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A Better Life: what older people with high support needs value

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Edited by Imogen Blood

This report explores what older people with high support needs want from and value in their lives, and suggests a model for exploring factors that are facilitatory or compromising in these terms.

People with high support needs in the UK are not a homogenous group, and although most are over 85 years old, there is considerable variation across age, ethnicity, health and social care needs, financial status and lifestyle. Little is known about what these people want and value, while negative assumptions are sometimes made about their ability to comment on and participate in decision-making and collective action.

The report:

- identifies current evidence relating to social, psychological and physical factors, barriers and enablers to accessing information, support and financial resources;
- considers everyday living with a small but diverse purposive sample of people with high support needs;
- suggests a framework for eliciting views from people with communication difficulties;
- presents emerging themes and identifies implications for older people themselves, policy makers and commissioners, practitioners and researchers; and
- recognises the importance of individuality for people with challenging lives.

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Executive summary

1 Introduction

This study is part of Joseph Rowntree Foundation's *A Better Life* programme. It aims to produce a framework for understanding what older people with high support needs want and value in their lives.

Until very recently, the experiences and wishes of this group have not been sought. We propose five explanations for this gap, linked to:

- **communication, reliability of data, and ethics**, especially in relation to the inclusion of people with cognitive impairment;
- **looking through the wrong lens**: undue focus on health and care needs at the expense of wider quality of life issues;
- **assumptions about older people** that ignore roles, individuality and choices;
- **equality and diversity**: stereotypes, language barriers and assumptions of homogeneity that ignore diverse voices;
- **developing a collective voice**: failure to encourage older people with high support needs to get involved in campaigning for their rights.

2 Review of evidence

We reviewed the relevant literature on what older people and/or those with high support needs have said they value. From this, we produced an evidence framework, including social, psychological and physical factors and things that act as barriers (or enablers), such as information, support and financial resources.

3 Validating the framework: a summary of our approach

We identified a sample of 26 people with high support needs, who were diverse in terms of their gender, ethnicity, geographical location and type of disability or health condition. Most were older, but their ages ranged from 40 to 93. Some lived in care homes or supported accommodation; over half lived in their own homes in the community. We had conversations with each about their lives and what they valued and aspired to, in order to test out the evidence framework.

4 Findings: the voices of older people with high support needs

In this chapter, we present and discuss quotes and themes from these conversations, under the headings of the evidence framework.

Overall, the participants agreed the importance of the themes drawn from the literature and were able to illustrate them with examples from their own or another's experience. The most frequently mentioned themes in the conversations were:

- personal relationships;
- support/good relationships with carers;
- self-determination/involvement in decision-making;
- social interaction;
- good environment/home;
- getting out and about;
- information;
- financial resources.

We summarise what we think are the most interesting of these findings in Chapter 6.

5 Introducing our model

In this chapter, we present a visual model to reflect the themes validated by our participants (see Figure 2 on page 41). Our model distinguishes between the things older people want and value (shown in the outer circle) and the factors that hinder or help them to access these things (shown in the inner circle).

The older person is at the centre of this circle – a reminder that this is about people and what they want from their lives, not about what services and policies say they can have.

We have put the individual person at the centre rather than the broader group of older people with high support needs, since one size will not fit all. Each individual will have different needs, values and aspirations; different assets and resources at their disposal to achieve these; and will encounter different barriers.

We have represented this person as ‘me’, partly to give ownership of the model to the individual (rather than it forming part of an assessment being done to people) and partly to remind ourselves that this is – or will be – about almost all of us (not about ‘them’).

Our findings and framework have many parallels with those of the two most comparable recent studies: by Bowers, *et al.* (2009), who spoke to care home residents, and Williamson (2010), who focused on people with a dementia diagnosis.

The key differences are that:

- ‘Personalised support and care’ was key to a good life for those in care homes, whereas our broader constituency of older people with high support needs described support more as a means to an end (and Williamson’s sample did not mention it at all).
- Our participants, like Williamson’s, valued humour, physical activities and contact with nature. These did not emerge from Bowers’ study, perhaps again because of the different characteristics of the sample.

6 Reflections and implications

We begin our concluding chapter by presenting the most interesting themes from our findings, under the headings of the framework.

Cross-cutting themes

Our findings emphasise the importance of individuality in shaping what people want and value. All of us, regardless of age, need opportunities to show others who we are and to feel good about ourselves. The study gives an insight into the challenges which sometimes accompany high support needs in later life, such as social isolation, uncertainty, loss, fear and frustration.

Social

Not wanting to impose on others was a concern, though some described reciprocity in relationships and others made (or wanted to make) a valued contribution to their communities. We expected people to place a high value on their relationships and social interactions; however we were struck by how important both the prospect and reality of meeting *new* people was for many.

Psychological

Self-determination, and the related concepts of independence, involvement in decision-making, autonomy and control, was important to everyone but it meant different things to different people. Many seemed happy to delegate key decisions or take advice from those they trusted. While continuity was valued, many of our participants demonstrated considerable adaptability to a wide range of changing circumstances, though some wanted more support to help them adjust to change.

Physical

The number and severity of participants' health problems and disabilities was striking. Given this, deciding how best to promote health was often a difficult balancing act. Most wanted to keep their minds and bodies active, though few had the opportunity for any physical exercise; the importance of contact with nature and the outside world was a recurring theme. Many described compromises they had made in relation to their accommodation.

Barriers and enablers

Other people's time was a key enabler for those we spoke to, in particular the amount and quality of time spent with them by paid carers. With sufficient time, carers were able to understand their life stories and how they wanted particular tasks carried out.

The provision of information was haphazard and lack of money was a common barrier. Some described the negative impact of restrictive care plans, over-stretched carers, inflexible support and poor staff attitudes – though a number valued the good relationships they had with individual workers. Others were missing out on, or had waited years for, suitable mobility equipment or access to basic technology.

The way in which the categories are interpreted, prioritised and applied will differ from person to person and will be shaped by culture, gender, social class, sexual orientation and so on. Many of the categories will apply to everyone and it is not clear at this stage whether the framework will work for other groups of people who use services.

Implications: what can we learn from this study?

Communication, reliability of data and ethics

Our study confirmed that many older people with dementia want and are able to tell us about their views and experiences, even if they are confused about some factual details of their lives.

Looking through the wrong lens

The research shows the complexity of people's lives. These people are part of social networks with much to give but also with needs to support their health and well-being. To enable personal autonomy, it is necessary to consider things that can be done differently to help older people with high support needs

achieve and retain the things they value in life, rather than simply assuming they no longer have the motivation or ability to participate.

Assumptions about older people

Our findings challenge negative assumptions about older people and their willingness to participate in activities which could enhance their own lives or those of others. Some of the people we spoke to were keen to be involved and told us about a range of things they valued – such as culture, physical activities, humour, getting out and about, contact with nature and so on.

Equality and diversity

Our model encourages a person-led, individual and holistic approach, yet it recognises shared social barriers which people may experience because of particular shared social characteristics. These include aspects of geographical location, cultural background, experiences of ill-health and disabling conditions, education, income and language.

A collective voice

For whatever reasons, some older people with high support needs do not engage in group lobbying: for example, some choose to reserve their energies for very personal priorities. However, given the rarity to date of collective action, there were some promising signs of the potential for developing a collective voice. Despite our study targeting those not ‘already consulted’, some people were keen to impart their experiences to improve things for others; some also wished to volunteer or take on active roles.

How can the model be used by ...

... older people with high support needs and those working with or supporting them?

As a prompt to identify and explore what individual older people with high support needs primarily want and value from their lives, in order to reach practical solutions and decisions.

... policy-makers and commissioners?

As a starting point for understanding the trade-offs that people (especially individual budget holders) make and for developing an outcome-based approach to commissioning (rather than an input-based one).

... researchers?

As a framework for exploring quality of life issues for older people with high support needs, in the other *Better Life* research projects and beyond. As a reminder to consider imaginative methods, and the current best practice in working appropriately with isolated individuals with high support needs.

We look forward to further testing and refinement of the model by researchers, practitioners and diverse groups of older people with high support needs.

1 Introduction

Our aims and approach

The Joseph Rowntree Foundation (JRF) programme, *A Better Life* (2009–13), takes up the challenge of improving the quality of life of the increasing numbers of older people in the UK with high support needs. This report sets out a framework for understanding what quality of life means to these people.

The programme has used the following working 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.

In a review of the evidence collected so far for *A Better Life*, Blood (2010) points out that this group includes people whose circumstances and needs are very diverse. For example, some will have grown older with disabilities and health conditions; others will have acquired these in their later years.

This study was commissioned as part of the ‘vision’ strand of the *A Better Life* programme, which sets out to inform and challenge the different elements of the programme by providing a baseline of the things that older people with high support needs most want and value in their lives.

The primary aim of this project was to produce a robust framework which would:

- inform the work of the whole *A Better Life* programme;
- further the understanding of policy makers, practitioners, regulators, researchers, and older people and their carers; and
- provide a base against which future project work can be considered.

This framework has been achieved through a two-phase approach:

- 1 We reviewed current evidence concerning what older (and some younger) people with high support needs have said about what they value and wish for, in order to identify the headings for an evidence framework.
- 2 We had conversations with older (and some younger) people with high support needs about what they want and value in order to validate the framework and develop a visual representation of it.

The current evidence base

The views of older people with high support needs have rarely been sought by researchers or policy-makers. Most of the research about members of this group has been based on the views of professionals, carers or family members, with older people themselves tending to be dismissed as too ‘hard to reach’, or too difficult or unreliable to interview.

At least two recent studies have begun to fill this gap. Bowers, *et al.* (2009), commissioned by JRF, talked to older people who lived in care homes, extra care housing or supported living about their experiences, producing a framework called the *Keys to a Good Life*. The Alzheimer's Society (Williamson, 2010) asked people who have a dementia diagnosis to prioritise quality of life indicators.

When we broadened our literature search to include younger adults with high support needs and older people in general, we identified a growing evidence base regarding their experiences and views. For example, Bowling (2005) and McCormick, *et al.* (2009) have explored quality of life for older people, including but not focusing on those with high support needs. Similarly, research into the aspirations of groups of people with high support needs has sometimes included older or, as in the case of Fender, *et al.*'s (2007) study of people with Down's Syndrome, relatively old participants. Most of the studies into quality of life are small-scale and qualitative, usually focusing on people living in a particular setting; those with a specific disability or health condition; or those from a minority group.

We will provide some context for the development of research that gives service users a voice. We hope this can help us understand what has, until now, prevented us from hearing and acting on the voices of older people with high support needs.

Context: user involvement in research

There has been increasing interest in involving service users in health and social care research during the last decade (Toronto Group, 2005). Disability research pioneered giving users a voice or, as Forbat and Wilkinson (2008) put it, 'positioning people with [in the case of their work] learning disabilities as experts on their own lives and living circumstances' (p. 7).

Most studies of *older* people with learning difficulties are qualitative and have very small numbers of participants. Nevertheless, their findings remind us why it is important to give a voice to people who use services. When Forbat and Wilkinson (2008) interviewed people with learning difficulties (of whom half also had a dementia diagnosis), it gave them insight into the *complexity* of users' views. When we speak directly to people, we realise how diverse and individual their preferences, motivations and aspirations are.

Kerr, *et al.* (2006) found that staff working with older people with learning difficulties were making false assumptions about dementia behaviour and failing to respond properly to physical pain as a result. This is a salutary example of how ageism can operate in services and the very real impact it can have. It also reminds us of the limitations of depending on the views of a proxy. This was reinforced by Williamson (2010), who found that people with a dementia diagnosis select slightly different quality of life indicators for themselves from those that family carers select on their behalf.

As researchers have turned their attention to service users' perspectives, there has been an accompanying critique of the power imbalance between researcher and participant. Duckett, *et al.* (2010) undertook innovative research with people who have sight difficulties, often alongside other health conditions. He sought to reduce the inequalities in the relationship between researcher and participant by creating 'space for participants to talk about visual impairment research in their own ways rather than in ways dictated by the interviewers' (p. 3). They co-produced guidelines for making research with visually impaired people more empowering. Projects like this exemplify a shift from conducting research *on* users to developing research *involving* users. For some, research *led* by users is the logical and desired best form of involvement in research. For older people with high support needs, however, opportunities for active involvement in both research and the design of services have been rare.

With regard to services, where their opinions have been sought, older people with high support needs want their voices to be heard and their specific needs addressed (Potter, 2009); others have told researchers that even when they have been asked for their views, these have sometimes been overlooked (Ekdahl, *et al.*, 2010). Bowers (2009) and her team found that many of the older people they interviewed in care homes lacked control over both day-to-day and bigger decisions such as moving into

care homes. *This is My Home* Housing Project in Norwich found that older people with learning difficulties (some of whom had high support needs) had had no opportunity to choose where or with whom they would live when moving from a long-stay hospital to community homes (personal communication). It is hard to imagine that this would still be the case today for a group of *younger* people with learning difficulties.

So why have services and researchers working with older people with high support needs generally been slower than those working with younger people to ask, hear and act on their voices?

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

Communication, reliability of data and ethics

Participatory research with people who have learning or sensory disabilities has been facilitated by (and has, in turn, encouraged the development and piloting of) innovative communication methods. For example, Makaton was developed by researchers in the 1970s as a way of communicating with those who are deaf and/or have learning disabilities (Walker, 1977).

The Alzheimer's Society (2007) estimates that one in six people over 80 have some form of dementia. Dementia (and other types of cognitive impairment) has presented different challenges for participatory research: can people with a diagnosis of dementia consent to be involved in research and can we take what they tell us as reliable? These practical dilemmas have reflected a general societal attitude that regards people with dementia as having little to contribute. The acknowledgement that people with cognitive impairments could and should participate in decisions about their care and lifestyle has been relatively recent (e.g. Feinberg and Whitlatch, 2001; Trigg, *et al.*, 2007).

However, the past few years have seen a promising growth in the development of new techniques for gathering the views of people with a diagnosis of dementia. These have included Talking Mats (Murphy, *et al.*, 2010), unstructured conversations (Clare, *et al.*, 2008) and the SOFI framework developed by Bradford University and the Commission for Social Care Inspection (CSCI) to enable people with dementia to participate in care home inspections (Blood and Bamford, 2010). Such approaches address the ethical issues of including in research those with cognitive impairments, while at the same time producing data that is methodologically sound.

Looking through the wrong lens

Blood and Bamford (2010) point out that the 'social model' of disability (in which it is the barriers that prevent disabled people from participating that disable them) has rarely been applied to older people. They argue that older disabled people are generally still viewed through the 'medical model' (in which the focus is on the impairment) and the discourse is one of dependence, care, dignity, frailty and pity. Older people with high support needs have therefore tended to be viewed as passive recipients – rather than active consumers – of care. The focus has been on their needs in relation to services, rather than their broader aspirations in relation to their lives.

If they are viewed through the lens of ageist attitudes and the medical model of disability, older people with high support needs will be seen as having health conditions that overshadow their humanity and individuality. As Scourfield (2007) argues, "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" (p. 1136).

Assumptions about older people

Paternalistic and ageist assumptions have acted as a barrier to researchers asking older people with high support needs to tell them about their views and experiences (Bowers, *et al.*, 2009). Such assumptions ignore the diversity of later life and the individual experiences that inform expectations and preferences, as well as the roles of older people with high support needs as active consumers and experts about their own lives. Service providers and carers may act as barriers to inclusion too – although this was not an issue in this study. Bowers' (2009) team found that people running care homes often told them that the residents would be too tired or insufficiently interested to attend interviews or meetings, or that they would find them too taxing or stressful if they did. The older people they spoke to refuted this and were keen to be included and involved. Nevertheless, the team found it very difficult to get them or those involved with them to talk about – or even conceptualise – a vision for the future.

Equality and diversity

Older people with high support needs have tended to be missing from debates about 'equality' and 'diversity' (Blood and Bamford, 2010). Older people, especially those living in care homes, are vulnerable to being de-humanised (Bowers, *et al.*, 2009) and the negative stereotype of the 'typical' older care home resident means that society often assumes homogeneity among the oldest generation.

Where the diversity of older people with high support needs has been recognised, there has been a tendency towards reductionism, with assumptions being made – that an Asian older person will not need any formal care (Platt, 2002), or that sheltered housing will not be appropriate for some people from religious minorities. However, recent studies such as that by Cattan and Giuntoli (2010) have asked diverse older people about their own experiences and perceptions and emphasised the diversity within ethnic groups.

Where ageism 'connects' with other forms of discrimination, older people with high support needs may experience multiple institutional discrimination (Ward and Bytheway (eds), 2008). Language and cultural differences may place further barriers in the way of us hearing the voices of people from minority groups; homophobia may work against older lesbian, gay and bisexual people getting the housing and care services they need (Age Concern, 2006).

A collective voice

Older people with high support needs do not have a collective voice. As Priestley and Rabiee (2002) pointed out, the disability movement has tended to focus on employment issues while older people's campaigning organisations have tended to distance themselves from the language and campaigns of the disability movement. On a practical level, and as a result of lack of transport, money and accessible information, older people with high support needs get few opportunities to come together and develop a shared voice (Branfield and Beresford, 2010).

There are some encouraging examples of grassroots user-led groups, such as the Scottish Dementia Working Group, and Talkback for people with learning disabilities, both of which include older people with high support needs. Blood and Bamford (2010) have identified other projects which are working to provide groups of older people with high support needs with a collective voice.

In this chapter, we have described the nature and development of the evidence base regarding what older people with high support needs want and value. We have found that research with service users involving younger adults with high support needs and, to a lesser extent, older people in general, is fairly well developed. However, it is only more recently that researchers have begun to ask older people with high support needs, including dementia, for their views.

In Chapter 2, we present the key themes that emerged from our review of this literature – both the specific studies (that is, of older people with high support needs) and, given the limited number of these, the generic evidence (that is, of younger people with support needs or older people in general). The evidence framework is developed from these themes.

2 Review of evidence

Early writers such as Maslow (1943) and Bradshaw (1972) proposed hierarchies or taxonomies of human needs. Our prioritisation of these needs and the way in which we meet them varies between individuals and is likely to change over our life course. However, we will continue to have ‘higher level’ needs – for love/belonging, esteem and self-actualisation – until we die. As we begin to develop our framework, then, we should surely start with the assumption that older people with high support needs will value and want the same fundamental things as everyone else.

We have organised the key messages from the literature under three broad headings, which have been used elsewhere in ageing studies (Peace, *et al.*, 2006; Peace, *et al.*, 2007) and reflect different but interconnected aspects of well-being:

- **social** – relationships, social engagement and cultural interactions;
- **psychological** – relating to the mental and emotional state; and
- **physical** – the built and natural environments and the ageing body.

We highlight in bold the key themes under each of these headings and then briefly summarise what the literature tells us about the *barriers* people face in relation to them. At the end of this chapter, we present the evidence framework which we have developed using these themes and headings.

Social well-being

In both Bowers, *et al.* (2009) and Williamson (2010), older people with high support needs have said that having meaningful **personal relationships** is of prime importance to them. These may take many different forms: ongoing or new relationships; with partner, family and/or friends; both face-to-face and long distance. Many older people will have experienced bereavements, so memories of past relationships, perhaps linked to places or objects, can be particularly important (Sherman and Dacher, 2005).

Regular **social interaction** means having people to talk to and the prospect of future meaningful relationships. This may occur as a result of maintaining some element of a previous social life (Gilroy, 2009) or by developing new networks based on activities or communal settings. Structured opportunities for social interaction can be particularly important for older people who cannot get out and about without support and may be at particular risk of isolation.

Day-to-day, paid support workers are also an important source of social interaction for those with high support needs. **Good relationships with formal carers** are based on: **respect** for individuality (Blood and Bamford, 2010); friendliness (not necessarily friendship); kindness; reliability; and continuity (Potter, 2009).

Being engaged in some kind of activity is identified as important to most older people, as is continuing to **make a contribution** to society and feeling valued as a result (Gabriel and Bowling, 2004). This contribution may take the form of having a role as a volunteer, club member or grandparent. There is also anecdotal evidence of individuals valuing the opportunity to make small contributions to communal life, such as setting the table in a care home, or tending a section of garden in sheltered housing (Blood, 2010).

The need to participate in **cultural activities** remains, despite the changing circumstances and opportunities which increased support needs may bring (Blood and Bamford, 2010). People may value music, reading, television or radio; cultural or religious events and celebrations; sporting events or club membership. Some of these activities bring social interaction as well as cultural stimulation. There is currently little evidence about the ways in which older people with high support needs maintain or aspire to maintain their cultural lives.

Psychological well-being

Research has repeatedly demonstrated the high value that older people place on retaining independence and autonomy, and the impact this can have on their sense of self and well-being. What it means to be 'independent' will vary for individuals and may differ across cultural groups (Gandhi and Bowers, 2008; Moriarty, 2008). However, a fundamental sense of **self-determination** is likely to be important to everyone. For older people who need support, this will usually mean having control over key factors such as where and how they live; and when and by whom support is provided (Collopy, 1988; Welford, *et al.*, 2010; Leece and Peace, 2010). Not everyone will want to be actively involved in every aspect of decision-making, but the evidence suggests that people want the opportunity to be included in the process or to have their views represented by somebody else if they prefer (Ekdahl, *et al.*, 2010).

Personal identity and self-esteem emerged as key components of quality of life in both Bowers, *et al.* (2009) and Williamson (2010). Where there are losses, changes and the surrender of important aspects of control, older people want to be able to hold on to the parts of their lives that represent **continuity** between past, present and future (Bigby, 2004) and to maintain as much control as they can over their daily lives (Bowers, *et al.*, 2009; Potter, 2009). This is vital to a continuing **sense of self**, and in order to promote certainty, security and self-esteem while **adjusting to changing circumstances**. Older people with high support needs often find themselves having to make difficult decisions to balance independence, support and risk, and the research shows that they may find it particularly hard to do this where their sense of self is threatened (Tanner, 2001).

Humour is another important way of retaining control and personal identity in the face of loss and change. The literature describes jokes being used to make light of ageing bodies, to manage concerns about accidents, and also to engage those with communication difficulties through practical jokes (Hubbard, *et al.*, 2003; Williamson, 2010). People of all ages need to enjoy themselves, although what gives **pleasure** to individuals is highly personal and may change with time and circumstances (Johnson, *et al.*, 2010).

People often worry about the possibility of cognitive decline as they age and some older people with high support needs will experience periods of depression or anxiety as they come to terms with loss; cope with pain or new limitations on their day-to-day activities; and reach the end of their lives. Older people may take a number of steps to promote their **mental health** and cognitive functioning. Keeping mentally stimulated is felt to be important, as is having a sense of **purpose in life**, through roles, activities, relationships or the home. Achieving existential balance, or making sense of your own place in the world, may involve spiritual or religious beliefs, political affiliations or a sense of cultural belonging (Dementia Voice, 2000).

Physical well-being

Safety and security and a **good living environment** have been identified by older people with high support needs as part of the *Keys to a Good Life* framework under the heading of 'home and personal surroundings' (Bowers, *et al.*, 2009). Safety and security may include actual and perceived physical safety, financial security, emotional security and other kinds of security such as tenure or continuity of care (Means, 2007).

Being and feeling safe in the local neighbourhood is also important (Peace, *et al.*, 2006; Peace, *et al.*, 2011) and older people who have disabilities, especially those who are also from minority groups, can feel particularly vulnerable to crime, anti-social behaviour or harassment (Neighbourhood Renewal Unit, 2005). A good living environment produces a strong underpinning for security (Williamson, 2010). Conversely, a poor environment can impact on both physical and mental health, or curtail independence (for example, by delaying discharge from hospital, or limiting movement around the home).

The majority of older people express a desire to remain living in their current homes for as long as possible. Familiarity and attachment to place can be particularly important for people with cognitive or visual impairments or other disabilities. However, the homes of those with high support needs have to be functional, accessible and warm if they are to provide a good environment in which independence can be safely maximised (Habinteg, 2010). Where this is not the case, older people may need information, support and advocacy to help them make adaptations or consider relocation options (Johnson, *et al.*, 2010).

Being able to **get out and about** is commonly cited by older people with and without support needs as being important to their physical and mental well-being as it allows for social interaction and variety as well as some physical exercise (Holland, *et al.*, 2005; Bowers, *et al.*, 2009; Williamson, 2010). Evidence suggests that most people benefit from some kind of contact with nature: fresh air; a sight of the sea, woodlands or flowers; or being able to see the birds out of their window (Bhatti, 2006).

Older people with high support needs value the positive aspects of their **physical health**. Most want to do what they can to improve or maintain it and receive support to do so, provided it is on their own terms (Bowling, 2008). Older people vary in the degree to which they recognise and perceive their illnesses, health conditions and disabilities. Like the rest of the population, they also vary in their knowledge of how to improve their health and the measures they are willing or able to take to do so.

In the literature, there is a resurgence of interest in the ageing body as an important aspect of our experience in later life (Twigg, 2010; Martin, 2010). Unsurprisingly, older people are keen to be in control of their bodily functions and personal hygiene, and keep these as private as possible. Older people in general, and people with a diagnosis of dementia (Williamson, 2010), have also said they value the opportunity to do some form of **physical activity**.

Barriers and enablers

The literature also gives us an insight into what prevents or enables the promotion of social, psychological and physical well-being for older people with high support needs. Information, money and support are the most frequently mentioned barriers in the literature, but other people's time, access to transport, equipment and technology are also significant.

Good **information** can enhance people's lives by opening up social and leisure opportunities; improving access to services, financial entitlements, rights and health information; and relieving anxiety (MacDonald, 1999). In an age where information is transmitted in new and different ways, some older people will find it particularly difficult to access. In addition, those with high support needs and/or those who do not speak or read English well may require information to be presented in accessible formats (Bowes, *et al.*, 2009; Godfrey and Johnson, 2009).

Older people in general often express anxiety about having sufficient **financial resources** to remain independent and enjoy quality of life now and in the future (Cattan and Giuntoli, 2010). The link between poverty and health in old age is well established (Centre for Social Justice, 2010) and those with high support needs are likely to be doubly disadvantaged, both by having fewer financial resources in retirement and by needing more financial resources in order to pay for support, adaptations, transport and so on (Blood and Bamford, 2010). Where finances are limited (and this is particularly true for those who have low incomes but do not qualify for publicly funded social care), older people with high support

needs may not be able to meet even their most basic aspirations – for a hair-cut, an occasional trip out or to buy a birthday present (Coalition on Charging, 2008).

The amount, quality and type of **support** received from both formal and informal carers and supporters can act as an enabler or a barrier to the well-being of older people with high support needs. Having the **time** to communicate effectively with supporters is, in itself, socially and psychologically beneficial. It is also essential if care is to be provided respectfully (Bowers, *et al.*, 2009; Blood and Bamford, 2010) and other aspirations are to be identified and supported. This can be particularly important to people with a dementia diagnosis, who may need additional time, skills and creativity from carers to communicate effectively (Williamson, 2010).

Access to **transport, equipment** and money to pay for taxis are key enablers to being able to get out and about (Holland, *et al.*, 2005). **Technology** can improve well-being by reducing anxiety about falls or crime, or making homes more accessible. There are advances here, for example, in design and technology for people with a diagnosis of dementia (Dementia Services Development Centre, 2010). However, budget restrictions combined with a lack of knowledge and vision of those working with older (as opposed to younger) people sometimes means that access to appropriate assistive technology or even basic mobility **equipment** for this group can be poor (Blood, 2010).

What people with high support needs value: our evidence framework

The evidence framework in Table 1 summarises the key themes from our literature review (as highlighted in bold in this chapter). We have added in italics some of the sub-headings we have mentioned, which we will also explore under each of these themes.

Table 1: Evidence framework

Aspects of well-being	Theme headings	Barriers & enablers
Social well-being	Meaningful relationships (<i>personal and with paid carers</i>)	Information Financial resources
	Social interaction	
	Making a contribution (<i>including roles</i>)	
	Cultural activities (<i>including religious activities</i>)	
Psychological well-being	Self-determination (<i>including involvement in decision-making, control, independence, autonomy</i>)	Support Time Technology
	Continuity and adjusting to change	
	Sense of self (<i>including self-esteem</i>)	
	Humour and pleasure	
	Mental health (<i>including existential balance, sense of purpose in life</i>)	
Physical well-being	Safety and security	Equipment Transport
	Good environment (<i>including contact with nature</i>)	
	Getting out and about	
	Physical health (<i>including living in an ageing body</i>)	
	Physical activities	

3 Validating the framework: a summary of our approach

Introduction and objectives

The next stage of the project involved talking to people with high support needs about what they want and value, in order to test the interim framework.

JRF wanted us to engage and talk to both older and younger people with high support needs who had not previously been involved in research or consultation. Specifically, we were asked to ensure that we heard the views of people with dementia and/or a variety of other health conditions and, where possible, of people from minority ethnic groups as well as lesbian, gay, bisexual or transgender people (LGBT).

The Open University (OU) team drew on its experience of working in a range of environments with diverse older people and facilitating participatory project work (Bytheway, *et al.*, 2007; Peace, *et al.*, 2006; Holland, *et al.*, 2007, 2010). We were joined for this part of the project by some additional *discussants* (listed in our acknowledgements) who were also experienced researchers.

We provide further details of the profile of our participants in Appendix I.

The participants

We held face-to-face conversations with 26 people who met JRF's definition of high support needs.

We recruited our sample using local contacts of the OU's network across the UK, rather than through national organisations. This helped us to identify a mix of people who are not usually consulted.

The majority of participants were aged over 80, but we also spoke to three younger people aged between 40 and 60 years.

We identified more men than we had anticipated, based on national statistics (Blood and Bamford, 2010). Ten of the 26 people we spoke to were men.

Our sample included people from Scotland and Wales as well as different regions of England. We also spoke to four people from black and minority ethnic backgrounds and to two homeless people. Despite various attempts, we were not able to speak to anyone who openly identified themselves as LGBT.

All participants had complex health conditions and the sample included people with physical disabilities, people with learning difficulties and people with a diagnosis of dementia. Some people had been born with disabilities and others had acquired them in adult or later life.

We also spoke to a number of volunteers and professionals working with people with high support needs in a variety of organisations. Most of these conversations were held on the phone, but we had more detailed face-to-face discussions with two people: a voluntary sector care manager working with Bangladeshi people in London and a support worker for older people with dual sensory loss in Yorkshire.

Our approach

We adapted an existing interview tool called the ‘facets of life wheel’ (included in Appendix II), using the concepts identified through the literature review and included in our interim framework. The wheel had previously been found to support user-led but semi-structured discussions (Peace, *et al.*, 2006). The wheel enables people to lead on topics as much as possible and talk about different aspects of their lives including their wishes.

Carers or supporters sat in on some of the discussions. Our conversations with two participants included carers acting as interpreters because of communication difficulties. One further participant needed a language interpreter and a family member played this role.

Most conversations lasted between 45 and 90 minutes.

Participants commented that they valued their opinions being sought.

The conversations were recorded (with permission), transcribed and analysed against the categories in the evidence framework, with new categories added as necessary; then cross-checked by team members.

Most people were happy for us to use their real names or nicknames; four chose pseudonyms.

We present the key findings from these discussions in Chapter 4, and then in Chapter 5 discuss how we used these to develop a model.

Reliability of the data

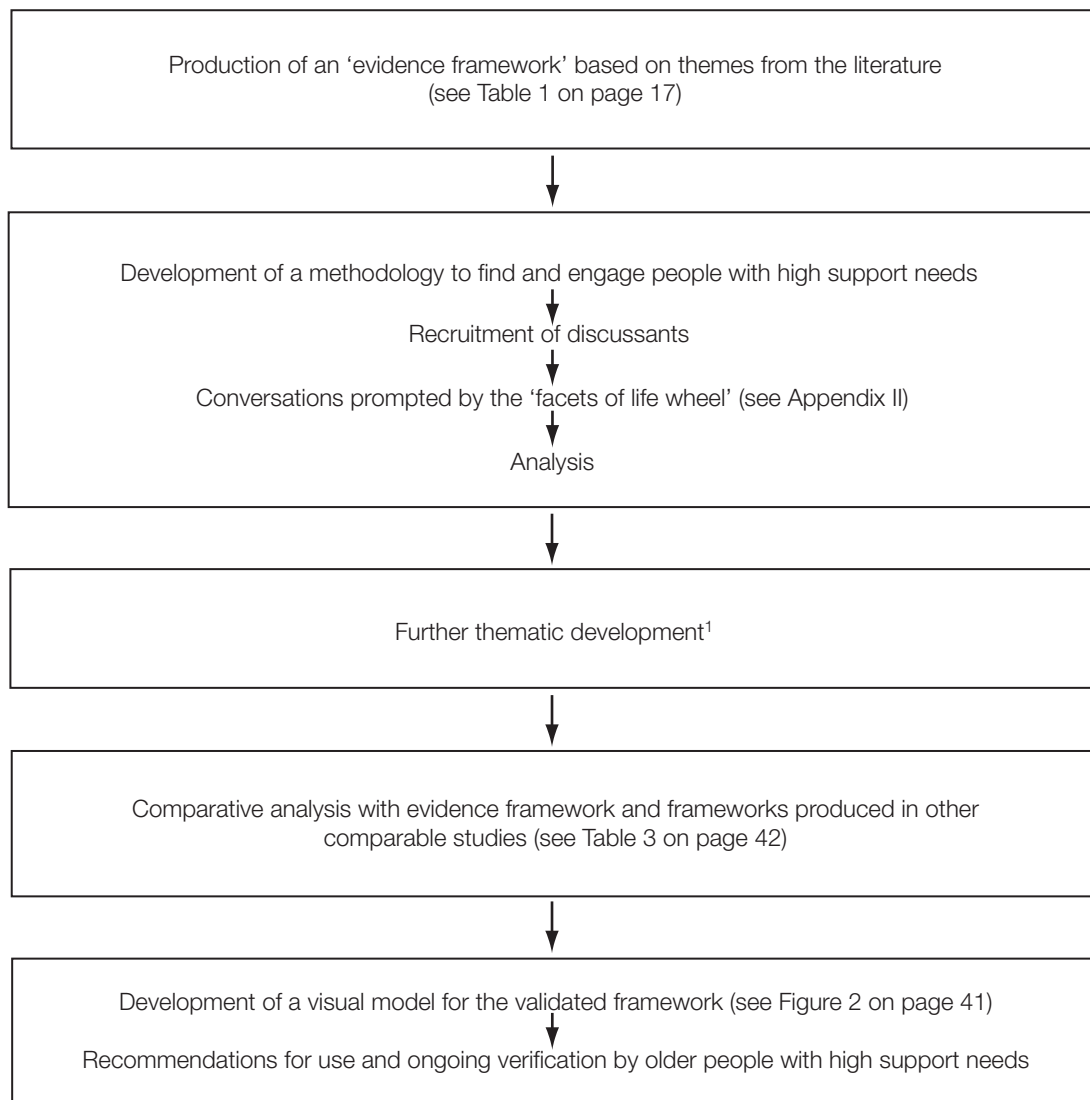
Although we were successful in engaging with a diverse group of participants, we recognise that the findings of our discussions with such a small sample of people may not be representative. Nevertheless, the conversations provided some verification by older people with high support needs of the recurring themes from other studies.

Some of the participants who had dementia were not able to give factually accurate information about their current circumstances. Where appropriate, we checked accuracy (for example, age or current living arrangements) with carers. However, the ‘wheel’ was a good stimulus for discussion with these participants in particular, prompting them to express their views and emotions about their current well-being and the things they found supportive of it, and their aspirations for improving it. Although a visual tool, it also worked well with people with sensory impairment as it is straightforward to explain.

While we recognise the limitations of gathering certain types of factual information from people with cognitive impairments, we 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.

Summary of the process

Figure 1: Summary of the process used in this project



¹ This stage of the process included development by the JRF editor, Imogen Blood

4 Findings: the voices of older people with high support needs

Overall, the participants validated the themes from the evidence framework. In other words, they agreed on the importance of these themes and were able to illustrate them with examples from their own or another’s experience. Different themes resonated more strongly with some individuals than others and some people suggested additional nuances or new categories.

We did not ask participants to rank the importance of different themes. We preferred to take a more natural conversational approach, prompted by the ‘facets of life wheel’. In our analysis, we grouped themes or sub-themes (shown in brackets in Table 2 below) according to how frequently they were mentioned and the emphasis they were given by participants. Those in the top band were the most frequently mentioned.

Table 2: Frequency of mention of themes

Themes
Personal relationships Support/good relationships with carers Self-determination (involvement in decision-making) Social interaction Good living environment Getting out and about/mobility Transport Equipment Information Financial resources
Cultural activities Sense of self (self-esteem) Self-determination (autonomy and independence) Pleasure Physical health (living in an ageing body)
Other people’s time Good environment (contact with nature) Safety and security
Making a contribution Continuity Mental health (purpose in life)
Adjusting to change/continuity Technology Humour Mental health (‘existential balance’)
Physical activities

Given the size of the sample, we cannot assume that this weighting would hold true for other groups of older people with high support needs. However, our conversations have generated some interesting *qualitative* data which gives us insight into what our diverse participants value in their lives and why. In the remainder of this chapter we present and discuss the recurring and/or most interesting points which emerged from our conversations.

Social well-being

Personal relationships

Our findings echo those of previous studies (e.g. Bowers, *et al.*, 2009) in confirming the importance of meaningful relationships to older people with high support needs. The personal circumstances and family histories of the people we spoke to were very diverse, as were their current living arrangements and levels of mobility. There was considerable variation in the number, type and depth of relationships which were significant to people. Some interviewees described close relationships with paid carers and support staff; and some of the newer friendships people had made within communal living settings or day centres were also clearly important to them. Subsequently, we found it difficult to draw a clear boundary between this theme and the following themes of 'social interaction' and 'good relationships with carers'.

Most participants said they had close emotional relationships with family members and friends, even though geography, illness or disability, access issues and time sometimes meant that contact with them was infrequent or difficult.

Several people mentioned the impact that hearing impairments and problems with hearing aids had on their relationships. Millie explained that she refused invitations to her son's home at Christmas because she cannot hear what people are saying when everyone is talking at the same time. Hughie longed to be able to pick up the phone and talk to his niece, who had looked after him for 27 years, but he could not hear well enough to have a conversation over the phone.

The people that ring me up, they'll say what they have to say, then I'll turn round, I'll say my little bit, I can't hear what you're saying, I'm very sorry, you're going to have to write me a postcard, and that's where it ends. I haven't fallen out with anyone over it, at all, I haven't had any arguments ... they just accept it.

Hughie, 90, who has dual sensory impairment

As support needs increase, relationships with partners, family and friends often change. Some of the people we spoke to were (or had been) caring for or being cared for by their spouse; some couples were having to live separately due to the care needs or access requirements of one or both of them. Many found their increased dependence on others, especially younger family members or friends, difficult at times: not wanting to 'impose' on people was a recurring theme in the conversations. For example, Jenny, who lives in sheltered housing and has mobility problems and dementia, explained that:

If I'm not feeling very well, well then my daughter-in-law will come and ask me what I need ... but I don't impose upon them.

Jennie, 93

June wanted to be able to get out and about more without having to 'depend' on her daughter and granddaughter and Vera worried about being a 'nuisance' because someone would have to drop her off and pick her up if she went out anywhere. These concerns are linked to the theme of 'other people's time', to which we will return under 'Barriers and enablers'.

Our conversation with Sylvie, who does not have family living locally, highlighted the difference between the kind of support you might reasonably ask of friends and that which you could expect only from family.

I have made lots of friends and I can call on people to help most of the time, but it's not having family and, for instance, I have to stay overnight, stay in the hospital for a couple of hours, and come home and have someone sleep in my house, be with me overnight, and I can't ask anybody to do that. I can get taken there and brought back, but people have their own lives to lead, and so things like that become very awkward, and I am afraid, because should I have to be taken to the hospital in the middle of the night, or something happens, there's no one I can call on really.

Sylvie, aged 85 with mobility problems and some memory loss, living in own housing

Social interaction

Our study confirmed the value which older people with high support needs place on social interaction. For many of the people we spoke to, this happened within the communal areas or organised activities of their care homes or residential schemes; six (of whom five lived in their own homes) regularly attended day centres. For those that live alone, having regular transport to a day centre, or having the option to join other tenants or residents in the communal area, helps to counter boredom and loneliness and gives them a choice about whether and when to socialise.

I have my own flat, my own door, we have a lounge downstairs, we have meetings, so if there's whatever, something's going on downstairs, I'll join them.

We are very lucky to have a day centre like this, very lucky, because after all when you live on your own, and you've done your shopping, so what will you do, look at the television, so at least you mix with people here, when you come here.

Both quotes from Jennie, 93, who lives in a 'retirement' apartment but also receives transport to attend a community day centre in Essex

Our conversations suggested a number of ways in which social interaction can boost the self-esteem of older people with high support needs: by being in a social setting where they fit in and by enabling them to laugh, relax and 'be themselves'. Participants particularly emphasised *new* relationships that had developed as a result of their increasing support needs: with their neighbours in residential settings; with peers (and sometimes younger people) at community centres; and through meaningful relationships with carers. Meeting new and diverse people can bring a sense of promise and development.

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, I normally does art, craft, it make you felt you're somebody, when you're doing something.

Gertrude, 74, who lives in the house she owns and receives transport to a black elders' community centre in London

The person next door is quite new, but given the weather, I sit out here, we've got a seat here [outside] and I can walk around the garden ... [my neighbour is a] totally different kind of person which is nice for me, she's very outgoing and loves the garden ... quite content here really, the people are quite nice.

Jo, 85, who lives in a private retirement housing flat but cannot walk as far as the central meeting area where there are occasional day events

Again, sensory impairments made it difficult for some people to mix socially. Hughie, 90, who uses a wheelchair and has dual sensory impairment, had stopped attending a day centre since, "if you get two or three people talking together it's just a noise, you don't hear what's being said".

Good relationships with carers

Paid care workers provide older people with high support needs with regular social contact, which can help prevent isolation.

I'm going to need help in the mornings, and I'm glad of the help really, because I wouldn't see a soul otherwise, and I'm woken up and they are wonderful really.

Sylvie, 85, living alone in her own home

Given the social benefits of receiving paid practical care, people told us that it was particularly important for carers to be *friendly* as well as effective and dependable. Beyond this, a number said they had closer friendships with certain care workers.

I like the carers, most of the carers, the ones I know, got one special carer, works upstairs, she comes to see me when she comes in and before she goes home, each time she comes and goes.

Jill, 71, physically disabled from birth, living in a nursing home

Rob, 50, who has tetraplegia following an accident, described how his life in a nursing home had been greatly enhanced by the fact that he had pre-existing friendships with staff members. One of Jo's carers facilitates communication between Jo and another person she supports, having recognised that the two share common interests. Jo now enjoys sending and receiving cards and messages via the carer to the other person, who is blind.

Good relationships with carers are an end in themselves in that they can provide positive social interactions and friendships; they are also important to ensuring that the care provided is appropriate, effective and respectful. These kinds of relationships usually need time and consistency in order to develop – themes to which we will return at the end of this chapter, when we consider barriers and enablers.

Making a contribution

At any stage of life, making a contribution that is valued is important in order to maintain self-esteem and a sense of connection with others. For some of those we spoke to, mutual exchange was seen as an important aspect of the friendships they had with paid carers, since it brought greater equality and respect to the relationship.

I hope I can understand other people as well, because they have needs, the people that come in here, and they can talk to us ... they are quite open and they will come out and say so and so.

Jo, who is 85, and has osteoporosis and macular degeneration

We also found examples of older people with high support needs taking on more formal roles in their communities. For example, Hughie, who is 90 and has a dual sensory impairment, told us that he enjoys both the responsibility and status of being the bingo caller. Sylvie is a committee member of a local inter-faith group and produces theatrical shows: both of these roles help her to connect with others, given that she does not have family in this country.

Older people with high support needs often need practical support and encouragement to fulfil such roles. For many, a lack of time, vision or other resources on the part of those who support them means that their need to make a contribution goes unmet.

I want to do some more work, helping out ... voluntary, do some voluntary work ... helping out with tea or something like that or serving customers ... helping out, I like to help people out.

Jack, aged 73, with learning difficulties and a heart condition, living in sheltered housing

Some people described the roles that they used to fulfil and talked about the impact of giving them up. Jimmy had been very active in his local community prior to caring for his wife, who had recently died. He told us about the uncertainty he now faces as he decides which new roles to take on.

I served on one or two local councils, I was a church secretary for over 50 years ... I had more or less to give that up, and anyway at my age I shouldn't still be doing too many of those things, so what I'm actually doing now is a little bit uncertain ... this winter hasn't helped because it's tended to tie me down a little bit ... the local community policewoman spoke to me the other day and said would I like to be the centre of the Neighbourhood Watch in this area so I said yes I'd take part. I'm quite happy to take things up, another villager has spoken to me about maybe joining a little group she's setting up to lobby for improvements to the village, ... if I can do anything in the community obviously I will do it within my limits now ... so I will do it, it's just this element of uncertainty.

Jimmy, 89, who lives in rural Cumbria and until recently cared for his dying wife

Cultural activities

Many of the participants told us how important it was to them to maintain a cultural or intellectual life. People mentioned listening to music; doing arts and crafts; going to church; watching or being involved in theatre; having intellectual discussions or using a range of media to keep themselves informed and mentally stimulated.

Some people, such as Rob, described the social benefits of participating in cultural activities.

It's nice getting to know people, doing things with other people, with the other residents, so you get to know them ... you got bingo with the other residents, you got the concerts and stuff like that, you got games, and we do arts and crafts and stuff like that, so there's always plenty on, and if you go downstairs, you know, in the common room, there's usually quite a few down there.

Rob, 50, who lives in a nursing home

For others, like Jo, who cares for her husband despite her own health problems, listening to classical music on the radio last thing at night helps her to *relax* and sleep well. For Jo, who has sung in choirs and quartets, and for Irene, who had wanted to be an opera singer and showed us her extensive collection of classical music recordings, music is a lifelong passion, which provides *continuity* with the past.

It was clear from a number of our conversations that many older people with high support needs get a sense of *achievement* and increased *self-esteem* from their participation in cultural activities. Gertrude takes pride in producing art and craft items.

When I'm doing something, like when I'm doing the art, anything with [an] end product I like doing ... knitting, when it's finished I admire it, when I do a bit of painting here and it finish I admire it.

Gertrude, a Guyanan woman of 74 who has osteoporosis and arthritis

A number of people told us how important it was for them to keep their *minds active*. James, a retired medical professor with muscular dystrophy, attends regular lunches with former colleagues, at which he continues to participate in intellectual discussions that draw on his medical expertise.

The church played an important part in the social and cultural lives of many of those we spoke to. Mrs A said that she enjoys going to a church where other Nigerians worship, and particularly likes listening to the music there. A number of people were no longer able to attend church and missed this but had found alternative ways to keep in touch: Gordon and Jo read the church magazine and receive visits from a couple of fellow church members. Memories of church were important for several participants. Hughie felt it was significant that he now lives near to the church where he was married. Jimmy had been a church secretary for over 50 years and reminisced about this role.

I was brought up to go to church morning, noon and night, my mum was in concert parties there, I used to sing in the choir there, my whole life was centred around the chapel until it was pulled down.

Irene, 85, who has dual sensory impairment and mobility problems

Some of those we spoke to had adapted their activities as a result of illness, disability, or a change in their living or support arrangements. Some people seemed philosophical about this; both Jo and Irene have visual impairments and, as Jo explained, "... if I can't see very well I can listen to Classic FM". Some, like Rob who had discovered an interest and talent for painting since moving into his care home, were pleased to have had the opportunity to try something new.

However, for others, these adjustments were accompanied by sadness and loss. Since moving to a care home, Terry has had to substitute going out to bingo, where he ran sessions over many years, with indoor crafts such as making Christmas cards – an adjustment he tolerated rather than welcomed. Participants mentioned past cultural activities when reflecting on what they like to do: Lena longs to tour Europe again; June misses the theatre, which is currently inaccessible to her.

I can't go the theatre or anything like that anymore ... because I can't sit in the seats; last time I went with the guild to the theatre it was absolute agony getting up and down from the seats, so I decided there and then I wouldn't go back ... I like to do all these things, but I just can't ... I just can't do them, because as I say, it's too difficult.

June, who is 85 and has limited mobility

Some, especially those who attended day centres, felt supported and encouraged to have a cultural life. Monty, who is 82 with advanced dementia, spoke about regularly attending shows, especially musicals. Jill, who is physically disabled, is taken by care home staff to buy materials for her tapestries, some of which were framed on her wall.

Other participants in the study appeared to be unsupported in maintaining their access to culture. Vera could no longer hear the television and hoped that her support worker would get a loop system fitted for her but in the meantime she missed the connection with the wider world.

People should tell me things, I don't know what's happened, not through being inquisitive, I'm interested ... I need some contact with the news and things like that.

Vera, who is 89 with dual sensory impairment

Psychological well-being

Self-determination

Under this heading, we also cover the related ideas of independence, autonomy, involvement in decision-making and control. These concepts had slightly different meanings for participants. For many, remaining in control of key aspects of their lives was central to their self-esteem. As we have already mentioned, a number told us they found it hard to depend on others, especially friends and younger family members, for practical support.

For some, particularly women, independence was closely linked to the home, household management and cleanliness.

I think I've been on my own so long, I've always been independent, but I can't be now, not as I'd like to be ... it's been very hard, very, very hard, when you have to sell your house ... and I went through a war, you know, my husband went through a war ... I really want to be independent ... I want to keep clean.

Vera, 89 who has dual sensory impairment

Irene, who has dual sensory impairment, wanted the opportunity to take each new carer around her kitchen and introduce her system to them.

Being partially blind I have to know where everything is and I have my big plates there ... my saucers there ... she put the saucers on top of the big plates, course I went in there ... whole lots went crash on the floor ... now when they come I say to them ... don't put anything on top of those big plates.

Irene, 85, who has dual sensory impairment

On a practical level, this is vital if she is to move around confidently and avoid accidents but she also seemed to be expressing a deeper desire to retain control over her home and her way of doing things. Where people were living in institutions and no longer had control over the day-to-day running of the household, some had simple requests for things to be made available to them. Jill wished that the nursing home staff would keep the food residents asked for in the kitchen: she particularly wanted fresh ham.

Where some of those living in care homes described occasional tussles over control, some participants living in their own homes were happy to delegate certain actions to others. Winnie wanted to stay firmly in control in many areas of her life, saying "my poor family know better than to try to make decisions". However, she was happy to delegate authority in the handling of administrative matters to other people.

I would rather they did it now, because I don't hear very well, and they could perhaps answer questions quickly, which I can't.

Winnie, 89, who has poor vision, some dementia and limited mobility

Similarly, June had delegated banking matters to her daughter.

She [daughter] does all my banking for me, and there was so many things I wasn't telling her about, and now everything's been transferred for her to do, because I'd made a muck of things, 'cause I ... didn't realise what was happening, but everything's been sorted out now and she's got the permission to do everything ... it's fine, I don't bother, as long as she's able to do it, it's fine.

June, 85, who has limited mobility

We encountered some examples in which participants felt aggrieved because they had been excluded from having a say in decision-making. For example, Vera, with dual sensory impairment and living in her own home, had not been able to access the application for planning permission of the neighbouring house. Terry felt pressured into agreeing to move to a care home by his relatives and care workers, who told him they were concerned about his physical safety.

For some, like Rob, day-to-day quality of life seemed to be the main driver and having longer-term 'control' over life felt less important, provided his needs for stimulation, variety, connection with others and self-esteem were met in other ways.

Control over what's happening in your life important? No, not really ... as long as like I'm up and about regular, as long as I'm not stuck in bed all day and stuff like that, just getting up and doing different things.

Rob, aged 50, with tetraplegia

Continuity and adjusting to change

Continuity was important to participants. Many of those still living in their own homes were very keen to remain there, even though this presented challenges. However, many of the people we spoke to had adjusted very well to significant changes to their living arrangements, health and lifestyles. Having a sense of self-determination and a strong continuing sense of self seemed to strengthen this resilience.

Our literature review suggested that older people in general often invest emotional meaning in objects and places and this was validated by some of our participants. Remaining in or visiting places which have links to the past or keeping objects which have sentimental value helped some of the participants to remember, share and maintain continuity with the past. For example, Gordon told us about his sound recording and interviews: keeping his equipment and tapes was clearly important to him, even though they are now technologically obsolete.

I used to do sound recording ... I had two reel-to-reel tapes and a cassette ... sometimes I'd go out to people's homes and interview them, and I really love that ... no, not now because, although I've got one reel-to-reel, it won't, it wants a bit of attention, but they don't do reels-to-reels now ... I've got a 16mm projector which you can't hire films for now ... or you pay the same price as the cinema ... history, local history, I like to talk to people and get them talking about their experiences, I interviewed the editor of the Exmouth, one of the Exmouth papers, I've still got that reel-to-reel.

Gordon, 78, who has cerebral palsy and lives in a nursing home

Consistency in support arrangements is, as we have seen, necessary if good relationships with paid carers are to be developed. For Jill, the regular exchanges she enjoys with one particular carer contribute to her routine, which gives her some certainty and a feeling that she is well supported.

Other people that we spoke to were trying to adjust to changing circumstances. Mrs A was struggling to adjust to a supply carer while her regular carer was on holiday. Jo and her husband received support from an ever-changing roster of eight different care workers but explained that, at this point in time, their need for continuity in terms of 'staying put' was greater than their need for continuity of care. Some people said they were anxious about how they and their partners would be able to continue supporting each other as their needs and capabilities changed.

Sense of self

Many participants proudly showed us evidence of their previous lives, especially things they had made themselves, which a number had displayed in their homes. These objects enabled them to give a sense

of themselves, both past and present, to formal carers and the research team. They were keen to maintain their individuality and described different ways in which they expressed their personal identity and sustained their self-esteem. These included:

- cultural stimulation and self-expression, e.g. through art, crafts and music;
- maintaining control/independence;
- continuity of relationships with people, places and objects;
- roles and making a contribution/having mutual relationships/humour.

Humour and pleasure

Participants agreed that humour was important to them: many made fun of their situations, both past and present. They used it as a way of expressing their own identity and to manage some of the challenges that they faced. Some used humour as a way of conveying the 'real me' and showing others what they used to be like. Others joked to help them manage some of the current challenges that they faced: laughing while saying things like "don't put me on the roads" or while describing how they fell out of a wheelchair.

Terry described in a humorous way his resistance to the constraints placed on his independence by living in a nursing home. He jokingly referred to the care home staff as "warders" and described how he sometimes broke the rules. For Terry, humour seemed to be a way of retaining the control he felt he had lost on moving into an institution.

I haven't got anything to grumble about here ... I don't obey the laws, that's the trouble ... well I went out there the other day, I came down in the lift, then I went out there, and I wasn't supposed to ... oh I had a right bollocking, off my sister and all [sister was visiting].

Terry, who is 80, has severe Parkinson's disease and lives in a nursing home

It was clear from our conversations that older people with high support needs, like any other diverse group of people, gained pleasure from a range of experiences. Jennie described the pleasure she gets from meeting people and participating in activities at the day centre. Many, such as Mrs A with severe dementia, get pleasure from spending time with family. Hughie derives pleasure from his role as bingo caller; Denise from activities such as watching television, listening to music, painting or doing embroidery or cross stitch. Vera associates pleasure with mental stimulation, while James associates it with continuity.

They aren't new things that I look to for pleasure; they're just the preservation of the old things, for example going to the theatre.

James, 75, who has muscular dystrophy

Mental health

Several participants expressed concerns about memory loss.

I have become aware of the fact that my memory is not good ... there's something going on there which is quite worrying, which is taking me away from the intellectual skills that I had and I used to

enjoy and find interesting, and I don't, well I don't know what's going to happen about that ... I know that, as people get old, their memory gets, but 74 is not, not an age at which you would normally start losing your memory, so I am concerned about that.

James, 75, who has muscular dystrophy

For Sylvie, the fears of memory loss are increased by the fact that she lives alone.

I can walk into a room and think 'what have I come in here for?', and it happens to lots of people and younger people say 'oh well I forget', but it's frightening when you live alone, those are the things I worry about mostly, and being in reasonable health, other than that, there's not much else I can do.

Sylvie, 85, who has mobility problems and some memory loss

Many described things they did to boost their cognitive functioning or mental health, whether deliberate or not. Vera told us how she tries to keep her mind active.

I just want to keep active, do things, keep this going [brain] ... I don't watch rubbish on the television, I hate pop music, but there's some interesting programmes on, like travel and Countryfile and things like that, different things, you know, I listen to the services on the radio in the morning ... different people talking.

Vera, 89, who has dual sensory impairment

Some participants described experiences, roles and relationships that gave purpose to their lives. Sylvie told us how she had responded to feeling socially excluded (as a result of not having family in this country) by taking on active roles in community groups, which gave her a sense of purpose. Jimmy expressed his fears and anxieties about not having a clear direction following the death of his wife.

You begin to wonder in your moments of depression, have you got any time left to do anything ... which is ... where am I going, because up until now there's always been a sense of purpose. I've had things I've been doing ... and then when [wife] was ill it was [wife] I had to look after, and for two years my attention was almost entirely on her, she was priority one, and ... now I am not ashamed to admit that, for the first time in my life, I'm not quite sure where I'm going, and it's disturbing, because as you said I am the kind of person who, I'm not a control freak, but I have been able to make my decisions.

Jimmy, aged 89

For many of the participants, being able to practise their religion, or to remember times when they were more actively involved in church, was a central component of who they were. This echoed the findings of Williamson's (2010) research with people who have a dementia diagnosis.

We attempted to get a sense of what 'existential balance' and being at peace with oneself might mean for older people with high support needs. Some, like Jennie, expressed this as a form of contentment or acceptance; only a few spoke about dying.

I'm very thankful to be myself, I'm able to get around, I'm perfectly happy ... 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.

Jennie, aged 93, with mobility problems and some memory loss

Physical well-being

Safety and security

The most commonly reported concerns about safety involved becoming ill or falling when alone, whether within or outside the home. Experiences or fears of falling had led some people to restrict what they did.

At one time I used to walk up and down the path, but I can't, I've lost the confidence in doing that now, in case I trip. I've fallen so often ... I have been more careful, I just don't get up and about without my stick.

June, 85, who has mobility problems

For others, such as Millie or Hughie, fear of falling had been a prime reason for leaving their homes and moving into extra care provision.

One woman with severe dementia often wandered at night and was sometimes returned home by the police. This created concern for her family but she was unaware of what had happened, and indeed suggested that she could no longer walk.

None of the people we spoke to had particular concerns about their personal security and, apart from the two homeless participants who aspired to get homes of their own, all felt their current living arrangements to be secure.

Good environment

For most participants, familiarity with their surroundings helped them to feel relaxed and safe. This was particularly true for those who, like June, live in their own homes but also for long-term care home residents, especially those with dementia, like Denise.

I just feel relaxed in my own home ... It's good.

June, aged 85

I want to stay where I am; I've been there a long time now.

Denise, 85, with early-stage dementia

For people with visual impairments and mobility problems, familiarity often outweighed the risks of continuing to live in housing that was not fully accessible.

A 'good environment' is also one that is physically attractive and, ideally, allows some contact with nature. Two care home residents who could no longer get out and about were frustrated that they could not even see out of the windows in their rooms. Gordon missed the view from his previous room, where he could watch boats sailing by, since this brought back happy childhood memories for him. Thomas, aged 50, who has communication and mobility impairments and epilepsy as a result of a severe stroke, feels happy when he is in his garden mowing the lawn. Jo, with complex health needs, said "I love the garden" and is still able to take pleasure from being in it.

Many participants were struggling to decide whether they should stay put and get their properties adapted if need be, or move to a place where there would be more care. Some people suggested other alternatives, such as getting someone to move in with them, space permitting. Like many others, Gertrude had considered the prospect of moving out, but decided to put this off while she is still able to live independently.

I say when it comes I would have to accept it, if it comes I'd have to move, but at the moment I'm alright.

Gertrude, 74, who has osteoporosis and arthritis

In the meantime, and since the council put in a walk-in shower, she uses only the ground floor of her house.

Affordability was also an important factor to be weighed up in these decisions.

I have my name down for a flat, but I don't want to be poorer than I am here, and selling the house, you see, I've a lot to think about ... I don't want to go in a home.

Vera, 89, who has dual sensory impairment

Getting out and about

This study also confirmed the value which older people with high support needs place on being able to get out and about, or even just getting some fresh air or a change of scenery. For example, Millie told us:

It's lovely to go outside, and I've got the chair, that's where it's made the difference, and I can go outside now and get some fresh air, it's wonderful, and I can go down and have a game of bingo ... I'd love to go out, I'd love to go to car boot sales, anything, just, not that I want anything, I'd just be interested.

Millie, 89, who has dual sensory impairment

Some people were not able to get out and about and missed this greatly.

I'm exasperated at not being able to get out and about, not being able to get out and go on the bus into town ... quite a few years, I would say about four years at least ... I just couldn't get out ... I couldn't walk too far, I couldn't get on and off buses ... I just can't get out and about, 'cause I can't walk too far ... so I just make the best of each day as it comes ... just get on with it, that's it.

June, 85, who has mobility problems

Millie told us how she had been confined to her home for many years before she moved into extra care housing.

I didn't know anybody, and the lady living next door, she was in there three years and we never ever met, I didn't go out and she didn't go out.

Millie, 89, who has dual sensory impairment

The desire to access nature and the outdoors was mentioned by many participants. Those living on the coast valued walking along the sea front or seeing the sea. The care manager who worked with Bangladeshi people told us about one man who, following a stroke, had a strong urge to watch the birds.

For others, not being able to get outdoors, do the garden or go to the countryside was a significant loss.

I've always been an outdoor man ... no I can't get out now.

Terry, 80, who has severe Parkinson's disease

I used to like doing gardening, but I can't do that much now.

Gertrude, 74, who has osteoporosis, arthritis and some mobility problems

I wish I could do my garden, which I can't.

Winnie, 89, who has poor vision, some dementia and limited mobility

However, several people who are no longer able to experience the outdoors first-hand told us how they now liked to access the countryside – and their memories of it – through the internet or television.

When I was younger I used to go to beauty spots in Wales ... waterfalls and stuff like that, and I've been looking at the waterfalls of Wales, and ... I've found a lot of the waterfalls which I used to go to, I found that quite interesting, 'cause it's bringing back memories of what I used to do ... I can see photographs of them, but I have been to see 'em anyway, years ago.

Rob, 50, who has tetraplegia and lives in a nursing home

I select a few programmes. The ones going around the coastline I've watched most of those, even if I can't see them very well, I've been to so many of the places too, they bring back memories ...

Winnie, 89, who has poor vision, some dementia and limited mobility

Visiting familiar shops was felt by a number of people to be a 'real treat' or an aspiration. Several people told us that they would love to be able to go to Marks & Spencer again. Hughie explained that:

There's a lady at the end of this corridor ... a friend of hers takes her to Marks & Spencer's every now and again and she brings me little packets of sandwiches that she gets from there when she goes ... I'd love to go, I'd love to go round these supermarkets again.

Hughie, 90, who has dual sensory impairment

Irene values the social interactions of being out and about in town and, given her dual sensory impairment, sometimes takes considerable risks to get there, crossing roads or taking the bus.

I've always been one for going out and about, you know ... I go about four times a week ... [I like] the shopping, seeing the town, sat in the town square chatting to people and that, I like all that.

Irene, aged 89

For those who can still get out and about, the fear of no longer having transport (especially in rural areas) is strong. Jimmy, who lives in Cumbria, told us:

What I fear, what I would miss most ... is transport ... It's not a problem now, but it's the problem I foresee, getting out and about. It's the thing also, I've noticed with other people in my position, the great miss, is getting out and about. My wife missed it dreadfully, very much indeed ... she wanted to go out, she wanted to see a different view, even when she was quite ill, and we got her out when she was quite ill several times, but it was a terrific organisational thing ... she enjoyed that enormously. I think the need to see out from their own four walls, I think there is always a danger, I think, for old people to begin to feel they're imprisoned.

Jimmy, who is 89 and lives in a rural area

Some of the older people we spoke to said they value going out but wish they could do so without being dependent on family or friends.

... if I was able to get out and about more without having to depend on my daughter and granddaughter, that would be better.

June, 85, who has mobility problems

I feel a nuisance because someone's got to take me and fetch me back, and then I don't always catch what they're talking about.

Vera, 89, who has dual sensory impairment

Many of those we spoke to said they would like to be able to venture further afield, either for a day out or a holiday. Sylvie and Jennie, living in Essex, want to go to London to visit the shops and museums. Both Lena and Kathleen aspire to visit their countries of origin, respectively the Philippines and Jamaica. Terry wishes to return to Jersey where he took regular holidays with his late wife and her disabled brother or go abroad on a ship.

I would like to do some of the things I did before, like going on holidays, going on cruises, whatever ... I do miss things like that.

Sylvie, 85, who has mobility problems and some memory loss

Some of the people who voiced these aspirations to travel seemed to have resigned themselves to the fact that this was no longer possible because of their health conditions or the need for support.

I think, well, there's a lot more travelling I could do but of course I can't do any of that now, I couldn't go on my own.

Winnie, 89, who has mobility problems and poor vision

Rob, who was one of the younger people we spoke to, told us what he would need in terms of support and equipment in order to realise his dream to go on holiday.

The only thing I would say, that I could think of, would be just go away for a couple of days or something like that, like going on holiday for a week or something like that, but that's the only thing I can think of ... anywhere ... with my position, I'd have to go somewhere where they could hoist me in and out of the chair ... they'd have to have provisions for PEG feeding me and stuff like that.

Rob, 50, who has tetraplegia

Physical health

Our conversations confirmed previous research findings that older people with high support needs have high levels of both awareness and anxiety about their health. Some people we spoke to had been living with health problems or disabilities for many years and were now beginning to experience or worry about new problems developing as they got older, such as issues with continence, memory loss or mobility. The people we spoke to put a high value on aspects of their health which remained good, yet most seemed to accept that other aspects of their health would remain poor or deteriorate.

Many described declining health as an inevitable part of ageing; others were concerned that they were encountering reduced functioning of their memories, or parts of the body, at too young an age. Some people seemed very philosophical about the physical changes they were experiencing.

One is my knees and the other is the waterworks and the waterworks doesn't work very well, I have to wear nappies and that sort of thing, but it don't bother me that I have to wear them ... you've got to do, you've no choice, life goes on, irrespective of what.

Anonymised due to personal nature of quote

Many participants were coping with several, often complex, health problems. For example, Jo, who is 85, has had osteoporosis in the spine since the age of 50, which is currently painful; has problems with her teeth; suffers from gastritis; and is losing her sight due to macular degeneration. She continues, despite her own health problems, to support her husband and provide night-time care to him.

Most participants talked about the huge impact which their illnesses or disabilities have on their daily lives. Optimising health seemed to be a complex balancing act for many: the potential of surgery or medication to improve one condition needs to be weighed against the risks, side-effects and short-term impact on living and support arrangements and, for some, like Jo, the ability to continue caring for a spouse while in recovery.

They wanted to remove [my cataracts] ... I was taken aback and I needed time to think about it ... they couldn't guarantee that it would improve my sight ... I've got too many concerns here ... I don't really feel totally well enough for any more anxiety, personally.

Jo, 85, who has multiple conditions and is her husband's carer at night

Physical activities

Physical activity might help some people with high support needs to improve their physical health, and bring a number of other social and psychological benefits. Yet the amount of physical activity reported by the participants was very low and they appeared to lack opportunities. A few participants said they would like to receive more support in this area: to move around indoors; to access physiotherapy; to get outside more; or to participate in some structured exercise.

Thomas, aged 50, told us that physical activity had been an important part of his life prior to a severe stroke. He had found the physiotherapy provided at the residential unit he had stayed in immediately after the stroke very beneficial. When he returned home, this provision stopped and the only option offered was a class with people 30 years older than him, which he found depressing. He is able to mow the lawn, and this gives him pleasure, but it does not help him to rebuild his physical health in the same way.

Barriers and enablers

In this chapter, we consider a number of cross-cutting themes: information, financial resources, support, other people's time, transport and equipment, technology and communication. People described these resources as the means to other ends: to things they valued and that promoted their social, psychological or physical well-being. Where people lacked these resources – whether in quantity or quality – they acted as barriers to them achieving the things that matter to them.

Information

Participants' access to information was haphazard at best, and mostly provided by doctors, social services' staff, paid carers and family members, particularly adult children living locally. Participants tended to receive rather than seek information and the quality and consistency of the information was generally poor.

Accurate information is essential if people with high support needs are to access the care they are entitled to and the full range of housing and care provision. Lou (40), who is learning disabled, registered blind and has mobility difficulties, had missed out on a care package for 15 years because neither she nor her family had been made aware of her eligibility. Millie had not been aware of extra care housing until a social worker's visit coincided with a visit from her son.

The social services lady happen to come to see me when my son was visiting and she said, well have you thought of going into sheltered accommodation, I said no, they wouldn't let me do that, she said they would ... you're so independent, you're not safe, she said have you had a leaflet about [place] – she said If I were you, I'd go and look at it.

I didn't know anything about them, no ... I didn't know I could move into a place like this and it would just be like my own home, I thought if I moved I would be living with other people ... like my auntie was in a nursing home, she went private ... it cost her a fortune and all they did was sit in chairs in a room all day long, and I thought I hope they shoot me before I get to that stage, and that's what I thought it was, I never applied for anything like this.

Millie, 89, who has dual sensory impairment and uses a wheelchair

People with visual impairments were often dependent on others to read letters and documents to them. Irene (who has dual sensory loss) told us that her husband (who is terminally ill) had to read any information that came by post to her. She had insisted he read out one letter, which turned out to be a valuable offer of practical support. Winnie was concerned that she was falling behind with her correspondence and missing appointments since she could not see.

The majority of participants also found information hard to interpret once provided. The exceptions to this were Jimmy and James, both former professionals who had access to the internet and good financial and local knowledge.

I usually get it [information], I get loaded up when I want, I mean I went down the other day and picked up some information I wanted from the fire service. I know where to go if I have to; I know where to get it.

Jimmy, aged 89, living in rural Cumbria

Financial resources

Most of the people we spoke to seemed to be entirely dependent on state or work pensions for their income. Despite this, surprisingly few expressed general concerns about their finances, perhaps because older people may underplay these concerns to strangers. In our conversations, most people talked about money as the key to doing things which could (or did) improve their quality of life. This included: improving the home; being able to move to more supported accommodation; taking taxis; or pursuing hobbies.

For example, Gordon, who is mostly confined to his bed, longs to film again, but cannot afford to do so.

I can't afford to buy a video camera now, 'cause we're living on a very, very tight limited budget.

Gordon, 78, living in a nursing home

The few with some personal financial resources spoke about how these provided them with opportunities. For example, James explained that his financial position enabled him to remain in his own home, and Vera told us she valued the fact that she could afford to buy in some support. At the same time, older people are often very aware of the fact that their savings will not last forever. Jo realises that she and her husband could not afford for either or both of them to live in a care home for very long.

Information and finances were closely related for many participants: finding out how to purchase care or alterations to one's home was complex, and some participants suggested that local authority advisors did not always recommend the cheapest or most reliable options.

Support

Our conversations confirm the importance of appropriate and respectful support to this group of people. Where people need significant amounts of support, the quality of the care they receive and the relationships they have with carers are of particular importance in their own right: as we have seen, carers are the main source of social interaction for some of our participants.

However, timely and effective support are also a means to an end, and can enable older people with high support needs to get out and about, and to participate in social activities.

If I really wanted to go somewhere and I asked if they could sort it out, the staff, they would sort it out.

Rob, aged 50, with tetraplegia

Conversely, where support is unpredictable, inflexible, unresponsive or provided at the wrong time, it can prevent people from doing things that are important to them and may even make life more difficult. A number of participants told us about activities they would like to do, such as baking cakes, visiting friends or going to a garden centre, but were unable to do because of a lack of appropriate and timely support.

Several participants mentioned that their paid carers were overstretched and were not able to assist them with additional tasks, thereby implying that their care plans were restricted. Vera, who has dual sensory loss, prefers to manage as many tasks as possible by herself. She would like more help with activities such as cooking, but feels she cannot afford more care, which she pays for herself. June's routine was adversely affected by the timing of her morning care visit.

Sometimes she's not here till about 10.00, maybe sometimes after 10.00 ... she's got so many others to do, they need more done than what I do so I just have to accept it ... I'd rather it was a bit earlier, but there's nothing that can be done about it, so I just have to get on with it and accept it and that's it.

June, 85, who has mobility problems

Jill tells us why she would like one-to-one support on shopping outings.

I'm a one-to-one, when I go shopping I'm a one-to-one ... because I'm in an electric chair, they think there's a carer, put somebody else in a chair and me go beside them, but ... if they take the person where he or she wants to go then I miss out, if they take me where I want to go then the other person misses out, that's why I like to go shopping on my own with a carer it's not fair on the carer, it's not fair on the person.

Jill, 71, physically disabled from birth, who uses a wheelchair and lives in a nursing home

Irene explains the impact that inflexible support, negative attitudes and failure to take note of her instructions has on her and her home.

This girl came and she said I don't wash up and I don't do this and I don't do that, and I listened to her and my mind were going back to when I were a home help you know, and I thought I daren't say that when I were a home help, and she said I'm going now goodbye, and goodbye I said and I don't see the point of you coming any more ... I said, well I'm sorry I don't want you to come any more, any of you.

Irene, 85, who has dual sensory impairment

Those living in care homes, sheltered schemes or housing with care are also vulnerable to changes in policy, provision, management and organisational culture. Jo described the considerable changes in the type of support provided in her scheme over the past 13 years. These changes have clearly had a negative impact on her and her husband's social life and leisure activities.

It's changed a lot, we don't have, we have a manager here, but we don't have someone caring for the ... owners of the flats; when we first came here, about 13 years ago, a husband and wife ... used to really look after the people who owned the flats, and although you owned your flat they still did a meal ... it's totally different now ... there's just a young girl managing it ... twice a week they have somebody to cater ... it's not the same really ... there's 60 flats here ... there used to be [a communal dining room], it was very much up and running when we first came, but that seems to have gone ... it's changed tremendously, not to our advantage, unfortunately ... the minibus only caters for 20 people ... we used to go, they used to have concerts here, in the hall, and social evenings and bring and buys and that kind of thing, I went to all of those, that's very much behind me now I must admit, they don't do the same things, which I assume may be to do with the manager ... and [my husband] was on the committee at one time.

Jo, 85, who has multiple conditions including osteoporosis and macular degeneration

Other people's time

A recurring theme from many participants is the importance of carers having adequate time to spend with them, not only to give practical support, but also to listen to how they want tasks to be done. For those with severe communication difficulties, patience on the part of others while communicating with them was of paramount importance.

Good relationships and mutual exchange with carers can only be developed when there is sufficient time. People we spoke to were also conscious of how busy younger family members are and how they did not want to 'impose' on their valuable time. Yet contributions of time can be as valuable as money and we heard many examples in which other people taking the time to read out a letter, help with technology, offer a lift or tell them about a service had made a significant difference to their quality of life.

Transport and mobility

Where people had suitable mobility equipment and/or accessible transport in place, this clearly had an extremely positive impact on their quality of life. For example, Millie told us:

Tell you what's been a wonderful thing to me, has made a difference in my life, that wheelchair, it's given me a lease of life ... [had it] five months ... oh it's made a difference to my life.

Millie, 89, who has dual sensory impairment and severe osteoporosis

However, Millie had been unable to leave her home for 20 years prior to moving to extra care housing, where she was allocated a wheelchair. Hughie was given a scooter designed for indoor use only, but was frustrated that he could not use it outdoors (and he was entitled to only one scooter). The scooter was too big to fit comfortably in a standard taxi so he could not visit the friends he would have liked to visit using it. Similar problems with wheelchairs were related by Gordon who was unable to access his old home where his wife still lived.

Knowledge about local community centres and transport to get to them was haphazard; participants had tended to hear about them 'on the grapevine'.

Issues with accessibility and transport made organising outings difficult and the ensuing stress had put some people off attempting future trips. For example, participants told us that they found theatre seats too uncomfortable or had found themselves endlessly delayed waiting for taxis.

Technology and communication

A lack of appropriate technology and, for some, support in using it was preventing people with hearing impairments from communicating as well as they might. Hughie and Millie experienced problems with their hearing aids which made it nearly impossible for them to speak on the phone or to hear when in a group. For Vera, listening to the news and watching television programmes was her lifeline to the outside world but, without a loop system, she had to have the television on so loud that she disturbed the neighbours.

You see I have to have it on louder than I thought it was, 'cause I would hate to upset the neighbours ... I have to explain that I'm deaf and blind. I'm in trouble with my next door neighbours, I had the television on too loud, so hopefully [her support worker] is going to get me a loop system 'cause it's the only information I get on the news here ...

Vera, 89, who has dual sensory impairment

As discussed earlier, Gordon's reel-to-reel tapes were no longer usable. He told us he would love to continue with his recording of oral history but could not find an alternative (e.g. digital) that he could afford. Gordon's well-being and engagement would be enhanced by the provision of such equipment as part of his care plan. Assumptions about older people not wanting or being able to access technology may well contribute to the under-use of computers and similar equipment compared with younger people with high support needs. Yet there were examples of technology helping to keep people in touch with the world and with their interests. Rob, who is 50, enjoys looking at places of natural beauty online and Jimmy and James, who are both retired professionals, use the internet to access information. Others, such as Gertrude, would like to use a computer, but would need to be taught how.

Illness, pain and medical treatment

While the basic aspirations of many of those we spoke to could be met through better information, finances, support, equipment or transport, for some, illness, pain and frequent medical treatment meant that functioning on a day-to-day basis was a major challenge, and often exhausting. Some found it difficult even to identify aspirations beyond maintaining and not losing any further physical or mental function. For some participants, attending health-related appointments was their major activity during the week. For example, Lena, who has dialysis four times a week told us:

I cannot go anywhere. I'm sick; sometimes I don't do nothing, just stay in the house, lay down.

Lena, 61, with multiple health problems

5 Introducing our model

In this chapter, we introduce our model and explain how we developed it following our conversations with older people with high support needs. We reflect on the differences between our framework headings and those proposed by Bowers, *et al.* (2009) and Williamson (2010) and consider what makes ours distinctive. In the concluding chapter, we discuss the implications of our model and make some recommendations regarding its future use and refinement.

Was the evidence framework validated?

Most of the headings and sub-headings we had drawn from our literature review and included in our interim framework resonated with most of the people we spoke to. Since our approach was qualitative and involved a relatively small sample of people, the weightings our participants gave to each of these themes (as shown in Table 2 on page 21) should be viewed with caution. We did not, unlike Williamson (2010), explicitly ask people to rate the importance they place on these aspects of their well-being.

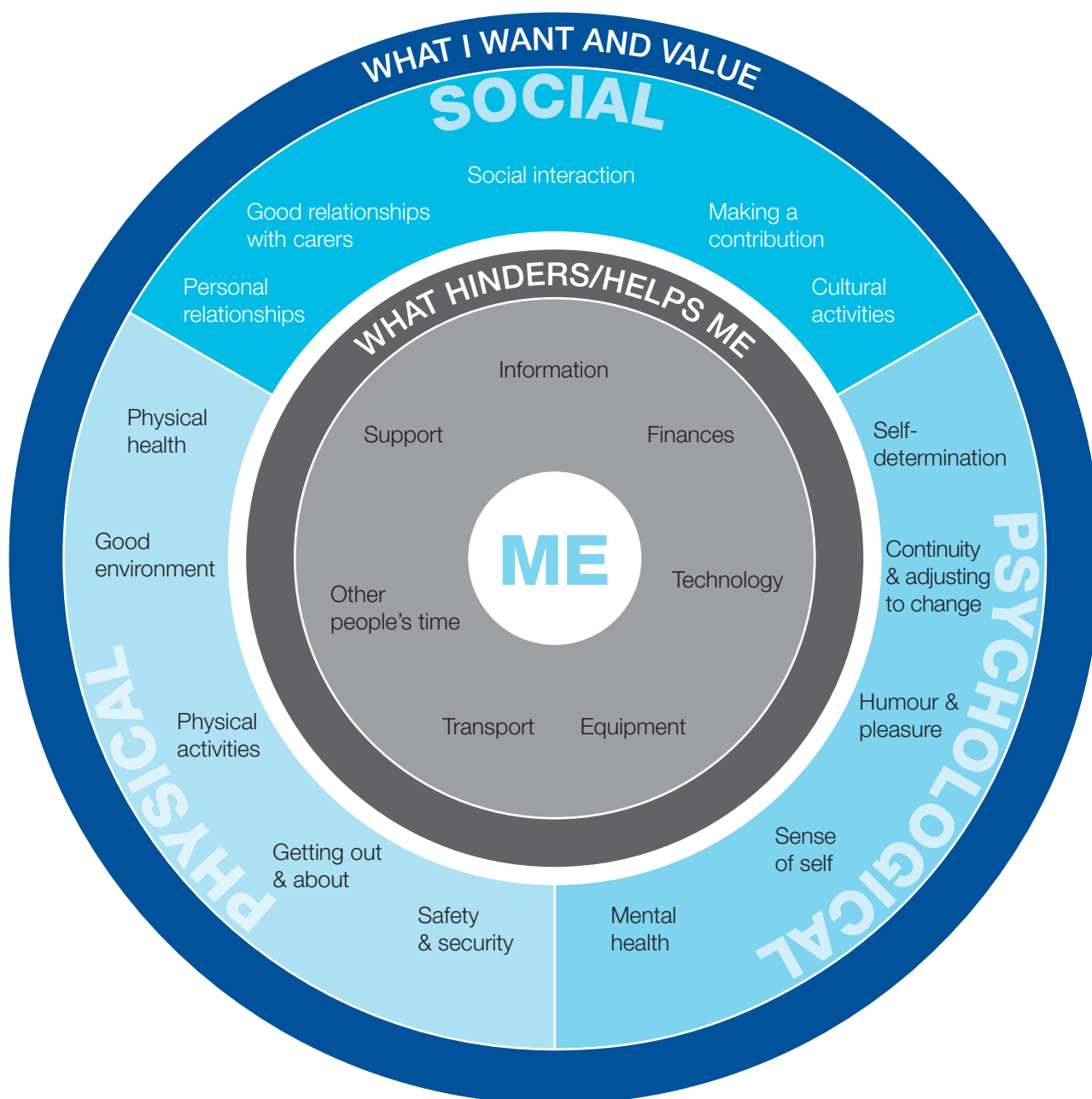
The most frequently mentioned themes in the conversations were:

- personal relationships;
- support/good relationships with carers;
- self-determination (involvement in decision-making);
- social interaction;
- good environment (home);
- getting out and about;
- information;
- financial resources.

This list broadly reflects the literature we reviewed in the first phase of our study, with no obvious omissions or unexpected additions. It includes themes from each of the three aspects of well-being – social, psychological and physical. The conversations highlighted the interconnected nature of these three and we acknowledge that this interconnectedness and complexity does not allow for easy categorisation. In particular, many of the themes categorised under ‘physical’ and ‘social’ are key determinants of psychological well-being. For example, opportunities to get out and about, mix with others, or do activities can generate self-esteem, pleasure and overall contentment.

Despite this complexity and the overlap between the categories, the final post-analysis model (see Figure 2 on page 41) retains the sense of the three aspects of well-being – social, psychological and physical. These have been placed around a circle to convey the dynamic relationship between them.

Figure 2: Post-analysis model



Introducing the new model

The new model distinguishes between the things that older people want and value (shown in the outer circle) and the factors that hinder or help them to access these things (shown in the inner circle). It focuses attention on what can be done differently to help older people with high support needs achieve and retain the things they value in life, rather than simply assuming that their individual social and/or medical conditions will inevitably place many experiences out of reach.

The older person is at the centre of this circle – a reminder that this is about people and what they want from their lives, not about what services and policies say they can have. The individual person (rather than the broader group of older people with high support needs) is at the centre, since one size will not fit all. Each individual will have different needs, values and aspirations; different assets and resources at their disposal to achieve these; and will encounter different barriers.

This person is represented as 'me', partly to give ownership of the model to the individual (rather than it forming part of an assessment being done to people) and partly as a reminder that this is – or will be – about all of us (not about 'them').

Table 3: Comparing our model with other frameworks

Bowers' Keys to a Good Life Older care home residents	Williamson's quality of life indicators People with a dementia diagnosis	Our framework Older (and some younger) people with high support needs
Personal identity & self-esteem	Relationships or someone to talk to	Personal relationships
Meaningful relationships	Environment	Good relationships with carers
Personal control & autonomy	Physical health	Social interaction
Home & personal surroundings	Sense of humour	Making a contribution
Meaningful daily & community life	Independence	Cultural activities
Personalised support & care	Ability to communicate	Self-determination
	Sense of personal identity	Continuity & adjusting to change
	Ability & opportunity to engage in activities	Humour & pleasure
	Ability to practise faith or religion	Sense of self
	Experience of stigma	Mental health
		Safety & security
		Good environment
		Physical health
		Physical activities
		Getting out and about

How does this model differ from other frameworks?

Our findings and framework have many parallels with those of Bowers *et al.* (2009) and Williamson (2010), as Table 3 (above) demonstrates.

Each of Bowers' *Keys to a Good Life* is highlighted in a different colour and the corresponding themes in Williamson's quality of life indicators and our framework are highlighted in the same colour. For example, 'meaningful daily and community life' is highlighted in pink. Williamson's 'ability and opportunity to engage in activities' and our themes of 'making a contribution', 'cultural activities' and 'getting out and about' all fit within Bowers' description of 'meaningful daily and community life' and are thus also highlighted in pink.

Most of the top ten quality of life indicators selected by people with a dementia diagnosis in Williamson's (2010) research were raised to a greater or lesser extent by our participants. Some, like 'ability to practise faith or religion' or 'ability to communicate', did not emerge as headings in their own right within our framework, but were touched on under other headings such as cultural activities, mental health, social interaction and other people's time.

Unlike Williamson's sample, none of our participants spoke of experiences of stigma in relation to mental decline. Most participants described different degrees of memory loss, but few were aware of 'diagnoses' of dementia. It may be that, since we focused on positive things that people valued or aspired to, and since stigma was not one of the themes on our evidence framework or 'facets of life wheel', participants did not think to mention it.

The six *Keys to a Good Life* identified by Bowers, *et al.* (2009) were all validated by our study, though there were some differences of emphasis and some additional themes which emerged from our conversations but did not feature in the Keys or their sub-headings (those that have not been highlighted in Table 3, above). The difference in samples is the most likely explanation for these: where Bowers

focused on older people with high support needs living in care homes, we engaged with a broader constituency of older and some younger people, many of whom live in their own homes. However, the sample sizes of both projects make it difficult to draw any firm conclusions.

'Personalised support and care' was one of the six *Keys*. This was confirmed in our research: support, good relationships with carers and adequate carer time all emerged as prominent themes. Although some of our participants valued their good relationships with carers, overall they seemed to describe support as a means to an end rather than an end in itself. We have therefore included support in our final model as a barrier/enabler, a means of accessing other valuable experiences and states of mind, rather than a valuable experience in itself.

Williamson's quality of life indicators do not mention support at all, though 'kind staff' was included in the list of indicators that people with more severe dementia living in care homes were asked to rate. Overall, Williamson found that those in care homes were more focused on the immediate, tangible aspects of their lives, whereas those living in the community expressed more of an interest in maintaining control, good physical health and independence. This lends weight to our explanation of the subtle differences between Bowers' framework and ours. For Bowers' care home residents, care and support is an integral part of the living environment. For our wider sample, it is key to people remaining in their own homes, getting out and about or remaining as independent as possible. Given that they live in care homes, it is also possible that Bowers' participants, as a group, have worse health and higher support needs than ours and Williamson's.

This may also explain why our participants, as a group, and like Williamson's, included humour, physical activities and contact with nature among the things they valued, yet these do not emerge as themes in Bowers' interviews with care home residents. Our focus was on what people want from life and we encouraged participants to focus on their broadest aspirations, not simply on services. For those living in care homes, as opposed to their peers in the community, it may be more difficult to separate out the two and, as Bowers observed, perhaps even more difficult to 'have conversations about a vision for the future' (Bowers, *et al.*, 2009, p. 38).

6 Reflections and implications

In this final chapter, we focus on what we think are the most interesting themes raised in the conversations, drawing out points that we hope can offer a fresh insight into what older people with high support needs value. We present these under the same headings of social, psychological and physical well-being that we have used throughout this report, with some additional, cross-cutting themes.

We will then reflect briefly on whether the model works for *all* older people with high support needs and whether it may be applied more widely to younger and/or non-disabled people.

We will end by drawing out the implications of the study: firstly, by identifying learning for all of us (returning to the five barriers from Chapter 1 that have prevented the voices of older people with high support needs from being heard); and secondly, by offering more specific implications for practitioners, researchers and policy-makers and commissioners.

Interesting themes

Cross-cutting themes

Our study strongly endorses the importance of individuality. All people with high support needs have their unique histories and preferences which, along with their medical conditions and current circumstances, impact on what they want and value. Our sample included a diverse mix of personalities, personal circumstances and expectations. Some people wanted to go on holiday, become volunteers or learn to use a computer; others chose to listen to the radio and look out of the window. Participants were keen to give us a sense of their individuality – to tell us about their lives, both past and present, and show us things they had made. They affirmed common human aspirations to feel good about oneself, to experience joy and pleasure, to have a sense of achievement and to feel respected.

In addition to the many positive messages which emerged, the conversations also gave us an insight into the challenges and difficulties which sometimes accompany health problems, their social reality or disabilities at this stage of life. People described social isolation, uncertainty over their changing roles and health, painful losses, fears of cognitive decline, a loss of confidence in body or mind, or feeling ‘imprisoned’ and not being able to get out and about.

Social

Not wanting to impose on people was mentioned by a number of people. One solution to this was to develop reciprocity within the context of a particular relationship with a carer or neighbour. Another way of retaining a strong sense of self, while having to depend on others in some areas of life, was to make a valued contribution elsewhere, perhaps through caring, volunteering or simply ‘mucking in’ where possible. Some were able to do this successfully in spite of significant health problems; others were not getting the opportunities and support to do so.

We expected people to place a high value on their relationships and social interactions; however we were struck by how important both the prospect and reality of meeting *new* people was for many. Social life is often assumed to close down at the later stages of life (or, at best, to focus solely on maintaining contact with those known previously). Yet our participants described new friendships they

had developed, often as a direct result of their support needs increasing, through moving into housing schemes or residential homes, through meeting care staff (and other people they were caring for) or through attending day centres.

Psychological

Self-determination is presumably important to everyone but seemed to mean very different things to different people. 'Independence' might be about managing as many tasks as possible on your own, remaining in your own home, keeping the house in order or being clean, not imposing on family and being able to pursue your own interests.

Many seemed happy to delegate key decisions. In fact we were surprised that only a few participants expressed with certainty that they wanted to make important decisions on their own. Most who had family or other trusted advocates valued their input in decision-making and some of those who did not have such people to advise and help them work through different options were finding it difficult to make big decisions.

This may be the result of reduced expectations and confidence or lack of information but it reminds us that we should not assume the type of 'choice and control' a person will want. For example, offering budgetary control to older people with high support needs will, as the Individual Budgets evaluation (Glendinning, *et al.*, 2008) suggests, miss the mark for many. However, we should not assume from this that all older people are happy to fit in with what others decide for them. To make choice and control a reality for individuals, we need to help *them* to identify the areas of their lives in which they want control (and in what form) and the matters that they are happy to delegate to others.

There are variations in responses to change within all age groups and older people should not be assumed to be resistant to change purely on the grounds of age. People's circumstances need to be considered in each case. Our conversations contained many examples of participants adapting to a wide range of changing circumstances, including moves to housing with care or to care homes, loss of sight or hearing and changes in support arrangements. The responses to these experiences were mixed: some felt the loss keenly; others were philosophical about it; some had found new opportunities as a result. While continuity was valued, many of our participants demonstrated considerable adaptability, although some said they wanted more support to help them adjust to change. For those providing support during periods of change, the challenge is to provide it without removing options for protest where people feel that changes have been forced upon them.

Physical

Even given the nature of our sample, the number and severity of the health problems experienced by many of our participants was high, and some continued to care for a partner as well. In the context of such complexity, and often with limited information, deciding how best to promote physical and mental health can be a difficult balancing act. Many described decisions they faced regarding treatment and surgery, and the impact that going ahead (or not going ahead) might have on other conditions, accommodation, partners, support needs, quality of life and mental health.

Most people we spoke to were keen to keep their minds and bodies as active as possible, though few had any opportunity for physical activity. Contact with nature was also a recurring theme and one that had not emerged in Bowers' or Williamson's frameworks. Some participants told us of simple but creative ways in which they managed to maintain some contact with nature, such as accessing the internet or television programmes about gardening, nature or travel. Supporters can make a big difference by helping older people with high support needs to find ways of introducing some physical activity and/or contact with nature into their daily lives.

Compromise, rather than positive choice, seemed to be the reality for many when it came to their accommodation. For example, people described losing a great view in order to have a room with more

space, or leaving familiar surroundings in order to access an appropriate level of care. We hope that our model can give older people with high support needs a structure for identifying and expressing their wants and aspirations as they make such decisions in this and other areas of their lives, and a framework to help the rest of us understand these trade-offs.

Barriers and enablers

Other people's time, particularly but not exclusively that of paid carers, emerged as a key enabler for older people with high support needs. This is partly about the amount of time but also about the quality of time spent and the attitudes, skills and knowledge of those providing support. Carers need time to get to know the person and understand their life story if they are to develop good relationships and work respectfully; they also need time to understand how they should approach specific tasks if they are to help rather than hinder.

We heard plenty of examples of the other barriers which prevent older people with high support needs from doing the things they value. Overall, the provision of information seemed to be haphazard and lack of money was a recurring theme. We heard evidence of the negative impact which restrictive care plans, over-stretched carers, inflexible support and poor staff attitudes have on quality of life.

A significant number of our participants were missing out on – or had waited years to receive – suitable equipment (such as wheelchairs or hearing aids) or access to basic technology (such as the internet or a loop system) that could make a huge difference to their quality of life. Additionally, many people spoke about the length of time they waited for a domiciliary visit from an optician or the replacement of outdated equipment.

Will the model apply to diverse older people with high support needs?

What people want and value from their lives is shaped by their individual histories, culture and other social constructs such as gender. While we have included men and women and some older people from black and minority ethnic (BME) backgrounds in our survey, the size of the sample did not allow us to compare their responses in a systematic way.

Although the categories we have identified might seem to have universal relevance, we are conscious that access to participants demands time and that diversity could be extended through a much larger sample. The themes that we have established may therefore not be comprehensive.

The way in which the categories are interpreted, prioritised and applied will differ from person to person, and there may also be patterns depending on ethnic or other equality groups. 'Safety and security' may be more about the absence of harassment or hate crime if you are a member of a visible minority group. If you are lesbian, gay or bisexual, the key issue under 'personal relationships' might be that carers recognise the status of your partner.

Language may act as an additional barrier for some black and minority ethnic people and it may be that some marginalised groups might want to add 'discrimination' or 'prejudice' to the list of barriers.

Five papers which reflect the diverse viewpoints of minority groups of older people with high support needs are due to be published as part of the *Better Life* programme in January 2012. We will be interested to see whether the themes in these match those of our model and would welcome more detailed feedback from these groups.

Is the model particular to older people with high support needs?

It has been beyond the scope of this study to determine whether this framework is particular only to older people with high support needs. Many of the categories that have emerged from this process seem to

reflect things that all of us want and value (and barriers that any of us may encounter, such as information, finance or transport).

The model may well apply to all those who use services and/or have a disability, though our focus on older people may explain why employment, vocational training and formal education are absent. We would welcome feedback from other groups of people who use services and those working with them.

There were some differences between younger and older participants in our study. In general, younger participants were more aware that they had rights as citizens, while the very oldest were more likely to express acceptance of their circumstances and gratitude for the care they received. This may reflect the observation (Bowling, 2009; Blood, 2010) that the younger cohort of older people with high support needs grew up within a very different social and economic climate from that of their parents' generation.

What can we learn from this study?

In Chapter 1 we identified five key factors which have prevented the voices of older people with high support needs from being heard. Here, we reflect on the implications of this study and its findings for each of these points.

Communication, reliability and ethics

This study, like that conducted by Williamson (2010), has confirmed the feasibility and importance of seeking the views of people with a dementia diagnosis, although we suggest that the success of a conversation will depend considerably on whether the person has mild or severe dementia, and how they are feeling on that day (Holland, *et al.*, ongoing 2011). Our conversations demonstrate again that many older people with cognitive impairments can reliably articulate what they want and value, even if they are confused about the more factual details of their lives.

While subscribing to the spirit of the social model of disability, especially with respect to removing barriers to inclusion, we do not discount the lived experience of real embodied impairments that older people with high support needs have.

Assumptions about older people

The model challenges negative assumptions about this group by reminding us about the *range* of things which older people with high support needs want and value – culture, physical activities, humour, getting out and about, contact with nature and so on.

Assumptions that older people will be too tired, 'private' or uninterested may have stopped some researchers from asking them directly about their experiences (Bowers, *et al.*, 2009). However, our experience was similar to that of Bowers: we found that the people we spoke to were pleased to be consulted. Some did have difficulty in communicating or were challenged by their circumstances to be able to identify aspirations for the future, but all were able to tell us about things they valued now or would like to be different in the near future.

Equality and diversity

Rather than pigeon-holing what people want and value, using one aspect of their social identity, our model encourages a holistic, person-led approach to understanding an older person's individuality. At the same time, the model recognises social barriers and can help us understand institutional discrimination linked to information, financial resources and support.

Collective voice

Although our discussions focused on asking older people about their *personal* experiences and aspirations, several participants also reflected on the needs and circumstances of older people with high support needs in general. Most participants were keen for their views to be used and hoped their involvement in the research might help others in similar situations. There were some who, while keen to share their views on this occasion, wanted to maintain their privacy and did not want to engage in group action or discussion. However, despite the fact that we had deliberately looked for participants who were not already linked into organisations and had not previously been consulted, we found several people who might be both interested and able to participate in some form of collective action (though we did not ask them directly about this).

This suggests that there is scope for developing a stronger collective voice for older people with high support needs. A minority of those we spoke to were also able (or wanted to be able) to access the internet. This might be one way of bringing some older people with high support needs together for campaigns, consultation, participation and information sharing, a point made elsewhere in the *Better Life* programme by Manthorp (2010).

What are the specific implications of the study for ...

... older people with high support needs and those working with or supporting them?

While we would not want the model to become a tick-box assessment tool, we believe that there is scope for it to be used as a prompt to identify and explore what individual older people with high support needs want and value from their lives (not just what other people think they need from services).

As such, it might be used by older people, their relatives, friends, volunteers and advocates, health and social care staff (including care managers, social workers, care home staff, and home care workers) and housing and housing scheme managers. It could also act as a useful tool in the training and education of these professionals.

In practice, the model could, for example, be used to:

- prompt a joint problem-solving approach which might end in care staff agreeing (and understanding the importance of, then remembering) to turn on the radio, bring a newspaper, open blinds or assist someone to go and sit in the garden;
- support people (especially individual budget holders or self-funders) to prioritise and make decisions about their lives;
- ensure that relevant professionals are notified about needs and changes to enable those who need particular services, adaptations or devices to receive timely attention.

... policy-makers and commissioners?

The model provides a starting point for an approach to commissioning which is based on *outcomes* for older people rather than on the *inputs* of services. Many of the aspirations highlighted by the framework are very modest and the benefits should easily outweigh the costs.

We also believe that the model can act as a tool for understanding the trade-offs people are (or are not) willing to make, which could be particularly useful for those involved in rolling out individual budgets to this group.

... researchers?

Researchers have to abide by professional codes of ethics. The model underlines the ethical imperative to make it possible for older people with high support needs to explain what they do and do not want and value.

Our experience of researching with diverse groups of older people shows that they often include people with high support needs. Successful research requires skilful listening, reflection and enabling people to find a voice.

A diagnosis of dementia or other conditions that might impede communication does not necessarily influence whether or not people would like to participate in research; however it may affect the choice of methods.

We hope that the model will prove useful as a framework for exploring quality of life issues for older people with high support needs, specifically in relation to some of the main projects in the ongoing *Better Life* programme:

- **‘Affordability, choices and quality of life in housing with care’** explores how finances enable or prevent access to housing with care and to care and support while living in such schemes. Here, the framework can provide a model for understanding the trade-offs which self-funders and individual budget holders make, e.g. deciding not to buy an additional hour of care so they can afford to take a taxi to get out and about, or hire a cleaner to ensure a good environment.
- **‘Whose responsibility?’** looks at how different agencies and professionals work together in housing with care and how this impacts on the lives of older people with high support needs. The framework will help us both to map professional roles and responsibilities against older people’s priorities and to organise our understanding of the impact which contexts and grey areas can have on older people with high support needs.
- **‘Not a one way street’** focuses on making a contribution, but the framework can also remind us of the other aspects of an older person’s well-being that might benefit from them developing relationships of mutual support and reciprocity.
- In **‘Living together, getting along’**, the framework can again help us to conceptualise the quality of life of older people with high support needs living in housing with care, and to identify the barriers and enablers to their social interaction and participation in activities and to their ability to make a contribution.
- The framework also offers us a baseline against which the conclusions and recommendations of the whole programme, as they come together in the final phase, can be checked and validated.

This study has tried to move forward our understanding of what older people with high support needs want and value by proposing a model based on the literature and our conversations with diverse members of this group. We would encourage comments about our model and further testing and refinement of it by gathering feedback from older people with high support needs and other groups of people who use services. This might be at future events and through networks, consultative groups and frontline projects.

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Appendix I

Further details about our methodology and profile of the sample

Age of participants

Age band	No. of participants
40–49 years	1
50–59 years	2
60–69 years	3
70–79 years	5
80–84 years	3
85–93 years	11
Not given	1
Total	26

Geographical location of participants

Country	County (England only)	No. of participants
England	London	6
	Yorkshire	4
	Cumbria	2
	Oxfordshire	2
	Essex	4
	Buckinghamshire	2
	Surrey	1
Wales		4
Scotland		1
Total		26

Accommodation

Accommodation type	No. of participants
Care/nursing home	5
Extra care housing	2
Sheltered housing	2
Homeless hostel	2
Own home in community	15
Total	26

Living arrangements

Living arrangements	No. of participants
Live alone	20
Live with spouse/partner	4
Live with family	2
Total	26

Health, disability and care needs

Most participants had mobility and/or sensory (deaf /visual) impairments.

Nine participants had been diagnosed with dementia and others complained of memory loss.

Most participants had at least one additional serious health condition. These included muscular dystrophy, diabetes, heart disease, cancer, osteoporosis, incontinence.

Two people had learning difficulties, one of whom was also blind.

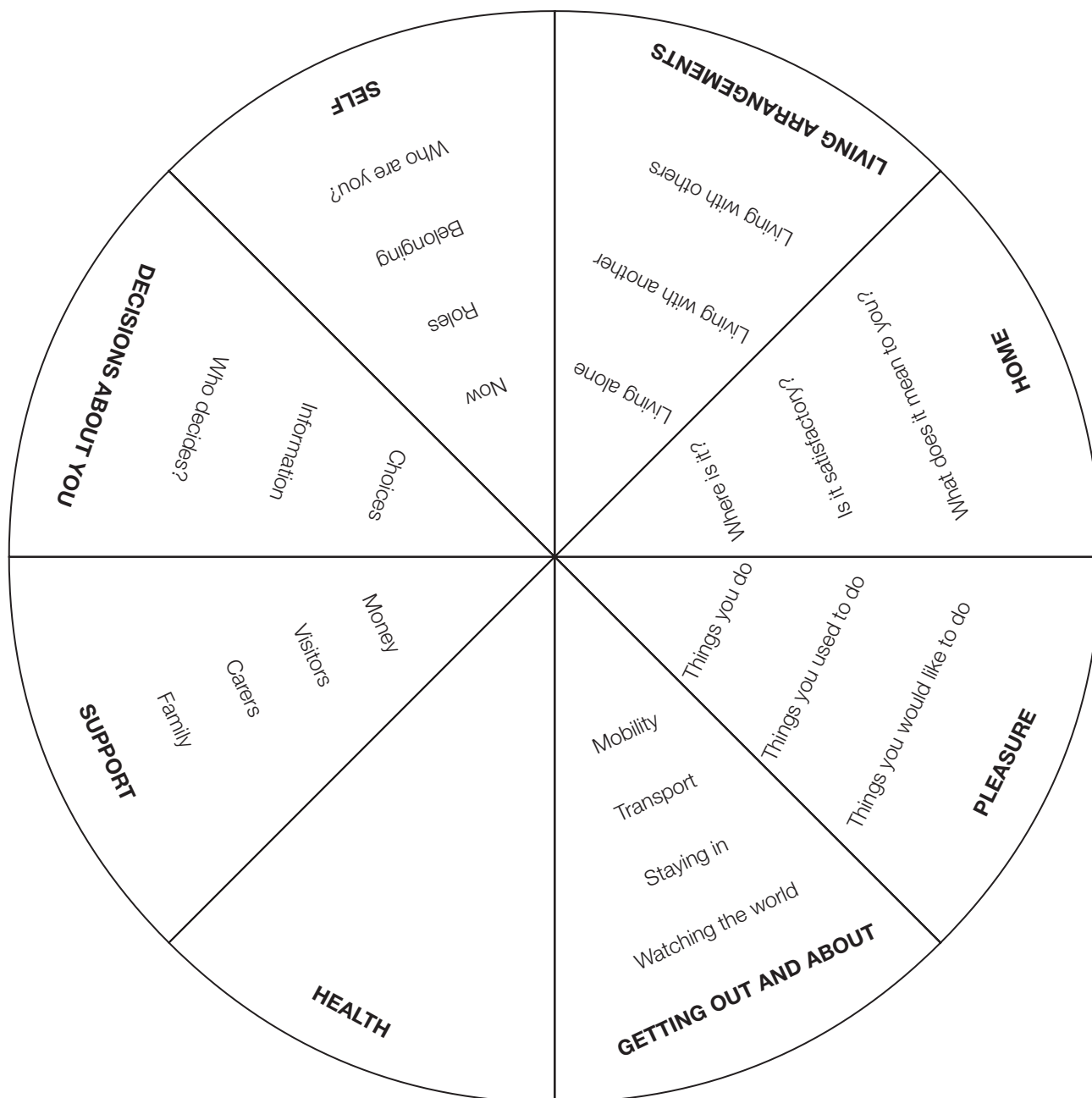
One younger person attended dialysis four times a week.

Two people had been born with severe physical disabilities.

Twenty-one participants were receiving formal care and many also received care from relatives or friends.

Appendix II

The facets of life wheel (adapted version)



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The authors are all members of the Faculty of Health and Social Care at The Open University.

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