

Older people with high support needs: how can we empower them to enjoy a better life

Round-up
Reviewing the evidence

October 2010

In 2009, the Joseph Rowntree Foundation launched a new programme to improve the quality of life of older people with high support needs. This *Round-up* draws out key messages from 11 reviews commissioned in the first phase of the 'Better Life' programme and other relevant research recently commissioned by the JRF.

Author

Imogen Blood is freelance consultant working across the public and not-for-profit sectors

Key points

- The group of older people with high support needs is growing, becoming increasingly diverse and changing, as new sub-groups emerge and the prevalence of some conditions, such as dementia, increases.
- There is limited evidence about what older people with high support needs want and value and ageism acts as a key barrier to hearing their voices.
- Older people with high support needs live in a range of settings including: residential or nursing care homes, sheltered housing and housing with care schemes, and in their own or relatives' homes, where many live in substandard private sector housing and an increasing number live alone.
- Older people with high support needs, their supporters and those working with them face a number of challenges in each of these settings. These include:
 - affordability;
 - navigating the system;
 - dementia and mental capacity;
 - social isolation;
 - recruiting and retaining a skilled workforce;
 - involving and supporting carers;
 - end-of-life care.
- Improving quality of life for this group is often about making simple changes to how existing services are run. Innovative models drawn from other countries and social groups can offer alternative options. Personalisation, assistive technology, and the development of user involvement in commissioning present opportunities as well as challenges.
- Future priorities include:
 - challenging ageism;
 - strengthening and listening to the voices of this diverse group;
 - comparing user-defined outcomes and cost effectiveness of different approaches (e.g. different models of housing with care), and using this evidence to develop a business case for change; and
 - developing wider ownership of the debate, since it concerns everyone's future quality of life.

Introduction

Developing an economically viable yet effective adult social care system is a key political objective, with the recession and change of government giving greater urgency to the debate.

Whilst this increased interest is to be welcomed, ageism runs through much of the discourse; older people are often portrayed as a 'time bomb' problem that needs to be solved.

In July 2009, JRF launched its five-year programme, *A Better Life*, to challenge these attitudes and question the political assumption that all older people want to and should, if possible, remain in their own homes. The programme focuses attention on developing best practice in residential care homes and housing with care schemes, as well as considering alternative approaches. Above all, the programme aims to strengthen and listen to the voices of older people with high support needs and their carers. It aims to challenge the service-led approach and replace it with a rights-based approach which recognises older people as equal citizens who are part of the solution.

This *Round-up* discusses what we know about the diverse group of older people with high support needs drawing on the 11 reviews in the first phase of *A Better Life*.

The profile of the group

Who are ‘older people with high support needs’?

The very term ‘older people with high support needs’ is contested. Both ‘older’ and ‘high’ are comparative and subjective and this begs the question of who decides: medical diagnosis, social care assessment, older people themselves or their families? Viewed from a social model of disability, an older person who is physically frail, has a chronic condition or multiple impairments, could have low support needs if they live in accessible housing with enabling technology, within a supportive community.

A complex combination of medical, social and personal circumstances therefore triggers the point at which we might need support; whether or not these needs are assessed will be shaped by our access to information, referral or signposting. How much support we are at this point deemed to need is then further shaped by budgets, eligibility criteria and, in the case of older people, ageist assumptions. As an older person, what quality of life are we entitled to through the input of support: to have a bath every other day; to remain in our own homes if we wish to; to be able to get out and about; or to be able to contribute to our local community? How and why does this differ from the current consensus about what a younger person might reasonably be supported to do?

Age is a good proxy for high support needs: 40 per cent of those currently aged 85 and over are estimated to have a ‘severe disability’, as measured by their ability to perform various activities of daily living (CPC 2010). However, many people in their 90s are active and in good health. Conversely, amongst the ‘younger old’ (aged 60-74), 10 per cent of men and 13 per cent of women reported difficulty in bathing and 6 per cent reported difficulty in getting out of bed unaided (CPC 2010). For the purposes of the ‘A Better Life’ programme, JRF has developed the following definition of older people with high support needs:

“Older people of any age who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. A minority will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, etc. Some of the very oldest people may never come into this category.”

A growing group

Improvements in life expectancy mean that people aged 85 and over are the fastest growing age group in the population. 1.3 million (2.1 per cent of) UK residents are currently within this age group, which is projected to increase to 3.3 million by 2033 (CPC, 2010). Current methods of demographic projection do not take account of government policies, economic circumstances, developments in healthcare or other relevant factors. Most assume that recent trends will continue and so far, this approach has led us to underestimate increases in life expectancy and the prevalence of dementia.

It looks likely that the average years spent with a disability and/or in poor health will continue to increase alongside, or even faster than, life expectancy. As the group of the ‘oldest old’ grows, it is quite likely that the *proportion* of that group who have high support needs will also increase (CPC, 2010).

A diverse group

The huge variations in financial circumstances, family and household composition, education, skills and experience make it impossible to describe a ‘typical’ older person with high support needs. The age range of this group covers two or even three generations; ranging from some homeless people or refugees who, due to early onset of chronic health conditions, might be included in the category in their 50s, to the UK’s 10,000 centenarians (CPC, 2010).

Some older people with high support needs will have spent much or all of their lives with a disability or health condition; some will have acquired impairments and conditions in later life. At any given time, some of this group will be ill; will be experiencing an acute phase of their condition; or will be recovering from a fall or operation. Others will be in good general health, in spite of, for example, an underlying diagnosis of cancer or a sensory impairment.

The group contains small but significant minorities of black and minority ethnic (BME) and lesbian, gay and bisexual (LGB) people. Population estimates for 2007 suggest that around 5 per cent of those over 85 in England and Wales were from ethnic backgrounds other than ‘White British’, though there are huge local variations within this (CPC, 2010). The Government currently uses figures of between 5 and 7 per cent of the total population to estimate the number of people who are LGB. Although older LGB people are less likely to be ‘out’ about their sexual orientation than younger LGB people (especially to service providers), this suggests that there are currently around 80,000 LGB people of 85 years and over in the UK.

We also know that some social groups are likely to be over- or under-represented within the group of older people with high support needs. This may be as a result of differences in life expectancy, patterns of migration, prevalence of health conditions, or social and economic circumstances. These factors can shape our likelihood of reaching old age as well as the amount and type of formal support we may need.

Significant gender differences in life expectancy mean that there are a greater number of older women than there are older men. There is roughly one man for every three women aged 90 and over (CPC, 2010). The nature of older people's support needs is also likely to vary by gender. Older women are more likely than their male peers to live alone, be poor, have osteoporosis (and subsequent fractures as a result of falls) or dementia. Older men have higher rates of morbidity and mortality from most cancers and from coronary heart disease. Research into the help-seeking and socialising behaviours of older men (especially those from working class backgrounds) suggests that they are at greater risk of untreated health conditions or social isolation than older women (Blood, 2010).

Other factors such as ethnicity and pre-existing disabilities can shape both life expectancy and support needs in later life, often as a result of the impact which discrimination can have on socio-economic status. People over 65 from 'Asian' and 'Black' ethnic categories are disproportionately affected by poor quality health and high rates of limiting long-term illness. The small amount of evidence we have on older gypsies and travellers suggests that poverty, poor living conditions on many sites and problems accessing primary health care can lead to the early onset of health conditions associated with older people. Older refugees, asylum seekers and long-term homeless people tend to experience a similar 'premature ageing', caused by stress, trauma, poverty and barriers to services (Blood, 2010).

However, poverty does not need to be extreme to affect mortality and morbidity in later life: those aged 50 and over who are living in council accommodation; living on a low income; and/or have histories of manual or unskilled work are much more likely to report long-term conditions than those who do not (Blood, 2010).

King (2010) reminds us that older people with the highest support needs often have complex needs and can experience multiple forms of discrimination. By breaking the population of older people with high support needs down into broad sub-groups or equality strands, there is a risk that we overlook the considerable diversity within each category. Case studies from the 50 Plus report on older people with HIV (Power, 2010) remind us how multiple conditions and forms of discrimination can interact with each other. For example, an older person with HIV may also have a sensory impairment, be a refugee from a black African background and be experiencing mental health problems.

A changing group

This diverse group is not only increasing in size; it is also changing in profile. As the gender gap in life expectancy narrows, we can expect the proportion of men in the oldest age groups to increase. As the cohort of BME people who migrated to the UK from the Caribbean and the Indian sub-continent in the 1950s and 1960s reach the oldest age groups, the UK's BME older population is predicted to increase dramatically over the next couple of decades. The prevalence of some health conditions is increasing – most notably that of dementia, of which 163,000 new cases are diagnosed each year (CPC, 2010). 700,000 people were estimated to have dementia in 2009 (or 820,000 if an estimate of undiagnosed cases is included), and this figure has been predicted to double in the next 30 years (Garwood, 2010/ CPC, 2010).

New groups of older people with high support needs are also emerging, as medical treatments are developed and society changes. In 2008, almost one person in six being seen for HIV care in the UK was aged 50 or over. The size of this group is predicted to double over the next five years as more HIV positive people live longer and others continue to be diagnosed later in life (Power, 2010). King (2010) highlights the rapidly-growing group of older people with learning disabilities as, for example, the life expectancy of those with Down's syndrome has risen to 50-60 years and there are more formal diagnoses of autistic spectrum disorders. There is a small but increasing group of older transgender men and women in the UK, with 7 per cent of the transgender population currently over 61 (Blood, 2010).

Some groups of older people with high support needs have been largely hidden. Some, because they are out of the sight and mind of service providers (such as older asylum seekers who have no recourse to public funds; older gypsies and travellers and some other ethnic minority groups who have placed less vocal demands on social care services for a range of reasons). Others have perhaps been overlooked because they have needs which do not fit with common stereotypes of older age – older people with alcohol and drug misuse problems; those who are homeless; have mental health problems; are LGB or have HIV.

Manthorp (2010) considers our collective assumption that “the ‘baby boomer’ generation will not go quietly into older age”. He is right to warn us against leaving it to this group to generate change (or indeed assuming that all of the generation above them will settle for what they are given). However, it is certainly true that the younger cohort of older people with high support needs grew up within a very different social and economic climate than their parents. This younger generation includes more women who have been educated and had careers; more divorcees; same sex couples joined by civil partnership; more people who chose not to have children; more disabled people who have lived independently within the community; and more wealthy (or at least asset-rich) middle class people.

Where do older people with high support needs live?

Around 85 per cent of UK residents aged 90 and over live in England; yet there is a significantly higher proportion of adults aged 65-74 reporting a limiting long-term illness in Wales, Northern Ireland, Scotland and the North of England than in the South of England (CPC, 2010). There is very little data at a sub-national or local level on the incidence of cognitive and functional impairments, and existing data excludes those living in institutional care, and does not allow disaggregation by ethnic group (CPC, 2010).

Of UK households living outside of residential care and in which the key reference person is aged 85 and over:

- 63 per cent live in their own homes;
- 29 per cent rent from social landlords; and
- 8 per cent are privately renting (ONS, 2005).

In 2001, 11 per cent of these households inhabited properties with no central heating and over half of the owner-occupied and private rented properties did not meet decent homes standards, mostly because they did not provide adequate thermal comfort (ONS, 2005). We know that there can be different challenges for those living in urban and in rural areas (Blood, 2010). There has been a significant increase in the numbers of older people living alone (CPC, 2010), with women and LGB people more likely to fall into this category (Blood, 2010).

410,000 older people were estimated to be living in care (residential or nursing) homes in the UK in 2004, though there are significant gaps in what we know about their key characteristics, such as ethnicity. We can, however, be confident that most of this group will meet the JRF definition of older people with high support needs: most are over 85, three-quarters have a ‘severe disability’ and 64 per cent have a form of dementia (Blood, 2010).

The concept of ‘extra care housing’ is difficult to define and accurate statistics about this rapidly-developing sector are not yet available. There are estimated to be between 20,000 and 35,000 *units* of extra care housing in England, depending on definitions used (Skills for Care, 2010). In the PSSRU (2008) evaluation of the extra care housing funding initiative, less than 30 per cent of those who moved into extra care housing were deemed to have ‘moderate or more severe levels of dependence’.

The Department of Health estimates that there are 170,000 older people receiving personal care at home from their local council (though over half of this group pay for some or all of the costs of this service) (Burke, 2010). There will also be a significant number of older people who are living in the community and either receiving informal or privately-arranged care or who are not accessing services, despite having high support needs.

In their recent response to the Law Commission Consultation on Adult Social Care, Joseph Rowntree Foundation (2010) challenges the assumption that home-based living should, wherever possible, be the ideal for older people with high support needs. They argue that living in your own home does not in itself promote ‘independent living’ (just as living in a communal setting does not necessarily preclude it) and that not all people with care and support needs can and want to live in their own homes indefinitely. The condition of housing and the extent to which it is, or can be made, accessible plays a large part.

There are also small but significant groups who cannot remain in their own homes as they do not have secure housing. The London Borough of Camden identified 400 residents aged 50 and over living in homeless hostels in the Borough, with similar care and support needs to the average sheltered housing resident aged 10 years older (King, 2010). Some people who have aged with a disability, especially those with learning disabilities and mental health conditions, will already be living in institutional settings.

The 2011 Census and the new UK Household Longitudinal Study (Understanding Society) offer forthcoming opportunities to enrich our understanding of the numbers, location and circumstances of older people with high support needs, but ongoing investment in analysis is required.

What do older people with high support needs want and value?

Bowers et al (2009) argue that:

“...the voices of older people with high support needs are so quiet as to be practically silent or indistinguishable from the other people who speak on their behalf” (p.5)

Barriers to hearing the views

Some of the barriers to hearing these voices include:

- Low expectations of older people with high support needs regarding the quality of life they can expect and their potential to be involved in decision making and service development (both by older people themselves and service providers);
- A service-centred approach which focuses on assessing needs and providing care as a series of tasks;

- An ageist culture which tends to de-personalise and patronise members of this group, viewing them as consumers of resources rather than citizens who can make a contribution and who should be treated with respect;
- Difficulties expressing views and feelings, because of disability, language barriers, emotions or the imbalance of power between them and care providers; and
- Fewer opportunities for older people with high support needs to come together to share their opinions and develop a group response.

The emerging evidence base

There is relatively little evidence that captures what older people with high support needs want and value. Where their views have been sought (e.g. Bowers, 2009; Katz, forthcoming) or where broader discussions have taken place with carers, younger disabled people and older people with a range of support needs (e.g. Branfield, 2010; Burke, 2010; Cattán, 2010), a number of themes emerge about what makes for a ‘better life’. These include:

- continuity, personal identity and self esteem;
- meaningful relationships;
- personalised and respectful support;
- autonomy, control and involvement in decision making;
- a positive living environment: security, access, privacy and choice;
- meaningful daily and community life: making a contribution, enjoying simple pleasures; and
- good accessible information to optimise health and quality of life.

Challenges and approaches

In this section, we explore eight key themes which have emerged from the recent JRF reviews and research: affordability; navigating the system; dementia and mental capacity; communal tensions; social isolation; recruiting and retaining a skilled workforce; involving and supporting carers; and care, communication and choice at end-of-life.

We briefly consider the key issues and evidence under each theme in relation to older people with high support needs and consider the challenges and promising approaches within different settings i.e. care homes, housing with care and in the community.

Affordability

The means-testing of state financial support for social care (outside of Scotland) hits those who are just above the thresholds for free or partially-funded care the hardest. Those with the highest support needs will have the most expensive care bills so there is a 'double whammy' for middle income members of this group, including many homeowners who may be 'asset rich but cash poor' (Keen & Bell 2009).

41 per cent of all care home residents are paying for all their care and this group also misses out on assessment and review by social services (Burke, 2010). There is a further risk that those who are not known to social services may not be able to access some housing with care schemes (King, 2010). The 'postcode lottery' of local authority home care charging is pushing older people with high support needs and their carers into greater poverty and worse health outcomes (Coalition for Charging, 2008). Qualitative research in Bradford highlights the level of concern and resentment amongst low-income self-funders who have worked hard all their lives, paid taxes and accrued modest savings, which they had hoped to pass on to their families (Cattan, 2010).

We do not have much evidence about the demographics, financial circumstances, experiences of, or outcomes for, self-funders. Current measures of poverty also have serious limitations in that they do not take account of frailty, disability and long-term illness amongst older people and do not incorporate assets and debts in their calculations (Blood, 2010).

As Manthorp (2010) points out, equity release schemes are vital if 'asset-rich, cash-poor' older people with high support needs are to be enabled to pay for some of their care, without being forced to sell and move out of their own homes.

JRF is supporting an independent assessment of pilots led by three local authorities working with an equity release provider and voluntary bodies in Kensington and Chelsea, Islington and Maidstone. The pilots aim to address some known barriers to the use of equity release to improve people's quality of life where they may be asset-rich but income poor (Terry & Gibson, 2010).

Shared ownership schemes, such as HOOP (e.g. at Notting Hill Housing) or shared ownership options within retirement villages like Hartfields (Croucher, 2010) can enable those with modest assets and income to access secure and suitable housing.

Navigating the system

Good information, advice and advocacy to help older people, their carers, families and professionals navigate the complex benefits, housing and care systems is vital. Without this, older people (especially those for whom language, literacy, or cognitive/ sensory impairments present an additional barrier) do not receive the benefits to which they are entitled and may not be aware of options which could improve their quality of life (Cattan, 2010; Blood, 2010; King 2010).

Within this, Burke (2010) highlights the particular information needs of self-funders (especially in relation to residential care); King (2010) identifies a need for clearer information about housing with care to overcome the confusing and inconsistent terminology in the sector; and Percival (2010) describes how complexities in the funding of long-term care make it difficult for housing with care to provide a home for life.

Many older people, especially those with high support needs, require more than information and signposting; they also need time and support to process the information if they are to make informed decisions (Cattan, 2010; Branfield, 2010; Horton, 2009). Some may need the kind of advocacy which Nubian-Life in Hammersmith and Fulham provides.

In the absence of close family or friends who can help, the **Nubian-Life** Advocacy Worker supports older Black Caribbean people with high support needs during crises. This might include visiting them in hospital, both for social contact and to check that they are receiving proper care and information, and liaising with professionals on their behalf to make arrangements for discharge.

FirstStop is based on a national partnership between Counsel and Care, EAC, Age UK and NHFA and also works to develop local partnerships. It provides a single telephone and website point of entry for queries relating to housing, health, finance and care. Where necessary, the frontline team can transfer callers to specialists or send out information packs. The initial evaluation of the service by Cambridge CHPR (2010) shows both an increasing volume of calls and high levels of user satisfaction with the service.

Residents and relatives at **67 Birch Avenue**, Sheffield, worked together to produce a 'welcome booklet' to help prospective residents and their families to understand what it was like to move into the care home. The booklet includes stories written by relatives and staff about their own experiences of moving to or working at the home. (My Home Life, Nov 2007)

Dementia and mental capacity

People with dementia make up 64 per cent of older people living in care homes (Blood, 2010) and a quarter of those living in housing with care schemes (Percival, 2010). In the community, we know that there can be barriers to the diagnosis, treatment and care of dementia and that these may affect BME older people even more acutely. Increasing numbers of older people with dementia will also have other disabilities or health conditions. King (2010) highlights the high incidence of early onset dementia for those with learning disabilities and Blood (2010) describes current research into dementia and the deaf community.

There is increasing evidence of carers and families seeking advice on mental capacity issues (Burke, 2010). Themes include: the use of Deprivation of Liberty Standards (in care homes and hospitals); access to complaints systems; and the availability of independent mental capacity advocacy (Burke, 2010). This is perhaps unsurprising, given the patchy knowledge of the Mental Capacity Act across the housing and care sector (Garwood, 2010; Samsi, 2010). The fact that judgements about mental capacity should, according to this legislation, be time- and decision-specific rather than absolute, does not seem to be widely understood (Garwood, 2010).

There are significant gaps in the evidence comparing different models of housing and care and their outcomes and cost-effectiveness for people at different stages of dementia (Garwood, 2010). However, in all settings there are examples of good practice in supporting older people with dementia.

Merevale Residential Home in Warwickshire, for example, is a specialist home for people with dementia, in which all members of staff view themselves as activity workers and seek to connect with and involve residents in every aspect of the home's life. The approach, which is about attitude rather than extra cost, has resulted in 'excellent' ratings and national awards.

Communal tensions

Moving into mixed communal settings can be stressful for older people with high support needs, especially those who are BME or LGB, who may fear or experience negative reactions from other residents or staff (Blood 2010, King 2010). Even in care homes and housing with care schemes, older people with high support needs, especially those who are visibly frail or have dementia, can receive a negative response from their peers. Percival (2010) suggests that such reactions in housing with care may be triggered by:

- fitter tenants' fears of their own possible decline or of the place becoming too much like a nursing home;
- the demands which someone with high support needs can place on staff time and other resources; and
- concerns that befriending might entail providing ongoing support.

There is evidence to suggest that fitter tenants are more accepting of neighbours whose conditions have developed since they moved in. The role of staff in challenging negative reactions; helping those with high support needs to participate in communal life; and creating a positive culture also seem to be important in promoting cohesion. Good building design, clear information about the scheme and its ethos for prospective residents; and initiatives to educate residents and link them into the wider community may also help. However, more research is needed to explore the impact of a number of variables on cohesion, including the size and ethos of the scheme, how it is portrayed, why people move in and the ratio of 'fit' and 'frail' at point of entry (Garwood, 2010).

Social isolation

Maintaining good social relationships, whether with peers, workers, family, friends or the wider community, is key to quality of life for older people (Percival, 2010; Bowers, 2009). Yet isolation and loneliness are problems shared by many older people with high support needs (Manthorp, 2010; Cattán, 2010). Being in a communal setting does not, in itself, protect older people from social isolation. Those with mobility, cognitive and/or sensory impairments are at particular risk of being excluded from the social life of housing with care schemes (Callaghan, 2009).

Potential barriers, across settings, include:

- time and inclination of workers to engage and support participation (Burke, 2010);
- receiving care at fixed times (Callaghan, 2009);
- communication: skills and confidence of staff (Samsi, 2010);
- language/ cultural barriers and other diversity issues, such as sexual orientation or gender (Blood, 2010);
- access, transport and funding to participate in activities in the community (Manthorp, 2010).

At **LinkAge Plus** in Tower Hamlets, a team of outreach workers identify isolated and vulnerable older people living in the community and provide them with support, both to link them into social activities and address any practical concerns. Last year they worked with 900 new service users. The flexible, individually-tailored support might include accompanying a person who is recovering from a fall on short journeys or supporting someone to attend art or tai chi classes.

The JRF-funded evaluation of '**Talking Mats**' (Murphy, 2010) has found that this simple system of picture symbols, placed on a textured mat, can improve dialogue between those with early and moderate stage dementia and their families and carers.

A skilled workforce

The better the knowledge and skills of the workforce, the better the quality of life of those for whom they care. Yet, the social care workforce is characterised by poor pay and conditions, which have in turn led to gender segregation, problems with recruitment and retention and a reliance on migrant workers to plug the gaps (Himmelweit, 2008). Combined with the exposure of poor practice to which older people with high support needs can be particularly vulnerable, these factors have led to what Manthorpe (2010) describes as, “a tendency to see the workforce as part of the problem as well as part of the solution”.

Working with older people with high support needs in any setting requires a broad set of skills. This should, for example, include: understanding dementia, mental health and learning disability; working with diverse people; and communicating with those who have cognitive and/or sensory impairments (Garwood, 2010; Manthorpe, 2010). Training, linked to an agreed set of competencies, is important but learning must be supported by good management, partnership working and strong leadership if it is to be embedded (Manthorpe, 2010).

The housing with care reviews identify a key question in connection with workforce, which remains unanswered by the current evidence base: What is the impact of a workforce that is drawn from different professional cultures – healthcare, social care and housing – and how can this workforce best be managed and developed?

A recent pilot to up-skill residential care home staff in basic clinical tasks and health promotion increased their confidence and joint working with health professionals (Wild, 2010). It is hoped that this kind of staff development could enable a greater number of older people avoiding a move to nursing homes.

The PEARL (Positively Enriching and Enhancing Residents' Lives) programme involves person-centred and resident experience training to promote staff understanding of dementia. Piloted in 10 **Four Seasons care homes**, the initial evaluation shows a number of positive outcomes for older people with dementia, including a 52 per cent reduction in the use of antipsychotic medication (Valios, 2010).

Involving and supporting carers

Approximately 12 per cent of the adult population provides care to a partner, adult family member or friend and a fifth of this group provides 50 or more hours of care a week. 70 per cent of those receiving informal care are over 65 (Carers UK, 2009).

We know that there are much higher rates of caring for older relatives with high support needs by women and/or people from Bangladeshi and Pakistani backgrounds. We also know that there is a significant group of older people providing care (typically for partners) who may themselves fit the definition of having ‘high support needs’ (Blood, 2010). As JRF (2010) points out in its response to the Law Commission’s consultation, ‘users’ and ‘carers’ cannot always be clearly distinguished from each other.

Despite being expected to provide high levels of care, carers of older people with high support needs regularly report that they are not as involved as they should be in decision-making and at key transitions such as hospital discharge or admission to a care home (Burke, 2010). The most commonly reported unmet needs for carers include: respite care; financial assistance; emotional support (especially to deal with guilt if the person they care for is admitted to a care home); and advocacy or mediation where there are conflicts of interest (Burke, 2010).

End of life

There has been plenty of good practice in this area from the care home sector. Examples from NCP (2007) and My Home Life (Oct 2008) include:

- providing staff training on end-of-life care;
- implementing advance planning models;
- organising funeral receptions or memorials in the home;
- providing appropriate spiritual care; and
- counselling other residents after the death of a neighbour.

However, this remains an area for development in much of the housing with care sector. Samsi (2010) highlights the variable levels of staff training on end-of-life care and the need for effective joint working with health, including palliative health providers. Blood (2010) considers the importance of responding positively to diverse religious, spiritual and cultural beliefs, needs and practices around end-of-life. Percival (2010) discusses the emotional impact of end-of-life on staff and other tenants, recognising the confidence, time and skill needed to provide effective support.

Where next?

Improving the quality of life of many older people with high support needs is as much about providing simple pleasures, or sometimes even meeting basic human rights, as it is about re-designing services. One older woman living in a residential home said that what she would like more than anything else in the world would be to 'go out for 10 minutes a day or every other day to feel the fresh air on my face, and eat a nice roast potato' (Branfield, 2010).

However, this is not to say that we should limit the possibilities. We need to learn from international practice and from approaches which have benefitted other social groups.

In this section, we consider some of the future possibilities – the implications of the current directions of travel in personalisation, user involvement and assistive technology for this group, as well as 'alternative approaches', such as co-housing and intergenerational projects.

Voice choice and control

Involving users in commissioning local services is a recurring mantra in adult social care but, as Scherer (2010) suggests, there is not always clarity around what this might mean in practice. As Bowers (2009) argues, there is a long way to go to ensure voice, choice and control in even personal day-to-day decision-making, let alone the meaningful involvement of older people with high support needs at a more strategic level in the development of services. Part of the problem is that members of this group get few opportunities to come together and develop a shared voice (Branfield, 2010).

The **Scottish Dementia Working Group** is one example where this has happened. The group is run by people with dementia and aims to influence public policy, improve services and challenge attitudes at a national level as well as provide peer support through the development of local groups.

There are also some encouraging 'top-down' initiatives. The **Care Quality Commission** is working to bring the voice of older people with dementia into their inspections, through their *Experts by Experience* programme. In this programme, older people with experience of using services and/or carers conduct conversations with other people who use services and staff as part of a care home inspection. Where people with dementia are less able to communicate, inspectors use a Short Observational Framework for Inspection (SOFI).

There are also examples of good practice in user involvement at a local, service level. Residents at **Milford Care Homes** get involved in menu planning, choosing entertainments, planning outings and looking after their own patch of the garden. One woman who had limited verbal communication following a stroke participated in interviewing staff by giving a thumbs-up or a thumbs-down (My Home Life, May 2008).

Personalisation

Personalisation seems to be the continuing direction of travel within social care. Although there are significant barriers to Direct Payments for older people with high support needs, personalisation in its broadest sense is about building voice, choice and control into how services are run and should, as such, be welcomed.

Co-operatives UK (2010) report on a series of self-managed care pilots for older people in which a mutual organisation acts as employer and provides training, quality standards, insurance and administration without reducing the individual's direct control of their care. This kind of model could work particularly well for groups of LGB or BME older people, who could use this approach to choose and control services that are safe, accepting and culturally or socially appropriate.

However, the pilot co-operatives, just like the older people within the Individual Budgets (IB) pilot, have hit financial problems. These seem to stem from a combination of ageist policies and an inherent contradiction over who has the final say in testing the quality of care. Older people received lower average levels of IB than younger people in the pilot and, given the high levels of personal care they needed, found there was little scope to improve their wider well-being (Glendinning, 2008). Meanwhile, the co-operatives have struggled to cover the administrative costs of achieving Care Quality Commission registration status, given that the direct payment rate is significantly lower than the rate paid for equivalent agency homecare (Co-operatives UK, 2010).

There are also big, unanswered questions surrounding the impact of personalisation for existing services and their workforces, particularly in the housing with care sector (Garwood, 2010; Manthorpe, 2010). Will the model still be tenable if residents are commissioning their own care from a range of different sources? Early evidence from the **Hartfields retirement village** (Croucher 2010) suggests that tenants are using their IB to buy in additional services that are not provided by the scheme (rather than choosing to opt out of those that are).

Housing 21 (2009) recommends that specialist housing providers should use personalisation as an impetus to involve their residents in reviewing the activities they offer, “ensuring there is a range of choices rather than a ‘one size fits all’”. Campaigning to extend direct payments to cover residential accommodation (JRF, 2010) will hopefully help to bring this vision to care home providers.

Housing

Accessible, secure and conveniently-located housing options are essential if independent living and informal networks are to flourish for older people with high support needs. Ensuring Lifetime Homes standards are applied in new developments would be a key step towards ‘future-proofing’. Developing and evaluating the role that retirement villages and other forms of housing with care can play in providing a ‘home for life’ for those with high support needs is also a clear priority.

Newer alternative approaches include **co-housing**, in which a group of people form a self-managing ‘intentional community’, living independently but with a commitment to proactive social interaction and some communal facilities to support this. The approach is well-established in Denmark (where 8 per cent of those over 50 live in co-housing) and the Netherlands (Vivarium, 2010). In the UK, several groups are operating with a specific (though not necessarily exclusive) remit to provide ‘ageing in place’ for their members. The Vivarium Trust in Fife works to promote and support co-housing for older people; the Older Women’s CoHousing network is in negotiation for a site in London; and Lifetime Cohousing Community (2009) is seeking to create a community in West Yorkshire ‘for people who want a co-operative, self-responsible lifestyle for their later years’.

KeyRing communities were developed by and for people with learning disabilities to stimulate and support community networks without requiring capital investment or development. Typically, a KeyRing community consists of 10 learning disabled people living independently in ordinary housing but in fairly close proximity to each other. They receive low-level but flexible support from a volunteer living nearby and from each other, with additional paid support being accessed as and when required. This model might be transferable to older people, either those with low to medium support needs or possibly, with a paid worker replacing the volunteer (and maybe funded by pooled IB) to support a smaller network of older people with higher support needs.

Inter-generational approaches

Opportunities for older and younger people to live, socialise and volunteer together are one way of challenging ageist stereotypes and breaking down barriers between ‘them’ and ‘us’.

In Paris, **Ensemble2Generations** carefully matches students with older people who can offer cheap accommodation in their homes in return for low-level practical assistance and companionship. In their promotional DVD, a music student is placed with a retired music teacher: they play music together, he walks her dog and gives her computer lessons and draws on her knowledge and library of music to boost his studies. **Homeshare UK** acts as a network for similar projects developing in this country and, whilst this model is unlikely to provide a substitute for the personal care that an older person with high support needs might require, it can help to counter social isolation and provide ‘that bit of help’ to support independent living.

In the Republic of Ireland, **Nas na Riogh Housing Association** has converted a disused convent and developed self-contained sheltered accommodation in its grounds. What makes the approach innovative is that the site is located in the middle of town and the old convent itself has been used to develop inter-generational facilities – an arts venue, a soundproof rehearsal space, meeting and activity rooms, counselling rooms and a community coffee shop. Volunteers of all ages are being recruited to staff these facilities.

Age UK and ILC-UK have secured funding from Pfizer and vInspired to develop a national LGBT Intergenerational Project, bringing together older and younger LGBT people. In Stockport, they will be working together to influence local housing, alcohol and drug services; in Leicester, they will develop an LGBT history archive and in Camden they will come together to produce arts projects.

Technology

Assistive technology (AT) can bring a number of benefits to older people who wish to live independently in the community. Emergency pendants can boost confidence and outcomes around falls; bogus caller systems can improve security; and remote control systems can enable those with substantial mobility impairments to control their environments without help from anyone else (SCIE, 2009). Jarrold's (2009) evaluation of the impact of telecare in Scotland demonstrates a number of positive impacts for carers. They reported being more relaxed and more confident where telecare was in place; the systems allowed them to take a break or even remain in paid employment, which in turn improved their relationship with the person they were caring for. As Burke (2010) points out, such technology can provide "round the clock reassurance".

Garwood (2010) argues that, within housing with care, AT may have the potential to:

- free up time for more meaningful contact between carer and cared for;
- reduce intrusive checking; and
- increase freedom and independence whilst managing risk for those with dementia.

However some older and/or disabled people consulted by Branfield (2010) warn that, whilst technology has the potential to enable people, its use can be driven by cost efficiency and there is a risk of people being isolated. A summary of recent research by SCIE (2010) highlights some of the ethical issues in balancing these risks and opportunities and argues that information, consent, integration and review within a broader care plan are all vital if AT is to promote rather than reduce choice, autonomy and privacy.

However, there seems to be limited knowledge of and capacity to use AT amongst those working with older people with high support needs, even in specialist roles such as occupational therapy or rehabilitation work (Jarrold, 2009). There are gaps in the evidence base around how AT is being used in housing with care; what safeguards and staff training are in place to support it and what the outcomes for older people are (Garwood, 2010, Manthorpe, 2010).

There is, however, developing good practice in the sector. For example, **Places for People** was able to draw on the expertise of its in-house AT Manager in developing the state-of-the-art Extra Care scheme, Manor Gardens, in Bolton. The scheme features a complete assistive technology infrastructure, so that design features and technical aids can easily be added to meet individuals' changing needs. Apartments (which are available for rent, shared ownership and sale) can be fitted with a range of devices such as remote control doors and windows, keyless entry, broadband internet facilities and electronic notice boards. The site also has an assisted bathing suite.

Conclusion

Difficult times undoubtedly lie ahead in terms of public funding but this makes a bold approach even more important. Some of the basic things, such as 'fresh air and roast potatoes' that are needed to improve the quality of life of older people with high support needs will not necessarily cost any more. They will, however, require a significant culture change away from needs-based models and ageism. Some of the alternatives highlighted can also be cost effective. In the current economic, political and demographic context, it will be vital to develop and evidence the 'business case' for good practice.

There is also a need to develop wider ownership of the debate: to explore the aspirations of older people before their support needs become high (as well as afterwards). We need to remind people of all ages that, as a recent Newcastle-based consultation was entitled (Horton 2009), we are talking here about 'Everyone's Tomorrow'. Vera Bolter is quoted by Manthorp (2010) saying: 'Unless you have a vision about how things could be you will be confined by what is available now.'

What will happen next?

By the end of 2010, JRF will have commissioned new research: a) to understand the potential for approaches based on mutuality and reciprocity; b) to address issues in housing with care that particularly affect older people with high support needs (affordability and choices; relationships; boundaries of responsibility). In 2011, we will publish a key report from a project on Older People with High Support Needs: Their Aspirations for a Better Life (Katz et al, forthcoming). This project will build on existing knowledge and directly involve older (and some younger) people with high support needs in identifying and validating what people want and value from life. The report will frame the rest of the programme. JRF will continue its partnership with My Home Life (City University and Age UK) to improve life for people living and working in care homes across the UK, including homes run by the Joseph Rowntree Housing Trust. We will seek to contribute to better policy, practice and understanding about how older people with high support needs – now and in the future – might have a better life.

About this Round-up

This Round-up was written by Imogen Blood, a freelance consultant working across the public and not-for-profit sectors to improve effectiveness and promote equality, and was commissioned as part of the JRF programme A Better Life. Imogen's background is in social work, research and evaluation, and equality and diversity training and consultancy. She is an associate of the International Longevity Centre (ILC-UK) and a consultant partner at Equality Works.

For more information:

Imogen Blood (imogen@imogenblood.co.uk)

Philippa Hare, Programme Manager (Philippa.Hare@jrf.org.uk)

Ilona Haslewood, Programme Manager (Ilona.Haslewood@jrf.org.uk)

Christine Appleton, Research Administrator (Christine.Appleton@jrf.org.uk)

References

Reviews from Phase 1 of 'A Better Life'
www.jrf.org.uk/publications/better-life-high-support-needs

Blood, I/ ILC-UK (2010) Equality and Diversity and Older People with high support needs

Branfield, F & Beresford, P (2010) A Better Life: Alternative approaches: a service user perspective

Burke, S (2010) A Better Life: Alternative approaches from the perspective of families and carers of older people with high support needs

Centre for Population Change (2010) Demographic issues, projections and trends: Older people with high support needs in the UK

Garwood, S (2010) Better life for older people with high support needs in housing with care

Katz, J, Holland, C & Peace, S (forthcoming) Older people with high support needs: Their aspirations for a better life.

King, N & Pannell, J (2010) Access and diversity in housing with care

Manthorp, C (2010) Joy in the evening: Better lives for older people with high support needs

Manthorpe, J (2010) Workforce issues in housing with care for older people with high support needs

Percival, J (2010) Attitudes to frailty, disability and end-of-life in housing with care

Samsi, K & Manthorpe, J (2010) Decision-making and communication in housing with care

Other sources

Bowers, H et al (2009) Older people's vision for long-term care, Joseph Rowntree Foundation

Callaghan, L, Netten, A & Darton, R (2009) Developing social well-being in new extra care housing, , Joseph Rowntree Foundation

Cambridge CHPR (Centre for Housing & Planning Research) (2010) Evaluation of the FirstStop information and advice service for older people , their families and carers, University of Cambridge

Carers UK (2009) Facts about carers, June 2009, Policy Briefing

Cattan, M & Giuntoli, G (2010) Care and support for older people and carers in Bradford, , Joseph Rowntree Foundation

Coalition on Charging (2008) Charging into Poverty: Charges for care services at home and the national debate on adult care reform in England

Co-operatives UK (2010) Self-managed care – a co-operative approach, Supported by the Department of Health, 2006-2009

Croucher, K & Bevan, M (2010) Telling the story of Hartfields: A new retirement village for the twenty-first century, Joseph Rowntree Foundation

Glendinning, C et al (2008) Evaluation of the Individual Budgets Pilot Programme, Final Report, IBEN

Himmelweit, S & Land, H (2008) Reducing gender inequalities to create a sustainable care system, JRF Viewpoint, Joseph Rowntree Foundation

Horton, C/ Quality of Life Partnership Newcastle upon Tyne (2009) Creating a stronger information, advice and advocacy system for older people, Joseph Rowntree Foundation

Housing 21 (2009) Building Choices part 2: 'Getting Personal': The impact of personalisation on older people's housing: overall project summary, Housing 21

Jarrold, K & Yeandle, S (2009) 'A weight off my mind' Exploring the impact and potential benefits of telecare for unpaid carers in Scotland, Carers Scotland/ University of Leeds

JRF (2010) Response to the Law Commission Consultation on Adult Social Care, Submission by the Joseph Rowntree Foundation, June 2010

Keen, J & Bell, D (2009) Identifying a fairer system for funding adult social care, Viewpoint, October 2009, Joseph Rowntree Foundation

Lifetime Cohousing Community (2009) The Executive Summary

Murphy, J, Oliver, TM & Cox, S (2010) Talking mats and involvement in decision-making for people with dementia, , Joseph Rowntree Foundation

My Home Life (Oct 2008) Supporting a Good End of Life, My Home Life: The bulletin for care home staff, Issue 6, October 2008

My Home Life (May 2008) Sharing Decision-making, My Home Life: The bulletin for care home staff, Issue 4, May 2008

My Home Life (November 2007) Managing Transitions, My Home Life: The bulletin for care home staff, Issue 1, November 2007

NCPC (The National Council for Palliative Care) (2007) Building on firm foundations: Improving end of life care in care homes, NCPC/ NHS End of Life Care Programme, June 2007

ONS (2005) Focus on older people, Office of National Statistics

Power, L, Bell, M & Freemantle (2010) A national study of ageing and HIV (50Plus), Joseph Rowntree Foundation/ Terence Higgins Trust/ Age UK/ MBARC

PSSRU (2008) Evaluation of the Extra Care Housing Funding Initiative: Initial Report, PSSRU Discussion Paper 2506/2, May 2008

Scherer, S & Sexton, S (2010) Involving users in commissioning local services, JRF

SCIE (2010) At a glance 24: Ethical issues in the use of telecare, May 2010

SCIE (2009) Telecare – providing more personalised care, Social Care TV

Skills for Care (2010) The state of the adult social care workforce in England, 2010, Skills for Care

Valios, N (2010) 'Best practice in dementia care home staff training and reduced use of antipsychotic drugs: Four Seasons Health Care's Pearl programme', Community Care, Thursday 22nd April, 2010

Vivarium Trust (2010) What is Co-housing? <http://www.vivariumtrust.co.uk/>

Wild, D, Szczepura, A & Nelson, S (2010) Residential care home workforce development: The rhetoric and reality of meeting older residents' future care needs, Joseph Rowntree Foundation