priorities which older people themselves defined as important for "living well in later life".

This *Foundations* summarises the main findings from 18 completed projects and identifies key themes for policy-makers, practitioners, researchers, society as a whole, and for older people themselves.

Strategies should start with older people's lives

- Older people are a diverse population; their definitions of "a life worth living" and the support needed to achieve that should be paramount.
- Much policy and practice are still based on the assumption that older people are a 'burden'. This is problematic for older people and means that resources fail to deliver their definitions of quality.

Services - though important - are only a part of the picture

- Despite modernising initiatives, barriers in attitudes, approaches, and resources remain within the way that health and social care services operate.
- There are also good practices and empowering ways of working. These need to be retained and developed.
- Health and social care services, however, are only a small part of the support that older people value and only a small part of the experience of growing older.

Citizenship, community and family

- Many older people remain isolated – living in one's own home with no support or contact can be as disempowering as the stereotype of a nursing home.
- Older people are citizens with important roles in supporting families and within communities. They are also the biggest providers of support to other older people.
- Contrary to common perception, there is a great deal of evidence of support within communities but these networks are often hidden and tenuous.

Involving older people – individually and collectively

- Involvement is both individual (about one's own life) and collective (about local and national initiatives). However, in current practice most involvement takes the form of set pieces, such as having an individual older person on a Social Services Committee. It is often simply about information-giving or consultations which have little effect in bringing about real change. Meaningful involvement requires standards about when older people are first included, how their involvement is resourced, their involvement throughout the whole process, and their scope to influence the outcomes.

Lessons from how the Older People's Programme worked

- Older people can set an agenda for programmes of work about older people.
- There are examples to build upon of involving older people as commissioners of research, researchers and co-researchers, reference group members, users of research findings and peer reviewers.

Introduction

The Joseph Rowntree Foundation's Older People's Programme was developed by the Older People's Steering Group. Members included older people themselves, working with officers, researchers and policy advisers. 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 on searching out the issues. A further nine ongoing projects are looking at bringing about changes from the programme's findings.

"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."

(Discussion, Older People's Steering Group)

This *Foundations* summarises the key themes from the 18 completed projects and highlights key messages for policy-makers, practitioners, researchers, society as a whole, and for older people themselves. The programme defined 'older people' as people who need that bit of help as they get older. A number – a specific age – is less important (for example, some people in black and ethnic minority communities may need this support in their fifties).

The *Foundations* – and the accompanying report – reflects two key strands within the programme: first, the rich picture the projects reveal of older people's lives – older people's voices give the feeling of a companionable walk alongside their lives; second, the development of the programme itself and the central involvement of older people in shaping it.

Strategies should be based on older people's lives

At the early stage of the programme there were comments (from analysts and services) that the measure of its success would be an expert commentary about very specific developments in modernising services for older people, such as improvements in home care or residential care.

In practice, however, the programme has always taken a different direction. Rather than beginning with the latest initiatives on Person-Centred Services, a Single Assessment Tool, or service targets, the programme has focused on what older people say and want about their lives. The evidence from the different projects is that there is still a mismatch between what older people want and what policy and practice are delivering.



The programme highlighted the following themes.

Start with older people's lives

Diversity

Older people are a highly diverse population – there are different stages of growing older, different minority groups, different lifestyles and beliefs, different attitudes and approaches to old age. Whilst diversity must acknowledge the needs of black and minority ethnic older people, it must not stop there. Nor should age and ethnicity be seen as a ‘problem’ to be solved. Often older people from within black and minority ethnic communities provide powerful examples of good practice that others would do well to follow (Butt, 2004; Chau, 2002; Dunning, forthcoming).

"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 in Godfrey, 2004)

Common experiences

Older people also share many common experiences. They are fully aware of the limitations of growing older, but also see gains. The projects found older people frustrated about services and society which they saw constantly defining them in terms of loss and of risk management (Bowers, 2002; Carter, 2000; Godfrey, 2004; Reed, 2003).

Old age brings strengths which need to be acknowledged. Older people have a lifetime of experience to draw upon, and often have internal resources and strategies – including humour – which need to be recognised not ignored. Growing older itself is a time of gain as well as loss. But older people sometimes need to negotiate their way through rapid changes (Godfrey, 2004; Kerr, 2003; Quinn, 2003).

Support

Health, in this context, is much broader than simply treating illness. The projects suggest that being ‘healthy’ is about being able to have a laugh, keep mentally active, do things which interest you, meet friends (Bowers, 2002; Godfrey, 2004). The forms of support or services which older people valued concerned negotiating the ordinary things in life – relationships, learning in later life, transport, housing, contact – "being comfortable", having "that bit of help" (Bowers, 2002; Butt, 2004; Carter 2000; Cordingley, 2001; Godfrey, 2004; Kerr, 2003).

Money is important in achieving these things and the projects found clear evidence of both individual poverty and a lack of funding of services that older people value (Cook, 2004; Godfrey, 2004). However, older people need a broader range of resources than money alone. Community, friendship and support – and the internal resources of individuals themselves – are crucially important to "a life worth living" (Bowers, 2002; Godfrey, 2004; Kerr, 2003).



Barriers

Older people also experienced particular barriers.

The older people in the projects did not commonly refer specifically to ‘ageism’ but there is strong evidence in the programme of its existence in a number of spheres. There are examples of frustration of poor access to employment (as a way of earning money and as a means of gaining meaningful activity) (Butt, 2004; Godfrey, 2004; Kerr, 2003). Poverty and a denial of opportunities in earlier life are also evident (particularly for the generation of women whose circumstances before or during the Second World War meant that they were denied education and careers). Partly this is because the current affluence and expectations of those currently working are not being enjoyed by significant populations of older people (Godfrey, 2004).

Crucially, current social images of older people often reflect the way that others want them to be seen – vulnerable (and needing care), aspirationally active or comically grumpy. Much policy and practice still frames older people in terms of being a burden, a problem to be solved, denied rights to the ordinary things in life because of the processes of ageing (Godfrey, 2004; Kerr, 2003; Reed, 2003; Older People’s Steering Group, 2004). There tend to be two contrasting models:

- The deficit model – old age is an illness with no cure; the ‘patient’ loses rights because of his or her need for health treatment or social care services;
- The heroic model – older people only age successfully if they can still compete with younger people in physically challenging activities.

For the older people in the projects, neither of these models works. They cast older people in passive or submissive roles or give aspirational messages which do not reflect people’s ordinary lives. In reality, old age is a constant (and at times quite rapid and radical) negotiation between losses, gains and quality of life (Godfrey, 2004; Reed, 2003; Older People’s Steering Group, 2004). At present, few services seem to have fully taken on board this aspect of growing older.

The central point which comes through all of the projects is that current policies, social images of older people, services, even some of the newer initiatives in policy and practice locally and nationally since 1997 all struggle to break away from the ‘deficit’ model. Even where new developments are beginning to move towards a more holistic view of older people’s lives, there is still a long legacy of thought which sees older people as vulnerable, needing protection, a problem to be solved, a burden (Herbert, forthcoming).

Yet the older people in the projects are not asking for a huge increase in resources. Often they are themselves the key people who can make a difference in their own lives and in those of other older people. However, they may need more appropriate support than is often on offer at present to achieve this.

Start with lives, then look at services

Most older people do not come within the umbrella of health and, particularly, social care, services. This is due to poor access to low-level support (such as help with shopping, cleaning or gardening), high eligibility criteria for services, a degree of stigma in relation to accepting support, and the inflexibility/ inappropriateness of practice in many respects (Bowers, 2002; Butt, 2004; Kerr, 2003; Godfrey, 2004; Petch, 2003; Quinn, 2003).

The projects have strong messages about the lack of resources. They also reveal that the rhetoric of ‘person-centred services’ is not always being put into practice (Herbert, forthcoming; Petch, 2003; Quinn, 2003). Despite policy direction, attitudes of front-line workers, service planners and commissioners on the ground can be problematic (Bowers, 2002; Quinn, 2003). Older people have had real concerns that ‘cost-effectiveness’ was simply about cost savings (Cook, 2004; Quinn, 2003; Older People’s Steering Group, 2004). Some groups (such as older people from black and minority ethnic communities and older people with dementia or communication problems) were particularly at the margin in terms of receiving any service or in terms of that service being appropriate to their circumstances

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(Butt, 2004; Chau, 2002; Kerr, 2003; Thornton, 2000; Older People's Steering Group, 2004).

There were, however, also examples of good practice. Some services recognised the need to start from older people's own ideas of what made life worth living. There were examples of both individual staff and particular providers working flexibly and adapting to circumstance (Clark, 2004; Dunning, forthcoming; Godfrey, 2004; Kerr, 2003).

However, even if conventional health or social care services do reflect what people want, that sort of service support forms only a small part of "living well in later life" for most people. Social services are not the only ones who have a part to play – and it is often Social Services Directors who are in the vanguard of saying this to chief executives and to those working in housing, transport, health, leisure and community services.

What comes through in the different projects and in discussions within the programme is the need for services to recognise the following:

- Communities, community organisations, family/friend/community networks (often of older people themselves) are the greatest providers of support to older people.
- Definitions of 'quality' need to be driven more by older people themselves.
- Services need to be more holistic, responsive and adaptable to people's needs.

At present, despite a seeming commitment to a more modern approach, often little has changed in service delivery since the Community Care Act in 1990. Yet the constant message through all the projects has been that approachable and flexible local services could make a substantial difference to people's lives (Bowers, 2002; Clark, 2004; Godfrey, 2004; Herbert, forthcoming).



Citizenship, community and family

For older people, living at home with no support or contact, apart from different professionals who come and go, can be as isolating and disempowering as that stereotype of residential or nursing care (Godfrey, 2004; Older People's Steering Group, 2004).

But older people can play an active role as citizens. They often provide unacknowledged support to other older people or child care within families. In addition, they often have citizenship and community roles, for example, as local community representatives, organisers of community groups and or participating in older people's forums. There is a need to address negative images of old age and to recognise and value the contributions that older people make to community life. Older people have a great deal of knowledge and experience that is not valued or recognised.

There has been mention in many of the projects about communities being more supportive in the past. However, even those who made these comments often had informal networks of support, albeit ones which could be hidden and tenuous (Godfrey, 2004). Older people themselves have also said that 'younger older' people (those more recently retired) could do more volunteering work to strengthen local communities (Older People's Steering Group, 2004).

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

(Comment, older person on Steering Group)

"We're fed up seeing 'grumpy old men' stereotypes on television!"

(Discussion, Older People's Steering Group)

Involving older people – the underpinning essential to good practice

The project evidence and discussions at consultations and within the Steering Group suggest that this could be a crucial and exciting time for change. The most crucial message from the programme as a whole, however, is that successful change depends on the meaningful involvement of older people in defining quality of services and quality of life.

Older people in the projects saw involvement as important at both the personal and the group level – not just about token representation on social services committees. However, despite the rhetoric, in most cases the real levels of involvement of older people (whether in services affecting their own lives or in local and in national initiatives) remain quite low (probably lower than those of disabled people).

Initiatives like Better Government for Older People (BGOP), the Health and Older People's reference group (HOPE), the National Services Framework for Older People, and Older People's Advisory Groups (OPAGs) may represent a sea change in policies about older people. There are signs, individually and collectively, of older people having a stronger voice in framing initiatives about their lives.

Given these initiatives, the question remains as to why convincing standards of involvement of older people in programme development are still not the norm.

There have been encouraging developments in other local and national strategies. Welfare and care agencies have shifted towards a more holistic, inclusive and ‘rights-based’ approach to older people as citizens. There is real recognition, often strongly promoted by Directors of Social Services themselves, that policy and practice about older people need to involve more than health and social care provision. It has also been encouraging to see attempts to draw together diverse research disciplines to reflect the diversity of older people’s lives.

Nevertheless, many national and local stakeholders still see older people as the passive recipients of services. The projects found examples where involvement of older people has developed following Better Government for Older People but such initiatives have a precarious existence (Carter, 2000; Herbert, forthcoming; Older People’s Steering Group, 2004). In the past four years, while the programme has been developing, it has also been a common experience for members of the Steering Group and Steering Group officers to attend regional and national meetings with many different professional stakeholders looking to develop a ‘joined-up strategy’ on older people’s services to find no older people on the platform or invited to be in the audience. This has been confirmed by experiences reported by older people themselves (Carter, 2000; Older People’s Steering Group, 2004). Involvement at the level of ‘information giving’ is common and there are many examples nationally of consultation. But real engagement (where older people are involved “right from the start” and where they have a real say in the issues to be addressed and in the outcomes) is rare, and a form of ‘glass ceiling’ appears to be operating. Reflecting the experiences of service users more generally, older people say they have been consulted interminably about different services or about community care plans. However, these consultations have often had little benefit for older people, and older people have said in the projects that they are sceptical about some of the motives for the consultations.

Drawing on both their own experiences and on the learning from the different projects, Steering Group members have commented that organisations developing Older People’s Strategies or funding research or development programmes about older people or ageing have poor standards on involving older people in defining the questions, undertaking the work or negotiating the meaning of the findings. Yet the projects suggest that unless you do this, it is unlikely that the policy or practice responses will robustly reflect what older people actually want.

Involvement in practice – developing the programme

The second theme from the programme has been about the actual process of involving older people in defining its work. The programme is not put forward as an example of best practice. There are many things within the programme that did not work (despite the best of intentions) or that could have been better negotiated. However, the following lessons have emerged.

Older people setting the agenda

Older people were involved right from the start in defining the programme. Preliminary consultations with older people prepared the way for a wider discussion with other stakeholders. As one older person said: “You’ve invited us in before you’ve set the goalposts”. Throughout the wider discussions, 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.

Meaningful involvement requires standards on:

- the numbers of older people included;
- the stage of development at which they are included;
- their scope to influence the outcomes;
- the resources to support their involvement;
- their involvement throughout the whole process.

Older people commissioning research, shaping policy, setting standards in practice, reviewing outcomes

Questions about involving older people in research are not new. Older people have acted as interviewers and as local researchers and have taken part in focus groups. However, the potential for involvement is wide. This programme gives probably the clearest example to date of older people as commissioners of research about older people.

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

(Older person in Quinn, 2003)

Older people have been in the majority on the programme's Steering Group (ten members with seven officers). They have also worked in partnership with the Foundation's officers, external researchers and policy advisers to the programme. This has often been a difficult road – for officers and older people alike – albeit one involving humour, affection and fun. A spirit of openness and respect has allowed honest disagreements to be aired and, more often than not, resolved. It has not been a perfect process, but there has been valuable learning on all sides. The programme shows that such involvement is possible and that it produces rich, valuable material.

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

Key messages

If only one message had to go out from this programme, it is that if programmes or strategies about older people do not have the fullest possible involvement of older people in their development they are very unlikely to stand the test of time.

In addition, the programme highlights specific lessons for those involved in the process.

Service purchasers and providers

- Older people say that their lives are about more than health and social care. Transport, housing, leisure services, money, companionship and community are all important. This is primarily an area for chief executives and leaders of councils to give a lead.
- Appropriate services for those older people who do need health or social care support are still important. However, health and social services need to break out of a dated, service-driven approach to such support. It would be disappointing if services were not able to respond to this challenge. Direct payments schemes offer a starting point.
- There is a great deal of talk about holistic approaches; about moving away from a welfare-based view of older people as vulnerable and towards a rights-based approach which sees older people as citizens. Service planning and delivery needs to put this rhetoric into practice.
- It is crucial that older people are involved 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.

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- Involvement in Older People's Strategies requires some standards. The programme suggests these should include: involving older people right at the start; involving more than one or two token older people; allocating the necessary time, resources and commitment to involvement; and being clear about exactly what older people might influence.

Central government policy-makers

- A focus on key government targets has brought some gains for older people. However, services can be so target-driven that they are less likely to be flexible and responsive to the specific needs of older people. There is a need to develop national standards to service delivery and approaches to 'person-centred' services which have been developed with older people themselves and reviewed by them. For example, the issues around intermediate care highlight some of the barriers and also some opportunities.
- Government needs to find a way to encourage local services to be more person-centred without simply controlling the agenda from the centre. National standards on service delivery (fully informed by the views of older people) can be important levers and drivers locally. However, national drivers can only do so much – and there is a need to develop locally driven approaches and standards. There is learning about direct payments, community organisation, user forums, involvement of older people in Older People's Strategies locally, development of information, advice and advocacy initiatives which need to be encouraged more generally.

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

(Older woman in Petch, 2003)

Funders of older people's strategies or research on ageing

- Most programmes and strategies still see older people as the passive objects of these initiatives. There is a need to involve older people during the development of strategies or agendas.
- Models are developing of ways to involve older people in all stages of agenda setting, implementation and review. Funders and strategists need to learn from good practice elsewhere and develop standards in their own practices. For example, in setting the questions, was an older people's reference group in place? What roles did the funder expect older people to play in the projects? How did the project (or the programme) validate the conclusions with older people? What standards did the funders have in feeding back the results to older people?

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.
- Older people are dealing with bureaucratic systems: recognising this and understanding some of the limitations may help them achieve more satisfactory results.
- 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 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 older people tend to be portrayed as either vulnerable and passive receivers of care, or as heroic and active rivals to younger people. There is a need to recognise the rich opportunities that come with old age as well as the losses. Older people in the programme have said that old age is a time of constant renegotiation throughout which it is vital to retain a sense of the older person as an individual.
- Projects within the programme are capturing the lives and times of older people. For example, reminiscence projects working 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 to communities and to schools. There is a need to develop, respect and use these personal histories.

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

(Discussion at Older People's Conference)

About the programme

This *Foundations* draws together an overview of 17 projects within the Joseph Rowntree Foundation's Older People's Research Programme (2000-2004). 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.

References to 'the programme' relate 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.



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

Members

Vera Bolter (Action for Health, Senior Citizens in Newcastle, from 2001)
Tony Carter (Greater London Forum, until 2003)
Stan Davison (Barnet Senior Citizens Forum and Steering Group Chair since September 2001)
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)
Pat McWeeny (York Older People's Forum)
Nell McFadden (Inverclyde Older People's Forum)
Jean Martin (Pepperpot Club, Kensington and Chelsea)
Tony Martin (York Older People's Forum, until 2002)
Olive Morgan (Wiltshire and Swindon User Network, until 2001)

Betty Porter (Strathclyde Elderly Forum, until 2000)
Gloria Williams (Pepperpot Club, Kensington and Chelsea)

Officers

Paul Bedwell (Department of Health, to 2001)
Peter Fletcher (Peter Fletcher Associates, to 2000)
Tessa Harding (Help the Aged, programme adviser, to 2002)
Melanie Henwood (consultant/analyst, programme R&D adviser)
Louise Keeble (JRF administration support, to 2001)
Jim Kennedy (member of JRF's Social Care and Disability Committee, to 2003)
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)

How to get further information

A full report on this programme, **Older people shaping policy and practice** by the Older People's Steering Group, is published by the Joseph Rowntree Foundation (ISBN 1 85935 244 8, price £14.95).

This *Foundations* is based on the following studies. Titles published by the Joseph Rowntree Foundation are (or will be) available to buy in print from York Publishing Services at the address above or through our website, www.jrf.org.uk/bookshop. More recent reports are also available for download free of charge from the bookshop. Reference numbers are given for any *Findings* summary published by the Foundation: you can read *Findings* on www.jrf.org.uk, or get printed copies by calling 01904 615905 or emailing publications@jrf.org.uk.

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Published by
Joseph
Rowntree
Foundation

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40 Water End
York YO30 6WP
Tel: 01904 629241
Fax: 01904 620072
ISSN 1366-5715

The Joseph Rowntree Foundation is an independent, non-political body which 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 and practitioners. The findings presented here, however, are those of the authors and not necessarily those of the Foundation.



Photos: www.johnbirdsall.co.uk (posed by models)