

A BETTER LIFE: VALUING OUR LATER YEARS

The Joseph Rowntree Foundation's (JRF's) major five-year programme *A Better Life* aimed to explore what 'quality of life' means for older people with high support needs, and to examine what can help us all to improve our final years. The main work of commissioning and publishing projects relating to this goal finished in 2013. Our subsequent work, to disseminate the findings and to reflect on the meaning of the evidence base as a whole, identified seven challenges:

Key points:

- We all need positive images and balanced narratives to challenge ageist assumptions. Old age is not about 'them', it is about all of us.
- We all need to make the effort to see and hear the individual behind the label or diagnosis, taking into account the increasing diversity of older people as a demographic group.
- We must ensure that all support is founded in, and reflects, meaningful and rewarding relationships. Connecting with others is a fundamental human need whatever our age or support needs.
- We need to use the many assets, strengths and resources of older people with high support needs through recognising and creating opportunities for them to both give and receive support.
- We must all be treated as citizens: equal stakeholders with both rights and responsibilities, not only as passive recipients of care. We must also have clarity on what we can reasonably expect from publicly-funded services and what we will need to take responsibility for ourselves.
- The individual and collective voices of older people with high support needs should be heard and given power. We must use a much wider range of approaches to enable this.
- We need to be open to radical and innovative approaches; but we also need to consider how, often simple, changes can improve lives within existing models.

The research

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BACKGROUND

The world has changed since this work began. We are facing a major crisis in the funding of public sector services, particularly in social care, with successive rounds of cuts forcing the withdrawal of services and tightening of eligibility criteria in many areas. Recent scandals in health and social care suggest that some over-stretched services are failing to provide older people with basic dignity and nutrition. Many of the voluntary sector organisations on which older people depended for practical, social and emotional support, transport and activities have reduced services or closed. Meanwhile, cuts are threatening the local infrastructure – community buildings, libraries and parks – which promotes the wellbeing of older people and those who support them.

Yet our population is continuing to age at a dramatic rate. The number of people aged 85 and over in the UK (1.4 million in 2012) is predicted to double in the next 20 years and nearly treble in the next 30. As this age group grows, it seems likely that the proportion with chronic conditions and (often multiple) disabilities will also increase. Around 40% of people aged 85 and over already have a severe disability that makes it difficult for them to carry out daily activities (Falkingham, 2010).

Public services in their current state cannot keep up with growing demand. The private sector plays a key role (particularly in England, though increasingly in Scotland, Wales and Northern Ireland), providing care homes, retirement housing and home-based care services. Much private provision is simply contracted-out local authority provision (and therefore subject to the same challenges of limited public funding) or, where it is a pure private exchange between provider and customer, is not affordable for significant swathes of the population. There is poor practice in parts of the private sector, where compassion seems to have been squeezed out to maximise profit, but as our evidence shows there is also plenty of excellent and creative practice here – driven by a real focus on what older people want (Owen 2012).

To date, most of the political debate on ageing has focused on the ‘demographic time bomb’ and on what the state can (or cannot) afford, specifically in relation to the funding of long-term social care for those individuals who need it. The *A Better Life* work has sought to widen the parameters of the discussion and to assert that a good life goes beyond just what the state can afford. It is also not just about social care or even wider services, and does not only concern individuals.

Building the evidence base

During the early stages of this work a team from the Open University (Katz *et al.*, 2011) talked to older people with high support needs about what they valued and compared their findings with those of similar studies. What mattered most included relationships, input into decisions, the opportunity to mix with other people, living somewhere pleasant and accessible and being able to get out and about. People also highlighted resources which could act as barriers or enablers, such as money, support, information, other people’s time, transport and technology.

Throughout the programme we presented stories, evidence and ideas to demonstrate what the seven challenges mean to older people and why they matter. We argue that these can provide the foundation on which to build a better life for older people with high support needs.

JRF commissioned over 30 outputs in all, including qualitative research into small-scale mutual support schemes, care homes and specialist housing with care schemes, and quantitative studies looking at demographic trends, housing market options and the affordability of retirement housing. The programme also included thoughts from diverse groups: ranging from lesbian, gay and bisexual older people to those trying communal approaches to ageing.

The Better Life book

A Better Life: valuing our later years was commissioned by JRF to draw out and reflect on the key messages from this body of work. A panel of advisors worked with the author, Imogen Blood, and JRF team in order to explore what the findings might mean now for different people. What do they tell us about the lives of older people and what they value? How can they begin to inform a manifesto for change?

The book draws out and reflects on the key messages from the body of work. It weaves the stories and words of older people into analysis and fleshes out the seven challenges, outlining practical examples and models for putting these into practice. A recurring theme in the programme is that ageing is about all of us; it is everyone's business – not just those working in care homes, commissioning health and care services, or developing government policies and programmes. We wanted to bring as wide an audience as possible with us and were keen to include some of the individual voices and group stories that had made a lasting impression on us as we read back through the material. We chose an approach which uses the stories and experiences of individuals, groups and organisations to illustrate the broader themes from the research. We feel that these offer a reality check, by grounding the broader vision in real lived experience.

"It's time for a grounded campaign which sets people alight and offers them practical advice at the same time. The message should be: you may need support as you age but there are ways of designing and shaping this yourself, or getting involved in schemes where your voice matters and your membership makes a difference."

Helen Bowers (Bowers et al., 2013)

Conclusion

It is clear that we need to make radical changes to create and sustain the kind of future we want – for ourselves and those we care about – as we get older. Moving forward involves not only changing the culture of services, but also the wider culture from one that undervalues older people, their rights, wants and assets, to one that values what they offer. To realise the vision of *A Better Life*, we urgently need to re-assess the way we view 'older people'; whether and how we think about our own ageing, our later years and our death; what we expect from the state, others and ourselves; and what we are prepared to give, use and spend.

Evidence from *A Better Life* points to seven challenges that we must overcome for older people to enjoy a good quality of life now and in the future. Although few would disagree with these at a general level, the greatest challenge will be to apply them in our daily personal and professional lives, our organisations and our communities.

These changes are not bits of sticking plaster to use while we are waiting for things to get better. Neither are they a luxury that we may or may not be able to afford. We should judge whether systems, practices and policies are working precisely on the basis of whether or not they are promoting good lives for older people. These challenges are not specific to a particular sector, service or profession: a key message from the programme is that these apply in care homes, health services, and voluntary sector organisations and generally in older everyday lives. This requires a considerable shift in cultures and attitudes. Change will be needed at all of these levels to succeed in building a better life for older people with high support needs.

We – the participants, researchers, programme managers and advisors – urge that the seven challenges of *A Better Life* form the bedrock on which joint solutions can be developed.

"When we are old we are aware of the beauty of life. Young people take everything for granted. We know that life is beautiful. We know a lot and we are conscious of this and this is a beautiful thing".

Alice Herz-Sommer 2012

References

Bowers, *et al.*, (2013), Widening choices for older people with high support needs

Falkingham, J, *et al.*, (2010) Demographic issues, projections and trends: Older people with high support needs in the UK. JRF programme paper

Katz, J, *et al.*, (2011) A Better Life: what older people with high support needs value (JRF)

Owen, T, *et al.*, (2012) Promoting quality of life in care homes (JRF)

About the project

This paper summarises the key messages from the body of work that makes up JRF's *A Better Life* programme of work. Publications and resources from the programme are available free from our website: <http://www.jrf.org.uk/work/workarea/better-life>

FOR FURTHER INFORMATION

The book, **A Better Life: Valuing our later years**, by Imogen Blood, is available as a free download at www.jrf.org.uk

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