

A BETTER LIFE: VALUING OUR LATER YEARS

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JRF

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FOREWORD



Hundreds of thousands of older people need a great deal of support. This book presents a vision of what life can be like, and should be like, for all of us as we get older. This vision is not unattainable, it is about being recognised as individuals, with our own passions, preferences and interests. It is about having a network of meaningful relationships, about being able to get the right support – no matter where we live. It is about being looked after by staff who are confident, who are able to relate to us and who are appreciated for the work they do. It is about new ideas, but also simple things that can matter a lot, like being able to get outdoors. It is about older people speaking up and driving change.

One of the strengths of the book, and indeed the whole programme *A Better Life* is that it is firmly grounded in experience. Thanks to the hundreds of older people, their relatives, friends, carers and all the professionals who contributed to the programme, the book paints a vivid picture of what it is like to need a lot of support. The stories bring to life the warmth, humour and camaraderie and sometimes the loss, pain and frustration of the older people who live with long term, often multiple, conditions and disabilities.

We live in a world that is still too often reluctant to acknowledge these needs. Even today, it is all too easy, and all too acceptable, to disregard, ignore and sideline those who can't communicate well or lack the power to get themselves heard. We are conditioned to see older age as having no value of its own, bringing only loss and decline, vulnerability and unwanted 'dependence'.

Perhaps the most important message to take away from the book is to make sure that we put the vision into practice in our everyday decisions, in our work and in our private lives. The great thing about *A Better Life* is that it touches all of our lives: most of us can immediately think of at least one person who needs support. All of us can imagine needing that support ourselves one day. It is not so difficult then to picture the way the ideas in the book can make a difference.

The people featured in the book are clear that the things that really matter are not directly about services but about their health, their relationships, and being valued. Services can help achieve these but will not be able to do it on their own. We need to recognise that we can't just leave it to those whose job is to care. If we all play our part, the vision of *A Better Life* can become a reality.

Julia Unwin

Chief Executive of the Joseph Rowntree Foundation

CHAPTER 1: AN OVERVIEW

Introduction

Angela lives in a housing scheme for older people. She has a long-standing interest in computing and is a regular blogger on the residents' network set up by her housing provider. She began helping friends and neighbours in her scheme to access the Internet and set up Skype. Her housing provider then encouraged her to visit other schemes and introduce more residents to new technologies. They supported her by paying for her transport and organising the visits. Angela describes the considerable satisfaction she gets from helping others to connect with the outside world in new ways.

Croucher and Bevan (2012) explore what motivates Angela and the many other older people they met in such schemes who actively volunteer their time to support others and organise community activities. Contrary to what we might expect, those who provide this kind of support to others in retirement communities are not always the youngest and healthiest: often they are disabled or in poor health themselves. Croucher and Bevan (2012) conclude that:

“People were keen to maintain and develop their own identities as they grow older and continue to engage with others, and use and share their skills and experiences” (p.11).

WRVS (2011) estimates show that in 2010 older people provided a range of formal and informal volunteering services to their communities which were worth over £10 billion per annum to the national economy, plus a number of benefits which cannot readily be quantified.

Maria and Pat met through a cardiac patient support group. Maria (who is recovering from a stroke) provides transport for Pat who is no longer able to drive following heart surgery: both women are in their eighties. They struck up a friendship through their shared experience of learning to live and cope with disability. Maria explains:

“Knowing Pat has helped me to rebuild my self confidence ... I get conversation and support, and [am] learning to accept help from others who share my love of poetry, art, walking and wildlife. What do we have in common? Like-mindedness and singing!”

Bowers *et al.*, 2013, p.22

Maria and Pat's story reminds us how much we can gain from our relationships with others who share similar experiences – and how important this emotional support can be when you are coping with loss, illness, disability or discrimination, as many older people are. On a practical level, older people with high support needs encounter major barriers trying to access transport and, especially in rural areas, many end up literally stuck in their homes. Simple solutions like car-sharing can open up the outside world again.

These are examples of older people offering their skills, and giving as well as receiving support and friendship. Their relationships with others are (to use the title of one of the projects from *A Better Life*), 'not a one-way street'. The kinds of help being given and received here – IT training, transport and emotional support – are at the very margins of what formal services can provide yet they can be highly valued: they can provide access to activities,

services, people; build confidence; make lives better. Whatever your age, life should include pleasure, friendships and shared interests – whether singing, having a laugh or messing around on the Internet – as well as meeting what professionals might term your transport or emotional support ‘needs’.

The *Older People’s Inquiry*, which the Joseph Rowntree Foundation (JRF) convened nearly a decade ago (Raynes *et al.*, 2006), found that many older people place great value on ‘that little bit of help’ and that, when they get it, it can often enable them to remain independent. There is some evidence to suggest that receiving a bit of practical or social support can reduce the need for health and social care services.¹ However, many older people will also need to connect with the statutory systems which provide care, support or welfare benefits.

A system in upheaval

We are facing a major crisis in the funding of public sector services, particularly in social care. Another round of cuts is forcing the withdrawal of more services and the further tightening of eligibility criteria in many areas. Age UK (2012) describes how council spending on older people’s social care stagnated then decreased in the years following 2005, decreasing by 8% in the year between 2010–11 and 2011–12 alone. Recent scandals in health and social care suggest that, at their worst, some over-stretched services are already failing to provide older people with even 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 been closed or are operating with reduced and uncertain funding. Meanwhile, cuts are threatening the type of 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 in the UK aged 85 and over is projected to rise from 1.3 million in 2007 to 3.3 million in 2033. As this age group grows, it seems likely that the proportion with chronic conditions and (often multiple) disabilities will also increase. For example, estimates suggest that, in England and Wales alone, there may be around 670,000 people currently living with dementia. Around 40% of people aged 85 and over have a severe disability which makes it difficult for them to carry out various activities of daily living (Falkingham *et al.*, 2010).

The portrayal of this as a ‘demographic time bomb’ has not been helpful (Mullan, 2002) and, alongside the rhetoric of ‘skivers v. strivers’ amongst the working-age population – can serve as a way of legitimising the narrowing of the welfare state. However, things will clearly need to change radically if we are to create and sustain the kind of future we want – for ourselves and those we care about – as we get older. Public services in their current state cannot keep up with growing demand (House of Lords Select Committee on Public Service and Demographic Change, 2013). The private sector plays a key role (particularly in England, though increasingly in the other nations of the UK), 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 (Aldridge *et al.*, 2012a and 2012b). There is poor practice in parts of the private sector where compassion seems to have been squeezed out to maximise profit. However, there is also plenty of excellent and creative practice here – driven by a real focus on what customers want (Blood *et al.*, 2012a and 2012b; Owen and Meyer, 2012).

Clearly, the efforts of people like Angela, Pat and Maria can be only part of the solution, but their stories and the stories of the hundreds of older people and organisations, groups and professionals who have participated in JRF's *A Better Life* programme do give us some important insights into what change might look like and where it may come from if the conditions are right.

There is hope here, but it is hard to see how communities will simply emerge from the ashes to take over where public services are leaving off without significant re-distribution to tackle widening inequalities and re-investment in areas where industries, businesses and community buildings have shut down. As Julia Unwin (Chief Executive of JRF) said in a recent lecture: 'We are producing communities in which people feel unsafe, disconnected and unsupported' (Unwin, 2013).

The sort of DIY support networks of which Angela, Pat and Maria are a part do not tend to sprout spontaneously (especially in these conditions). They may also need some support at critical times if they are to be sustained. Pat and Maria met through a support group run by health services and Angela has been encouraged and supported, financially as well as practically, by her housing provider.

A Better Life

In 2009, JRF launched the five-year, £1.5 million programme called *A Better Life* to explore what can help older people with high support needs to improve their quality of life (and what 'quality of life' means for them) now and in the future. JRF recognises that older people with high support needs are one of the most marginalised groups in the UK. From the outset, however, there was an awareness of the challenges of defining them or even trying to argue that they form a distinct group.

The prevalence of most health conditions increases dramatically amongst the oldest age groups (Falkingham, 2010) but this does not mean that we can base the definition solely on chronological age. There are large numbers of people who develop high support needs in their fifties or sixties, enter their later years with a pre-existing disability, or live to be over 100 with little need for assistance (Serra *et al.*, 2011). Many of the 'younger old' with high support needs are also disadvantaged by poverty or discrimination, which may have contributed to physical and/or mental health problems in the first place.

JRF's definition of 'older people with high support needs'

"Older people of any age who need a lot of support due to physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old, though some will be younger. Many will be affected by other factors including poverty, disadvantage, nationality, ethnicity, lifestyle etc. Some of the very oldest people may never come into this category."

JRF, 2009

In the 'social model' (as opposed to the medical model) of disability, it is the physical, attitudinal, economic and social barriers they face which disable people, rather than their medical conditions *per se*. Using this model (as JRF does), an older person might have a chronic condition or multiple impairments

but have low support needs if they are living in accessible housing with assistive technology, within a supportive community. As Vic Forrest puts it,

“... it is important for all of us to recognise that it is not being older that is a problem but being older in our current society”.

Forrest, 2013

“... it is important for all of us to recognise that it is not being older that is a problem but being older in our current society”.

Broadening the debate

To date, most of the political debate on ageing has focused on what the state can afford now and in the future, specifically in relation to the funding of long-term social care for those individuals who need it. *A Better Life* has sought to widen the parameters of the discussion.

A Better Life is not just about what the state can afford

The good news is that pensioner poverty has fallen over the last 15 years (Pannell, 2012a and 2012b) and the most recent Office of National Statistics (2012) figures show that a quarter of retired households are in the overall poorest fifth of households (compared to over a half in 1977). There is still considerable inequality between the richest and the poorest pensioners (those in the richest fifth have an average disposable income 3.8 times bigger than those in the poorest fifth), but this has reduced in the last fifteen years as more pensioners have been raised out of poverty.

However, this overarching picture should not obscure the fact that many older people have been hit hard by the recession (and not just through the reduction in services). The rising costs of food, energy and care combined with problems in the housing market and losses or poor returns on investments have squeezed the budgets and reduced the housing options of many individual pensioners. There are still 1.5 million pensioners living in poverty and concerns are growing about ‘the squeezed middle’: the 1.2 million pensioners living just above the poverty line and the 9.2 million pensioner households with less than £1500 in savings (Pannell, Aldridge and Kenway, 2012a).

The Institute of Public Care (2011) estimates that in 2010 around 170,000 (or 45%) of the registered care home places in England were self-funded. They suggest that a further 170,000 older people in England are paying for care to be provided in their own homes. *A Better Life* projects have explored how older people’s financial assets affect their housing and care options, the decisions they make and – as a result – their quality of life (Pannell *et al.*, 2012c; Aldridge *et al.*, 2012a and 2012b).

Housing has a huge impact on quality of life at any age, but this is particularly so when you are older and if you have a disability or health condition. We hear accounts from the JRF research of older people who had been living in one room, people who had been physically unable to get out of their homes for years, and people who had had to use commodes because they could not access toilets (Katz, 2011; Pannell, Blood and Copeman, 2012).

Increasing numbers of those who bought homes under the ‘Right to Buy’ scheme in areas where the housing market is not strong are entering retirement and we know that there are many older people living in older, poorer housing that they own. Research from *A Better Life* demonstrates that:

- 75% of older people (and 69% of sick or disabled older person households) are home-owners (Pannell, Aldridge and Kenway, 2012a, p.13)

- Owner-occupiers are widely spread across the income distribution: there are approximately 1.3 million pensioners in the UK who own their homes but are also in the bottom fifth of incomes (Aldridge *et al.*, 2012a); 67% of pensioners living in poverty are owner-occupiers
- 6% of pensioner owner-occupiers have less than £75K equity in their homes (Aldridge *et al.*, 2012a)
- Around a third of all pensioners live in homes that would not meet the government-set Decent Homes Standard (Pannell *et al.*, 2012)²

Older home-owners who are both cash poor and equity poor have few options for repairing, improving or adapting their properties (HACT Fit for Living Network, 2012); they are unlikely to be able to afford retirement housing and may find they are unable to sell at all in the current market (Pannell, Aldridge and Kenway, 2012a).

A Better Life is not just about social care

Although undeniably important, the question of who should fund and provide long term social care has tended to overshadow the vital contribution of a wide range of other services and resources to the lives of older people. Where we live or where we would like to live – both in terms of our homes and the surrounding neighbourhoods – is critical to our quality of life in older age. Housing, transport, town planning, community safety, and the presence and accessibility of local shops, post offices, libraries, cafes, parks, community centres, and adult education, culture and leisure facilities: all of these things are vital when you are trying to build a better life for yourself in older age. Many of these services are being cut, have experienced chronic under-investment and privatisation in recent decades, or have been forced out of business by the rise of the big supermarkets and the impact of the recession.

These themes of home, place and space crop up throughout the report. In Chapter 3, we look specifically at how they can contribute to the development of the supportive relationships, which older people with high support needs value.

Older people with high support needs are also regular and ongoing users of the National Health Service (NHS). Public debate has, until recently, tended to focus on the numbers and costs of older people who are ‘bed-blocking’ and the strain this can place on care for other patients. However, the Francis report on the failings at Mid-Staffordshire NHS Foundation Trust has re-focused attention on the *experience* of older patients and the importance of their relationships with staff: points to which we return in Chapter 3.

A Better Life is not just about services

Historically, much of the care for older people with high support needs was provided by relatives and within families. With the increasing use of paid care and formal assessment processes, social work professionals may overlook or underestimate the importance of relationships, families, friendship circles, networks and communities of which older people with high support needs are a part. Sometimes these relationships are even viewed as risky, at least within the context of providing care: friends and family members have not been professionally trained, they may burn out or simply not turn up, or at worst they may treat the older person badly.

It is, however, important to remember that many older people with high support needs are receiving very little from the state: they are looking after each other, and getting help from family, friends and neighbours. Age UK (2012) has estimated that 800,000 of the 2 million older people who have care needs are receiving no support from either public services or private care agencies. Whilst the charity is right to be concerned about how many of this

group are ‘suffering in silence’, there will be others who are making a positive choice to use informal sources of support and it is vital that we support them and learn from them – especially in an era of reduced public resources. The New Economics Foundation describes this ‘invisible and informal economy of family, the home, the neighbourhood and community’ as the ‘core economy’ (Penny, 2012) and argues that it must be nurtured and developed. In the current economic climate, streamlining the public sector and stimulating private markets alone cannot provide the quantity and quality of care we need to support a better life for the growing numbers of those with high support needs.

Even where older people are receiving intensive care packages in their homes, or are living in a residential home, care services are not the only things that matter to them. As Scourfield puts it:

“It is often assumed that when someone enters residential care, their disability or illness is so all-consuming that they have no interest in anything other than their personal care and their day-to-day comfort”.

Scourfield, 2007, p.1136

In Chapter 2, we ask why it is that personal identity risks getting overlooked at this stage of life.

A Better Life is not just about individuals

With care increasingly professionalised, disabled people (and those politicians who wish to reduce the power and spending of local authorities) raised concerns that people were being herded into services which were configured to suit councils and those working for them. The personalisation movement has sought to hand choice and control over how their portion of care funding is spent to the older and/or disabled person. The key mechanism for doing this has been the individual or personal budget.

There have been a number of challenges implementing personal budgets for older people (Routledge and Carr, 2013), but one of the fears explored in Blood *et al.*, (2012a) is that, if rolled out fully, this approach may threaten collective models. For example, if older people living in a housing with care scheme choose not to spend their individual budgets with the scheme’s care provider, this core service may cease to be viable (even though everyone in the community benefits from the peace of mind of having carers on-site to respond to *ad hoc* situations that crop up when their individual carers are not around).³ As personalisation beds down, it will be more important than ever to find a way of preserving the rights of individuals without precluding the possibility of collective approaches.

In Chapter 4, we look at the messages from *A Better Life* about what ‘choice’, ‘control’ and ‘independence’ mean to people as they get older. In Chapters 3 and 4, we also challenge the assumption that these concepts are inevitably individualistic: sometimes people choose what is better for their community, not just themselves; sometimes people want control as a group, not just as an individual; sometimes people want to be interdependent, not just independent.

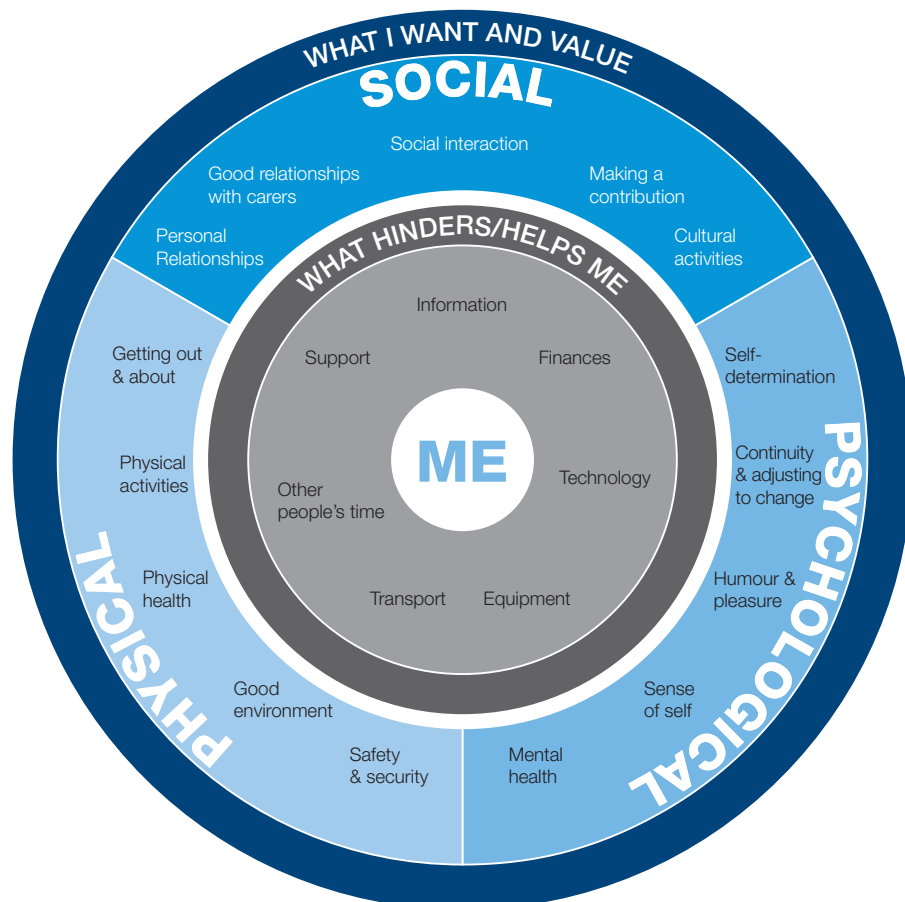
“We’ve gone so far down the individualised funding route that the recognition of the value of group or community has got lost”.

Advisory Panel Member

In Chapter 3, we consider the importance of personal relationships, groups and communities as we get older. What are the benefits where older (and younger) people give and receive mutual support, like Maria and Pat? What are the limitations of these kinds of arrangements? What sort of support do they need to get off the ground and be sustainable? How can a stronger sense of community be developed – in local neighbourhoods and in and around specialist housing and care homes for older people?

What is A Better Life about then?

JRF asked a team from the Open University (Katz *et al.*, 2011) to talk to older people with high support needs about what they value in their lives and compare their findings with those of similar studies. The things that mattered most to people included: their relationships; having input into decisions about their lives; having the opportunity to mix with other people; living somewhere pleasant and accessible; and being able to get out and about. People also mentioned the resources which could act as barriers or enablers to these things, such as money, support, information, other people’s time, transport and technology. This is shown visually in the following wheel:



What do older people with high support needs want and value? (Katz *et al.*, 2001)

Although people do not tend to frame the things they want and value in terms of services, such services are nevertheless important for many as a way of achieving these things. However, there are frustrations here: paid carers' time tends to be at a premium and many do not feel they have enough of it (and with the same worker) to get to know them. Others would like carers to provide different kinds of support, at different times, or just to do things slightly differently, but they do not feel able to change things.

JRF did not commission research to explore older people's experiences of health care specifically; however, there are striking parallels between the key messages from *A Better Life* and those emerging from recent nursing research about what matters most to older people. For example, Bridges *et al.*, (2010) found that when asked what made the biggest difference to their experience of hospital care, older people and their relatives talked most about whether or not staff had connected with them as a person, recognised and respected their relationships, and included them in decision-making.

Often it is the simple things that bring the most pleasure (and the lack of them can bring a sense of sadness and loss) but services do not always seem to be very good at delivering 'the ordinary'. The *Shaping Our Lives* project asked a mixed age group of disabled people to reflect on getting older and how older people with disabilities can best be supported to have better lives. One explained:

"I have a friend who lives in a residential home. I asked her what she would like more than anything else in the world and she said she would like to 'go out for ten minutes a day or every other day to feel the fresh air on my face, and eat a nice roast potato'"

Branfield and Beresford, 2010, p.18

Moving forwards

Changing the culture within services

Many of the services which provide care, housing and support to older people seem to spend a disproportionate amount of time fire-fighting crises; gate- and boundary-keeping; responding to the bureaucracy of performance management, regulation and funding; avoiding risks; and managing organisational change and complexity. In Chapter 5, we reflect on some examples of this from the programme and consider their impact on the lives of older people with high support needs.

The policy focus of the last decade or so has been on enabling older people with high support needs to remain in their own homes (and we should not forget that this is where the vast majority do indeed live) or to 'downsize', often into purpose-built retirement housing. As a result of this, the number of care home places fell by 10% between 2004 and 2010 (Pannell, Aldridge and Kenway, 2012a). Despite this, there are still approximately 400,000 older people living in care and nursing homes across the UK and there is evidence to suggest that numbers have been steadily increasing over the past few years (Owen and Meyer *et al.*, 2012). Two-thirds of care home residents have some degree of dementia or other cognitive impairment and three-quarters are classed as 'severely disabled' (Owen and Meyer *et al.*, 2012).

This sector faces some significant challenges. Managers wrestle with a complex funding, regulatory and inter-agency environment and the frontline workforce is poorly paid (as it is across the care sector as a whole).⁴ An unacceptably high number of older people have experienced disrespectful behaviour, neglect or even abuse in care homes. However, the way these

"I have a friend who lives in a residential home. I asked her what she would like more than anything else in the world and she said she would like to 'go out for ten minutes a day or every other day to feel the fresh air on my face, and eat a nice roast potato'"

incidents have been reported by some of the media has not exposed these deep-rooted challenges that face the sector but tended instead to play on the fears of older people and their relatives, reinforcing the policy line that going into a care home is a 'last resort'. The knee-jerk response to these problems has been to over-regulate care home providers and staff in a way that has created an atmosphere of mistrust.

Despite this, good practice is flourishing in some homes and it is important that its development is not stifled by negativity about the sector. The *My Home Life* project (part-funded by JRF's *A Better Life*) is working with care home managers and stakeholders to define and promote this good practice and, in Chapter 5, we include some examples of how change is being achieved.

Similarly, in the NHS there has been a recognition (strengthened by the findings of the Francis report) that the culture of services needs to change. Compassion and the quality of the patient experience must not be squeezed out by the drive for efficiency: values matter more than targets (See Oliver, 2013).

Changing the wider culture

One of the biggest obstacles to developing a positive response to the challenges and opportunities of our ageing society is the widespread culture that undervalues older people themselves and their rights, wants and assets. John Kennedy of JRF (Kennedy, 2012) writes of the need for 'a radical reassessment of our values if we are to have any hope of securing good services in health and social care for our future'.

If we are to realise the vision of *A Better Life* for older people now and in the future, we urgently need to reassess our values – how we view 'older people'; whether and how we think about our own ageing, our later years, our death; what we expect from the state, from others, and from ourselves; and what we are prepared to give, to use and to spend.

The following seven challenges have emerged from *A Better Life* and informed the development of the programme. We – the participants, researchers, programme managers and advisors – feel that they should form the bedrock on which joint solutions can be developed. 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, in health services, in voluntary sector organisations and generally in older peoples' lives.

A BETTER LIFE: THE SEVEN CHALLENGES

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.



We consider the first two challenges in Chapter 2; the next two in Chapter 3; and the next two in Chapter 4. Those familiar with the *My Home Life* project (Owen and Meyer *et al.*, 2012) will note the similarities between the headings and key messages of these three chapters and the *My Home Life* 'personalisation themes': 'Maintaining identity: see who I am!', 'Creating Community: connect with me!' and 'Sharing decision-making: involve me!'.

In Chapter 5, we look at some of the problems with current systems that have been identified by the programme. We return to review all the challenges in Chapter 6, as we summarise the key messages and draw together the practical ideas for change that we introduce throughout the report.

The evidence base arising from *A Better Life*

As part of *A Better Life*, JRF has commissioned qualitative research into small scale mutual support schemes, care homes, and specialist housing with care schemes; alongside quantitative studies looking at demographic trends, housing market options and the affordability of retirement housing. The programme has also included reflections from diverse perspectives: ranging from Gypsy families and lesbian, gay and bisexual older people to those trying to establish communal approaches to ageing. Outputs have ranged from a good practice guide aimed at providers and commissioners to a microsite including poetry and a photo gallery of centenarians.

We tell the story of the programme in more detail and list all the projects and publications from it in the references and appendices of this report.

About this book

This book was commissioned by JRF to draw out and reflect on the key messages from this body of work. An Advisory Panel was formed to work alongside the writer and JRF team in order to explore what the various 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 comments and ideas of the panel (whose details are included in the appendix) have shaped this book and quotes from them are presented throughout the text in shaded boxes.

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 engage with as wide an audience as possible, and we 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. There were, however, some important messages which could not be expressed effectively in this way, and as a result some sections include more stories than others.

Alice Herz-Sommer,
centenarian pianist



CHAPTER 2: SEE WHO I AM!

“Just because I am growing older doesn’t mean to say that I want to fade away. I have the same hopes, fears, passions and interests that I always had and I need help to facilitate them”.

Beth, older woman in Knocker, 2012

One of the key messages from *A Better Life* is the importance of looking for the person behind the stereotype, of hearing the voice through the diagnosis – and how little this seems to happen in the provision of mainstream services and out in the wider world.

The diversity of the older people we meet through the projects is impressive: we are introduced to older gay men, Ukrainian refugees from the Second World War and a centenarian who learns Bach by heart.

Perhaps it is not so much the wide variety of these lifestyles that is surprising but the reminder that this gives us that older people with high support needs actually have any sexuality, or a past which may include historic and traumatic experiences, or considerable talents. That we should need a reminder is, of course, shocking. Once someone becomes an older person, and especially where they develop a health condition or a disability, all the other facets of their identity tend to be subsumed under these other labels.

In this chapter, we examine the first two of the challenges that have emerged from *A Better Life* which we introduced on page 13:

- 1 We all need positive images and balanced narratives to challenge ageist assumptions. Old age is not about ‘them’, it is about all of us.
- 2 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 ask why the individual identities of older people with high support needs are so often overlooked, and present some examples of good practice from the programme as to how these identities can be ‘unlocked’. We consider the way in which older people are marginalised and viewed as ‘other’ and how *A Better Life* challenges stereotypes by hearing the varied experiences and outlooks of real people. We present information about the increasing diversity of older people with high support needs – in terms of ethnicity, gender, sexual orientation and wealth – and discuss how we can respond to this without losing the individual yet again in another layer of stereotypes and assumptions.

‘Unlocking’ the whole person

Issues with memory, learning disability or depression can certainly mean that more effort, time and consideration are required to understand the voices of some older people with high support needs. However, if we apply the social model of disability (introduced on page 10), what tends to disable people most are the attitudes of others. Many younger people – sometimes even those trained and paid to provide care – do not even think to try and find out what makes an older person with high support needs tick: what they want, who they are. It is as though we have forgotten that the older and disabled person even has an identity at all.

In their research into older people's experiences of home care for the Equality and Human Rights Commission, Sykes and Groom (2011) present a series of case studies in which people described feeling 'steamrollered' and depressed by some aspects of assessment and delivery which they experience as rigid, oppressive and insensitive. One carer squirts shower gel on a man but refuses to touch him; another carer talks to their friends on the phone while dressing an older person. After having care workers in for a fortnight to look after her and her husband, one woman recalls how she felt like 'a pudding, not quite a human being. My life was being taken over' (p.63).

We hear similar messages from the disabled people featured in JRF's collection of short films, 'Who has the power in your care set-up?' For example, Vicky explains that few carers do more than say 'Hello'; instead they focus on 'getting on with the job'. She explains, 'I'm a person here and I shouldn't be ignored, that's what makes me so angry' (Hevey, undated).

All groups which suffer discrimination have typically been portrayed as 'other' by those who discriminate against them; stereotypes are formed and generalisations made, which means that they are, at some level, 'all the same'. It may be particularly important from a psychological point of view to keep older people at a distance in this way, since 'we' will become 'them' at some point. As a participant in Branfield and Beresford's research points out:

"People like to think that old is different. They don't like to be reminded of their own mortality".

Branfield and Beresford, 2010, p.12

We hear examples of this in several of the reports from *A Better Life*. Vic Forrest (2013) tells us that one of his neighbours laughs nervously and says she will never grow old when the subject of getting older is raised. Residents of older people's housing schemes complain that their schemes are full of old people (Percival, in Garwood, 2010). Pannell, Aldridge and Kenway (2012a, p.39) report the findings of a project on resources in later life and comments that 'respondents did not think of themselves as old (even if they were getting slower or had less energy); other people were 'old' but not them'.

This is more than a case of individuals grappling with their own mortality; it is also a by-product of the way in which older people are portrayed and treated by government policy, the media and other institutions. The mainstream debate around an ageing society has so far tended to be one of 'how can we fix older people?' and 'how much will it cost to do so?' The main alternative to this line of thinking has been to celebrate those who 'defy' age: people who *still* do extraordinary things or manage to look youthful. This other extreme is just as destructive, as it is based on the same rejection of older age as a valued part of life.

Current social work practice focuses more on assessing the risk, dependence and vulnerability of older people than on looking at their strengths, resources and aspirations. The pressure on services, combined with the way in which performance is monitored and charges calculated, has tended to reduce the lives of older people with high support needs to a series of tasks to be undertaken – a point evident from the home care stories of Sykes and Groom (2011) and also one made by Bowers *et al.* (2009). Both in wider society and within some organisational cultures, there is a tendency to view and treat older people as a 'burden': others know what is best for them; and they are patronised or ignored.

A Better Life does, however, report several nuggets of good practice in which housing support or care home staff have succeeded in 'unlocking' the identity of an older person which had effectively got lost behind learning disability, dementia or sensory impairment.

"People like to think that old is different. They don't like to be reminded of their own mortality".

My Home Life urges us to 'See who I am!' and presents several stories of care home residents who were distressed, withdrawn or aggressive until staff took the time to find out more about them and find ways of maintaining their interests and links to the past. We hear, for example, about Mr Thomas who had a diagnosis of dementia and used to be very distressed first thing in the morning. Staff discovered he had been a dairy farmer all his life and was used to getting up at 4am and going out to round up the cattle. They found that they could help him overcome his anxiety if they made sure his work trousers and a glass of milk were by his bed when he awoke, and if they talked to him about the cows.

Finding positive ways of channelling energies and skills results in a better life for a number of the older people with high support needs who we meet across the programme. For example, in *Perspectives on ageing with a learning disability*, we are introduced to Eileen:

"Eileen is an older woman that we have supported for many years now. She has been in residential care more or less all her life and has no contact with her family. Over the years she has acquired a reputation for having some behaviour that is challenging. She wants to pick up everything on the floor or pavement she sees and can get very angry when anyone tries to stop her. Now we have found her a job where she picks up litter on the beach. She loves this job."

Team leader, Avenues Trust, see Ward, 2012, p.10

Eileen's story illustrates what is sometimes described as an 'asset-based approach': instead of focusing on needs and problem behaviours, her support workers have looked for interests and skills. In the right context, Eileen's desire to pick everything up can be a positive contribution. Similarly, in *My Home Life*, Mr Garrick (who had been extremely withdrawn) now tends his own section of the garden; Mr Jennings (a former handyman, who cannot express himself verbally and had previously been aggressive to hospital staff) has helped to decorate the home. Workers in these homes have had the time, values and vision to find out about the person and develop simple solutions to help them maintain key aspects of their identity.

Murphy *et al.* (2010) use 'Talking Mats' with visual images to improve dialogue and decision-making between people with dementia and their families and carers. This simple tool seems to work primarily because it provides a focus for the conversation, because it sets a tone of joint problem-solving, and because the images help when people forget words or get words muddled.

Many of the individuals we hear about through the programme challenge common stereotypes of older people as being passive and deferential, private and easily shocked, or desexualised. Their stories often contrast with those we typically hear about ageing, which tend to focus on the inevitability of decline and the closing down of aspirations and experiences.

Katz *et al.* (2011) introduces us to Terry who humorously describes how he 'rebels' against the rules in his nursing home. We meet older people who are co-habiting with partners they have recently met, and older gay men using the internet to meet and connect with other gay men. We meet activists with dementia who speak at international conferences and lobby politicians. We meet older people who open up readily and share very personal things with researchers and younger friends: attitudes to death, experiences of loss, and information about their financial circumstances.

We meet older people who are philosophical about the challenges of ageing. Their attitudes perhaps lend support to the ‘u-bend of life’ theory. The Office for National Statistics (2011) found in their British survey of subjective wellbeing that younger and older adults were more likely to report ‘life satisfaction’, feeling ‘worthwhile’ and having been ‘happy yesterday’ than those in their middle years. Some psychologists and economists explain this with the theory that we get better at controlling our emotions, accepting misfortune and are less prone to anger as we get older (*The Economist*, 2010). For example, Jennie says:

“I’m quite content, I’ve had my life, I’m not demanding, I take things as it comes, there’s a lot of people far worse off than me “.

Katz *et al.*, 2011, p.30

Not all the stories are positive and inspiring: we also encounter loss and pain, ‘difficult characters’ (Croucher and Bevan, 2012), and those who feel anxious and uncertain about the future. As Jimmy reflects:

“You begin to wonder in your moments of depression, have you got any time left to do anything ...”

(Katz *et al.*, 2011, p.30)

Whilst we need to challenge the negativity about ageing and older people, it is important to counter this with a balanced picture, rather than one which is relentlessly upbeat or focuses only on the extraordinary achievements of some older people.

Making sense of diversity

“It’s about individuality and it comes out time and time again that, even if people belong to a number of different equality groups, you cannot make assumptions about them because of that membership.”

Advisory Panel Member

Having considered why and how the *personal* identities of older people with high support needs risk getting lost and can be unlocked, let us turn now to the question of ‘social identity’ (Blood and Bamford, 2010⁵). Social identity is perhaps best viewed as a package consisting of our race or ethnicity, our gender, our disability (or perhaps our location on a continuum in respect of our physical ability, our mental health and our learning ability), our religion or beliefs, our sexual orientation, our age and our socioeconomic status. Social identity interacts with our personal identity and life experience to make us who we are. Understanding that we all have multiple aspects of social identity can help us to make sense of our overlapping membership of different groups (e.g., being older, disabled, a woman, etc.).

A Better Life demonstrates how the oldest generations are becoming more diverse in terms of their social identity as the gap between male and female life expectancy narrows and the UK’s black and minority ethnic communities age. There is also increasing variation in people’s lifestyles and domestic arrangements, with more ‘out’ lesbian and gay older people (some of whom are in civil partnerships) and more people who are divorced or who never married.

Ethnicity, gender and sexual orientation of older people: some facts and figures from England and Wales

In 2011, 2.6% of the white British population were aged 85 and over, where the age structures of ethnic minority groups in England and Wales were much younger. 1% of the African Caribbean community were in this age group, but only 0.2% of the Pakistani community and less than 0.1% of the Black African community were aged 85 and over at the time of the Census (Office for National Statistics, 2013). However, as cohorts of immigrants age, there is likely to be a dramatic increase in the number of older people from black and minority ethnic groups in the UK.

Estimates suggest that there are around 100 women for every 40 men within the 85 and over age group, and the average woman spends 17.7 years with a limiting chronic illness or disability compared with 14.6 years for the average man (Blood and Bamford, 2010). Although life expectancy remains higher for women than men, the gap is gradually closing: between 1987 and 2007, life expectancy at age 65 improved by 34% for men in the UK compared to just 18.5% for women (Falkingham, 2010). We should therefore expect to see more of a gender balance amongst future cohorts of older people with high support needs.

In the absence of accurate data, the government is currently working on the basis that between 5% and 7% of the UK population is lesbian, gay or bisexual (Blood and Bamford, 2010). This would suggest that (using 2011 Census population data) there are likely to be twenty or thirty thousand lesbian, gay and bisexual people aged 90 and over in England and Wales. Given the very different historical context for this generation, many will not have 'come out'.

What are the implications of this increasing diversity? It certainly seems to suggest a need to widen the choices for older people in terms of housing, support and care. One size will no longer fit all – if it ever did. But can these statistics inform our planning about what types of housing, support and care will be needed, and by whom and where? Or is there a risk here of making assumptions about the resources, preferences and needs of these groups and the individuals in them?

Understanding how social identity may have shaped someone's experiences, needs and preferences is a key part of 'unlocking' their identity and taking a person-centred approach to supporting them. For example, it is important that staff working with older people appreciate the 'history of secrets and violence' (Knocker, 2012) which shaped the lives of older lesbians and gay men, since it explains why trust and safety are so critical to them and why many still prefer to keep their sexual orientation hidden. Gender differences in education, employment and role expectations tend to have been much starker for the 'oldest old' generation and this can result in different needs for men and women: for example, many older women have had little experience of dealing with financial matters and some older men lack key domestic skills (Blood and Bamford, 2010).

However, social identity in itself should never be used as a shortcut for working out what people want or what matters to them. For example, understanding the medical condition of dementia, how others have experienced it, and what they have found useful should help us to engage with and support a person who has a diagnosis of dementia. However, this knowledge is no substitute for getting to know the individual, finding out what they can offer, exploring the challenges they face and asking what matters

most to *them*. Similarly, it is important that staff working with older people understand that people from different cultural and religious backgrounds may need or prefer to eat different types of food, but this does not mean they should automatically assume that a South Asian person will not want to have a roast for their Sunday lunch (Nijjar, 2012, p.7).

When Carr and Ross (2013, p.6) point out that ‘building up trusted relationships with consistent staff that respect and understand who they are and what their needs and preferences are is immensely important to older LGB [lesbian, gay and bisexual] people’, one reaction might be: ‘Well isn’t this important to everyone?’ It is, and this is why getting things right for diverse groups of older people should lead to better services for everyone. As a man attending an *Opening Doors* group told Knocker:

“I don’t want a different service. I want a good service. One that is acknowledging of me as an individual gay person, but not making a special case.”

Knocker, 2012, p.13

Good services strike the balance between appreciating a person’s individuality whilst also understanding them as members of different groups, communities and networks. A key message from the programme is that both of these aspects are equally important to older people with high support needs. In Chapter 4, we will look more at the question of how we can promote equality for older people with high support needs, but first, in Chapter 3, we will consider how and why relationships matter.

“I don’t want a different service. I want a good service. One that is acknowledging of me as an individual gay person, but not making a special case”.

CHAPTER 3: SEE MY RELATIONSHIPS AND NETWORKS!

The quality of our lives and the extent to which we need support as we get older is shaped as much by the relationships we have and the communities we live in as the health problems we may develop. The significance of relationships runs throughout the programme, and where people have good relationships – with partners, families, friends, neighbours and paid staff – their lives are clearly better.

In this chapter, we discuss the importance and diversity of relationships; the types of support people receive (and can reasonably expect to receive) from different types of relationship; and – often overlooked – the types of support older people provide in return. We draw practical examples from the programme which illustrate how supportive communities and networks can be encouraged.

The importance and diversity of relationships

Our relationships with other people matter as much to us – or perhaps even more – as we get older (Katz *et al.*, 2011; Bowers, 2009). They may provide a link to the past; a chance to relax and ‘be ourselves’; the opportunity to give and receive different kinds of support; fresh perspectives; and the chance to redefine ourselves (Ward, 2012). The relationships described in the projects from *A Better Life* are striking in their diversity: chance encounters in hospital waiting rooms; friendships spanning a 70-year age gap; new couples meeting, moving in and caring for each other in housing with care schemes; and a circle of friends rallying to provide ongoing practical support to a single gay man who has had a stroke.

Family relationships are similarly varied: we hear, for example, of the tightly-knit support structure of extended Gypsy families (Lane *et al.*, 2012) and a relationship of mutual care between a man with learning disabilities and his physically disabled aunt (Ward, 2012). There appears to be a huge variation in family input when it comes to supporting older relatives living in housing with care schemes, and this can be particularly significant where they live alone and have a diagnosis of dementia. One son refuses to pick up the phone when the scheme manager calls about his mother; another daughter visits daily and has only been on holiday once in the five years since her mother moved in (Pannell, Blood and Copeman, 2012).

Good relationships between paid staff and involved relatives are often key to ensuring a good quality of life for older people, especially those who need others to help them coordinate some aspects of their lives (e.g., Blood *et al.*, 2012a). This is a point that has been made elsewhere in research on nursing (e.g., Nolan *et al.*, 2006). Yet some evidence from the programme suggests that the input and knowledge of involved family and friends is not always acknowledged and that carers are not always involved in decision-making (e.g., Burke, 2010).

Modern families are often geographically dispersed. However, in the housing with care research, many continued to play a key role in supporting

decision-making, helping with the move and managing money, even if they are unable to provide day-to-day practical help (Pannell, Blood and Copeman, 2012). Family support for South Asian older people has also diversified and Nijjar (2012) describes how the older generation had not anticipated how quickly the lifestyles and attitudes of their children and grandchildren would change since moving to the UK. Some older people – particularly lesbians, gay men and bisexuals – have built their own ‘families of choice’ in the absence of or estrangement from more traditionally defined families.

Katz reminds us that relationships can change as support needs increase: partners may become full-time carers; couples may end up having to live separately; parents may come to depend more on their children. Adapting to these changing dynamics can be challenging for both parties and we hear examples of older people worrying about ‘imposing’ or becoming ‘a burden’ in Katz’s work (Katz *et al.*, 2011).

The care and benefits systems generally insist on distinguishing ‘carers’ from those who need care (Stone, 2010; Davis *et al.*, 1998), yet the reality is that many of us straddle both camps and the nature of these mutual exchanges shifts over time. This is particularly true of older couples (as found by Pannell, Blood and Copeman, 2012) who usually depend on each other for different things, and of older people with learning disabilities and their older relatives (Ward, 2012).

People have very different views about the kinds of support they would or would not want family, friends or strangers to provide. Ethnicity can be a big factor here – South Asian and Gypsy elders, for example, can be very resistant to the idea of outsiders coming in to provide services (Nijjar, 2012; Lane *et al.*, 2012). However, individuals’ preferences and the dynamics of their specific relationships also vary enormously. Some people would be horrified to think of anyone other than a family member doing some things for them; others find that getting support from friends or even strangers can be less of an emotional minefield:

“It’s a difficult truth but families don’t always ‘get it’; it can be easier to be honest about your needs and your contributions, and to work out mutually beneficial solutions, with friends and others outside your close family whose concern for you can override your choices and decisions”

Bowers *et al.*, 2013, p.48

However, there may well be limits to what many people feel they can ask or expect of people who are not close family members. Sylvie, who is 85 and lives alone with mobility problems and some memory loss, does not have any family in this country. She explains that she has plenty of friends who she can call on, say, to take her to hospital and bring her back home. However, on return from hospital, she does not feel she could ask a friend to stay overnight at her house and make sure she is alright, in the same way that she would a family member, since ‘people have their own lives to lead’ (Katz *et al.*, 2011).

There seems to be a general sense that mutual support between neighbours and friends – and even sometimes between close friends and family members – would not extend to personal care, or at least not on a regular basis. The Brunel Institute for Ageing (Dalley *et al.*, 2012) identify a key explanation for this from the research evidence. They argue that people are reluctant to accept help and support from people outside of their immediate families if they feel they cannot reciprocate. Once support turns into the need for care on a non-reciprocal basis, supportive relationships between neighbours and all but the closest of friends are likely to reach their limits.

“I like to chat and enjoy some banter with the carers, but you can’t do that if they change from one day to the next and don’t care about you as a person”

Supporting positive relationships with paid staff

Where older people with high support needs receive care or support from paid workers, they told researchers from *A Better Life* that they value friendliness, opportunities to spend some time building relationships with them, being treated with respect and having a laugh. Having the same worker or workers over a period of time is essential if this is to happen. As one housing with care resident told a researcher:

“I like to chat and enjoy some banter with the carers, but you can’t do that if they change from one day to the next and don’t care about you as a person”

Blood *et al.*, 2012b, p.5

There is an increasing drive to promote the importance of ‘relationship-centred’ care for older people in health settings too (see, for example, the Senses Framework by Nolan *et al.*, 2006). Alternative keywords for this currently include ‘compassion’, ‘communication’ and ‘dignity’. However, the things that older people say they value from their relationships with care and health workers – genuine compassion and connection within a holistic, person-centred approach – are difficult to measure, take time to do properly, and require workers to give much of themselves.

“We need to recognise that care work is emotional labour. Certain things may not cost anything *financially*, say the smile you give someone, but they can cost emotionally. So in order to do some of the more person-centred things from this programme you have to recognise and support the emotional labour of care staff”.

Advisory Panel Member

Sawbridge (2011) considers how the emotional labour of nurses can be supported in the face of NHS performance targets. Her findings resonate with those of the *My Home Life* programme for care home managers: she argues that frontline workers need regular opportunities for reflective practice or clinical supervision and managers who have the responsibility, time and skills to monitor and support their emotional health.

St Monica’s Trust is a local charity with four housing with care schemes in Bristol and North Somerset. They used focus groups to find out from residents which qualities they value most in their staff (Blood *et al.*, 2012b). Residents identified skills and attributes, such as patience, listening skills, being welcoming and keeping calm, and these are now used in the recruitment and selection process. Some of the care homes in *My Home Life* have involved residents directly in the recruitment process: one older woman who had significant verbal communication difficulties following a stroke was supported to sit in on the interviews and express her verdict using thumbs up or down (Owen and Meyer *et al.*, 2012).

Building social networks in later life

Gertrude, who is 74, lives in her own home in London and receives transport to a community centre for black older people. She tells Katz (Katz *et al.*, 2011, p.23) that:

“I like meeting with people. When I came to the day centre I felt like a new person ... I come here two days a week, the day centre is part of like a family, I relax and I'm comfortable here ... I come to communicate with other people. You don't want to stay at home on your own, you want to come and have a chat, and laugh, and do any activities going. I does painting and art... It make you feltyou're somebody, when you're doing something”.

There is an increasing trend towards living alone in older age: according to Falkingham *et al.* (2010), nearly half of men and two-thirds of women over 85 living in private households currently do so. Living alone (especially as an older person with high support needs) can increase the risk of loneliness, which in turn can impact not only on mental health but also on physical health and mortality (Bolton, 2012). However, as Gertrude's experience shows, living alone does not necessarily bring loneliness and retaining or building up your social life can make all the difference.

In this section, we present a number of different ways in which older people with high support needs can be helped to build up their networks. In addition to the more traditional model of transporting people to a day centre (which is highly valued by Gertrude and others), we look at peer support groups (which bring together those who share a particular disability or social identity) and an approach which begins with an isolated individual and helps him to build a network around himself.

The story of the Anchor Lesbian, Gay, Bisexual and Transgender (LGBT) Group

68-year-old Rowena McCarthy moved into a flat in an East London retirement scheme run by Anchor in 2006. She had left her home in Derbyshire following harassment by local people, determined not to tell anyone she was a lesbian unless she fully trusted them.

During her first year as an Anchor tenant, she felt very lonely and isolated. 'I couldn't say anything about the real me. It was almost like speaking a different language'. Then one day she contacted Anchor's marketing team to discuss a customer profiling survey she had received from them and ended up being invited to address the organisation's tenants' forum about her experiences of living as a lesbian in sheltered housing.

She now chairs Anchor's LGBT group, which has around 50 members (roughly 20 of whom are staff and the remainder are older tenants). The group provides peer support and guidance to the organisation and helps Anchor to make a clear statement about its ethos: that it has 'come out' as an organisation and will support and stand up for LGBT customers and staff. Anchor provides £5,000 of funding a year to support the group. This includes a contribution to the salary of a Tenant Participation Manager and funds for venue hire and individuals' expenses, which can include paying for a carer to support anyone who needs this.

LGBT staff members have received considerable support from older tenants on the group and, although it has not all been plain sailing, Rowena describes how setting up and being part of the group has transformed her life, giving her a social network of gay Anchor residents with whom she has a 'double affinity'. (Adapted from Rogers, 2012, Croucher and Bevan, 2012, and Pannell and Blood, 2012)

This story reminds us how valuable it can be for older people with shared backgrounds and experiences to meet and support each other. Nijjar (2012) believes it is particularly important to ask the older generation of South Asian families to talk about their life experiences – partly to give them the opportunity to remember and share; partly because there is so little written social history;

and partly to support those with dementia to reminisce and communicate with their younger carers and relatives.

Other groups provide peer support between those who share a diagnosis or disability. Agnes Houston, Chair of the Scottish Dementia Working Group (SDWG), which we introduce in more detail in the next chapter, describes the 'magic synergy that happens in the room when you get people with a diagnosis together' (Weaks *et al.*, 2012, p.11). She explains that, following her diagnosis of dementia, the people she met when she joined the group 'were the only people who made me feel safe and that I belonged, they gave me my confidence back' (p.13).

Connecting with others

Older people with high support needs can face particular barriers to finding out about and participating in peer support groups like these, including communication, transport, inflexibility of care provision, accessibility of venues, and the attitudes of those around them.

Several of the older people met by Katz and her team (2011) explained that they had stopped socialising or phoning relatives because they cannot hear well enough. Action on Hearing Loss (working in partnership with local audiology services) runs two support programmes targeting the increasing number of older adults with acquired hearing loss. *Hear to Help* provides practical advice and assistance managing hearing aids – cleaning, changing batteries and supporting their optimum use. *Hear to Meet* provides opportunities for people to meet each other and share experiences and information. The groups are facilitated by volunteers and usually held in community settings, such as older people's housing schemes (Croucher and Bevan, 2012).

Social media also has a key and increasing role to play in bringing older people together. Connecting with others online avoids many of the barriers which people with disabilities and health conditions tend to encounter when trying to meet face-to-face as a group. It removes the need for suitable transport; the synchronisation of care slots; concerns about energy levels, continence and access; and not being able to hear (or indeed see) need not be a problem. People can have ongoing interactions at any time of the day or night that suits them.

The potential to create a virtual community for older people has been recognised by *DropBy* <http://www.dropby.co.uk/> (Bowers *et al.*, 2013). The site provides online chat and instant messaging, hosts photos, videos and music and has an easy-to-use video link. It is intended to act as a safe and free hub for those over 60 to communicate with families, friends and each other. The site's founder, Mary B, explains:

"Like all communities, we are the sum of our parts. Members find new friends, share ideas and interests, ask for help or advice, and find ways to give support to one another. Sometimes just to know there are others experiencing the same difficulties can be reassuring, and a few kind, supportive words can make all the difference. Members are not embarrassed to ask for help, and always give support wherever they can. It's a give and take thing. My hopes are that we can use existing technology to make living as we grow older easier, and that we help to end isolation. There really is no need for anyone not to be connected these days – it's just a matter of finding the right approach."

Mary B., Founder of *DropBy*

Berry (2011) explains that internet access and usage has increased considerably amongst older people in the last decade, but that a generational 'digital divide' still remains, with 37% of one-person households above pension age having internet access, compared to 79% of those below pension age. There are a number of reasons for this: lack of money, knowledge, skills, confidence and interest can all be factors. The presence of sites like *DropBy* may motivate older people with high support needs to get online and housing and care home providers, or internet-savvy friends and relatives, may be in a good position to set up computers and internet connections. Volunteers and peer champions like Angela who we met at the beginning of this report also have a vital role to play in spreading the word and giving people the confidence to get started online.

For some people, the barriers to connecting with others – whether on line or in person – are not just practical: they may need intensive support to help them identify a way forward and build their confidence to mix with others.

Jakob's story: building a circle of support

Jakob is 78 years old and lives in a council flat in Portsmouth. Originally from the Ukraine, he has no living relatives, did not know anyone in Portsmouth, and English is his third language. Although he was not eligible for support from Social Services, he was ringing the duty team several times a week in great distress. When social workers made follow-up visits, he did not want to take up anything they suggested, was reluctant to leave his flat and seemed lonely, anxious and unhappy.

Julie – a tenancy support worker – met Jakob and used gentle reassurance and a structured 'Circles of Support' approach to help him think about possible solutions to his problems. He said that he would like to meet other men his age who share his passion for chess. Julie found out about and accompanied him to a local social club for older men. He now attends the club regularly, travelling there on his own on public transport. He plays chess with a man who shares his language and love of the game and has started to teach chess to others at the club. As a result of his increased confidence, Jakob now goes to his local pub on his own for a quiet drink, and he has joined a local 'good neighbours' volunteer scheme. He no longer calls the duty social work team (though he keeps in touch with Julie) and his feelings of anxiety and loneliness have reduced.

Adapted from Bowers *et al.*, 2011, p.29–20

Vitaly, Julie took time to build a relationship with Jakob – she did not impose her views of what she thought would help him or make a hasty referral to services which she knew to be available. Instead, she helped him to find his own direction, based on his interests rather than his 'needs'. He needed some initial hand-holding – it is unlikely that he would have made it to the club alone if Julie had simply given him the address – but he quickly became independent (in a way that he would not have done had ongoing transport been provided).

He has continued to build his circle of support organically, drawing on local resources that are not traditionally promoted by services, such as the pub and the local volunteer scheme. The outcome is a win-win situation: Jakob has a developing and hopefully (given his increased confidence) sustainable network of support. There are likely to be long-term savings to the public purse too if we compare the cost of Julie's input to that of the duty team call-outs and a possible residential care placement which may have resulted had he continued to use social services 'inappropriately'.

Mutuality and reciprocity

It is striking that, as soon as he finds an environment in which he feels comfortable, Jakob quickly begins to find ways in which he can make a contribution: he starts teaching chess to others and then becomes a volunteer himself.

Another recurring theme across the programme is that making a contribution continues to matter to most of us as we get older and/or become disabled. As we have seen, it may become even more important as a way of helping us to feel good about ourselves and restoring the power balance in our relationships as we find ourselves needing to ask for and accept more help from others (Dalley *et al.*, 2012).

What do we mean by ‘mutuality’ and ‘reciprocity’?

Bowers *et al.* (2013) argue that ‘reciprocity’ is a transaction, which works best when it feels like a direct exchange (ideally with the actions happening at the same time or soon after each other). ‘Mutuality’ is wider: it might involve a relationship between two people, or relationships between members of a larger network, from which both or all participants feel they derive support and benefits.

Bowers *et al.* (2013) found that older people seemed to be motivated more by mutuality and relationships: some were put off where there was an explicit expectation of reciprocity. Perhaps this is because, as Dalley (2012) points out, they worry about whether they will be able to offer like-for-like within the expected time scale. Viv and Miriam’s story demonstrates a more flexible, relationship-based form of mutuality in action.

Viv and Miriam’s story

“I am a single mum in my 20s and Miriam is a very old lady (91) and our relationship is based on a mutual need for friendship. From my end, I’m much younger than Miriam and feel I give out very little, for example helping with showering, picking up the odd thing, helping with shopping, etc. But we both have a need to be listened to, the freedom to be who we are without someone trying to rush in and overtake us or rescue us.

The reason our relationship has been so successful is that it is based on understanding each other, not feeling sorry for each other or trying to be a hero to each other. I had to be very careful I didn’t patronise her by stepping in too readily – that frustrated her – and I had to learn early on that she was very set in her ways and was extremely good at looking after herself. I knew how to do things quicker but it wasn’t about that, it was about allowing her to maintain control and independence whilst having the security of someone there to oversee just in case it backfired or went wrong, which it almost never does. She learned quickly that I was struggling with many things in my own life. She would never pressurise me into doing things for her if she could see I was worn out.

Miriam is the reason why all us neighbours still have a relationship. We are a little community because of her need and our need to be needed, it’s quite beautiful really. Marjorie up the road always gives her offcuts of meat and has her up to her house once a week and they share magazines, and in turn Marjorie still feels a sense of community in the street. Dave does odd jobs and in turn has not wasted away in retirement. Sally – the daughter of one of Miriam’s friends – fills in her

catalogue orders, picks up bits from the Co-op, and can talk to Miriam about her mother who has passed away. And together we have a very understated relationship that only felt its value when Miriam went to hospital and we were all thrown back into our own corners.

I am young and she is old and I suppose on the surface it looks like I'm the one doing all the giving. That is not the case at all. I don't think she will ever understand how much she gives back in return. I have learned so much, like what it's like to be an ageing woman; what matters when you're that age and what things I am wasting my time on. I can remember asking her what she felt when she looked in the mirror and what she thought of her old skin. It has been one of the most interesting relationships I have ever had. I have asked her if she is afraid of dying, how she has coped with her son growing up and being so far away, her husband dying, his last moments, how she coped, how she felt, how she survived.

We all need to be needed, that is the most important thing. I know she needs me and she knows that I need her and that is why it works. If it were one-sided it wouldn't have lasted or been as productive a relationship as it has been.”

Abridged from Bowers *et al.*, 2011, p.28–29

There are many lessons here for those who provide care and indeed for all of us. Viv understands that it is not about completing a task (which she could do faster herself): it is about Miriam – what matters to her, how she can retain control, how she likes doing things. It is also about Viv and the fact that she can be honest about her own fears and struggles and ask for support instead of having to play the hero or the martyr. Having the time to just be together, eat fish and chips, look at Miriam's roses, or sit in silence is also important here and is in sharp contrast to half- or even quarter-of-an-hour domiciliary care 'slots'.⁶

Once genuine trust and closeness have been established between the two, then conversations about death, ageing, loss and survival occur quite naturally and in a way that is mutually beneficial. This is in contrast to care home staff (Owen and Meyer *et al.*, 2012) who can, understandably, find it difficult to know when and how to raise the topic of end-of-life. The relationship lasts because both get something out of it but it is not a question of trying to quantify the inputs or outputs (though it is interesting how clearly Viv recognises the value of their different contributions). The relationship is equal because of the values on which it is based, not because both put in or receive exactly the same.

Many of the mutual benefits occur precisely because these two women are at such different stages of their lives and need and can provide different kinds of support to each other as a result. The story reminds us of the assets which older people have – just by virtue of the fact that they are older and therefore have more life experience – before we even begin to consider the talents, skills and experiences of each individual.

“It is particularly striking how Miriam becomes the hub of the neighbourhood: the reason why all the neighbours still have a relationship with each other”.

Advisory Panel Member

There is routine here (the weekly visit to Marjorie's) but also the *ad hoc* (odd jobs and picking up bits of shopping as and when) and the whole network ebbs and flows over time – as, for example, when Miriam is admitted to hospital. However, there are implicit boundaries here – everyone has their own front door; we do not get the impression that they are coming and going from each other's homes continuously, and Miriam does not pressure Viv to help if she can see she is exhausted.

Viv mentions that she sometimes helps Miriam to shower, but would she wish and be able to offer more regular long-term personal care if Miriam needed it in the future? Would Miriam prefer to receive this sort of help from Viv or from a paid carer? We know Viv is a single parent but we do not know about her circumstances in relation to work, benefits or other income. If Miriam could pay her as a Personal Assistant, would it make it easier for Viv to offer more support on a regular basis (and indeed continue the balance between what each gains from their relationship)? Or would this change the dynamic and values of the relationship in a way that neither woman would want?

Whatever answers we may envisage to these questions, it seems clear from this example that informal relationships – including the sort of mutual relationship Viv and Miriam have, as well as those between family members, partners or friends – are important, and so is paid care. They may do different things at different times to support individuals. Viv and Miriam's story demonstrates the power and value of meaningful relationships and how they can sustain and fulfil people, no matter how much care and support they need.

Encouraging mutuality in older people's housing

“... a sense of community does not just happen merely from putting people together”.

Brenton, 2013, p.2

In this section, we turn our attention to the sense of community within specialist housing schemes and care homes and how older people with high support needs can be encouraged to develop mutually supportive relationships within these settings. Although we have organised this into a separate section, moving into a care home, or housing scheme, should not mean that you can no longer sustain or start up mutually supportive relationships with people who live in the wider community, including people of all age groups.

The *My Home Life Essex Community Association* believes that those living in care homes are just as much part of their community as anyone else and is supporting care homes and helping them to reach out and interact with their local communities (<http://mhleca.org/>). They recruit local volunteers who provide a befriending service to care home residents who do not receive visitors, and they also train and support volunteers to act as informal advocates for older people, residents and staff (Owen and Meyer *et al.*, 2012). They highlight the strengths and skills which care home residents as well as the volunteers can bring to these relationships.

Some older people decide to move to a retirement community as a way of improving their social life, though for many it is the support, care and accessible environment that such schemes generally offer which is the primary driver. Some of the older people in the housing with care research had decided to make the move while their health was still reasonably good. Some had found a scheme near to a relative or friend; others had hoped that they would meet new people within the scheme. The majority had done so, but a few were disappointed to find the community less 'vibrant' than they had expected it to be, or were struggling to fit in for a range of reasons, some but not all linked to disability. Others seemed to be happy getting on with their own lives – alone in their flat, with their partner, or family and friends from outside of the scheme.

Many of the older people with high support needs who contributed to the projects that are a part of *A Better Life* described the challenges of settling into such communal settings. Some, especially those with dementia or visual impairments, needed time and support to orientate themselves: one woman described how her mother was 'lost in the building' for the first six months.

Croucher and Bevan (2012) describe the *Enriched Opportunities Programme*, which provides a dedicated key worker (known as a 'Locksmith') to people with dementia or other significant mental health challenges living in extra care housing schemes where residents have a range of needs. The Locksmith works with individuals to find out what they enjoy doing and how they can improve their quality of life, and then supports them to participate in activities in the scheme and the surrounding area. The formal evaluation found that those receiving this service reported feeling more involved, supported and accepted (Bradford Dementia Group, 2009).

In schemes where this approach is not available, some residents receive intensive support from scheme managers or key workers to rebuild their confidence, having experienced isolation, poor mental health or domestic abuse. Some withdraw to preserve their dignity in the face of incontinence; others are (or find themselves struggling to get along with) 'difficult characters'. Given all this, Croucher and Bevan (2012, p.12) wonder whether we have 'underestimated the adjustments that some people have to make to live comfortably in a community'. This should probably not come as a surprise, given that few have experienced living in this kind of community, and for those who have – perhaps in the army or at university – the memories will be distant.

John Percival (in Garwood, 2010) has researched the relationships in sheltered and extra care housing between those who have high support needs and those who do not. He observes that more active residents can sometimes resent those with high support needs as they make the place feel 'more like a nursing home'. More active residents may be more likely to befriend and offer support to others if they have got to know them before their support needs increased and if they feel comfortable with the balance between 'fit and frail' residents within the scheme. The fear of opening a Pandora's Box of demands and expectations are real and understandable; which is why some kind of monitoring or backup system may be needed.

Croucher and Bevan (2012) present a case study of an informal *resident volunteer group* within a rural sheltered housing scheme. The volunteers offer low level support to and organise social activities for their fellow residents. They identify two key factors which have enabled this group to develop and continue (in addition, of course, to the goodwill and personalities of those involved). Firstly, there are two fairly distinct groups of residents: some who have 'aged in place' within the scheme and many of whom now have high support needs, and others who are newer to the scheme and (following the relaxation of the scheme's eligibility criteria) tend to be younger with fewer

support needs. The core group of volunteers consists mostly of the newer and younger residents. Secondly, the two scheme managers (who have both been in post for a number of years) informally but carefully coordinate the provision of support, linking the skills and interests of the volunteers with the needs of other residents for help and support.

A key part of encouraging a mutually supportive community in housing schemes and care homes involves clarifying expectations about the mix of care needs and making an inclusive ethos explicit from the outset. This can be a bold step for housing providers; many of whom (and particularly those in the private sector) are seeking to attract prospective leaseholders and tenants by portraying their schemes as vibrant communities, showing images of healthy-looking couples working out in the gym or joining friends in the café.

Linc-Cymru provides sheltered housing and housing with care in South Wales. They have taken a number of steps to promote an inclusive and tolerant sense of community within their schemes. They have, for example, run awareness-raising sessions with staff and residents, considering the experiences of people with dementia and/or sight loss, and exploring practical ways of communicating and demonstrating respect. They have developed an information leaflet as part of the residents' welcome pack, which clearly sets out the organisation's aim to accommodate people with a diverse range of needs (Croucher and Bevan, 2012).

Encouraging mutuality in other neighbourhoods

“All housing is older people's housing”.

Julia Unwin, Chief Executive of the Joseph Rowntree Foundation

In this section, we consider how mutually supportive relationships and a stronger sense of community can be encouraged outside of care homes or housing schemes which specifically cater for older people. We look at a number of alternative models suggested by the programme, which either seek to develop 'intentional communities' (where people have consciously planned to live together as a community) or to facilitate supportive relationships between neighbours in naturally occurring communities (where people happen to be living alongside each other).

The social network which has developed around Miriam may be attractive to many of us and is presumably something which, in this time of austerity, politicians are also keen to encourage. But many of us live in areas where neighbours keep themselves to themselves and it can take many years – even decades – to build the sort of friendship that Viv and Miriam enjoy. This can be particularly challenging for those who need or choose to move house, especially in later life. How can we develop neighbourhoods which are more supportive of each other in older age?

We begin by looking for insights from Vic Forrest's account of his work within Brixton Housing Co-operative (which probably sits somewhere between an intentional and a naturally occurring community). Although full of hope and practical ideas, Vic also warns us that 'it is hard to develop a mutually supportive community (even inside a housing co-operative)' (Forrest, 2013).

The story of the Navigation Group

Vic writes about 'preparing to grow old together' in a diverse South London housing co-operative (co-op).

“When I moved into our flat I was a young man, surrounded by young people. I’m now 57 and with a few exceptions most of us in our community are well into middle age and older”.

Forrest, 2013

When he first began to talk with fellow co-op residents about how they might organise now to maintain their independence in old age, some laughed or clearly found the topic sensitive and uncomfortable. He formed a small group of active co-op members to plan a way forward and they became known as the ‘Navigation Group’.

The group decided that: ‘if we were to stand any chance of supporting each other better in the future across the whole span of the co-op’, they needed to ‘try and develop situations that had the potential to facilitate more of our members to become active in the co-op or just to mix together socially more’. They have taken a number of steps so far to achieve this:

- They recognised the importance of having a space to mix in and, in particular, how sharing food together can be both a socially bonding experience and a good way of pooling resources. They have developed the old office into a working kitchen and a former store room into a social space, and they have held a number of social and fundraising events here and in the gardens.
- They have turned the co-op newsletter ‘from a relatively dull document that just contained the formal minutes of the Management and Maintenance Committees to a more lively and intimate communication between our members, including poetry, photos, artwork, adverts for and reports of events held at the co-op’.
- They are exploring ways of developing a structured support system within the co-op, which might put people in touch with each other and monitor levels of activity. They have surveyed members to find out what sort of support they might be able to offer.

Having opportunities to meet your neighbours through community celebrations, street parties, fundraising events or clean-up initiatives is an obvious but nevertheless challenging first step to starting to build mutual relationships with them. Identifying shared interests, values or goals also helps to develop and cement relationships, whether it is Jakob and his passion for chess or the environmental projects which develop incidentally out of Vic’s efforts in the co-op.

Vic soon sees the bonding potential in sharing a meal and this is a theme that resonates through other parts of the programme too, and this is something which those involved in lunch clubs have long recognised. Having the opportunity to eat together is a distinguishing feature of housing with care schemes and something which many residents value; Viv and Miriam eat fish and chips together, and in *My Home Life* we hear about care home staff taking tea with the residents and how this informality helps build better relationships between them.

The Navigation Group quickly recognised the importance of having some structures in place to facilitate interaction between neighbours. These include places, such as the shared kitchen, garden and social room, and communication mechanisms, such as the newsletter, meetings and surveys. Vic’s reflections on the need for and challenges of developing a structured support system are particularly interesting. The quarter of residents who are ‘active’ already sometimes feel they do too much within the co-op; if extra support was to be provided to individuals, they worry that ‘they would end up doing it, stretching themselves even further’ (p.16). This, as we have heard, echoes the concerns

Vic Forrest –
member of the
Brixton Housing Co-Op



sometimes expressed by more active residents of sheltered or housing with care schemes (Percival 2010; Croucher 2012).

The group recognises the need for a way of monitoring activity and wonders whether a 'Time Bank' model⁷ might work, but they do not want a system that is too rigid:

"We felt that some people might give a bit more than they receive or receive a bit more than they give. However, at the same time we didn't want this to get out of control to the point where some people could feel pressured to give more than they want to, and others were only taking when they were capable of giving support themselves (Forrest, 2013, p.17)."

This resonates with Bowers (Bowers *et al.*, 2013) finding that many people feel more comfortable with more flexible mutual relationships than with strict reciprocal arrangements. Whilst the group had not finalised the exact mechanism for structuring support at the time of writing, their first steps are significant. They 'did not want to split the people who need support from the people who can give it. We felt that people might need support in one area and want to give it in another' (Bowers *et al.*, 2013, p.17). Instead of asking people what they might *need*, they have surveyed residents to find out what they could *offer*, reassuring them the system will be centrally coordinated and their details will not be handed out to others. The project is also clear that it will not be an emergency service: 'It is about ways of offering support and comfort without feeling pressurised' (p.18).

Focusing on identifying strengths, assets and potential contributions (rather than needs, deficits and eligibility) is, as we have already noted, a key message from the programme. Bowers *et al.* (2013) point out that this is what those who develop and coordinate mutuality schemes seem to spend much of their time doing. This brings us to the question of leadership and the skills which are needed to achieve a vision of mutually-supportive ageing communities. Although it is the group which is navigating, it needed someone like Vic to start the ball rolling, to find and connect with others who feel strongly enough to take action, to ask tricky questions, and to help the group reflect and agree the best way forward.

This is reminiscent of the skill set of community development workers or the Coalition Government's 'Community Organisers'.⁸ Miller and Chanan (2013) argue that, despite the rhetoric of the 'Big Society' and initiatives such as Community Organisers, community development has been hit hard by the cuts in England. They suggest, however, that it has gained increased vigour in Scotland, Wales and Northern Ireland in response to the pressures of austerity. They set out a vision for a 'system of flexible, resident-led, cross-sector and cross-issue neighbourhood partnerships to join up professional services and living communities' (Miller and Chanan, 2013b). Such a system could provide a strong foundation for community members to support each other in older age in ways that complement formal services.

Another key piece of learning from the story of the Navigation Group is that we need to be realistic about how challenging and time consuming it is to build a supportive community network of this kind. It is vital to recognise the amount of time and energy which community development requires, the personal contributions and risks taken by all involved, and the limitations of the type of care and support that can be safely and sustainably provided even if the system succeeds. There is a great deal of hope here for making lives better, but 'the community' cannot be a quick, cheap fix where public services are suddenly withdrawn or reduced.

Cohousing

Cohousing (which is very well established in Denmark and the Netherlands) is a form of group living in which individual homes are clustered around a 'common house', or shared space and amenities. Run and controlled entirely by members of the group working together, it is an intentional community, in which people sign up to certain values, including mutual support and active participation in the life of the community (Brenton, 2013).

There are a number of groups in the UK currently trying to set up their own cohousing communities so they can (to recall Vic's phrase) 'grow old together'. The process is, at present, extremely slow. Hugh Hoffman is from the Vivarium Trust, a Scottish charity which aims to promote the concept of cohousing, particularly for older people, and is working to set up a demonstration cohousing project. He explains:

"We've been going nearly 9 years and now we're nearly there. A lot has happened and is always happening – it's very time consuming – each step involves a lot of time and energy and discussion. We're learning all the time. Group development and people management is key – everyone has something to contribute, e.g., some people are financially literate and able to deal with banks, building societies, grants, housing associations, etc."

Bowers *et al.* 2013

Several of the UK's older people's cohousing groups have now been partnered by housing associations which, it is hoped, will speed up the land acquisition and development stages. Brenton (2013, p.17) also suggests a role for a 'trailblazer' local authority here. She points out that 'for a far-sighted authority, the encouragement and facilitation of a senior cohousing community would not require a huge financial investment and could pay dividends'.

Where suitable plots for cohousing (or indeed any older people's housing scheme) are hard to find, Manthorp's (2010) suggestion of looking to convert disused office or factory buildings may be worth exploring: he cites a successful example from Switzerland. *Homeshare* (Bowers *et al.*, 2013), which might involve one or more lodgers living in an older person's home providing some support in exchange for low rents, has the potential to offer some of the benefits of cohousing, albeit on a very small scale. Another approach – this time from the Netherlands – is to develop a 'retrofit' cohousing scheme around an existing neighbourhood rather than building new homes (Brenton, 2013).

KeyRing

The retrofit cohousing approach is only a step or two removed from the *KeyRing* model which, although developed for people with learning disabilities, might also be used to improve the wellbeing and independence of older people in the community (Branfield and Beresford, 2010). *KeyRing* communities (www.keyring.org) are a network of local flats and houses with people linked by a commitment to support each other. People are encouraged to develop relationships with each other in the *KeyRing* neighbourhood and a support worker is appointed who also lives locally and supports members on a flexible basis.

One clear advantage of *KeyRing* is that it avoids people needing to move house: moving house may pose financial difficulties for some owner-occupiers (Aldridge *et al.*, 2012a); may take people away from places they are familiar with and neighbours they know; and involves a significant practical and psychological upheaval in later life (Pannell, Blood and Copeman, 2012;

Croucher and Bevan, 2012). The model is also flexible enough to include younger people, perhaps with physical or learning disabilities and/or as volunteers, thereby avoiding the risk of developing more ‘islands of the old’. Another advantage is that the paid worker can provide (or coordinate) the backup that people often need in order to give and receive support from each other in a sustainable way. The presence of the worker should remove the pressure to ‘cross the boundary between being a supportive, good neighbour, to taking on tasks and roles that should be undertaken by professionals’ (Croucher and Bevan, 2012, p.45).

There are many parallels between the role of the *KeyRing* support worker and that of the traditional on-site sheltered warden – a role which, as Pannell and Blood (2012) describe, has tended to have been replaced in recent years by floating support staff. Their evidence review suggests that having a support worker at least based in (if not actually living in) a sheltered housing complex (and we can see how this might be extended to a neighbourhood) can have a positive impact on the quality of life of older people with high support needs. Specifically, wardens have ‘kept an eye on’ people’s wellbeing; linked them into services and activities; promoted the life of the community; and responded to unforeseen needs or crises, ranging from a sudden snowfall to discharge from hospital.

There seems to be scope to renew some parts of this traditional sheltered model by untying it from the age-specific complex building (and hence opening it up to home-owners and a range of tenants) and bringing volunteers (many of whom will also be recipients) with different assets, needs and circumstances into the model. Methodist Homes is offering opportunities to some of its housing with care tenants who have high support needs to participate as volunteer befrienders in an emerging phone-based befriending service (Croucher and Bevan, 2012). This reminds us that even those with very restricted mobility might be able to provide support to others in the *KeyRing* community by phone.

“A lot of the innovation I saw in the papers had come from outside the system and managed to fight its way in, rather than being generated within the system. Or, where it had happened in existing services, it was almost in spite of the current system rather than because of it.”

Advisory Panel Member

Bowers *et al.* (2013) have shown that models which promote mutuality and reciprocity work best when they are locally focused and delivered or experienced on a small scale. If they are to reach more people, the challenge will be to scale them out (and encourage more arrangements like this in more places) rather than to scale them up (and try to expand individual initiatives). Creating the conditions for this to happen will require us to change both our attitudes to older people and the systems which currently operate to support them. An important first step will be to listen to the voices of older people and empower them to take control of their lives, and we will consider this in the following chapter.

CHAPTER 4: HEAR OUR VOICES!

A Better Life has sought out and amplified some of the diverse voices of older people with high support needs, rather than relying (as is too often the case) solely on their carers, professionals or those who campaign on their behalf to speak for them. Though the word itself is rarely used, many of the projects explore different aspects of the ‘citizenship’ of older people with high support needs: their rights and responsibilities; how they do (and wish to) exert control over their lives; how they get along with those they live with or near to; what they expect and receive from services; and how they contribute to their communities.

In this section, we focus on the next two challenges from the list on page 13:

- 5 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.
- 6 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 begin with a brief consideration of rights and how they might be used to promote equality for older people with high support needs. We then devote the remainder of the chapter to stories and findings from the programme about how the individual and collective voices of this group might be heard and given power, if the vision of older people with high support needs as ‘equal stakeholders’ is to be put into practice. This is not only the just thing to do but it is also the most effective way to achieving a better life, since the people who know most about what older people with high support needs want are older people with high support needs.

“It’s this idea of expertise. If you are not ‘the expert’ you can encounter a wall of defensiveness and resistance to change”

Advisory Panel Member

A rights-based approach to ageing and disability

Older people with high support needs have tended to be viewed more as dependants than as citizens: they are generally portrayed as being needy and unable to give, and are therefore seen as ‘a drain’ on public, and sometimes family, resources. The idea that they deserve to be treated with dignity (though clearly a vital first step, following the findings of the Francis Report (Francis, 2013) and the earlier Equality and Human Rights Commission (EHRC) inquiry into domiciliary care (Sykes and Groom, 2011) does little to challenge this fundamental state of disempowerment. As Charlton (1998) writes:

“Paternalism lies at the center of the oppression of people with disabilities. Paternalism starts with the notion of superiority: We must and can take control of these ‘subjects’ in spite of themselves ... [they] must be cared for (for their own good) ... Paternalism often must transform its subjects into children or people with childlike qualities ... It is ... the assumption that people with disabilities are intrinsically inferior and unable to take responsibility for their own lives”

Charlton, 1998, p.52–53

Older people with high support needs have rights, enshrined in law and in a range of standards, which set out what they as tenants, lease- or free-holders, consumers, service users, citizens, and human beings are entitled to (i.e., not just what they are judged to deserve). Such rights set out the bottom line, which for some older people with high support needs, still represents a significant improvement in quality of life. This is discussed further in *Putting Rights at the Heart of Housing with Care* (Blood and Pannell, 2013), which grew out of the research from *A Better Life*.

Rights can help those providing, commissioning and regulating services to focus on quality of life (rather than other measures of performance) and on supporting the principle of choice and control, even when people do not always have the capacity to make clear choices in practice.

The part of the Equality Act 2010 which protects older (and younger) people from discrimination linked to their age in the provision of services was implemented in late 2012. Similar protection had been introduced years before this around disability, sexual orientation and religion, and decades before for gender and ethnicity. Despite a number of significant exceptions, the recent age provisions do establish the principle that older people with high support needs should not be disadvantaged as a result of their age (as well as their disability).

Within the Equality Act 2010, the Public Sector Equality Duty requires public bodies to consider and take reasonable actions to reduce any negative impacts of their actions and decisions on older and disabled people (as well as those who share other ‘protected characteristics’ such as ethnicity, sexual orientation, sex, etc.). There should be leverage here to push for more consultation and better monitoring of access, experience and outcomes for older and/or disabled people (Blood and Bamford, 2010).

As a flip side of rights, older people with high support needs also have responsibilities: how they behave in relation to neighbours and paid staff; financial responsibilities; responsibilities as a tenant or leaseholder and as a member of civic society. They also have responsibilities in relation to their own wellbeing and can choose to take risks (like smoking when they have been diagnosed with a lung condition), or to maximise their participation, or to withdraw and remain as private as possible.

Ageing as a gender issue

As we saw in Chapter 2, older people with high support needs are much more likely to be women than men. Older women are nearly twice as likely as their male peers to live alone or to suffer a fracture (due to higher rates of osteoporosis) (Blood and Bamford, 2010). Women’s occupational pensions are, on average, nearly 40% lower than men’s; many have been disadvantaged by years of paying the ‘married women’s stamp’; and many find that their pensions end or are significantly reduced on their husband’s death (Altman, 2013; Pannell, Blood and Copeman, 2012).

Sexism and ageism can intersect to create a ‘double whammy’ for older women (and this can be further compounded where disability is also a factor or where racism or homophobia is experienced). ‘Old dears’ are typically women. Being patronised, marginalised or made to feel invisible (and not feeling able to challenge or even identify when this is happening) are more of a danger when you have experienced this throughout your lifetime. It can be difficult to begin to demand that your voice be heard in older age if it has not been heard much throughout your life.

Women make up three-quarters of those living in care homes; two-thirds of community care users over 65 (Mitchell, 2013); and typically around two-thirds of those living in housing with care (Blood *et al.*, 2012a; Pannell, Blood and Copeman, 2012; Netten *et al.*, 2011) They also make up 90% of the nursing workforce (The Nursing and Midwifery Council, 2007); 80% of the paid care sector and the majority of younger family carers (though older partner carers are more likely to be male) (Himmelweit and Land, 2008). As Easterbrook (2013) points out, care brings younger and older women together – as neighbours, friends, relatives, or as paid staff in any health, housing or care service. As we heard in the account of Viv and Miriam’s relationship, each has much to learn from the other.

Himmelweit and Land (2008) have argued that the level of public expenditure on care is a gender issue, since women are most likely to need it, most likely to be employed in the lowest paid jobs in the sector, and most likely to step in to provide unpaid care when good quality paid care is not available. The 2011 Census found that although 15% of men aged 85 and over (compared to 6% of women in the same age group) were providing unpaid care, women are more likely to be providing unpaid care at all of the age groups below 75 years old (Office for National Statistics, 2013). Pannell *et al.* (2012c) noted that daughters and daughters-in-law typically played a pivotal role in supporting their parents to move into housing with care.

The overlap between sexism and ageism has perhaps made it easier to overlook the needs and voices of older people with high support needs. However, it is unlikely that the barriers which have prevented us hearing the voices of this group will simply disappear as more men survive to this life stage without a concerted effort to tackle ageism, as well as sexism, and other forms of discrimination.

What has prevented the voices of older people with high support needs being heard?

As self-help group members told Bowers *et al.* (2013, p.42):

“Nobody’s really asking people what it is they want – lots of people in the professional sector have little idea of how to involve people to address their needs”

The programme’s findings challenge a number of myths and barriers which have typically reduced the participation of older people with high support needs in decision-making about their own lives and in the collective ‘co-production’ of services.

Older people with high support needs are too tired or ill to be involved

When Bowers and her team (2009) went to speak to older people living in care homes, some staff felt that older people would not want to come to a meeting or attend an interview or small-group discussion because ‘they are

too tired', 'it is too taxing for them', or 'they really wouldn't be interested'. The researchers found that such comments were always refuted by the older people concerned, who expressed a keen desire to be included and involved. 'Protecting' older people with high support needs in this way can actually take away their opportunity to be heard, and is part of the paternalism which Charlton (1998) describes.

This is, however, not to underestimate how all-consuming the pain and exhaustion associated with some conditions and treatments can be sometimes. There will, of course, be times when the last thing you want to do is to be involved in the recruitment and selection of staff or be consulted on a policy. Clearly attempts to involve older people with high support needs have to be sensitive and flexible around often fluctuating health and energy levels.

Many older people with high support needs do not have the capacity to give their views

The idea that older people are experts on their own lives has been particularly radical in the dementia field, where there are strong assumptions that professionals know best. Some of the research from *A Better Life*, alongside other JRF-funded work, has added to the growing evidence base that people with a diagnosis of dementia can be facilitated to express their views, experiences and aspirations.

Katz and her team experienced challenges in 'gathering certain types of factual information from people with cognitive impairments', but, using a 'topic wheel' as a prompt for their conversations, they 'felt confident that we were able to gather useful information about their perceptions of their lives at that moment in time, and the extent to which they valued particular activities or relationships' (Katz 2011, p.19). Methods may need to be adapted and used flexibly as Blood *et al.* (2012a) found when they used a version of the topic wheel to explore quality of life in housing with care schemes.

Older people are often happy to delegate decisions

The programme certainly found that people varied in *how* and over what aspects of their lives they want to exercise control, and what they would rather other people did for them. For example, we meet Winnie who is 89, has poor vision, some dementia and limited mobility. She – like a number of those in the affordability study (Pannell, Blood and Copeman, 2012) – is happy to delegate administrative and financial matters to others because she cannot hear very well, and she feels that others could perhaps answer questions quickly which she cannot. However, she is clear that 'my poor family know better than to try to make decisions' (Katz *et al.*, 2011, p.27).

Many are not interested: they do not want to 'make a fuss'

"I was in a discussion last week where someone said he'd talked to a group of older people about the notion of 'co-production'* and nobody wanted it ... well ... it's probably because of the word! So I suppose it's about unpacking exactly what is meant".

Advisory Panel Member

* 'co-production' is the active involvement of people who use services in improving services

“I’m too old to care and it’s debatable as to whether they [staff] want my opinion”.

Unpacking jargon is clearly a key first step to encouraging older people to take part in decision-making. There were similar reports from a provider in Blood *et al.* (2012a), who explained that older people had been put off when someone from the council came to gather their feedback and started using terms like ‘empowerment’ and ‘safeguarding’.

It is also important to be able to set your own agenda and get involved in ways that suit you. Someone may not be interested in feeding back on a specific policy but they may still have views about a service which they would like to express. Some will prefer to talk on a one-to-one basis than to speak out at a meeting; some may be reluctant to make a formal complaint. Taking a tailored approach will be particularly important for those with high support needs who may find it difficult to read a document or may not want to attend a meeting because they are concerned about whether they will be able to hear, be comfortable in the chairs, or get to the toilet.

Sometimes it takes more than an invitation to a residents’ involvement meeting to undo the damage done by a culture of ageism and professional power. As one care home resident explained:

“I’m too old to care and it’s debatable as to whether they [staff] want my opinion”.

Bowers *et al.*, 2009

The practical barriers are just too great: information, transport, communication, accessibility

Examples from the programme show that even older people with significant disabilities can participate though they may need other people’s time and support to do this. Blood *et al.* (2012a) meet a man who had been completely immobile when he moved into his housing with care scheme four years previously. Although his mobility has since improved, he still uses a scooter to get around and has had a heart attack and a diagnosis of diabetes in recent years. He explains that:

“The chap who was secretary [of the residents’ committee] resigned so they asked me to be secretary. I didn’t really think I could do it, with my disability, but I got all the help I needed from the staff here.

Blood *et al.*, 2012, p.20

Being in control of your own life

“I think what is most interesting is how, if people have some sort of vision of how they want to be cared for, they want to take control over what happens to them, it becomes difficult to see what mechanisms there are to enable them to do that.”

Advisory Panel Member

It is hardly surprising that older people with high support needs want to have control over their lives. What is more interesting is how different individuals define being in control and being independent and how this relates to their quality of life.

'Independence' and 'control' meant different things to different people in the projects. For some in the housing with care research, independence means having your own front door and being in control of your own privacy or being able to move around within your own flat without having to depend on someone else. Others in Katz *et al.*, (2011) associated being independent with keeping your house or yourself clean and presentable or with challenging yourself to remain active or get better.

'Independence' has become a contested term in policy discussions: it has at times been equated with 'staying in your own home'. Although this may be the priority for many who are faced with the prospect of (or have experienced) institutional care, within the disability movement, 'independence' describes the process and power of being able to choose:

"People used to say that independence is doing everything for yourself. We, as disabled people, know that is not true. Independence is about being able to make choices about what you want to do. It is the same for everyone whatever your conditions, wherever you live, whatever your age".

Branfield and Beresford, 2010, p.13

Most of the residents interviewed by Pannell, Blood and Copeman, (2012) were clear that *they* had made the decision to move into housing with care schemes, having weighed up relatives' advice and wishes, risks, affordability, and potential losses and gains. As they told these stories, they were keen to emphasise their power and responsibility, describing their deliberations, or, in some cases, their bold, come-what-may decisions. The research team observed that, for many, their subsequent happiness in the scheme seemed to be closely tied up with how they felt about this decision to move; where the decision had turned out to be a good one, they were further bolstered by the fact that they had taken the plunge and had succeeded in creating a better life for themselves.

On the other hand, where people had not had sufficient mental capacity to make a positive decision to move, there was a sense of loss and disengagement with their new home, even if the place they had moved to ticked all the boxes on a practical level. As part of a study of how affordable older people found housing with care (Pannell *et al.*, 2012c), researchers met Mary, who was living in a housing with care scheme. When asked how she came to move in, she explained:

"I had had a stroke (though it wasn't initially recognised as such) and I had been moved about all over the place from pillar to post. I have been in virtually every home in Scotland while they were working out what was wrong with me, who should pay for me, where I could live. And I couldn't speak at the time; I couldn't explain my situation or anything. This was about a year ago. When I came here, I didn't even know what it was I was coming to. My daughter made the decision I think, as far as I know. There was a social worker involved at that point too – they dropped out as soon as I had moved in. It was stressful in a way, but at the same time I didn't feel anything much at all. They said 'this is your house – this is where you will be living'".

Pannell *et al.*, 2012c

We also know that many older people with high support needs are pressured into decisions to move into care homes by family members, social workers or hospital staff, and this often has a negative impact on their subsequent quality

of life (Bowers, 2009). The fear of ‘having to go into a home’ is expressed strongly by many who have contributed to *A Better Life*. However, there are, as *My Home Life* points out, others who do make a positive choice to move to residential care and their situation feels significantly different because they have been in control.

A Better Life shows that it is particularly important for people with learning disabilities and those in the early stages of dementia to identify their preferences for the future and be supported to record or plan for these. Ward (2012) points out that, in a worst case scenario, if a parent suddenly becomes ill or dies, a learning disabled adult can lose their home, their primary carer and all that is familiar to them on the same day.

This can be avoided where ‘older families’ projects work with people like Ben, who had lived with his Auntie Mabel since he was a child, to develop a person-centred plan which includes his life story, likes and dislikes, and fears and wishes for the future. As a result of such planning, Ben was supported to build his independent living skills and social life, and his name was added to the tenancy. When his aunt died suddenly, he was supported to stay in his own home by workers that he already knew, and he did not have to ‘go into care’ as he had feared.

The importance of the ordinary

‘Choice’ is a central tenet in government policy in relation to health and social care. The social care white paper, *Caring for our future: reforming care and support* (Department of Health, 2012), promises ‘radical reform to promote people’s independence and give them real choice and control in their lives’ (p.9). There is a danger, however, that choice and control are offered for some things – such as choice over which care provider you want or control over your individual budget – but not for others. One of the key messages from the programme is that it is often the little, ordinary things and the day-to-day choices which matter most to older people with high support needs.

There is evidence to suggest that this finding resonates across a range of services and settings. Spilsbury *et al.* (1999) highlighted over a decade ago that ‘the Little Things Count’ when older people are attending accident and emergency departments. Meanwhile, the Older People’s Commissioner for Wales has a current campaign to gather examples and raise awareness of ‘the 1000 little barriers that get in the way’ of older people enjoying better lives.

As another of the disabled people contributing to Branfield and Beresford’s work (2010) put it: ‘Ordinary things are not seen as being in the role of the professional, despite their importance’ (p.18). With limited public resources for social care being increasingly focused on crisis interventions and those in the severest need, it can be difficult to get ‘that little bit of help’ (as highlighted by the JRF Older People’s Inquiry, Raynes *et al.*, 2006) to prevent crisis or simply to make life better.

“Getting out always keeps coming up but when we think about it, it always seems to have a cost attached – it becomes about moving house or sending people round and putting you on a bus and taking you to a day centre with a garden ... but what are the cost-free examples of getting fresh air, like buddying you up with someone to go to the park?”

Advisory Panel Member

Older people with high support needs told researchers from *A Better Life* some of the simple things that did or could make a big difference to their lives. These included:

- Having a hearing aid that works/a loop system in your lounge so you can hear the television without disturbing the neighbours
- Having a seat outside (and support to get to it, if needed) so you can look at the garden, get some fresh air, talk to neighbours, feed the birds
- Being able to listen to the radio
- Being able to eat the food you want, at least some of the time (roast potatoes, fresh ham)
- Getting support to buy materials for crafts or other hobbies
- Having a way of keeping up-to-date with the news regularly
- Being able to keep and display things that you have done, that are important to you, that bring back memories
- Having a laugh
- Being able to make a contribution – being the bingo caller, laying the tables for the lunch club, providing some emotional support to staff, peers or others
- Looking out onto an interesting view if you can no longer get out and about very often
- Watching nature programmes or looking at photos of beautiful places on the Internet
- Being able to do some physical exercise – walking, yoga, stretching – or mental exercise – doing the crossword, having a stimulating debate, etc.
- Being in a room where there is not too much background noise when you are communicating with others

“The range of decision-making possibilities and the lack of a concrete and reliable road map with which to navigate these options is in itself a stressful set of circumstances to have to find a way through”

Making choice meaningful

“Information is power: people can only make informed choices if they have it. The problem is they are not getting the information”.

Chanan, older Asian man, in Nijjar, 2012, p.10

For many people, getting older and potentially needing support can open up a dizzying number of choices and decisions. Lindley *et al.* (2012) points out:

“The range of decision-making possibilities and the lack of a concrete and reliable road map with which to navigate these options is in itself a stressful set of circumstances to have to find a way through”

RSA, 2012 (p.36)

Sometimes having lots of choice can be as stressful as having hardly any choice. Many of us will have experienced ‘option paralysis’ in the supermarket when presented with too many versions of essentially the same product. At least in this situation (unlike when we try to plan for older age), all of the choices are clearly laid out in one place and the consequences of the decisions do not usually have a lasting impact on our lives and the lives of our families.

In the following chapter, we explore how many of the systems with which older people with high support needs come into contact are so complex that it can be almost impossible to ‘navigate the maze’ without someone to advise, broker and advocate for you, especially if you are facing additional barriers resulting from disability or ill health. People need information, and they need

individually tailored, locally-specific advice if they are to make truly informed choices which bring the outcomes that matter to them.

Choice *per se* is also not much use if none of the options are all that good. Most of us would probably agree with the older woman who explains to Knocker:

“I don’t want too much choice in healthcare, etc. ... I just want good, clean, local efficient services”.

Knocker, 2012, p.11

There is some emerging evidence that user choice helps to focus the providers of health, housing, care and other services on user experience, but the jury is still out on whether choice and competition are the most effective mechanisms for driving up quality (Dixon *et al.*, 2010). There are also question marks about whether increasing the control and purchasing power of individual consumers automatically promotes diversification within the market (and with it more things on the menu that older people actually want). One of the issues identified by *Think Local, Act Personal* is that markets have not (yet) responded to personal budgets by generating the range of alternative service models for older people which would make the prospect of choice real and exciting (Routledge and Carr, 2013).

Blood *et al.* (2012a) met Ron who had been severely disabled by a stroke. He told us he was very happy with the housing with care scheme he lived in but that he was having problems arranging care visits at times to suit him. Without carers to help transfer him to and from his bed, wheelchair or chair, he remains too long in one position which can become painful. He explained:

“The social worker has said that if ... [the HWC provider] can’t sort out the hours, she can get it from outside but I don’t want that, I don’t want loads of different carers and that would possibly be a recipe for lots of bad feeling ... I’ve got eight or ten or twelve different carers here, and I know them very well and they know me, I class them as friends so I wouldn’t want another bunch of strangers coming in. I want to give [the HWC provider] a bit longer to sort it out.”

Ron is aware that he has choices here but for him, and for many other people interviewed as part of *A Better Life*, the thing he values most are the relationships he has with his current carers. As Furedi (2012) points out, the majority of older people place great value on consistency of care. Where personal budgets can enable someone to *retain* a carer despite a house move or a commissioning change then they can clearly make a big difference to quality of life, but most people will not take the decision to change care providers lightly.

Older people with high support needs value choice and control then, but they need services which deliver the things that matter most to them, and they need good information to help them identify and select between the options. They also need to be offered choice in the areas of their lives where it matters most to them – which might be around the ordinary as well as the bigger decisions in life.

Agnes Houston, member of the
Scottish Dementia Working Group



Collective voice

One of the younger disabled people contributing to the programme argued that:

“There needs to be a lot more support for older people to be able to come together and discuss things with each other. We know how important this has been for us [disabled people].”

Branfield and Beresford, 2010, p.16

The collective voice of older people with high support needs is generally underdeveloped. Younger or more active older people are more likely to be involved in older people's groups and consulted on ageing issues; younger disabled people tend to be better organised in user groups and have most input around disability issues. Older people with high support needs have risked falling between these two stools (Blood and Bamford, 2010). Even in some of the otherwise good housing with care schemes visited by researchers from *A Better Life*, collective resident involvement had barely got off the ground.

However, the programme also found some inspiring stories and good practice examples which show what is possible and what can be gained when the collective voice of older people is nurtured and acted on. We have already heard some of these examples in the previous chapter, such as the Anchor LGBT group, and the St Monica's Trust focus groups which informed the recruitment and selection of frontline staff. This section focuses on the story of the SDWG, though we introduce a number of other examples as we reflect on the learning from this.

The Scottish Dementia Working Group

In 2001, James McKillop, who had been diagnosed with dementia, became involved in a research project and went on to present some of the findings at a conference for carers, policy makers, and practitioners. The talk was well-received: people told James it had made them see things differently and this got him thinking that he could 'speak for others with dementia who cannot speak for themselves' (Weaks, 2012).

The following year, a conference on dementia (which, unusually, was attended both by professionals and people with dementia) endorsed the idea of setting up the SDWG, which was to be made up of people who had been diagnosed with dementia. A small steering group was formed and funding identified for a room and sandwiches. Up until this point, James remembered: 'People with dementia did not meet together. For some reason we were segregated and kept apart; what did people fear in us getting together?' (Weaks, 2012)

Today SDWG has 112 members from across Scotland and is coordinated by a committee of 18 members and 4 co-opted professionals. It now sits under the umbrella of Alzheimer Scotland: it has retained its own constitution, decision making and priority setting, but it benefits from expenses, an office base and a salaried coordinator.

SDWG aims to highlight and challenge stigma, and to promote early diagnosis, good post-diagnosis support, and a well-trained workforce. They do this through campaigning, training, consultancy, speaking at events, sitting on strategy groups, and producing and selling DVDs and other materials. They have been involved in shaping Scotland's National Dementia Strategy; campaigned successfully for the withdrawal of a drug company's advert which portrayed dementia in a very negative light; and continue to receive very positive feedback from the training sessions they run for professionals and students. As Agnes Houston of the SDWG puts it:

"I have decided I will speak out about dementia, not hide it away. I believe I have a duty to let the public know that a diagnosis of dementia is not the end, but the beginning of a new life".

Agnes Houston, member of the SDWG

The benefits for members of the group are evident here: the sense of camaraderie and achievement, the peer support and the infectious positive thinking. Being part of the group has clearly made life much better than it might have been (perhaps even without a diagnosis of dementia). Although most of the active members of the group are at the relatively early stages of the condition, James reflects on the preventative impact which he believes the group has had for him:

"My supporter, Brenda, brought me back into the community and I am now contributing to society. If it was not for her, I would be a big burden to the state ... I am not getting any support from the services now ..."

Weaks, 2012 p.6

These benefits, however, are all effectively a by-product: the main contribution of the group is the difference that it makes to the learning, training and understanding of others, challenging by example the fears and stereotypes that surround dementia.

Family Housing Association in South Wales have also realised that it is good to involve older people in improving services, not just because it gives them a sense of purpose and achievement but because they often come up with better ideas and solutions and can gather more honest feedback from their peers than staff can. Tenants can volunteer as 'Service Assessors' and, recently, two residents from Hazel Court housing with care scheme in Swansea came up with a proposal to review the use of the scheme by the local community. They surveyed community groups and businesses which hire rooms at the schemes (and some of their participants and customers) and gathered residents' views about community usage of the scheme. From this they developed a series of recommendations around a number of issues including security, signage, public information, and booking procedures (Blood *et al.*, 2012b).

A commissioner from Essex County Council told Blood *et al.* (2012a) about how they had set up an older person's reference group from the outset when developing their most recent housing with care scheme. She explained that:

"I have decided I will speak out about dementia, not hide it away. I believe I have a duty to let the public know that a diagnosis of dementia is not the end, but the beginning of a new life".

“This group has considered a whole range of issues in relation to the development and management of the scheme. In fact we included some of the older people from this group in the bid assessment process for care providers and I think this gave us a much stronger insight into what potential residents are looking for in the way a scheme is run”.

Blood *et al.*, 2012a

Although there is still a long way to go, the programme has shown that older people with high support needs can provide input into service development which is not only coherent but extremely valuable. Older people really are the experts in what makes a better life for themselves and their peers.

The programme has also highlighted the fact that there are many groups and bodies of older people in existence and that some groups are struggling in the face of severe cuts to their funding from local authorities. Some of these groups already include people with high support needs; others could be supported and challenged to involve more.

In the next chapter, we turn our attention to the systems and services that older people with high support needs often come into contact with. We consider examples from the programme of some of the problems which they sometimes experience in getting their voices heard by these systems and the impact this can have on their quality of life. We also present some of the solutions suggested by the programme to improve access to and experience of services and systems.

CHAPTER 5: CONNECTING TO THE SYSTEM

As we get older – and particularly when we get ill or become disabled – we are likely to come into contact with a number of public sector ‘systems’, sometimes for the first time. We may become eligible for means-tested benefits (such as Pension Credit or Housing Benefit) and benefits linked to disability, especially Attendance Allowance.⁹ We are likely to become more frequent users of a range of health services. We may apply for grants to adapt or maintain our homes or apply for specialist housing from a housing association. We may need personal care or housing-related support, and Adult Social Care or other council teams may assess us to see if we are eligible for state-funded services.

Ironically, although many of these services are increasingly seeking to prioritise only those with the highest level of need, the programme suggests that they are often not well-equipped to engage, communicate with and respond to older people with high support needs.

A key issue here is the complexity and interplay of these various (and frequently changing) systems. The rules and criteria are complicated and peppered with jargon, and even specialist advisors and the most determined lay people can struggle to understand how they interact with each other.

“One of the things that I suppose I shouldn’t have been surprised about was the lack of clarity in the funding models – the uncertainty, the inconsistency – I suppose one does have this faith that, if you only sat down and got your head around it, there would be some logic there.”

Advisory Panel Member

The increasing specialisation of many professional roles, combined with frequent restructures in the NHS and local authorities means that many (like Mary on page 43) have the experience of ‘being passed from pillar to post’ through a maze of referral routes, often with agencies or teams disputing who is responsible for what. Behind the scenes, frontline workers and managers are often so busy reporting to different funding streams and regulators, liaising across professional boundaries and recording steps taken to manage risk that they do not have enough time to sit and listen to older people with high support needs and find out what they want and need to make their lives better. The cuts to local authority budgets have not created these problems, but they are making many of them worse.

The research projects from *A Better Life* identified a number of consequences of this complexity from the older person’s perspective, including:

- The complexity creates uncertainty – about what you are entitled to and what will happen in the future. This is stressful and it also makes it difficult to exercise your rights; this is particularly true around affordability, charging for care and state benefits. People with disabilities or health conditions

(especially those for whom English is not their first language) may find it particularly difficult to crack or even face going through the system.

- Even though you and those close to you are the experts on what you need, professionals usually know and understand the system better: what you want risks getting drowned out by what you are eligible for and what is currently possible within it, which is both limiting in terms of the outcomes and disempowering in terms of the process.
- This disempowerment can be particularly acute when older people first come into contact with these systems when they are in crisis (which they often and increasingly are, especially as these services are increasingly able to respond only to those with the highest levels of need). Many older people come in and out of the system (particularly the social care system) either because they recover or the current crisis is averted, perhaps by a move to a more supported environment; others die relatively soon after entering the system. This can be quite different from the experience of younger disabled people, who may be more likely to become ‘experts’ in how the system works and build longer term relationships with professionals and advocates working in it (Routledge and Carr, 2013).
- There is a risk of gaps, duplication or delays at the boundaries between professional roles, teams or agencies – if you or a relative, friend or advocate are not able to identify, express and chase these up, you can end up ‘falling between the cracks’.
- The way in which housing, care and support services are commissioned and charged for can vary considerably across the nations and local authorities in the UK. This means that people often need very locally specific information and advice. Moving home, which many older people do (or would like to do) as their needs begin to increase, can be complex if it involves crossing authority boundaries. There can be significant variation in practice, policy and service provision in different local areas and these transfers can incur delays and gaps in some services.
- The complexity of the system and the way in which services are commissioned, regulated and funded can sometimes act to stifle more innovative, grass-roots approaches by older people, community groups or the voluntary sector.

The distinctive contribution that *A Better Life* makes to our understanding of systemic and service-level problems is that it has focused on the experiences of older people with high support needs. Since their relationships with frontline staff and managers have such an impact on quality of life, there has also been some consideration of the issues from these perspectives.

Most of this evidence comes from the research conducted in housing with care schemes and care homes (through *My Home Life*), though there are also useful insights and stories about older people’s experiences of services and systems in the *Perspectives* series (which focus on different groups of older people, such as South Asian or learning disabled people) and Katz’s (Katz *et al.*, 2011) research into what older people with high support needs value. The programme did not, however, include a large scale research project looking at the experiences of older people with high support needs who are living in their own homes in the community and trying to connect with services.

Silos and service-led approaches

The existence of a ‘silo mentality’ in health, social care and other sectors working with older people is well-documented.¹⁰ In *A Better Life*, we hear examples of poor collaboration leading to gaps, delays or duplication between

John,
Growing Older with a Learning Disability
(GOLD) group member



adults' and older people's social care teams; between staff providing housing-related 'support' and those providing 'care'; between services in different areas; and between the health, housing and social care sectors.

For example, in the housing with care research (Blood *et al.*, 2012 WR), we hear how the care workers in one scheme took a meal up to the flat of a resident who was too ill to come down to the restaurant but they refused to take her husband's meal on the same tray. Support workers had to make a separate trip up to the flat with his dinner to enable the couple to eat together.

This vignette reinforces the point made in Chapter 3 about the care system tending to see only the individual service user and often overlooking the partnerships, families and networks of which they are a part.

"I really think these bureaucracies have an independent life and may have no value base whatsoever except that this is the way we've always done it full stop."

Advisory Panel Member

We hear examples throughout the programme where applying the criteria, adhering to the care plan or meeting the target becomes the end rather than the means to it. Workers can become so preoccupied with what they are *not* supposed to be doing (according to their job descriptions or care plans) and maintaining the boundaries between this and what they are supposed to be doing, that they fail to achieve their core objectives, namely to promote wellbeing. In their attempt to conserve the precious resources of time and energy by guarding funding, or professional or team boundaries, such bureaucracies risk wasting them with absurd duplication: instead of one trip to the flat with two meals on one tray, two trips are made with two trays. Ironically, as budgets get tighter, it seems likely that these sort of scenarios will increase, leading to a vicious and self-defeating circle.

However, when frontline staff regularly overstep their boundaries in an attempt to provide a more flexible and holistic approach it can bring its own problems. The Business Implementation Coordinator at Aster Living (a housing with care provider in South West England) described how, in the past, staff were frequently overstepping their boundaries on a one-off basis out of the goodness of their hearts but three months later they were still doing it. She explains: 'Workers were overstretched but didn't feel they could stop as they had raised the expectations of customers' (Blood *et al.*, 2012b, p.6).

Aster developed a table which identifies all the tasks that typically need doing by staff in a housing with care scheme and uses a red, amber, and green colour coding system to show who is responsible for what: green means you have lead responsibility for that task, red that you should never be responsible for it. With the amber category (which is carefully monitored), Aster explains, '... we are recognising that people will want and need to be flexible at times but that it is not sustainable for them to flexible all the time' (Blood *et al.*, 2012b, p.6).

Managing change in services

The way in which services are tendered out or commissioned can have a huge impact on the lives of older people with high support needs – by creating uncertainty and sudden changes and by threatening the consistency of workers, which we know from Chapter 3 is central to relationship building. Yet, all too often, the potential impact of this on service users is not fully considered.

Blood *et al.* (2012a) tell the story of a series of changes at a housing with care scheme which impacted negatively on residents.

A charity, a housing association and a local authority worked in partnership to develop and manage the 50-unit, new-build scheme. They had clear and detailed protocols setting out who was responsible for what. After a while, structural and staffing changes at the housing association meant they could no longer manage the scheme. This coincided with the local authority deciding to tender out its care and other services to outside agencies. This ended with two new and different housing associations running the scheme, with the original charity retaining responsibility for the housing management alone.

With all these changes, the original protocols no longer worked and nobody knew who was responsible for what. Residents complained that they saw a lot of different people in the office; that the scheme manager was no longer able to do things for them that she used to do; and that there were an increasing number of residents with high support needs moving into the scheme. They felt they had no control over the changes, had lost confidence in management, and reported that the scheme had a more institutional and less homely feel.

A key problem in this example is that older residents had not been properly involved in the decision-making and process of change. Staff believed that they had been 'shielding' them from any impact until they received a petition from residents stating their concerns. We hear other examples from the research (Blood *et al.*, 2012a) in which changes like this one were managed well, but this was only where significant resources were invested in involving residents and supporting them through the transition.

Focusing on the criteria

As budgets tighten, 'assessment' in adult social care is increasingly focused on working out whether or not someone is eligible for a service – 'gatekeeping' – rather than looking holistically at their lives, their wellbeing, their resources and their options, as both the 'care planning' and 'person-centred' models have proposed.¹¹ Having determined eligibility based on financial circumstances and severity of risk, the assessment process then (typically) seeks to identify deficits and needs – usually those that correspond to what services are able to offer.

Fair Access to Care Services (FACS) criteria (SCIE, 2010) have attempted to standardise the allocation of social care resources by assessing the level of risk to which individuals are exposed and placing them in bands. Meanwhile, tiered models (e.g., Draper *et al.*, 2006) which are common in health and mental health match the intensity of intervention to the assessed severity of need. The risk here is that once you develop high support needs the horse is assumed to have effectively bolted the stable, and the fact that you may well still benefit from 'preventative' services is overlooked (Bowers *et al.*, 2013).

One result of service provision being driven by the rigid application of criteria is the sort of scenario in which John finds himself (Ward, 2012). John lives in a group home with three younger men, but when he reached 65 he was 'retired' from the day centre he had been attending for many years, presumably because his case has been transferred from the learning disability team to the older persons' team. The minibus still collects the other men each morning and the support staff at the group home say: 'He gets very angry and upset and we don't know how to explain it to him in a way that will make sense.'

“This example really shocked me. There’s a total disdain for the value of the informal support networks that people have built up and that could be such a continuing resource for them ... and for the state ... as they get older”.

Advisory Panel Member

Focusing on the task

Another consequence of this ‘service-centred approach’ for older people with high support needs is that personal care risks being reduced to ‘a series of tasks’ (Blood 2010). In the rush to complete the tasks, and given the high turnover of staff, few workers stop to ask people what they actually want or how they want the tasks doing. For example, Irene explains:

“Being partially blind I have to know where everything is and I have my big plates there ... my saucers there ... [the care worker] put the saucers on top of the big plates, course I went in there ... whole lots went crash on the floor ...”

Katz *et al.*, 2011, p.27

One of the housing with care interviewees explains to researchers that her carers push her around in a wheelchair (she thinks this is because they find it easier and quicker to do so) but she would rather they helped her to use her walker, though she does not know how she could go about getting this changed. We discussed in Chapter 4 how, if you have a clear vision of how you want to (or would rather) receive care, it can be difficult to identify and use the mechanisms for changing things. These examples illustrate the disempowerment which many older people experience within the care system.

Navigators and brokers

The importance of having someone on your side to coordinate, navigate, advocate or advise is a recurring theme throughout the programme. For example, Blood *et al.* (2012a) introduce us to the concept of ‘Ringmaster’ – a role which might be played by a relative, scheme manager or key worker – who coordinates the input of different services, filling gaps along the fault lines between them as necessary. Croucher and Bevan (2012) emphasise the importance of ‘brokerage’, or of staff making sure that individuals with higher support needs are able to take advantage of activities within housing with care schemes and linking them up to each other and the group. Forrest (2013) describes how members of the housing co-operative have sometimes acted as advocates for each other, helping to link them into appropriate services and supporting them to get their entitlements. Of course, some older people are more than capable of representing themselves, researching their options and coordinating their own affairs, but the system can be so complex that many – especially those with high support needs – will need some of this support, at least at certain key times in their lives.

Kal and Sarbjit's story



In *Perspectives on Ageing in South Asian Families*, Nijjar (2012) introduces us to Kal, who is the sole carer for her mother, Sarbjit, who has a diagnosis of dementia and a number of physical illnesses, including rheumatoid arthritis. Kal enlisted the help of a dementia advocate working for Wolverhampton Elder Asians and Disabled Group to find out about and access the services that were available to her and her mother.

Kal feels that every service she has tried to access for her mother has meant a battle with statutory services. She reports having to 'navigate through a maze of bureaucracy associated with the medical profession' to get an appointment for her mother with incontinence nurses and physiotherapists. 'You have to tell your story time and time again'. She feels that the onus is on the patient or their family to push for information or treatment. Information is not readily available and the continued use of jargon is a particular barrier if English is not a person's first language.

Ironically, we hear evidence from Kal and others in the programme that, in some areas, the mechanisms which were intended to increase choice and control have simply increased administrative obstacles for older people and their families. Kal explains: 'Getting direct payments took, with the help of Louise [Carer Support Officer, Wolverhampton], from October to February – and it is not acceptable. I had someone who was fighting for me'.

Kal explains that 'The whole day is about mum', (p.7) but what happens to older people with high support needs who do not have a relative, partner or close friend who is willing and able to play this kind of role? Are there sustainable alternatives to residential care for those who cannot act as, or supply, their own 'navigator'? How far can professionals such as housing scheme managers and social workers realistically go in providing this type of support? How sustainable is it if, as we heard in the previous section, this work means overstepping their professional boundaries and straying into their own time?

The role of 'navigator' is also identified as one of four key roles for twenty-first century public servants in a recent report by the University of Birmingham Policy Commission (2011) in collaboration with Demos. They describe this as someone who can 'guide citizens and service users around the range of possibilities that might be available'. Whilst most of us would undoubtedly need such a guide, this does beg the question asked by Duffy and Fulton

(2009): 'Should we ban brokerage?' Instead of inventing another layer of professional roles, would it not be better to focus our resources on creating a system that is simpler and more accessible in the first place?

The University of Birmingham/Demos (2011) also emphasise the need for 'architects' to work alongside navigators to create coherent local systems of support from the resources available in the state, voluntary and community sectors. For the foreseeable future, it is likely that both of these roles will be key: older people with high support needs (and others) will continue to need individualised and at times intensive 'navigation' support; yet 'architects', commissioners and policy makers must work to simplify systems in order to make more efficient long-term use of public resources and to empower older people and their families to link directly and positively into the system.

The case for information, advice and advocacy has been made clearly elsewhere (e.g., Horton, 2009; Dunning, 2005) and has been recognised in a number of significant national policy documents and initiatives. *FirstStop* is a national partnership of advice providers funded (in part) by the Department of Communities and Local Government to provide a single telephone and website point of entry for queries relating to housing, health, finance and care. NHS Choices features an online guide to social care, which includes information for carers and for those who may need to pay for their own care. The Care and Support Bill will also require (and start-up funding has been promised for) local authorities to provide information and advice services on care and support.

A key message from *A Better Life* is that advice will need to be very personalised and detailed if it is to respond effectively to diverse individual circumstances and preferences, and to the loopholes and local variations that have been highlighted by the research. Many older people prefer to receive information through word of mouth and have the opportunity to weigh this up with people they trust (RSA, 2012), so it will also be important to ensure that relatives and paid workers know about options and entitlements and can access accurate information. There is hope for the future, but in the meantime, a number of the older people in the JRF research told us that they found out about life-changing services by chance, and even those living in specialist housing for older people were sometimes not aware of welfare benefits to which they may be entitled (Pannell *et al.*, 2012c).

Individuals and affordability

For self-funders and owner-occupiers, the planning and decision-making around affordability can be extremely complex. Class and wealth play a critical role here, of course: the risks and options are very different for a low-income owner-occupier who has little equity in their home (and little prospect of being able to sell in the current market) to someone who owns a valuable property in a desirable area. However, one of the striking things about the findings of the affordability study is how far up the property and income ladder the worry goes. Individuality also plays a part here: individuals differ dramatically in their personal circumstances, values and attitudes to financial risk and inheritance. Consequently, they make different decisions in the face of what they know and what is uncertain.

“Where risk came out strongly for me was around the money and the complexity of making decisions. I can just imagine you get faced with this impenetrable system and I’d just be absolutely paralysed. How do you make decisions when it’s just totally impenetrable? And that’s really risky; there’s a high risk of making the wrong decision”.

Advisory Panel Member

Most of the self-funders with high support needs in housing with care interviewed by Pannell *et al.* (2012c) were pleased with the quality of their housing and care. Yet the costs – both the financial costs and the emotional cost of uncertainty – were often high. Statistics from the Dilnot report (The Commission on Funding of Care and Support, 2011) suggest that 25% of those over 65 will never need to spend anything on care while at the other extreme 1 in 10 will spend over £100,000.

Even the ‘careful planners’ in the study of how affordable older people found housing with care had often not factored in the likely future cost of care when deciding whether or not they could afford to move to housing with care schemes. Some couples were caring for each other and therefore had not expected to need to buy in care; others had been healthy when they moved in and not expected to get ill; others had found it hard (and who would not?) to decide how to plan in the face of this care gamble.

Brian and Maggie’s story



Brian met two residents of Barton Mews (a housing with care scheme run by Shaw) on a Dial-a-Ride bus for disabled people. ‘They told me it’s fantastic here!’ He discussed it with his children who agreed that he could not continue as he was. A widower with increasing health problems, Brian was struggling to manage the house and garden, even with help. He was calling paramedics ‘all the time’ because of breathing difficulties and frequent falls out of bed. One of Brian’s daughters worked out how much it would cost to move to the scheme. ‘When I realised how much it cost I said ‘Bloody hell!’ but I came anyway’.

Brian sold his house to fund the move into the 2-bed leasehold flat (he needed the extra space because he uses a wheelchair). He explains ‘My pension is rubbish – I worked from the age of 14, fifty years, and because of Robert Maxwell, I get £28 a month’. His mobility problems have got worse since

moving to Barton Mews. He is in his wheelchair most of the time, and needs more help to transfer in and out of it, including at night. His oxygen levels and nebuliser use is monitored daily due to serious lung disease.

Since moving into Barton Mews, Brian met his new partner, Maggie. Both said they had never imagined having another relationship so late in life and that all their family and friends are very positive about it. Brian's care costs had been over £500 a month. Maggie explained: 'He said, 'I'll be bankrupt' so I said 'I've done care work, I can do it – if I did it for a little while then we could put some money behind us. We could use the money we save on care for treats and for travelling.'

With Maggie providing care, Brian's care costs have now reduced to the minimum £7 for half an hour weekly housework, but he still needs to draw down on his savings each month to cover the service charge and other outgoings. Both agreed that he will get worse because of his lung disease. 'Do you go for treats now while you can, or do you save it for the future?' The couple are keen to stay at Barton Mews and neither wants to be dependent on their children, but they do occasionally splash out on an accessible taxi so they can get to a family wedding or go for a meal. Brian reflects, 'The worst is the uncertainty, especially around future care costs ... I gave my youth away for this country; I was in the forces for four years, on board a ship based in Ceylon and up and down the Burma coast. I think the government should pay us back now in some way.'

Adapted from Pannell *et al.* (2012c)

Brian and Maggie have made a series of good decisions – both from a personal point of view and also from the perspective of the public purse. Firstly, Brian worked all his life and paid into a regular pension fund; he then 'downsized', freeing up a family-sized home, which the government is particularly keen for older people to do. He decided to move (at his own expense) into an accessible and supported environment in which support is available around the clock, which has reduced his use of paramedics and acute hospital services.

Yet the current system in England tends not to reward these 'good decisions'. For example, if older people decide to downsize, some are likely to end up taking themselves over the current capital limits for social services care funding, through turning equity into savings (Aldridge *et al.*, 2012a). This will hit those in the 'squeezed middle' the hardest, whose savings are not likely to have been above the threshold initially. Brian's pension has not provided the income he hoped it would and, although it is over twenty years since the death of Robert Maxwell, the question of how much the financial sector should be regulated and who should pay for its mistakes is still as pertinent today as it was then.

The Coalition Government seems to be moving slowly towards implementing some of the recommendations of the Dilnot Commission in England, but the proposed cap on care costs of £72,000, to come into force in 2016¹², is unlikely to reduce much of the anxiety over future care costs which couples like Brian and Maggie experience (and certainly not in the immediate future). The position is different and generally more favourable to self-funders in Scotland and Wales. In Scotland, there is no charge for personal care (though this is very tightly defined and there have been disputes about where free personal care ends and 'hotel' or accommodation/domestic charges begin). The Welsh government recently introduced a cap on care charges which means that no individual's bill should go over £50 a week.

Pannell *et al.* (2012c) highlight just how much people's financial circumstances, their need for formal support, and their decision-making around affordability are linked to whether or not they are (or have been) part

of a couple. In Brian and Maggie's case, the fact that Brian was living alone (following the death of his wife) was one of the factors which prompted his move into Barton Mews. Pannell, Blood and Copeman (2012) met a surprising number of newly-formed couples in their visits to housing with care schemes. They also met couples who were providing substantial amounts of care to each other, often supported and sustained by the fact that they were now living in an environment where they could easily access additional support if one or both needed a break, fell ill or died.

Ensuring a better life for those, like Maggie and Kal, who provide high levels of care to partners, parents and others is vital, yet the social care and benefits systems do not always fully recognise and support their contributions. Some policy decisions may even penalise them. For example, as part of the recent welfare reform, couples only become entitled to Pension Credit when the younger member reaches 66 (Aldridge *et al.*, 2012a), which is likely to impact on couples where a younger partner is providing care and support to an older partner.

Another key finding from the affordability studies (Pannell *et al.*, 2012c; 2012a) is that, because the systems for social care and public housing are driven by eligibility, if you are not financially eligible for assistance, it is very difficult to get any help from the system for anything. This can leave self-funders on what Henwood (2011) has termed a 'journey without maps', and sometimes even those living in housing with care schemes will be unaware of advice or preventative services, their rights, and welfare benefits to which they may be entitled.

Geographical variations

Where you live matters in various ways if you are an older person with high support needs. There are, inevitably, different profiles, issues, markets and resources in different countries, regions and places across the UK. We also know that older people's experiences and priorities are shaped by whether they live in rural or urban areas (Blood and Bamford, 2010; Pannell and Blood, 2012).

There are also national and local differences in many of the policies, practices and services that affect older people with high support needs. As we have seen in the last section, for example, the four nations of the UK take very different approaches to whether and how they charge individuals for social care. Although similar *themes* about the causes and consequences of complexity emerged from across the UK in the housing with care research (Blood *et al.*, 2012a; Pannell and Blood, 2012), significant geographical variations also emerged around:

- the supply of housing with care and other supported housing;
- the types of models and tenures available;
- the quality of the stock;
- the commissioning approach of the local authority;
- the degree of collaboration with health and social services;
- the charging policies for social care;
- the administration of housing support funding (Supporting People).

Local variation is not inherently a bad thing – there may be many advantages to local areas having the power to prioritise and find the best way of responding to local needs. However, it does add to the complexity of the system, and this can have a number of implications for older people with high support needs which need to be mitigated.

Firstly, it means that there is less clarity and consistency over what you might expect from a particular service and whether or not it is actually available in your area. This is a particular issue when it comes to supported housing. Housing with care, sheltered accommodation, leasehold retirement housing, retirement villages – some of these are not available at all in some parts of the UK; in other areas, they can mean quite different things or offer different services. This means that the advice and advocacy which will be needed by many older people with high support needs, if they are to navigate the system and make informed decisions in relation to affordability, has to be locally as well as individually specific.

Secondly, it can make it difficult to move from one area to another. Pannell, Blood and Copeman (2012) interviewed the daughter of a woman whose decision to move from her bungalow (where she was feeling increasingly isolated and unsteady on her feet) into housing with care had meant moving from one (nearby) authority to another. The previous local authority had provided her care package though she had paid towards it. That authority said they would continue to fund care for the first few weeks after the move but, at the last minute, they refused. In the end, the local authority in the area to which she had moved agreed that their own re-ablement team would visit her for eight weeks while they did a full assessment.

Although they were extremely grateful for this flexibility on the part of the new authority, the woman and her daughter experienced a great deal of uncertainty and stress (and several changes of care team within a short space of time). The outcome was that the woman was assessed as needing the same level of care as in her previous authority, which suggests that the original assessment could have been brought with her and saved a lot of stress, hassle and worker time. Despite the level of care remaining the same, the bills have gone up and the family do not understand why – presumably this is because of different charging mechanisms in the different authorities.

Managing risk and performance

The impact of the performance culture is evident in many of the projects from *A Better Life*, with its focus on measuring processes and inputs, accountability, safeguarding and regulation. The systems that promised to make public services more accountable seem, in many instances, to have created a culture of fear, blame and anxiety which allows little room for enabling older people to live the way they want to.

For example, a care home manager tells *My Home Life* how he decided to support an older person's wish to walk down the stairs unaided, having discussed with them (and documented) the risks involved and helped them to reach an informed and positive decision. Sadly, the older person later died as a result of falling down the stairs. The manager described his profound sense of loss and guilt over what had happened. However, instead of being supported by the wider system to deal with these emotions and identify any organisational learning, he described how it 'felt as though the world was caving in on him', as various professionals intervened with their own statutory requirements to investigate from, as he experienced it, a position of mistrust towards him. His immediate reaction was to 'tighten the reins' in the care home: he told the staff to minimise any risks associated with the activity of older people within the home (adapted from Owen and Meyer *et al.*, 2012, p.44).

We hear other stories of safeguarding legislation and procedures being used inappropriately in an attempt to protect older people from their own decisions. In one case described by Blood (2012a), a resident with swallowing

problems and a choking risk needed PEG (tube) feeding, for which the care staff received specialist training. However, the situation deteriorated, the resident was admitted to hospital and regular suctioning was needed. The family and the tenant himself wanted him to return to the housing with care scheme and would have paid privately for nursing care. The scheme's staff members were also happy with this, but social services decided it was a safeguarding issue so he had to leave.

“The only way that the service could be managed better in terms of improving my quality of life would be if the staff had more time to spend with me.”

“So the poor man is moved out of a setting and network he is familiar with because somebody has applied safeguarding rules where it's not a safeguarding issue at all: this is an individual who had capacity to make his own decisions. Who was abusing him?!”

Advisory Panel Member

The sheer volume of the paperwork and the pressure of business targets and performance indicators can take the managers of care homes and housing with care schemes away from (as we heard in Chapter 3) the vital work of building relationships with older people, relatives, staff and other professionals. In *My Home Life*, we hear of skilled and committed care home managers being overloaded by inspections and made to jump through endless bureaucratic hoops. One of the housing with care residents points out that 'we are human beings not robots': she explains that the support staff at her scheme are all kind and helpful individuals but that they have so much paperwork to do that 'they don't really have much time to spend with anybody' and certainly not to 'chat with you' (a summary of the quote is contained in Blood *et al.* (2012b).

This example and others from the programme highlights a major problem with the preoccupation with public sector 'performance'; it is so often not measuring the things that really matter to older people and drive their quality of life. There have been similar findings in the health sector, where Patterson *et al.* (2011) found many examples where the 'target driven culture' on older people's hospital wards were taking staff away from 'doing the 'little things' that help maintain dignity and build a relationship with the patient' (p.4). It is ironic that while staff across health, social care and supported housing settings are frantically trying to record their actions and decisions to ensure they are accountable (presumably to a senior manager, funder or regulator who wants evidence of outcomes), they are not doing the one thing that most older people really want. As one resident of a housing with care scheme explained:

“The only way that the service could be managed better in terms of improving my quality of life would be if the staff had more time to spend with me.” (Blood *et al.*, 2012b, p.5)

In their research into developing supportive communities in housing with care schemes, Croucher and Bevan (2012) reflect on how gradual and subtle the evidence of 'success' may be. One scheme, for example, threw a celebration to mark the royal jubilee. One resident with significant short-term memory loss still spoke about the party the following day, and the scheme manager reflected that this was really significant for this particular person. Crude quantitative measures (like the numbers of people who attended the party) do not capture this subtle but important progress, and how could they when the milestones are so specific to that individual?

The scheme manager is only in a position to judge the significance of this person remembering the party because they have been able to build a relationship with them. We need to rebuild the fundamental trust in frontline staff and give them the time and discretion they need to build relationships with older people with high support needs. Not only do these relationships improve quality of life (Furedi, 2012), but they may also enable staff to measure when things are working (and when they are not).

Trusting frontline staff and respecting the choices which older people make (even if, like walking down the stairs unaided, they are risky) does not mean that we should in any way reduce the focus on safeguarding older people with high support needs from abuse and poor treatment. In fact, as the SCIE Social Care TV online video, *Safeguarding adults in care homes*, shows, safeguarding policies and practices are much more effective in an organisational culture where everyone is encouraged to be open about their concerns, feelings and mistakes. In the next and final section in this chapter, we consider some of the ways in which such change can be and has been achieved within some of the *My Home Life* projects.

Engaging in a cycle of change

We heard how the care home manager who supported a resident's choice to walk unaided down the stairs experienced a barrage of investigations by partner agencies when things went wrong. We also heard how his initial and understandable reaction to this was to minimise any risk-taking in the care home, which will almost certainly have led to a reduction in residents' quality of life (even if it made them physically safer).

At *My Home Life Essex*, there has been a multi-agency attempt to change this vicious cycle of mistrust and defensive practice. It began with a series of 'Appreciative Inquiry' events, which brought local stakeholders together to help them get to know each other and their different contexts, and to develop joint solutions to problems that were getting in the way of supporting older people living in care homes. One of the outcomes from this stronger sense of partnership-working was the decision to change the name and philosophy of the council's former 'Quality Monitoring Team'. The previous approach to 'monitoring' was creating anxiety and stress for care home managers and actually having a negative impact on the quality of relationships and care.

The new 'Quality Improvement Team' (QI) aims to work in partnership with homes in a positive way to help them deliver the best possible quality of life for service users. One care home manager spoke powerfully about how the relationship with the QI team was now more trusting, helpful and supportive. Meanwhile, one of the QI officers observed that they feel they are getting a truer picture of homes because managers and staff are more relaxed and don't feel they have to 'put on a show'. (Drawn from Owen and Meyer *et al.*, 2012, pp. 55–58)

The change in the team's name and stated aims makes a difference here because it has grown out of a change in relationships: people have got to know each other better and can understand each other's perspectives more. When we can develop this kind of empathy and shared ownership, it is much easier to start from a position of trust, support and partnership. Without such relationships, it is almost impossible to give and receive the critical feedback which is needed to make and sustain positive change in services and organisations.

My Home Life also recognises the negative cycles which can exist *within* care homes (or indeed any organisation which provides housing, care and

support) and the pivotal role which care-home managers can play in turning the culture of the home around. Their *Leadership Support Programme* engages groups of between 12 and 15 care home managers in a 'journey' of positive culture change over a 12–14 month period, through the delivery of leadership skills training and action learning sets. Managers are free to steer the sessions, in which they share and listen to each other's experiences in a safe and confidential environment and aim to develop skills and solutions as a group.

Sessions have explored issues such as setting personal and professional boundaries, coping with stress, changing leadership style, and improving relationships with staff and residents. Here are the reflections of some of the participants:

"*My Home Life* does help you a lot in managing your staff. We tend to rush around telling them to do this, do that, but to actually give them, the staff, time to unpick it, to see it for themselves, to feel it, to have their goal in mind and they can see how they can get there. If we all have a common goal, they have got to feel it, I can't just tell them to do that, they have to go through the same process."

"Because I am not so stressed, not so angry with staff for not doing it right, I am more approachable, staff are less defensive with me; they talk to me as an adult rather than coming with excuses. They do not feel the need to play out their insecurities and anxieties; they are calmer, they don't feel they have to be seen to be doing a task in order to ensure that they are not going to be criticised. This has a major effect on the resident experience and the quality of relationships between staff and residents."

"Everything has a knock-on effect, people feel more relaxed – staff and residents – they take the initiative, feel safer to try things, residents appear to feel listened to and valued. It's hard to put your finger on what has changed." The residents seem to be taking greater responsibility for roles in the home – watering plants, flower arranging, feeding the fish – "like that our new relational approach has helped them feel more engaged and closer to the home, rather than ordering the staff around as if they were servants".

Various participants in *My Home Life* (Owen and Meyer *et al.*, 2012, pp. 50–54)

These relatively simple (and relatively inexpensive) interventions seem to have the potential to bring radical change to services and, in turn, to the safety and quality of life of the older people living in them. If we know where and how to turn the cycle around and have sufficient time, leadership and vision to do so, there is hope that the sheer momentum of the 'knock-on effect' can bring better lives for older people and the staff working with them. It is significant that the practical changes in these examples are driven by a change in attitudes, values and relationships.

In the next and final chapter, we return to our key challenges or values and draw together the practical steps we can all take to turn the cycle around.

"Everything has a knock-on effect, people feel more relaxed – staff and residents – they take the initiative, feel safer to try things, residents appear to feel listened to and valued. It's hard to put your finger on what has changed".

CHAPTER 6: BUILDING A BETTER LIFE

At the start of this book, we introduced the challenges which have emerged from and informed the programme. In the intervening chapters, we have presented stories, evidence and ideas from the programme to demonstrate what these challenges mean to older people and why they matter. We have argued that these can provide the foundation on which to build a better life for older people with high support needs.

Few could disagree with these challenges and many would no doubt say they already rise to them, but we – the programme managers, advisory group members, researchers and older people involved in *A Better Life* – challenge ourselves and you, in this chapter, to think about what more we can do to apply them in our personal and professional lives, in our organisations, and in our communities. We also consider how we can tell whether this is actually resulting in better lives for older people with high support needs.

Under each challenge, we summarise the key messages and some of the related ideas for change from the programme, referring back to previous chapters as necessary. There are more ideas for change from the programme for some areas than others. The examples also vary in their nature. Some are very practical and specific, focusing on everyday practice or behaviour; others involve changes to systems and processes; and some aim to influence attitudes and thinking. Evidence from the projects suggests that change will be needed at all these levels if we are to succeed in building a better life for older people with high support needs. We need to change the way we think about older people if systemic changes are to be both envisioned and implemented, but at the same time it is hard to change cultures if systems seem to be working against you.

We have argued throughout this book that if our society is to age successfully we will *all* need to play a role: businesses, media and transport providers as well as those providing direct care to older people. Since it is the interface between the individual, family, community and state which is so critical, we discuss the actions which need to happen at all these levels in one place, rather than separating them out into different sections.

1. Old age is not about ‘them’: it is about all of us

The challenge: We all need positive images and balanced narratives to challenge ageist assumptions. Old age is not about ‘them’, it is about all of us.

Older people are not a separate species to be studied and understood: we may change as we age but we retain our personhood. Whatever our age, we share fundamental human needs – for meaningful relationships, some control over the things that matter to us, an ongoing connection with the outside world, and so on.

If we are going to make an ageing society work well for all of us, we need to break down these barriers between ‘us’ and ‘them’ and promote a much wider conversation about getting older. We also need to plan positively – as individuals, couples, families or other groups – for getting older and perhaps

needing more support, and we may need to do this emotionally, practically and financially. A big part of the problem is that ageing tends to be portrayed and hence perceived as something entirely negative: a period of loss and decline towards death. Since getting older gets such a bad press, many of us find it easier to put it out of our minds altogether or tell ourselves it is something that happens only to others.

The media and arts sectors have a key role to play here by challenging ageist stereotypes, introducing us to real people or balanced fictitious characters, and exploring our fears, emotions and insecurities about getting older. For example, a number of recent films, such as *Amour* and *Quartet*, have explored issues around ageing, relationships and dementia in a bold but sensitive manner. *A Better Life* has a microsite (<http://betterlife.jrf.org.uk/index.html>) which contains a gallery of centenarians' images by photographer Chris Steele-Perkins and a poem written and read by Sir Andrew Motion.

For most people, preparing for older age involves – at best – trying to save for retirement and preparing instructions for what should happen to their body and estate after they die.

We also need to get better at envisioning, communicating and planning *how we want to live* as we get older, especially if and when our health deteriorates.

This should begin with working out what is important to us personally, in the way that Ben (p.44) planned what he did and did not want to happen when his Aunt Mabel died. As the programme has demonstrated, there are various options to consider about where you live and what type of care and support you may need or wish to access there, including:

- **staying put in our own homes and neighbourhoods** and if this is a priority for us, we should consider whether there are things we could do in advance to make these more accessible and supportive;
- **moving to specialist housing**, which includes a range of different models under the umbrella of 'supported housing' or 'housing with care': key considerations here should include affordability, tenure and housing rights, living in an age-specific community setting (albeit with your own front door), and the availability of care, support and other facilities;
- **moving to residential care**, which can be a planned and positive choice – *My Home Life* gives a sense of what we should expect from a good care home;
- **moving to non-specialist housing**, to somewhere smaller, more accessible, nearer to family and friends, in a more pleasant setting or perhaps a different country: transport, proximity to services and networks, tenure and the implications of turning equity into savings (Aldridge *et al.*, 2012a) may be considerations here;
- **developing mutual or shared models**, such as an extended family, a community of people with common values or interests; or an existing neighbourhood (as discussed on p.33)

There are practical resources to guide us, for example, the forthcoming *Rough Guide to Ageing* (supported by JRF) which will provide information, advice and further resources on areas such as health, money, dementia and residential care.

The evidence and stories from *A Better Life* suggest that we should not just plan for getting older in isolation, but that we should also plan as groups, whether with friends, extended-family members, neighbours, or communities with shared backgrounds or interests. Vic Forrest reflects on the steps that he and his neighbours have taken to do this, and suggests:

“you may need support as you age but there are ways of designing and shaping this yourself”

“I think that perhaps the most important and significant action we have taken has been to begin talking with others about the issue of ageing and mutual support in general and how as a community we might want to help ourselves. It’s the *idea* that perhaps we can face up to our ageing and do things together to help ourselves that some of us have found inspiring. Other groups of people could do this.”

Forrest, 2013, p.25–26

If individuals and groups are to be enabled to plan effectively for getting older, they need clarity about what public services and the private sector will be able to offer them. There seems to be more constructive public debate about our ageing society now than there was five years ago when JRF first launched *A Better Life*. For example, a wider range of think tanks and charities have published reports on ageing issues; and there have been panel discussions on the topic on programmes like *Newsnight*. However, more is needed: the House of Lords Committee on Public Service and Demographic Change (2013) warns that ‘the Government and our society are woefully underprepared for ageing’. It argues that more open debate and cross-party political leadership is needed. It is vital that the collective voice of older people with high support needs and their carers is heard within this debate, and that professionals involved in providing or commissioning a wide range of services and those in the business sector are also actively involved.

The media has an ongoing role to play not only in challenging attitudes but also in stimulating and informing this public debate. *The Guardian* (supported by a group of sponsors which includes JRF) has set up an online hub to explore the issues facing older people, their families and the services supporting them, at: <http://www.guardian.co.uk/society/older-people>

“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.”

Bowers *et al.* (2013, p.75)

2. Older people are individuals and they are, as a group, becoming more diverse

The challenge: 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.

As more diverse generations reach old age, it will be even more important to understand how different backgrounds may shape (but do not *determine*) the resources and priorities we have in our later years.

The evidence from *A Better Life* suggests a number of practical steps which organisations – from GP surgeries to community groups and from housing providers to private care agencies – might take to ensure they are genuinely inclusive of diverse older people with high support needs.

- Taking confidentiality seriously and making it clear that any harassment or discrimination will not be tolerated and taking anyone seriously who reports it (we know from Rowena at Anchor on p.25 just how important this is). It will also be important – through training, education, awareness-raising and discussion – to make sure that all those who use, live or work in your organisation can identify and challenge more subtle forms of discrimination (in relation to age and also to gender and other aspects of social identity).
- Offering those who are in the minority and who may be at risk of isolation opportunities to mix and connect with others who share their backgrounds (this might include men in care homes and housing schemes as well as ethnic minorities, LGBT people, etc.). At one end of the spectrum, it might involve setting up a group like that at Anchor (p.25) but it might also be a question of taking simple steps to find out how individuals can be supported to join a social club (like Jakob on p.27), socialise online (like one of the gay men interviewed by Klocker, 2012), or receive mail-outs from the church they are no longer able to attend (like an older woman in Katz *et al.*, 2011);
- Taking time to listen and find out if there are things that would make life better – often relatively simple things can make a big difference, like being able to watch or talk about the football with someone (Blood *et al.*, 2012a); being able to access African Caribbean hair care (Croucher and Bevan, 2012); or knowing how the crockery is stacked so that the blind person will not knock them down (Katz *l.*, 2011);
- Challenging our own and others' assumptions about what an older person will or will not want to do, when those assumptions are merely based on the fact that they are older, disabled or because they are a member of a particular equality group.

3. Relationships matter to us whatever our age; we have a fundamental human need to connect with others meaningfully

The challenge: 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.

Our relationships and interactions with other people may become even more important to us as we get older and if we encounter health problems. We may need support to maintain our existing relationships and to meet new people, especially if our partner, family members and friends have died or if we move to a new area. The programme has demonstrated that nurturing social networks boosts most people's quality of life, can protect mental health and generate opportunities for mutually supportive relationships. For some older people with high support needs, relationships with care and support workers become the most regular and important ones.

In some areas, changes to funding and commissioning practice have reduced or removed roles such as wardens in sheltered schemes (Pannell and Blood, 2012) or activity coordinators in housing with care schemes (Blood *et al.*, 2012a): workers who were in a good position to provide companionship to, and support the participation of, older people with high support needs. Closing day centres (or 'retiring' people like John (p.55) from them at 65) may seem like the best way to prioritise increasingly scarce public resources, but this is short-sighted. These services prevent isolation and encourage friendships for many with high support needs, significantly improving the lives of people like

Vic and Jack sharing a meal at Brixton Housing Co-Op



Gertrude who we met on p.24). This is likely to matter even more if the state withdraws further into the background.

A Better Life has identified a number of practical ways in which relationships, networks and communities can be supported:

- **Identifying and supporting existing relationships:** Many older people with high support needs are part of a couple (like Brian and Maggie on p.59); others are in mutually supportive relationships with their children, parents, siblings, etc., (like Ben and his Aunt Mabel on p.67). It is important that others see and understand the importance of these relationships (and the fact that they are often 'two-way') and find ways to support the whole family or network.
- **Brokerage:** The programme demonstrates that a wide range of people – including those working in shops, pubs and cafes as well as in housing schemes and care homes – can act as 'brokers', introducing older people with high support needs to each other and supporting their friendships. Margaret and Betty are introduced to each other by the hairdresser in their housing scheme (Blood *et al.*, 2012a) and Jo's carer recognises that she and another woman she supports have shared interests and exchanges cards and messages between them (Katz *et al.*, 2011).
- **Equipment and Technology:** Katz *et al.* (2012) identified these as key barriers or enablers to relationships. Some people had withdrawn from socialising because they could not hear well enough, whereas others had been able to get out and see friends again since getting a mobility scooter. Some older people may need support to chase referrals to Occupational Therapists for aids and adaptations: for example, Blood *et al.* (2012a) heard how scheme managers had often spent a lot of time and energy doing this on behalf of residents. Meanwhile, simple practical projects like Hear to Help (p.26) can ensure people are getting the most from their existing equipment. We saw on p.26 how the *DropBy* network can help older people with high support needs to connect with others online and how some will need support and encouragement to do this.
- **Sharing meals:** Meeting to cook for each other and eat together helped members of the Brixton housing co-operative get to know each other (Forrest, 2013); many older people living in housing with care say they value the opportunity to eat lunch in the restaurant with their neighbours; and in *My Home Life* we hear how having tea together can help build the relationships between care home staff and residents. Initiatives like *The Big Lunch* (<http://www.thebiglunch.com/index.php>) can help facilitate neighbours living anywhere to come together and share food.
- **Having places to meet:** Whether it is a bench or a community café, the programme shows how communal spaces enable us to meet and mix with others. The Elders Council of Newcastle (Manthorp, 2010) produces maps showing the location of benches, toilets and other 'journey breakers'. Yet libraries, post offices and other community facilities are being closed in many areas. There may be scope to develop older people's housing schemes to act as 'hubs' for the local area (Croucher and Bevan, 2012; Manthorp, 2010). Businesses can also play a role here (Bazalgette *et al.*, 2012), though some will not be able to afford to use places like cafes and hairdressing salons regularly to meet others, even with pensioner discounts.
- **Relationships with (paid) carers:** Consistency of staff is essential for relationship building, yet the programme found that this was sometimes threatened by commissioning decisions and high turnover (Blood, 2012a). Workers need shared values, time and flexibility, and opportunities to debrief if they are to demonstrate compassion and really get to know the people they are supporting. The *My Home Life* and housing with care

research recommends a whole organisation approach, in which all staff and managers (including cooks, gardeners, etc.) create a supportive environment. We have seen on p.24 how involving older people in the recruitment of staff can also help organisations prioritise the skills and values which matter the most to those receiving care or support (Blood *et al.*, 2012b; Owen *et al.*, 2012).

4. Older people with high support needs have many assets, strengths and resources

The challenge: 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.

Being able to make a contribution, fulfil a useful role, or provide support to others is important to many older people with high support needs: it can boost self-esteem, reduce loneliness, make it easier to accept help from others and, of course, bring value to the lives of others. However, older people's actual or potential contributions are often not recognised because they are typically framed as the service user or the welfare recipient with problems and needs.

Taking an asset-based approach to supporting someone means focusing on their skills, interests and resources. For example, we have heard how staff in some care homes (p.18) and the 'Locksmith' in extra care housing schemes (p.31) spend time identifying residents' interests and skills and finding opportunities for them to use them. We need to train all health, social care and housing professionals so that they see the person and their relationships and so that they hear what they say they want and value.

Throughout the programme we hear examples of older people with high support needs providing as well as receiving support. These range from caring for a partner, to offering emotional support and friendship (like Miriam on p.28, or the volunteer phone befrienders on p.37). Others lay the tables for the lunch club, coordinate the local Neighbourhood Watch or act as Secretary to the residents' association.

This kind of mutuality and reciprocity may happen spontaneously between individuals, but the programme suggests that, if they are to happen and be sustained at a *community* level, active facilitation by someone in a formal or informal community development role and some investment of resources are needed. The projects from *A Better Life* have also identified a number of approaches to doing this. We have, for example, heard about the *KeyRing* model (on p.36); the Navigation Group's work to set up a structured support scheme (p.34); and various steps taken by providers and residents of sheltered housing schemes to promote supportive communities (e.g. the resident volunteer group and Linc-Cymru initiatives p.32). We have also seen several examples of the power of peer support groups and how they can act as springboards for mutually supportive relationships, like Pat and Maria (on p.4) who met at a patient support group.

We have heard about the potential benefits of intergenerational relationships in Viv and Miriam's story (on p.28). Several of the projects identified within the programme link older people with high support needs with younger people, such as the *My Home Life* Essex community volunteers (on p.30) or the resident volunteer group (on p.31). These initiatives can act as a way of bringing people together, breaking down barriers and sparking mutually supportive relationships.

Bowers *et al.* (2013) have identified a number of promising small scale mutual support initiatives and they provide emerging evidence of their benefits for older people with high support needs. However, awareness of these approaches amongst older people, relatives and those commissioning and providing services is generally low. Organisations that provide traditional care and support services and community groups have a key role to play here, finding out about existing initiatives, signposting people to them and (in Vic Forrest's words) planting the *idea* of what may be possible, and providing technical advice to those who are trying to take alternative approaches.

A wide range of people will be in a good position to bring isolated people together or link them into existing networks around places of worship, social clubs or more informal circles. Others could volunteer at a local care home or may have the time, vision and community development skills to promote better relationships in their neighbourhoods, though they are likely to need support from volunteer organisations to broker placements or from community development teams to support this in the longer term.

5. Whatever our age or support needs, we should all be treated as citizens: equal stakeholders with both rights and responsibilities

The challenge: 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.

Older people with high support needs are frequently portrayed as dependants who need to be cared for, rather than citizens who have entitlements and responsibilities. The power of professionals and the complexity of the system, combined with prevailing ageist attitudes, means that they are often not treated as equal stakeholders, even in their own lives.

A rights-based approach can help here, and by this we do not necessarily mean one in which people are constantly threatening court action but one in which, according to Alan Miller, the Chair of the Scottish Human Rights Commission, human (and other) rights provide a 'common framework of values and understanding of how best to improve the quality of life of those who receive care'. The Commission provides helpful, free online resources, particularly targeted at those working with older people who have high support needs, on their *Care about Rights* website: <http://www.scottishhumanrights.com/careaboutrights/>

The Equality Act 2010 can also provide the impetus for public bodies and other providers, including businesses, charities and community groups, to take proactive steps to improve access, experience and outcomes for older people with high support needs. The law can provide leverage for older people and their supporters to challenge organisations when things go wrong, but there is also a business case for attracting and retaining this group of customers. The Equality Act 2010 has brought together legal protection against discrimination on age, disability, gender, sexual orientation, ethnicity and a number of other so-called 'protected characteristics'. This should make it easier to tackle the sexism, disablism, homophobia and racism that older people experience at the same time as tackling ageism.

The actions and decisions of organisations and individuals need to be underpinned by what Julia Unwin has recently described as 'a new social contract between individual and state' (Unwin, 2013). A key part of this

contract will be to carve out our rights and responsibilities as we get older: what we can reasonably expect from publicly-funded services and what we will need to take responsibility for ourselves if we are to enjoy a good life in old age. This debate is also part of the wider picture of welfare reform. Key messages from *A Better Life* to inform this are:

- Complexity in the benefits and pensions systems needs to be tackled to reduce the risk of older people with high support needs missing out on their entitlements and the ensuing impact this can have on their quality of life (Pannell, Blood and Copeman, 2012);
- Self-funders are a significant and expanding group, yet they remain underneath the radar of too many of those commissioning and providing housing, care and support services (Pannell, Blood and Copeman, 2012), primarily because, as we saw on p.61, the social care and public housing systems are eligibility-led. If you are not financially eligible for help with social care funding or Housing Benefit, it can be difficult to get any help at all from publicly-funded services, regardless of whether or not ongoing funding is needed;
- The current system can penalise decisions which are good for both individual and state (as we saw in Brian and Maggie's story on p.59). Inconsistencies (such as the fact that, under the current system in England, selling your house and freeing up capital will take some people over the capital limits for publicly-funded social care) need to be ironed out and consideration given to ways of incentivising 'good decisions' – for example, through Stamp Duty Land Tax exemptions or holidays (Pannell, Aldridge and Kenway, 2012a).

6. The individual and collective voices of older people with high support needs should be heard and given power

The challenge: 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.

Older people with high support needs should be able to make choices about their day-to-day lives: what they wear, what they eat, how they spend their time. They should also have as much control as possible over the bigger questions of where they live and how they are supported.

The programme has found that even people with conditions like dementia (which may reduce their capacity to make decisions some of the time) want to and can have a voice and exercise choice and control. They will, however, vary in how they want to do this, what they are happy to delegate, and the support they need to make and express informed decisions. Collectively, older people with high support needs can be involved in shaping services and policies, and in supporting and educating peers, professionals and members of the public.

Focusing on what matters to people and helping them to define what a 'good life' means to them is a vital first step in achieving greater control. The programme presents a range of tools and techniques for doing this, such as:

- **Katz's (2011) wheel** (see p.10), which can be used as a prompt to identify things which a person wants to sustain or change in their life, the resources they can draw on to do this, and the obstacles they encounter. This exercise could be carried out with a client, friend, or family member, or even by yourself;

- For people who have dementia or learning disabilities, simple practical techniques like **Talking Mats** (on p.18) may help to structure these discussions;
- A **Circles of Support** approach brings together those who care about and provide support to the 'focus person' to help them identify their own goals and to problem-solve as a group (see www.circlesnetwork.org.uk/ for more information). We also saw how the values and structure of this model can be used to build a circle from scratch in the case of Jakob (p.27).

It is important to make sure people know how to get things changed. It is essential to have an accessible complaints procedure and, in some services, to conduct regular formal reviews. People also need a way of providing day-to-day, low level feedback in a non-intimidating way. For example, one of the care homes in *My Home Life* encourages residents (rather than staff) to write their own daily-life notes. Older people who had never complained about anything before started to use this opportunity to communicate some of the things that are important to them and issues that have affected them during the day. Staff members are then able to respond positively – rather than defensively – to these points.

People also need information, advice and advocacy if they are to make informed choices within the current maze of services and benefits. For some people – especially those with high support needs – this support will sometimes need to be intensive and personalised: simply receiving an information leaflet is unlikely to be enough. Such 'navigation' or 'brokerage' might be provided by a friend, family member, a paid worker or a volunteer.

The programme has shown how beneficial it can be for older people with high support needs to come together and share experiences, input collectively into decision-making, service or policy development, and campaign for change. There are a number of things which housing, care and support professionals (but also a whole range of other people) may be able to do to nurture these kinds of groups, without smothering them or taking over.

- Challenging professional assumptions about who the 'experts' are and how power should be distributed between services and those using them (as we saw in the example of the Service Assessors at on p.49 or the care home resident asked to sit in when prospective workers were being interviewed and give the thumbs up or down (p.24);
- Identifying potential leaders (often in unexpected places) and giving them opportunities and encouragement (like James McKillop, who was invited by a researcher to speak at a conference and then encouraged to develop a vision for the SDWG, as we saw on p.48) ;
- Providing funding or practical support – this might range from a scheme manager helping to produce a newsletter or organise a residents' meeting in a housing scheme to the administrative support, office base and paid coordinator provided by Alzheimer Scotland to the SDWG on p.48;
- Bringing people together so that connections can be made and ideas developed (as in the St Monica's Trust focus groups on p.48, or the conference which involved people who had a diagnosis of dementia as well as the professionals working with them on p.48).
- Reducing the physical and communication barriers so that older people with high support needs can attend and participate. We saw, for example, how expenses for those attending the Anchor LGBT group (on p.25) can include paying for an accompanying carer. Online communities such as that provided by *DropBy* (p.26) can provide a springboard for self-organised groups of older people, who can set up interest groups to share news and messages between members and promote events through the site. If the

collective voice of older people with high support needs is to be heard and given power, it will be important for those making policies and commissioning services to engage meaningfully with groups. We have heard, for example, how the Scottish government has involved the SDWG in developing and implementing its national dementia strategy or, on a smaller scale, how St Monica's Trust used the feedback from their focus groups to shape their staff recruitment and selection processes.

7. We need both to innovate and improve existing models

The challenge: 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 programme identifies and explores a number of promising alternative models for organising our housing and support as we get older. For example, we heard on p.36, about the potential (but also the slow progress to date) of the UK cohousing movement. On p.37, we suggested that aspects of the traditional warden role, who provided *ad hoc* practical, social and emotional support to sheltered housing tenants, might be brought out into the wider community and delivered to dispersed residents of mixed tenures, ages and needs by a *KeyRing* Support Worker who also coordinates peer support within the network.

Important though they are, innovative ideas should not distract us from the vital work which needs to happen within existing services. Models like cohousing (p.36) and *Homeshare* (p.36) are exciting but they are likely to remain as niche sectors for the foreseeable future. These models do not offer a blueprint which can simply be scaled up or rolled out: they are usually very locally specific and are strongly linked to individuals.

However, as a society, we do not need to choose between existing and more radical models.

The 'scaling out' of small-scale innovative approaches and the improvement of current models (including widening the age-specific and general housing options on offer) can and should happen side by side. We will also have to streamline systemic bureaucracy and change attitudes within mainstream services and beyond in order to deliver the seemingly simple things that matter most to older people. Ultimately, we need to get better at supporting those individuals who simply have a clear vision of how they want to be cared for and want to take control of this, whether in a care home or a cluster of individual homes.

A key message from the programme is that there is plenty of hope and good practice within existing models.

'Housing with Care' (in which older people rent or lease self-contained flats within a complex where on-site care, support, catering and other facilities are available) was generally found to promote the wellbeing and rights of people with high support needs (Pannell, Blood and Copeman, 2012; Blood *et al.*, 2012a). The next challenge will be to ensure access and affordability for larger numbers of older people who want to live in this type of housing (especially those in the 'squeezed middle') across the UK.

My Home Life demonstrates that relatively simple changes to the culture and leadership of care homes can make a big difference to residents' quality of life. For example, we heard in Chapter 5 about the impact which a development

programme for managers can have on practice, attitudes and relationships throughout a care home.

“In almost every *Better Life* publication and project, it comes down to leadership and how important it is we invest in the growth of leaders”.

Advisory Panel Member

“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”.

Leadership is clearly vital if we are to achieve the vision of *A Better Life* – both in existing systems and services and in new approaches. However, a key message from the programme is that ‘leadership’ is not the exclusive preserve of paid managers. Leaders also crop up in unexpected places and they play a range of roles – inspiring, ‘nudging’ or facilitating others, or linking them up to other people, resources or initiatives.

Much of the leadership in the programme is shown by older people (some with high support needs) themselves: James McKillop realises he can engage audiences and make a difference to others with dementia; Vic Forrest encourages his neighbours to plan together for growing older; members of the resident volunteer group (p.31) take it upon themselves to organise events within their sheltered housing scheme. In all these examples, there is a sense of courage, of initiative, of taking responsibility and, vitally, of bringing others along with you.

We need different kinds of leaders at different levels – perhaps reflecting what Owen and Meyer *et al.* (2012) describe as ‘dispersed leadership’. We also need leaders who can facilitate, listen to (and perhaps also personally offer) the voice of older people with high support needs.

Creating a positive ageing society

Some of the changes we have suggested in this chapter are relatively straightforward practical steps or attitudinal shifts. However, we recognise that there are significant challenges – fiscal, systemic and cultural – in moving towards a better life for older people with high support needs.

“The financial challenges we face make all the things we are talking about here even more important but probably also even harder to do. ... Just finding the headspace in many services to engage with more innovative approaches is challenging at the moment”.

Advisory Panel Member

However the key point is that these changes are not bits of sticking plaster we might stick on the system while we are waiting for things to get better. The challenges we have set out here are not a luxury add-on which we may or may not be able to afford: they form the very heart of the matter. We should judge whether our systems, practices and policies are working *precisely* on the basis of whether or not they are promoting good lives for older people with high support needs. To do this, we must recognise that older people are themselves the experts on their own lives. This will require wider shifts in attitudes in which, as we saw at the start of this chapter, we all have a part to play.

Ultimately, we must open our eyes to the strengths and wisdom of older people if we are to succeed in creating a positive ageing society.

“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, speaking to Chris Steele-Perkins in ‘What is it like to be 100?’ <http://betterlife.jrf.org.uk/gallery.html>

NOTES

- 1 The National Evaluation of the Partnerships for Older People Projects (a government-funded programme of preventative projects working to tackle social isolation and promote health and wellbeing) suggests that this kind of support is likely to reduce the need for secondary health and social care services (PSSRU, 2010).
- 2 To be assessed as a 'Decent Home' by this test, a house must be free of major hazards, in a reasonable state of repair, have reasonably modern facilities and services and a reasonable degree of thermal comfort.
- 3 Blood *et al.* (2012b) describe how some authorities are developing new hybrid commissioning models to guarantee core funding for services like housing with care, whilst allowing a degree of personal choice and flexibility within it.
- 4 Recent figures from Skills for Care (2012) show that the median gross pay of care assistants and home carers has decreased by almost two percent since 2010, with actual pay rates ranging from £6.09 to £12.03 per hour, slightly above those of retail cashiers and check out operators.
- 5 This model is one which has been developed by the EW Group (<http://www.theewgroup.com/> where the author is a Consultant Partner.
- 6 United Kingdom Home Care Association (2012) found that 73% of homecare visits in England (87% in Northern Ireland and 42% in Wales and Scotland) appear to be 30 minutes or shorter, though there has been some debate by the Directors of Social Services regarding the extent of this practice.
- 7 'Timebanking' is a means of exchange used to organise people and organisations around a purpose, where time is the principal currency. For every hour participants 'deposit' in a timebank, perhaps by giving practical help and support to others, they are able to 'withdraw' equivalent support in time when they themselves are in need. <http://www.timebanking.org/about/what-is-a-timebank/>
- 8 See <https://www.gov.uk/government/get-involved/take-part/become-a-community-organiser> for more information on Community Organisers.
- 9 There have been significant reforms to Housing Benefit from April 2013. People over 60 are exempt from the new 'bedroom tax' but people in their 50s with high support needs are vulnerable to having their Housing Benefit reduced through the new rules. The amount of Housing Benefit which can be paid to a landlord has also been capped over the last couple of years and this may impact on older private tenants, especially those in London and other high demand areas. There have also been changes to the rules for Pension Credit which mean that couples only become eligible for it when the younger partner reaches the qualifying age.
- 10 See for example Dennis Kodner's recent presentation, 'Integrated Care Models That Work for Frail Older People' at The King's Fund's Integrated Care: Key Factors for Success' Conference, London 18th September 2012 at: <http://www.kingsfund.org.uk/sites/files/kf/dennis-kodner-integrated-care-frail-older-people-kingsfund-sept12.pdf>
- 11 It should be pointed out, though, that this was also true in the 19th century, where social care had its origins in the principle of less eligibility and sifting the deserving and undeserving poor!
- 12 As announced in the 2013 Budget.
- 13 See the Founder's Memorandum at <http://www.jrf.org.uk/about-us/our-heritage>

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A *Better Life* publications are followed by an asterisk.
 All Joseph Rowntree Foundation publications are available at:
<http://www.jrf.org.uk/publications/browse>

APPENDIX 1

A Better Life – the story of the programme

Joseph Rowntree originally launched his trust in order to ‘search out the underlying causes’ of social problems, whilst focusing on achieving ‘practical results’.¹³ Today JRF – with its aims to ‘Search – Demonstrate – Influence’, seeks to learn from research and real experience in order to influence change.

In 2009, the Joseph Rowntree Foundation (JRF) launched a five year, £1.5 million programme, *A Better Life*, to explore what can help older people with high support needs enjoy a better quality of life, now and in the future.

JRF already had a well-established tradition of commissioning projects which sought to empower older people and disabled people to talk about their lives and come up with their own solutions. Examples from the disability field included Cole *et al.* (2000) and the *Changing Days* project, and Hende and Pascall’s (2002) work with younger disabled adults. The *Older People’s Programme*, running from 2000 to 2005, had been defined and directed by older people and looked at the issues around growing older that were important to them. It culminated in the *Older People’s Inquiry* (Raynes 2006) which highlighted the value of ‘That little bit of help’.

In 2009, demographic trends and their impact on the cost of social care were (and still remain) hot on the agenda, and JRF was concerned that older people with high support needs were often excluded from these debates (as they are from many other areas of life). There was a lot of talk of ‘active ageing’, and when those who were living with chronic conditions and multiple impairments were discussed, it was purely in terms of their care needs rather than their wider wellbeing. Most of the policy focus was on older people living in their own homes, and little attention was being given to those who had already moved into residential care or supported housing, many of whom had not been able to continue living in their previous homes.

From the beginning of *A Better Life*, JRF and its advisors were clear that they wanted it to embrace and develop the social model of disability and focus on hearing the voices of the excluded: both challenges which lie at the heart of JRF’s mission. The direction of travel was informed by a Programme Advisory Group of around thirty people: researchers, policy-makers, providers, academics and older activists, drawn from the four nations of the UK.

A Better Life has already influenced the development of other JRF programmes. Several other programmes, including *Dementia without walls*, *Risk, trust and relationships* and *Neighbourhood approaches to loneliness* have developed as off-shoots from the projects within *A Better Life*. The emerging key messages and challenges from *A Better Life* have also shaped the values underlying these and other programmes, for example, the focus on hearing the voices of people with dementia and the focus on relationships and community.

APPENDIX 2

Overview of the body of work from *A Better Life*

A Better Life has identified good practice and challenges within existing models and sought out promising alternative approaches; it has included large scale qualitative research projects, quantitative studies, evidence reviews and reflective pieces written from a range of perspectives.

These projects were developed within four strands of work:

- Defining what makes ‘a better life’ by hearing what diverse older people with high support needs say about what they want and value.
- Improving residential and nursing care by building our understanding of how to maximise older people’s choice and quality of life in care settings so that we can influence policy and practice development. This work, led by *My Home Life*, also included direct work with managers of Joseph Rowntree Housing Trust care homes.
- Researching housing with care schemes in order to inform those involved in policy and practice about how such schemes can support older people with high or increasing support needs.
- Widening choices by exploring other accessible and affordable approaches to support, housing and community for older people who have (or develop) high support needs.

The outputs from the programme include:

- Around a dozen evidence reviews or ‘think pieces’ on a range of topics, including: housing with care; supported housing; cohousing and other innovative approaches; equality and diversity; and user/carer perspectives;
- Six reports and the accompanying ‘Findings’ of qualitative research projects, exploring housing with care, residential care and what older people with high support needs value;
- Three quantitative reviews, looking at demographic trends and projections; affordability of retirement housing; and downsizing and ‘under-occupation’ of housing;
- A series of five *Perspectives on Ageing*, which explore diverse experiences, including those of people with a learning disability or dementia, those living in Gypsy or South Asian families, and lesbians, gay men and bisexuals;
- Three summaries of other papers, including a ‘round-up’ of the first phase papers and a review of housing with care outputs at the end of each of the two phases;
- A collection of practice examples for housing with care drawn from the research and workshop material for commissioners wanting to widen choices;
- The microsite of *A Better Life*, which contains poetry, photographs and personal accounts of ageing and around a dozen blogs on the main JRF site;
- Many events, both large and small, and numerous presentation blogs.

APPENDIX 3

The Advisory Panel

JRF was keen to explore what the findings of *A Better Life* mean now for different people. The sheer breadth of the programme meant that it was important to reflect on what this whole body of work tells us about the lives of older people and what they value. Given the time that had elapsed and the significant developments that had occurred since the programme's inception, it also felt important to tackle the potential challenge from older people, professionals and politicians of "so what?"

JRF decided to commission a panel of nine advisors who, along with the two programme managers, a chair and a writer, formed the Advisory Panel. The panel included older and younger people; activists; researchers and consultants; a journalist; and people working in the Third Sector. We met in York to 'break the ice', and then each received the substantial pile of publications from *A Better Life* to digest. At a second meeting in London, we shared these reflections, debated their significance and attempted to marshal our responses into themes. At our third meeting, the group responded to an early draft and discussed the ideas for change emerging from the programme. Members were then given a final opportunity to comment on the advanced draft.

The panel members were:

Sue Garwood is an independent consultant in services for older people and those with dementia. She specialises in housing with care, advising on technical, practice and service-quality issues where housing and care intersect. Sue has written a range of learning material for the Housing Learning and Improvement Network and others.

Professor Norma Raynes is Executive Director of the charity Intergen UK. Norma had always been committed to forging strong links between research and practice working in multi-disciplinary research and development, focusing on service quality for children and older people. She is a happy grandmother of twin girls.

Professor Jon Glasby is Professor of Health and Social Care and Director of the Health Services Management Centre at the University of Birmingham. A qualified social worker by background, his research, teaching and consultancy focuses on inter-agency health and social care, personalisation and community care.

Dr Ilona Haslewood co-leads the programme *A Better Life* with Philly Hare, as well as the new JRF programme *Risk, trust and relationships*. Prior to joining JRF she was a Senior Researcher at Skills for Justice, producing labour market information and analysis relating to the justice sector workforce.

Philly Hare is involved with two JRF programmes: *A Better Life* and *Dementia without Walls*. Her particular interests are the empowerment and inclusion of older people, including people with dementia. A qualified social worker, Philly has experience within the NHS, Local Authorities and the voluntary sector.

Claire Turner joined JRF in 2010 and manages JRF's Ageing Society programmes of research. Before joining JRF she worked as a freelance researcher and for a private sector regeneration consultancy firm. Prior to this she held a number of roles within Barnardo's Policy and Research Unit.

Dorothy Runnicles is an advisor, researcher and advocate, a past social worker, community worker, academic, former long-term carer of her mother, life-long volunteer in community activities, and older person service user. Her main interests now are in tackling ageism and strengthening community groups, regionally and locally.

Alison Petch spent much of her life carrying out research across health and social care, based at a number of Scottish Universities. Now at The Institute for Research and Innovation in Social Services (IRISS), she seeks to support the workforce to ensure positive outcomes for people, building on the use of evidence, creativity and partnership.

Professor Heather Wilkinson is Director of Research and Knowledge Exchange, School of Health and Co-director of the Centre for Research on Families and Relationships at Edinburgh University. Her key areas of work focus on improving the care of older people.

Caroline Bernard was Programme Lead (Older People and Ageing) for the National Development Team for Inclusion (NDTi) whilst on the Expert Synthesis Panel. Prior to this, she held policy roles at the National Skills Academy for Social Care, and Counsel and Care. Caroline is passionate about better care and support, and embracing an ageing society.

Vera Bolter, a founder member of the Elders Council of Newcastle, currently chairs the Working Groups on Health and Social Care and Older Person Friendly Environments. Previously she was a member of JRF's Older People's Programme, and was involved locally and nationally in the Better Government for Older People Programme.

David Brindle is Public Services Editor of The Guardian. He has won awards for his coverage of social services, mental health, nursing and disability issues. He chairs NDTi and is a board member of Richmond Fellowship.

JRF is also grateful to the members of the wider programme advisory group for their support and advice over the five years of the programme, especially to the chair of the group, Don Brand MBE.

About the author

Imogen Blood is director of Imogen Blood & Associates (www.imogenblood.co.uk), an independent research consultancy working to improve effectiveness and promote equality across the public and not-for-profit sectors. She has a particular interest in challenging the discrimination faced by older people and improving their housing, care and support options.

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