

Older people's vision for long-term care

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A research project exploring the voice, choice and control of older people with high support needs commissioned by the Joseph Rowntree Foundation's Independent Living Committee.

Older people with high support needs constitute a large and growing sector of our population. Recent developments in independent living, which enable people who need support to have choice and control in their lives, have been slow to respond to the varied needs and aspirations of older people. This report:

- presents the results of a scoping study exploring the current role of long-term care and sets out the policy context;
- summarises key messages from older people with high support needs and presents their vision for a good life;
- highlights the need for radical change in long-term care policy and services to achieve this vision;
- recommends a multifaceted change programme to enable this vision to be achieved for individuals and their families; for local populations; and at a national policy and societal level.

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Executive summary

Older people with significant support needs constitute a large and growing sector of our population. Recent developments in independent living have been slow to respond to the needs and aspirations of older people, whose voices are rarely heard. There is a strong case for fundamental change in long-term care, based on older people's vision for a good life.

This report presents important messages from a research project exploring older people's experiences of living with high support needs, commissioned by the Joseph Rowntree Foundation and undertaken by the Older People's Programme and the Centre for Policy on Ageing. The research involved a scoping study; a series of discussions with older people, their families and professionals; synthesis of key messages with a diverse advisory group; local feedback; and a national 'sounding board' event to identify the key messages to be shared.

The lack of a voice for older people with high support needs

In terms of long-term care policy, and in service delivery, the voices of older people with high support needs are so quiet as to be practically silent, or indistinguishable from the other people who speak on their behalf (professionals, relatives, commissioners, policy-makers and politicians). There are numerous explanations for this situation (some shared in this summary), but the central message remains: if you have no voice, you cannot exercise choice and control over your support or your life.

Many older people in residential or nursing care, and in other supported accommodation, are living in situations that are difficult to talk about:

some have experienced a frightening, difficult and often very rapid move into care; there is a great imbalance of power between people living in care and those providing care; many people involved in this project had very low expectations of their lives, their surroundings and themselves; others speaking about them had equally low expectations about the support provided, the possibility of this changing, and of older people's potential to have a good life if their need for support was very high. This combination of low self-esteem and low expectations affects everyone involved. In particular it affects older people's assessment of whether they are happy, and their ability to speak out if they are not.

Care homes are not easy places to express personal feelings, even where arrangements have been made for residents to do so. Older people living in supported environments need a much greater variety of ways to both contribute and express themselves. Above all, they need encouragement and support to do so, and a right to self-expression as a clear indicator that they are valued and equal citizens.

While recent strategies and policies seek to address this issue, much more needs to be done to increase the strength and influence of older people's voices when they need a lot of support; and to increase their choice and control over that support.

Learning from the reasons why older people move into care

A range of events and circumstances can lead older people into care. These include bereavement, concerns about health, poor or unsuitable housing, inadequate care arrangements at home, and other people's concerns.

Things can happen very quickly when options for support are being discussed, and points of no return (homes being sold, for example) are reached from which there is no way back. A move into care is often precipitated by a breakdown in support arrangements at home, compounded by a real as well as perceived lack of alternatives. Without information and impartial advice, people quickly become convinced that the 'last resort' (moving into care) has been reached.

This reveals two things. First, many of the people interviewed did not want to be living where they are living, and this feeling can increase following a move (for example, as a result of the power imbalance referred to earlier). Not being in control of small daily events and bigger decisions about where you live is bewildering and increases feelings of vulnerability. Second, many people (not just older people) are not aware of or encouraged to find out about different options for support. This is especially hard for people who are very disabled, very ill, dying, or caring for someone who is dying.

For some of the older people interviewed, the move into care had been a positive one. Some were making the best of new living arrangements, enjoying company and reduced anxieties. These stories were, however, in the minority.

It is usually other people (families, GPs, social workers) who are in control of older people's decisions, arrangements and financial transactions at this critical period. This situation does not change once people have moved into a care home.

The research concludes that if any of the precipitating factors outlined here had occurred at a younger age, the push into care would not happen. Outside the world of services for older people, alternative and creative support has moved on immensely. Yet person-centred approaches and support that promote choice and control remain hard to find for older people with high support needs.

The dominance of money and the market in long-term care

Debates about long-term care are dominated by money concerns and industry matters. This can be at an individual level, at a population or local authority level, and at a national level. There are two distinct debates going on: one concerned with global trends in ageing, and the other with the individual support needs and decisions of older people. The second tends to be cut short by the first, hence long-term care policy and practice is dominated by 'money matters' which are complex and confusing.

Older people and their families are confused about the options available to them, how they can fund care themselves, entitlements for state support and how various benefits fit together. This area is also confusing for professionals. There is a widespread lack of knowledge about what is covered in care fees, how to establish if someone is paying a fair price, and how to respond to individuals' preferences through creative ways of planning and organising budgets.

Developments taking place at a policy and practice level to increase financial control (for example, in the form of individual/personal budgets and support systems that enable people to use these) still tend to exclude older people who live in care homes and other supported accommodation. This may change, and is under review, but much more work is required to increase take-up and to design systems of support that make sense to older people with high support needs.

The idea that control over one's money equates to control over one's life needs further exploration. There was a feeling among study participants that people with money had more control over their care. In this context, they were talking about 'self-funders', but the same principle should apply to individual budgets. Most older people, however, did not feel this described their situation; as indicated earlier, it is usually other people (family members, care staff) who are in charge of major decisions and personal finances.

Discussions about money and the care market led to the conclusion that older people with high support needs are seen and treated as commodities, not as consumers with rights, entitlements and purchasing power.

Older people's vision of a good life

The starting point for addressing the lack of voice, choice and control is to develop a strong, shared vision of a good life for older people with high support needs. This is not a vision about care services or systems. It is more closely aligned with a rights-based approach based on what older people said was important to them, and shaped by subsequent discussions with the Research Advisory Group and national sounding board.

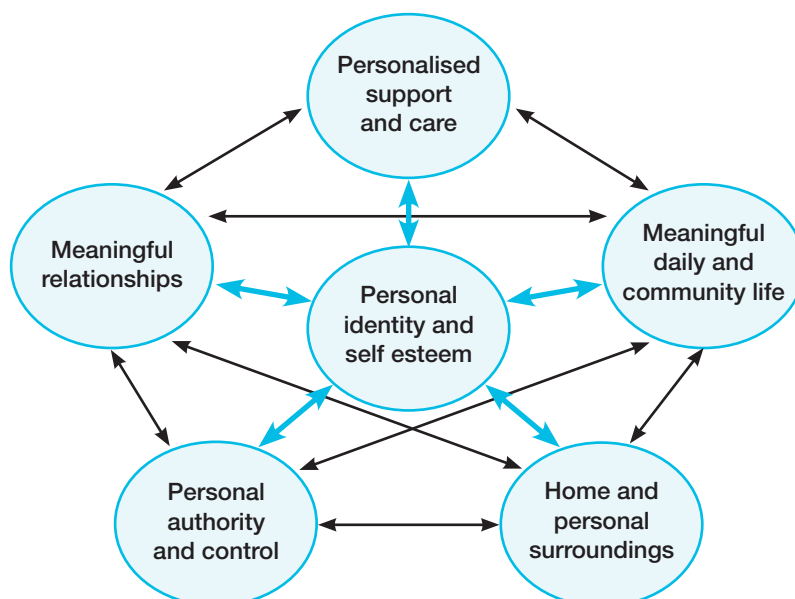
The notion of a shared vision, and conversations about the possibility of a different future for older people with high support needs, is a difficult concept for many people to comprehend. On an individual level, it can be extremely difficult to discuss the future when talking with and about older people with high support needs. Few of us want to think about our own future needs for support, despite the benefits of planning ahead. It can be difficult for older people to imagine how things could be different and distressing for those experiencing fluctuations in their physical, mental or emotional health. Nevertheless, many people involved in this research were desperate for the opportunity to have these conversations.

Locally, these conversations can be difficult because of the narrow view of options and possibilities that commissioners and providers consider for this population. Many organisations are still commissioning very traditional models of support for older people; intensive home care and care home placements are still the default position. This feels like a deeply embedded set of beliefs and models, from which it will be difficult to widen choice, increase control and strengthen voice.

Nationally, conversations about a vision for a good life can be difficult because there is currently no visible discussion going on around rights, equality and opportunities for this population of older people (though this may start to change with developments to extend the coverage of the Human Rights Act to include older people living in care homes). The focus is largely on professionals, providers and policies rather than on people, possibilities and hopes for a different future.

The majority of stakeholders believed that ageism and stigma associated with extreme old age, frailty and intensive support are rife. Older people with high support needs are not consistently well served by public services and existing statutes or by families, friends and professionals who know them well. At the same

Figure 1: Keys to a good life for older people with high support needs



time, many people are battling cultural and structural barriers to achieve a good life for an older person close to them.

Despite these challenges, older people with high support needs and those supporting them gave a great deal of feedback on what contributes to a 'good life' when someone needs a lot of support. Figure 1 summarises the six key elements emerging from these discussions. Personal identity and self-esteem were referred to frequently and are placed at the heart of this framework. Without this element, all others will fail to deliver choice and control for older people.

Developing an agenda for change

As well as a strong vision, there is a need for a multifaceted approach to sharing, testing and embedding this vision to ensure it becomes a reality, not yet more rhetoric that disengages, alienates or excludes the very people it seeks to benefit. Huge cultural change is required alongside structural changes in how support is funded and delivered.

This change is required at three levels: for individuals who need support and their families; locally for organisations and teams providing that support; and nationally for public policies and public services, social care systems and the care market.

All those involved in this study emphasised the need for all sectors, interest groups, Government and society as a whole to work collaboratively to ensure that older people's own vision for their future is widely owned and used to drive change. This includes a shift in long-term care arrangements away from the current default model of residential care towards a flexible range of different options and opportunities, based on the Keys to a Good Life framework.

The changes required are fundamental. They will not be realised if this is treated as an incremental or quality improvement model of change. This is not just about dignity and respect, already current cornerstones of government policy and best practice guidance. This is about a completely different, rights-based approach, beginning with an increased focus on citizenship, personal identity and self-expression.

1 Introduction

Background

The proportion of people over 65 in the UK has grown from 13 per cent in 1971 to 16 per cent in 2006, and is expected to reach 22 per cent in 2031 (ONS *et al.*, 2006). The largest percentage growth in the population in 2006 was among people aged 85 and over, the age group most likely to be in receipt of care services based on current information and trends.

Older people with high support needs therefore represent a significant sector of the population, yet they have largely been left out of innovative service and practice developments. Residential care is still regarded as the only feasible option for many older people who need support, especially those aged over 85 and those with high support needs.

A number of recent policies and initiatives, national reports, bills and White Papers emphasise the importance of older people retaining (or regaining) choice and control over all aspects of their life. Within health and social care, the emphasis is on promoting dignity and choice, for example through the ongoing work in developing individual budgets and direct payments.

Take-up of direct payments and individual budgets is, however, still lowest among older age groups. Person-centred planning has been shown to be an effective approach for older people but is only happening in a few forward-thinking localities.

The Government recognises the opportunities, challenges and trends associated with an ageing population, but much of the current debate is concerned with problems in social care spending and capacity. It does not explore the varied characteristics, contributions and aspirations of our ageing population, why and how individuals age differently and their need for different kinds of support. While a great deal of work is taking place, there is a clear need for a more joined-up policy approach in this area.

Against this background, the JRF's Independent Living Committee commissioned the Older People's Programme (OPP¹) and the Centre for Policy on Ageing (CPA) to explore older people's experiences of living with high support needs. This work focused on those moving to and living in care homes now, and those using other kinds of supported accommodation or living arrangements (e.g. extra care and adult placement schemes).

Aims and objectives

The aims of the project were to:

- explore the current and potential role of long-term care within the spectrum of future services and support for older people, focusing on aspects that promote independent living;
- learn from the experiences and aspirations of older people who currently live in care homes or other very supported accommodation;
- pay attention to older people's experiences of having a voice, making choices and being in control of their lives.

As the work developed, it focused increasingly on older people's experiences and aspirations and how these could influence the role of long-term care in the future. This supports the core aim of the JRF's Independent Living Committee 'to identify approaches to choice and control which have credibility with users and viability in practice'.

The research

A phased approach to the research involved:

- a scoping study including a literature review and Call for Information;

¹OPP is now part of the National Development Team for Inclusion

- initial fieldwork in four study sites involving commissioners, providers, older people's organisations, residents, tenants, families and, where possible, care home staff;
- fieldwork visits with older people with high support needs;
- analysis and synthesis of key messages;
- local feedback and discussion events;
- a national 'sounding board' event with policy-makers, older people's organisations, commentators and the JRF's Research Advisory Group;
- pulling it all together, reporting and dissemination.

The study design involved as many older people as possible in a variety of roles and locations. Older people were involved as researchers and carried out fieldwork in four diverse locations in England and Scotland. The wider scoping study involved a literature review and Call for Information from individuals and organisations with experience of living with high support needs.

Exploring a vision for the future posed some difficulties. On an individual level, it can be extremely difficult to discuss the future when talking with and about older people with high support needs. Few of us want to think about our own future needs for support, despite the benefits of planning ahead. It can be difficult for older people to imagine how things could be different and distressing for those experiencing fluctuating physical, mental or emotional health. Nevertheless, many were desperate for the opportunity to have these conversations.

Locally, these conversations can be difficult because of the narrow view of options and possibilities that commissioners and providers consider. Many organisations are still commissioning very traditional models of support for older people; intensive home care and care home placements are still the default position. This feels like a deeply embedded set of beliefs and models, from which it will be difficult to widen choice, increase control and strengthen voice.

Nationally, conversations about a vision for a good life can be difficult because there is currently no visible discussion going on around rights, equality and opportunities for this population of older people (though this may start to change with the recent announcement from the Department of Health about extending the coverage of the Human Rights Act to include older people in care homes). The focus is on professionals, providers and policies rather than on people, possibilities and hopes for a different future.

Commitments to change and future work

At the end of the national sounding board event, participants shared personal commitments to take this work forward. There was a clear and widespread appreciation of the need for change to achieve older people's vision of the future. The impressive range of commitments related to three levels of change required: at a personal or individual professional level; at a local policy and service delivery level; and at a national or organisational level.

There is still a need to engage fully with the care home industry itself. This key perspective proved difficult to achieve at every phase of work. Limitations of time and resources also prevented researchers from sharing the key messages and overarching findings with study participants at the end of the project. Developing an ongoing dialogue with older people who need a lot of support and talking to those living in a wider range of situations will be essential to future work in this area. This could begin with a return visit to the four sites involved in this study to explore how to ensure this vision can become their reality.

2 Introducing the project and what we did

Purpose/focus, aims and design of the project

The stated purpose and aims of this project were to:

- explore the current and potential role and contribution of long-term care within the whole spectrum of future services and support for older people, focusing on those aspects that promote independent living (choice and control);
- learn from the experiences and aspirations of older people who currently live in care homes or other very supported accommodation about what they want their future to be;
- pay attention to older people's experiences of having a voice, making choices and being in control of their lives.

Our focus in this work was on older people's experiences of the choice and control that they have over their lives and the support they need to live their lives when experiencing high support needs. As the work developed we increasingly focused on the voices and experiences of people with high support needs rather than concentrating on the type of accommodation in which people live. In this way, the second and third points outlined above became the specific focus of our work, following which we felt we could then turn to the question of the first point – in other words, older people's own experiences and aspirations should influence our assessment of the current role of long-term care; and certainly shape the potential role and contribution of such support in the future. This focus was also felt to best support the core aim of JRF's Independent Living Committee

– namely 'to identify approaches to choice and control which have credibility with users and viability in practice'.

We adopted a phased approach to the work which is outlined in more detail in the following section. The design reflected a key aim of directly involving as many older people as possible in a variety of different roles and locations. As such we involved older people as researchers and carried out the fieldwork in four diverse locations within England and Scotland, engaging partners within these locations who could help us to identify and engage older people with high support needs within these areas. In addition to the fieldwork, a wider reach was established through the scoping study which involved an extensive literature review and a Call for Information from a wide range of individuals and organisations with direct experience of either living with high support needs as an older person or working with people in this situation.

The framework used for analysis within this project was based on 'realistic evaluation' (Pawson and Tilley, 1997) which seeks to answer the question 'What works, for whom, in which circumstances and why?' We used a combination of clear and consistent research questions in the fieldwork; search terms and parameters in the scoping study; and common interview/group discussion schedules and coding frameworks to ensure that our analysis of the findings and implications was rigorous and transparent.

Key phases of work

The work was carried out in seven phases over 12 months – the box shows the key activities that took place in each phase.

Phase 1: Scoping study (spring 2007–winter 2007/08)

- An extensive review of the literature on voice, choice and control relating to older people with high support needs and care home life
- A Call for Information asking for examples of good practice and other developments promoting voice, choice and control

Phase 2: Starting fieldwork in four areas (July–September 2007)

- Identifying and confirming inclusion of the four study sites (Inverness, Leeds, West Norfolk, Royal Borough of Kingston); getting to know local examples of good practice
- Holding first discussions with local stakeholders (commissioners, providers, older people's organisations/forums, residents, tenants, families, and where possible care home staff) through workshops within each area

Phase 3: Fieldwork visits with older people with high support needs (October–November 2007)

- Holding discussions with older people living in residential care and nursing homes, extra care housing and adult placement schemes in the four areas about their experiences of and aspirations for voice, choice and control over their support

Phase 4: Analysis and synthesis of key messages (November 2007)

- Identifying common messages, themes and important lessons to date (what helps; what gets in the way; the critical issues from older people's perspectives)

- Production of the draft paper 'Keys to a Good Life'

Phase 5: Local feedback and discussion events (November 2007–January 2008)

- Half-day events held in each area to share the above messages, and work together on a vision for how older people with high support needs want to live their lives
- Further analysis and refining of the Keys to a Good Life for older people with high support needs
- Finalising common messages and areas for attention to help make this happen

Phase 6: A national 'sounding board' (20 February 2008)

- A national one-day event with policy-makers, older people's organisations, researchers, commentators and JRF's Research Advisory Group to share the work so far; work together on the vision for a good life; and develop images with a resident artist on the day to share this vision clearly and widely

Phase 7: Pulling it all together, reporting and dissemination (Spring 2008)

- Finalising key actions and priorities for attention
- Producing a full report and summary 'Findings' for publication
- Finalising a series of dissemination activities, events and materials needed to increase the voice, choice and control of older people over the support they need to lead their lives

The project team

An experienced team from OPP and CPA carried out the work, including desk-based researchers from CPA who undertook the scoping study; and a fieldwork team drawn from OPP's network of associate researchers/consultants, all of whom have a background and expertise in researching and undertaking development work around issues directly affecting older people and later life. All project team members also had extensive experience of direct engagement work with older people in a variety of situations.

A nominated project manager co-ordinated fieldwork activities and plans across all four locations; a scoping study lead ensured that detailed search activities linked with the fieldwork during all phases of the project.

The fieldwork team was a role model in co-production with older people. Each of the four locations was supported by a pair of researchers/consultants consisting of one experienced OPP consultant and one older person with a background and expertise in engagement, research, long-term care and independent living. This approach not only ensured local credibility in the field and a robustness in our analysis – keeping us grounded in daily realities of what it means to need intensive support in your life – but has also influenced the way in which OPP now works in its commissioned research and development work.

The advisory group and links with the JRF Independent Living Committee

A Research Advisory Group was established by JRF to provide expert guidance and advice to this project. Representatives from a variety of different organisations and groups with a key interest and involvement in the area of long-term care for older people were invited to join the Research Advisory Group (these organisations included older people's councils and groups, government departments, voluntary sector and research and development bodies). A group of 12, from a diverse range of organisations and backgrounds, joined representatives from JRF and the project team to form the Research Advisory

Group. Several members of this group also belong to JRF's Independent Living Committee. Three distinct Research Advisory Group meetings were held throughout the project to review and help to guide progress at different stages and to ensure that the project's focus continued to support the core aim of the Foundation's Independent Living Programme. Members of the advisory group also had extensive involvement in facilitating and contributing to the sounding board event and in shaping the final report and papers from the project.

Sounding people out and shaping the vision

A one-day 'sounding board' event was held towards the end of the project (Phase 6 of the work) to share our findings and central messages; to sound people out on the emerging vision; and to work with national stakeholders to shape this vision and identify priorities for action to make the vision real. We designed a programme that allocated time for sharing and exploring the six central messages and the emerging vision; but discussions around actions and priorities for change were deliberately focused on the overarching message about the absent voices of older people with high support needs.

The programme (see Figure 2) included a number of readings from members of the Old Spice drama group. Poems, written by members of the group, which have a particular resonance within the area of long-term care for older people were read at different points in the day. This was found to be a particularly impactful part of the event by many people attending the sounding board.


We invited a mix of participants from government departments; national and regulatory bodies involved in implementing policy and ensuring best practice is delivered in care services; national 'age sector' and older people's organisations; disability organisations and partnerships leading the way in developing self-directed support and initiatives in independent living; and researchers/commentators with an interest in this field. We also invited providers of long-term care services from care home


Figure 2: Programme for sounding board event

Older People's Vision for Long Term Care

Increasing the Voice, Choice and Control of Older People with High Support Needs

A One Day Sounding Board Event to Shape a Different Future





20 February, 10.15am - 4.30pm
(registration from 09.45am)

Hilda Porter Hall,
Methodist International Centre,
81 - 103 Euston Street,
London NW12EZ

10.15am
How I would like others to see me - Old Spice Drama Group
Welcome and about today - Helen Bowers, Director OPP

10.40am
Overview of the Voice, Choice and Control Project
- Helen Bowers OPP, Gilly Crosby CPA


11.20am
Key messages and themes from the scoping study & fieldwork
- OPP/CPA Project Team

11.40am
Sounding Board Discussions (help yourself to refreshments)

12.15pm
Feedback & discussion on older people's vision for long term care

12.40pm
Being Myself & They are all asleep - Old Spice Drama Group

12.45pm
Lunch



1.35pm
Don't & A Good Shaking Up - Old Spice Drama Group

1.45pm
Increasing the Voice, Choice and Control of older people with high support needs - OPP/CPA Project Team

1.50pm
Groupwork on priorities for change & commitment to action

3.00pm
Break and poster display

3.30pm
Feedback and discussion

4.00pm
Next steps and personal commitments

4.20pm
Final reading from the Old Spice Drama Group

4.30pm
Closing Remarks - Simon Parker, Demos (tbc)

provision to extra care and alternative housing developments.

We were disappointed that no one from the care home or care market provider perspective was able to join us on the day – despite targeted and follow-up invitations to be involved. As a result, further discussions do now need to be held with this key group, about the vision but also about priorities for change identified during this work.

Many of the people present had been involved in similar, if not exactly the same, projects and discussions over a number of years. Certainly many had been involved in reviewing or understanding the policy, research and practice worlds of long-term care. We therefore used a mix of techniques to capitalise on this expertise and knowledge in order to expose commonly held assumptions around this subject; test and tease out the vision and its key components; and explore the scope for fundamental change.

In particular we explored three levels of change to identify specific barriers and potential for action in order to increase both the volume and influence of older people's voices.

These three levels were:

- increasing the strength/influence of older people's voice/say over their own personal support and wider aspects of retaining choice and control;
- ensuring that teams and organisations (all providers, all teams and all commissioners) engage with, listen to and take full account of the direct voices of older people who need a lot of support – so that what they do and the decisions they make reflect what is important to older people with high support needs;
- ensuring that older people with high support needs have a direct influence over and say in the policies and strategies that ultimately affect their lives.

For each of these three aspects of 'voice' we asked participants to consider, discuss, agree and identify:

- What are the barriers that prevent this from happening now?
- What would be different at this level if a strong and influential voice was achieved?
- What will help to make this happen and work well?

Finally we asked participants which of these three levels they could continue to work on and contribute towards, in order for these actions to occur and to be effective in dismantling the barriers to voice, choice and control. In other words, what could they individually commit to doing after today, to help move this work forward together? These personal commitments are shared in Chapter 6.

3 What we know about the current situation – scoping study and policy context

Overview

This chapter presents the key messages from the two elements of the scoping study, the literature review and the Call for Information.

The scoping study became an increasingly complex and significant feature of this project, generating a huge amount of interest and information. We found a plethora of studies and initiatives on good practice in care homes and other models of long-term care, and we received a good response to the Call for Information and local/individual examples. However, our central finding from this study is that many of these examples and studies (both in the literature and in the Call responses) focus on the ‘mechanics’ of care rather than the essence of choice and control or self-determination that lies at the heart of independent living. Those that were directly relevant or touch on these issues highlighted the lack of a clear voice and low levels of engagement and empowerment among older people with high support needs.

Older people are rarely heard in many academic analyses of policies and consulting older people as consumers and purchasers of services is a relatively new phenomenon.

(Leeson *et al.*, 2003, p. 22)

The reality is that after nearly a decade of modernisation, older people in residential care appear to be as marginal to the rest of society as those surveyed by Townsend (1962) in the Last Refuge.

(Scourfield, 2007, p. 1141)

This in turn seems to have impacted on the low level of understanding generally – reinforced in

the fieldwork visits – about notions of choice and control relating to older people with high support needs.

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. While efforts have been made to engage with the issues of an ageing population and represent older people in all their diversity, older care home residents have effectively been excluded and disempowered.

(Scourfield, 2007, p. 1136)

Our conclusion is that older people’s voices within the literature (and in the examples that people typically think of in relation to this subject area – long-term care) are subdued, or represented or illustrated through other people’s experiences and perspectives (carers, care workers, families, professionals). Very little comes directly from older people themselves.

In addition, much of the literature (including more recent studies) focuses on specific aspects of communal life in and functional arrangements of a care home: the building and environment; the daily routines; standards of care delivery; and increasingly (but still marginally) the involvement of families and residents in the running of the home. All of these aspects are crucially important and very relevant to voice, choice and control. However, explicit examples of good or innovative practice in these areas were limited in their scope and ambition; focused on either risk avoidance or management of risk, health/illness and aspects of safety including security; and tended to be about services and quality of care rather than support in its broadest terms and having a (good) life.

It has therefore been challenging to capture good practice in relation to choice and control and

for people to imagine what they think long-term care and intensive support should or could be like for older people in the future. This may well be because the language of ‘voice, choice and control’ is still very new, almost alien, to this sector, i.e. long-term care and the ‘older people service world’ more generally.

It is also apparent from responses to the Call and the literature that it is difficult for various people (older people, families, providers and researchers) to envisage a different scenario of support from what is available and experienced now – especially on a large scale. The Call for Information did, however, produce some examples of innovative practice and projects designed to support older people to live independently which go some way to setting out a route to greater choice and control.

Finally, it is clear from the scoping study that there is a distinct lack of planning for the future at an individual, community and society level. The important message here is that at every level this lack of planning (and within that we would add imagination) impacts on both what support is available and what is accessed and then experienced.

Before turning to specific messages from the literature and the call, we reflect on the key national and policy contexts within which this work and concurrent debates in social and public policy have taken place.

National context and policy overview

In 2006, according to mid-year population estimates (ONS *et al.*, 2006), there were 9.648 million people aged over 65 and 12.76 million people aged over 60 in the UK. The proportion of older people and the oldest older people has grown, a significant portion of them live alone, and they are more likely to have physical and mental illnesses.

The proportion of people over 65 has grown from 13 per cent in 1971 to 16 per cent in 2006, and is expected to reach 22 per cent in 2031.

The largest percentage growth in the population in the year to mid 2006 was among people aged 85 and over – the number of people in this age group grew by 69,000 or 5.9 per cent

during that year, reaching a record number of 1.2 million. This is significant as those aged over 85 are most likely – among all age groups – to receive any sort of care, including living in care homes.

In 2005, 19 per cent of men and 33 per cent of women aged 65–74 lived alone; and 29 per cent of men and 60 per cent of women aged 75 and above lived alone (ONS, 2006). The likelihood of living alone increases with age: 47 per cent of people aged over 75 live alone compared with 12 per cent aged 25–44. Living alone remains a significant ‘risk factor’ for moving into a care home (Laing & Buisson, 2007).

In 2005, 60 per cent of people aged 65–74 and 64 per cent of people aged over 75 reported a long-standing illness in the General Household Survey; 37 per cent of those aged 65–74 and 47 per cent of those aged 75 and over said they had a limiting long-standing illness.

The Alzheimer’s Society estimates that there are currently over 700,000 people in the UK with a dementia, of which 15,000 are aged under 65. In addition to these global forecasts, the following trends give important contextual information for this study:

- One in seven people over 75 has ‘major’ depression which is severe, persistent and disrupts their day-to-day ‘functioning’ – rising to one in four if all depressions that impact on quality of life are included (Godfrey and Townsend, 2005).
- The number of older people living in a care home in the UK decreased slightly from 421,000 in 2006 to 420,000 in 2007 according to Laing & Buisson’s latest market survey (Laing & Buisson, 2007). This figure is expected to fall further to 415,000 in 2012, primarily because of non-residential alternatives being sought for people. However, the increase in the numbers of people over 85 is predicted to lead to a rise in the population of older people in residential care to 444,000 in 2017.
- In England between April 2005 and March 2006, 309,000 people aged over 65 received home help or home care services, 99,000 people over 65 received day care and 101,000 received meals (Government Statistical Service,

2006). The total number of older people supported has dropped significantly since the introduction of the Community Care reforms in 1993. By 2000, the numbers receiving home help or home care were one-fifth less than those receiving this in 1992. Fewer people now receive support, but on average each person receives more support than in previous years as targeting continues to focus on those in 'greatest need'. Alongside this, people report experiencing less flexibility, choice and control over the support they do receive.

- In 2001, 4.5 per cent of people aged over 65 were living in communal settings (including sheltered housing, extra care housing and residential and nursing home accommodation), with the greatest proportion being over 90.
- In 2006, in the UK, an estimated 468,000 places for the nursing, residential (personal) and long-stay hospital care of older people and chronically ill and disabled people were provided across the NHS, local authorities, and private and voluntary sectors. There were 12,208 registered care homes for older people (Laing & Buisson, 2006).
- The chance of living in a long-stay hospital or care home was:
 - 0.85 per cent in 2006 (compared to 0.9 per cent in 2005) for people aged 65–74 years;
 - 4.1 per cent in 2006 (compared to 4.2 per cent in 2005) for people aged 75–84 years;
 - 17.1 per cent in 2006 (compared to 19.1 per cent in 2005) for people aged over 85 years.

It is interesting to note how the chance of living in a care home is estimated to have reduced across all of the above age groups in the relatively short period of one year – particularly for people over the age of 85.

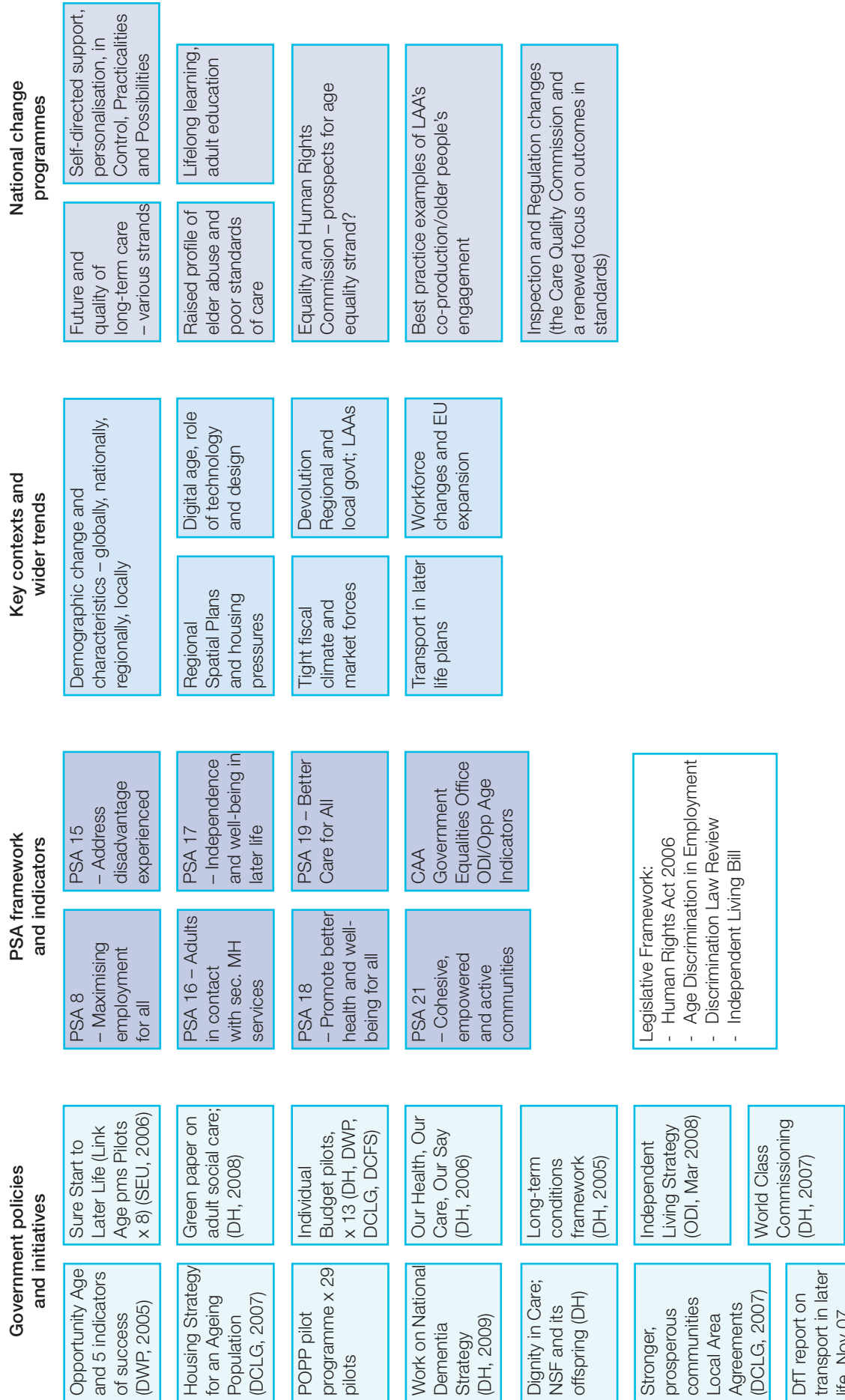
Older people with significant support needs constitute a large and growing sector of our population; yet they have often been left out of

innovative service and practice developments. Recent developments around independent living support that enables individuals to have choice and control in their lives have been slow to engage with and respond to the varied needs of older people. For example:

- Residential care is too often still the norm or regarded as the only feasible option for older people, especially those aged over 85 years and/or those with high support needs. It is certainly the only likely service to be offered for those needing support beyond extra care housing.
- The lowest take-up of direct payments is among older people (although this is slowly changing).
- The work of the individual budget pilot sites is already showing that these are further behind for older people than for other sections of the population.
- Person-centred planning has been shown to be an effective approach with older people but is happening only for small numbers of individuals in a few forward-thinking localities.
- Although residential and nursing homes are often described as being part of a continuum of care for older people, in practice care and support services are largely organised around a hierarchy – arguably supported by the current system of eligibility criteria. For older people, the highest levels of need are most commonly met by institutional or communal care settings such as care homes.

A number of recent policies and initiatives, as well as numerous national reports, bills and White Papers, have been produced over the last five years (illustrated in Figure 3, along with wider areas of context for this project) which highlight a wide range of issues for the existing older population as well as for younger adults reaching retirement. Many of these emphasise the importance of older people retaining (or regaining) choice and control over all aspects of their life. Within health and social care the emphasis is very much on

Figure 3: The policy and initiative landscape



promoting dignity and choice, for example through the ongoing work in developing individual budgets and direct payments.

Recent policy frameworks, not least the national strategy on ageing (HM Government, 2009), illustrate the Government's recognition of the challenges and trends associated with an ageing population, including the oldest older people. At the same time, it is noticeable that much of the current debate in this policy agenda is concerned with problems in social care spending and capacity associated with growing numbers of older people who, it is assumed, will need support in their later years. It does not explore or reflect the varied characteristics of our ageing population, and why and how individuals age differently, especially with respect to their health, well-being and disability – and therefore their need for different kinds of support. Nor does it tell us much about older people's aspirations and their rights and demands for equality, choice and greater control, regardless of their need for support on a day-to-day basis. And neither does it say much about older people's contributions to life or about the dynamic nature of ageing – the changing patterns and trends in terms of housing, family and social networks, employment and other types of economic and social participation.

While a great deal of work is taking place, we believe there is a strong need for a more joined-up policy approach in this area. Instead of excluding older people with high support needs (which the national service frameworks and *Opportunity Age* both do), this population needs to be fully integrated into government commitments and policy aims that seek to increase the health, well-being and inclusion of our ageing population while transforming public services for everyone.

Key messages from the literature review

This section sets out the key messages from the literature review presented under the following headings:

- rights and the voice of older people;
- transition to care/moving home;

- aspirations and options available;
- person-centred care;
- commissioning services;
- independent living;
- control and empowerment;
- social participation and inclusion;
- life in residential care.

Rights and the voice of older people

Ageism and discriminatory practices tacitly accepted and embedded in society have led to older people being systematically denied resources and opportunities that others enjoy.

Older people are not acknowledged as full and equal citizens within society or as people with equal rights as valued and as valuable as everyone else. They continue to be perceived as passive recipients of care first and foremost. As a result, the voices of older people are rarely heard, including in many academic analyses of policies, and consulting older people as consumers and purchasers of services is a relatively new phenomenon.

In particular, the voices of older people in residential care have not been captured adequately to inform the Government's 'agenda for change' to transform services. Older care home residents have tended to be excluded and disempowered with neither their own voices nor those of their advocates speaking up on their behalf. The effective disenfranchisement of people in institutional settings contributes to their sense of loss of identity, lowering of self-esteem and a reduced sense of personhood (Scourfield, 2007).

Transition to care/moving home

Decisions about moving in older age are complex and are highly dependent on individual circumstances. Outcomes are most positive for those who have planned their move for some time, but this is rare. The process is made harder for older people who lack access to information and advice on how best to change their living

arrangements, especially about options and support services available (including those less familiar or more recently introduced such as individual budgets rather than day care). Many older people find the prospect of moving home extremely daunting, even overwhelming.

It is now well recognised that the vast majority of older people want to stay living in their own homes, guided in their decisions by continuity of lifestyle and social/family networks, aspirations for security, accessibility (both internally and externally) and sufficient space. A choice of different kinds of support at home (both high and low intensity), therefore, form a vital means of enabling older people to stay at home.

People who fund their own care rarely have access to assessment and tend to be left without any form of independent review, advice or support. They are often given no option but to enter residential care, especially at a time of crisis, and often there is no way back as homes are sold (often very quickly) to pay for care. Those people ineligible for council-arranged services and unable to purchase care privately 'often struggle with fragile informal support arrangements and a poor quality of life' (CSCI, 2008, p. viii).

Service providers tend to report that it is older people who make the decisions about accessing some form of care, yet describe a decision-making process that is out of the control of older people and in which access to resources is restricted by professionals, presenting considerably limited choices. Older people's expressed needs and wants are therefore filtered by a range of professionals throughout the decision-making process. A contradiction arises between the rhetoric of choice, control and independent living and a 'system' driven by eligibility criteria, budgets and responsibilities.

Aspirations and options available

The current debate on planning for an ageing society does not consider sufficiently the need for different kinds of support, which cannot be dealt with by a 'one size fits all' approach. In addition, it does not 'tell us much about older people's aspirations and their right to equality, choice and greater control – regardless of their need for support on a day-to-day basis' (Bowers *et al.*, 2007, p. 10).

Older people who are unable to look after themselves at home are often required to leave it and live communally with others in a segregated community, whether they want to or not; there are few alternative options.

People moving to long-term care settings also often suffer from very limited options for tenure and can find themselves moving from a situation of outright ownership of their home to one of being completely dependent on the intentions of others (i.e. care home owners), with a significant lack of control and rights which many of us take for granted.

At the time of writing, the Human Rights Act does not apply to people receiving publicly funded services from private sources. However, the Government announced in March 2008 its intention to extend the Human Rights Act explicitly to publicly funded residents of private homes as the majority of care services for older people are not provided by the state but by private organisations.

Since April 2007 older people have been the only group without protection from discrimination in goods, facilities and services. The new Equality and Human Rights Commission (EHCR) operational in 2007 offers a real chance of progress in protecting the rights of older people and in equality matters, tackling specific issues such as the protection of older people's human rights in health and social care, and empowering older people to exercise their right to choice and control over their lives.

'Supported living' is a model designed to enable people to live as full citizens rather than requiring people to fit into standardised models and structures. It differs in its aims from residential care because the organisation of support and assistance is crucially determined by the needs of the individual and what they need to live where and how they choose, rather than by the type of building people live in. Importantly, however, it still assumes that for a significant number of older people the solution to their housing and support needs is to move from their home to an assisted living environment – albeit on the basis of 'apartment living' rather than communal living.

There is little evidence to show which types of supported housing people might prefer if they reached a stage where their current home

arrangements were no longer sustainable or desirable (i.e. a move was on the cards). Without this evidence it is difficult to know what ‘models’ or features are likely to encounter resistance from older people and which models of care are likely to give the best support.

There are a number of findings in the literature which indicate that future generations of older people (e.g. the so-called baby boomers) will expect and demand a different standard of accommodation – specifically more space, en suite bathrooms and additional bedrooms for family and friends or a live-in carer to stay in. In reality people of all ages need and want space to enjoy their everyday life, participate in work, family and community life, pursue interests and engage in social activities – and the right to choose where they live, and with whom they live. The Northern Architecture HOME Project report outlines this situation from the perspective of older people (Northern Architecture, 2006).

Real choice should include choosing with whom one lives, not just where one lives, related to the concepts of communities of attachment and communities of interest.

More recent initiatives that have explored alternative models of supported housing/living arrangements (such as assistive technology, telecare and housing-related aids, adaptations and equipment) highlight the importance of co-production with older disabled people in their design and implementation. In a review of the evidence, Frances Heywood reported that ‘home modifications can also help prevent or defer entry into residential care for older people’ (Heywood and Turner, 2007, p. 2).

Some commentators have suggested that models of supported housing and care homes available today may become unacceptable to future generations (Help the Aged, 2006). In this case, as well as for current generations of older people who would prefer something else, the shift to different options of support needs to begin in earnest now – especially given the present numbers living in care homes and other forms of intensive supported living arrangements (see the previous section on ‘National context and policy review’).

Person-centred approaches to care and support

Person-centred approaches are founded on a rights-based approach, and embrace principles and practices of self-determination (choice and control), inclusion and empowerment. The aims are to help a person get a better life on their terms and to support them to achieve their aspirations and wishes by focusing on what is important to the people in their everyday life and what support they need in order to fulfil that desire.

Much of the literature on person-centred approaches with older people focuses on ‘person-centred care’, in which there is a strong bias towards the voices of practitioners and academics and care delivery, rather than the life of the person concerned. The disability literature, however, is far more comprehensive in its breadth and depth of coverage on person-centred approaches – not least because of the focus on both the philosophical underpinning and practical applications (e.g. person-centred planning) in *Valuing People* (Department of Health, 2001), the first government White Paper on transforming services and support for people with a learning disability. In contrast there is, as yet, no such policy framework that makes this requirement explicit for older people with high support needs.

Commissioning services

At present ‘the views and aspirations of people who use services are not yet at the heart of commissioning processes’ (CSCI, 2006, p. 3). However, engaging with people means not just listening to them but also providing them with information on services available so they are aware of options and are supported to make choices.

Alternative models of support and care need to offer more than a simple choice between interventions that typically ‘promote independence’ and residential care (Platt, 2007).

Commissioners are responsible for the whole community they serve, not just those whose care they expect to fund. ‘They will need to rise to the challenge of ensuring that there are services available for all their local community’ (Platt, 2007, p. 8) so that people can make real choices.

A key question is how commissioners and providers across all agencies, sectors and investors can work together to increase the supply of innovative support and services, including self-directed support, and new and assistive technologies.

Independent living

Independent living as a phrase, concept and approach to commissioning and delivering support is not well understood either among older people with high support needs (nor the wider population of older people generally), or commissioners and service providers, policy-makers and leads focusing on older people's strategies and services. This is clear from the literature and from the Call where references are made instead to 'independence and well-being'.

This section therefore draws on the key messages from the literature on 'independence' rather than the ethos and approach that independent living embodies, as follows:

- Older people and providers of services do not always have a shared understanding of independent living – or of 'independence'.

The literature emphasises that 'independence' can mean different things to different people. For some older people the continued ability to look after themselves, including domestic activities, is central to independence; others highlight choice, i.e. having the option of privacy or social engagement. Residents in extra care housing cite 'having your own door' as a key feature of independence, related to privacy, autonomy and making choices. Mobility and the ease with which people can access the community 'outside' are also seen as important elements of independence.

A striking feature of much of the literature reviewed is that the concept of independence in later life is often freely and widely used but never explicitly defined by the authors.

A clear definition of independent living, as set out in the recently published *Independent Living Strategy*, would make explicit the importance of choice and control over any support or assistance that people need to go about their daily lives. Intrinsic within this goal is the importance of lifestyle and opportunities for family, social, economic and civic participation.

One of the key things that the literature does highlight is that older people want to maintain their sense of independence, to minimise the impact of any physical limitations on their lives as a result of illness, health conditions or impairment; and they develop compensatory strategies to achieve this. Independence is therefore very much about independent living for older people – less about doing things for oneself (the standard definition applied by existing policies and commissioning strategies) and more about choice and control over decisions, support, resources and lifestyles.

Control and empowerment

Control and empowerment are central to older people's own sense of well-being and quality of life – and also to the kinds of options for support that are linked to independent living. For example, in rating future accommodation, the factor rated most highly by older people was control of life. Few think residential care would satisfy this requirement. This message – that what older people want is at the heart of independent living developments and not at the heart of strategies that promote independence – is clearly important for shifting the debate from one of 'promoting independence' to increasing choice and control.

Older people want to be involved in decisions that affect them. Yet, the research literature reveals that neither care home residents nor older people in their own homes currently feel involved in care delivery processes such as assessment, care planning, service delivery and review. 'Their power is limited in fact and the idea of empowerment rather meaningless (Leeson *et al.*, 2003, p.24).

Older people's choice is often constrained by informal carers and staff who make decisions on their behalf, e.g. when to bathe, what to wear. A mismatch can arise between the individual's desire for control over their daily life and the degree of control afforded by the institutional or private environment. Older people are therefore being denied basic choices in their everyday lives, or are not provided with the assistance to enable them to exercise choice – and this applies to people living in their own homes as well as in an institution.

Risk is a critical and complex set of issues and can be a persistent barrier to change and improvement. For many older people, definitions of risk and deciding whether to take a risk frequently

involve weighing up potential costs and benefits. Older people take risk actions covertly, unbeknown to their informal or paid carers, in order to exercise personal choice and to have some degree of control. Some risk-taking behaviour is felt to be worth it as the perceived personal benefits, especially psychological benefits, are felt to outweigh potential negative dangers or consequences.

Many people in the literature voice anxieties about the process of dying, place of care and who would look after them. They generally perceive they have little control over such issues; and fear dying in pain, dying in a care home or a 'geriatric' ward, or dying alone. This area of choice and control at the end of life was not a key focus of this study, but is clearly a major issue and aspect of independent living which warrants further detailed work.

Social participation and inclusion

The literature indicates that regardless of care setting, those who are able to remain socially active are more likely to maintain or achieve a positive self-image, social integration and satisfaction with life.

Activity and social engagement are essential to the psychological and physical health and well-being of everyone, and this includes older people in institutional and other settings. The literature that specifically focuses on life in a care home or other institutional environment interprets these as being broadly based on what people say they want, such as the everyday experiences younger and non-disabled people take for granted – like making a cup of tea, sitting in the garden, going for a walk; variety in the day; to feel loved and needed; conversation and company; treats and fun to spice up life. It also points to the need for care staff to develop skills in listening to people's wishes about the ways in which they like to spend their time. Interestingly it emphasises that this listening process should happen 'informally' – as if this is not a central or key aspect of what care staff do.

Other factors such as access to local amenities and services are also highlighted as central to participation and social inclusion, especially access to good transport links and support to use them.

It is widely felt in the policy and research literature that options described as 'housing

with care' (or extra care housing) offer greater opportunities for social interaction and companionship, and mutual support such as helping with a patio garden, or keeping an eye on residents with higher support needs. In contrast, residential care is felt by some to provide better opportunities for organised activities and socialising.

It is clear from the literature that there is no agreed definition of 'extra care housing' but there is a general consensus that its aims are to focus on enabling support which encourages independence, healthy living and individual lifestyles, and can also act as a focus for care or support for older people living outside the schemes.

Older people with extremely high support needs, including people with sensory and cognitive impairments, are consistently reported to be on the margins of social groups and networks experiencing social isolation, i.e. they are the most isolated and excluded from opportunities to participate.

Life in residential care

There are conflicting messages in the literature about the role, status and scope for development in and around residential care. On an individual level, while it appears to be a positive choice for some older people, for others it has profoundly negative connotations, with older people reportedly having a 'fear and loathing of residential care'.

The picture that is presented is one of contrasting, or conflicting, perspectives, with the views and experiences of older people (in relation to a move into a home) contrasting with those of professionals, families and society as a whole.

On the other hand, the literature also points out that a move into a care home can be seen as a conscious change of living arrangements, which can enhance personal feelings of 'independence' and minimise 'dependency'.

The positive effects of moving to a care home described in the literature include being looked after and having cooking, cleaning and washing done by others. The negative effects include loss of freedom and individuality, especially freedom of movement.

Having the opportunity to ‘be oneself’ in a home is identified as the key to a good quality of life. People’s ability to feel ‘at home’ in a care home is described as the extent to which ‘residents’ are able to be themselves by making choices including how they dress, items they choose to bring into the home and control over personal space.

In addition, quality of life is inhibited if people are unable to feel ‘at home’ in the home and to feel comfortable in expressing their sense of self positively.

Key messages from the Call for Information

A key message from the Call for Information carried out as part of the scoping study indicates there is a lack of ‘real choice’ in the alternatives that people often assume will lead to greater choice and control, e.g. extra care housing and retirement villages. Examples were provided in the Call of how respondents’ initiatives/programmes have enabled and supported older people to have a strong voice in local services and support, as key mechanisms for exercising choice and control in different environments and approaches to providing support.

- STEP (Support to Empower People) is a project in Kingston upon Thames to train facilitators and set up service user groups in larger care homes to focus on greater empowerment and involvement of service users. The aim is to empower people to take more individual control of their lives and to understand the importance of working together. Respondents noted that it is relatively rare to find older people engaged in their own day-to-day facilities and services and the project sought to assist them to change this. As a result, and with support, older people felt more confident about speaking out in order to try and bring about improvements and change.
- Experts by Experience is an initiative designed to promote older people’s voice in speaking up on behalf of their peers about matters that are important to them when using services that are registered and regulated by the Commission for Social Care Inspection (CSCI). It does this

by recruiting, training and supporting older people to work alongside CSCI inspectors, in inspections of residential care homes for older people and local authority services.

- ‘Having Your Say’ is a joint initiative between Herefordshire and Worcestershire Age Concern, Worcestershire Citizen Advocacy and Worcestershire Social Services. It was developed to enable vulnerable people to have an active voice in their care environment. It also aimed to raise standards and improve practices within care organisations. It was hoped that it would change cultural perceptions of residential care and provide quality assurance of user involvement in shaping their lives and everyday activities.
- Waltham Forest Borough Council, in partnership with health planners, the voluntary sector and other agencies, is planning to develop small, self-supporting groups of older people as better-informed consumers available to offer advice to older people coming into contact with the care system for the first time.

There is a central issue of enabling and recognising the importance of older people having choice and control over who they live with, including for/with specific communities, e.g. Jewish Care, Methodist Homes. Importantly this is not just about sharing a faith but is also about having a shared history, a shared view of the world and a common underpinning philosophy or outlook on life.

- Nightingale, based in Clapham, London, is a large facility which brings together residential, sheltered and nursing care offering continuity of care, without moving as needs change. It is culturally focused care, i.e. Jewish care, and maintains strong links with the community and relatives, bringing them into the home for religious and cultural events.

The Call for Information elicited responses which capture a number of lessons and messages about how different respondents currently define or understand the term ‘person-centred’ and how they put this into practice. The most common interpretation of what person-centredness means

to providers is listening to residents and valuing them. This includes:

- obtaining detailed life histories of people, and maintaining contact with family and friends to enable staff to really get to know the person as a unique individual;
- creating an individual person-centred care plan which takes account of likes and dislikes and making sure all staff are fully aware of choice;
- recognising that the person's family is integral to support and that they are involved in every step in the process and have input to every decision.

Some examples of different responses highlighting these approaches include the following.

- The Royal Borough of Kingston has appointed an Eden Champion (leader) in each of their four council-run homes. The stated aim of the Eden Alternative philosophy is to combat the chief 'plagues' of residential home life – loneliness, helplessness and boredom – through care based on principles designed to enhance community, meaning, companionship and human growth. Key changes include enriching the physical and social environment of the home, and moving the decision-making closer to the residents or the staff closest to them. Feedback from one home, where the Activity Co-ordinator is the leader, is that residents, having been familiarised with the principles of Eden, have regular and spontaneous meetings where topics identified by them are discussed.
- Avalon is a charity in Cumbria that currently supports 12 people, who would otherwise be living in or using residential or nursing home placements, either long-stay or short-term (respite), to live as part of a family. Avalon supports adult placement schemes that put the person firmly in control and create the support to suit the individual circumstances. The person's family is integral to this support and is involved in every step in the process, and has input to every decision with knowledge

of the consequent implications. Family living facilitates choice by allowing the individual to lead their own service provision.

- The Dementia Care Partnership (DCP) is a charity in Newcastle upon Tyne that provides independent supported living houses for people with dementia and a commitment to 'home for life'. It was founded in 1993 by carers and former carers with the support of health and social services to develop services for people with dementia and their carers. It is now the largest specialist dementia service provider in Newcastle. The same carers became the board of trustees, ensuring DCP remains a truly carer-led organisation. The Partnership is built around a central idea known as the PEACH philosophy, which respects personal dignity, control and choice based on P – person-led approach/partnership; E – empowerment; A – attachment; C – continuity of care; H – hope. It is a philosophy of non-discrimination and combating isolation for people with dementia or people experiencing other mental health difficulties within the local community by focusing on their abilities rather than their disabilities.
- Eastleigh Southern Parishes Older People's Forum interviewed older people on their housing needs and aspirations in retirement. Older people revealed what is important to them to retain a sense of 'personhood'. Lack of space to live a normal life is a key issue/barrier which was identified during this process.

Some respondents made important links between what they are doing to promote autonomy in long-term care settings and wider agendas such as prevention. Examples here include linking new service developments to community-based preventative strategies, and empowering consumers to provide a basis for genuinely innovative social care. The stated aim in all of the following examples provided through the Call is to build relationships and links with the local community and for the service being provided to become the hub of that community.

- There are practical ways of working that can help people with dementia and other mental health problems lead happier and fulfilled lives within housing schemes, increasing participation in activities and reducing anxiety and social isolation, without the need to move into nursing home care if their mental or physical health deteriorates. A joint research project with the University of Bradford and Extracare Charitable Trust, the Enriched Opportunities Programme is a care model which supports vulnerable older people within sheltered housing schemes suffering from dementia and other mental health problems. It aims to enhance their quality of life and well-being. It includes individualised assessment and a programme of activity that is rich, integrates with the local community, is variable, flexible and practical, and provides opportunities for residents to experience optimum well-being.
 - Liverpool Personal Service Society (PSS), a charity pioneering new ways of delivering services, and the Royal Borough of Kingston upon Thames are, like Avalon, commissioning and providing adult placement schemes where older and disabled people live as part of a family. Adult placement schemes can provide alternatives to residential care, including other services in addition to long-term placements such as ‘at home’ day care, kinship networking and respite/short breaks. Access to intermediate care services and the benefits of assistive technology enable people to live independently ‘enjoying all the rights and responsibilities of citizenship that come with family life’.
 - The ExtraCare Well-being Assessment project run by the ExtraCare Charitable Trust offers a preventative health and well-being assessment by a Well-being Adviser (an RGN), who gives information and advice on how to live a healthier lifestyle and encourages residents to be proactive in managing their own conditions. In supporting older people to be as active, healthy and independent as possible for as long as possible, ExtraCare has successfully supported many people to reduce their need for support/care by regaining mobility and independent living skills and to make informed lifestyle choices to reduce the likelihood of more complex needs developing at a later stage.
 - Outreach services are part of the POPP (Partnerships for Older People Projects) pilot in Gloucestershire. These services aim to develop the capacity of care homes to provide different types of care and support to a greater number and wider range of older people and carers in the community, for example assistance in planning for older age (finance, housing, care, healthy ageing advice) and use of IT for those in care homes and in the community etc.
 - Housing 21 runs a dementia services advice, information and guidance service to sheltered and extra care housing managers in supporting residents with dementia and their carers. The overall aim of the service is to support tenants in maintaining their autonomy and their tenancy, and avoiding the need to move if their needs increase or change dramatically.
- Some examples were provided through the Call of how commissioning decisions and provider developments are changing to both reflect and embody person-centred approaches and greater choice and control.
- Belong Village in Macclesfield provides dementia, residential and nursing care alongside self-contained flats, run by CLS Care Services. The vision is that residents will be encouraged to take control over their own lives living in a village concept. CLS Care Services are providing smaller living environments that meet the intimate, private needs of individuals, while providing larger spaces to accommodate the more public needs of the community. Each Belong development has its own village centre where residents can meet, spend time together and socialise; it offers a range of facilities with a variety of leisure activities. The service provision is designed to enable residents to take control of their lives by playing a big part in the daily running of the home. The ethos is to extend choice to how people spend their time rather

than fitting into the routines and patterns of others; and support workers are there to support the needs of older people living within a safe environment.

- Spirita Ltd in Nottingham consists of two sheltered housing schemes each with a registered domiciliary care and support agency based in the scheme. The agency provides individual care and support packages to older people (aged 55 years and upwards) varying in need from a daily 'warden call' to maintain confidence through to the service that might be provided in residential care. The ethos and aim of the schemes is to support older people to maintain their independence in a supportive environment where services are tailored to individual need. Tenants receive an advanced care and/or support service in a supportive environment while retaining control of their life and home and the organisation emphasises that they are not in care.

Other examples provided through the Call include:

- assistive technology linked to a control centre enabling a quick response from a warden to support older people at home if they are at risk of falls or have mental health support needs;
- dedicated support teams to help older people move into extra care housing, working with them, their family, carers and other professionals involved in the process;
- tenants in extra care accommodation in receipt of direct payments who have their own private care provision but who spot-purchase care and support from care providers when required;
- new ways of making information available via toolkits and websites so local people know of services available – health, social and cultural/leisure – and how they can be best accessed, also focusing on direct payments.

4 What older people experience – fieldwork findings

Overview

The purpose of the fieldwork was to build upon the themes emerging from the scoping study and explore a number of examples of innovative practice in depth, to further understand the key features, experiences and designs/approaches involved in promoting voice, choice and control for older people with high support needs. Our focus was on older people currently living in a small sample of residential and nursing homes, extra care housing facilities and adult placement schemes.

While the scoping study was UK-wide, the fieldwork took place in four sites: three in England – Leeds, Norfolk and the Royal Borough of Kingston – and one in Scotland – Inverness. The Scottish site was included to consider the situation in one site of the devolved nations operating under a different policy and regulatory framework.

OPP led this phase of work and two associate consultants (experienced in participative action research and development work with older people) were allocated to work in each fieldwork site.

We particularly wanted to engage areas where it had been identified that good and/or innovative practice had been taking place in long-term care services for older people. Existing knowledge and contacts obtained through our shared networks, and information which emerged during the scoping study, were used to identify potential locations that would give a balanced and varied sample. We identified 'local leads' within areas, i.e. individuals who would be able to promote the project within their area and enthusiastically engage a range of organisations and individuals to participate in the project. Following much discussion and consideration of local circumstances, organisations and the collective enthusiasm for the project within localities, we agreed to proceed with the fieldwork in the four areas named above.

Fieldwork in four locations

The fieldwork took place over three visits to each of the four sites, as outlined below.

Visit 1

The purpose of the first visit (each lasting two days) was to get to know the local areas better, and to engage local stakeholders in initial discussions about voice, choice and control for older people who need a lot of support in their lives, especially those who live in care homes. This was carried out through a series of focus group and workshop discussions to explore and capture different views about the future role of and opportunities for accessing, using, purchasing (as individuals), commissioning and providing long-term care support.

We used a standard set of headings to guide discussions in each area, summarised in the box. For each of these areas, we also asked specific questions on: how voice, choice and control are exercised/reflected; what helps this to happen; what gets in the way; and what is missing.

Key questions in visit 1

- What we understand by voice, choice and control (focusing on those living in long-term care settings)
- The ethos and values of different homes/ settings
- Moving to a care home/other long-term care settings
- The culture of different care settings
- Maintaining a sense of identity

- Relationships with family, community, staff and other residents
- Developing and sustaining interests and activities
- Decision-making
- Maintaining good emotional, physical and mental health
- Dignity in death and dying
- Maintaining financial independence
- Our vision for long-term care (for this we explored: what an ideal vision would look like; how we should start to define or unpack this vision; what could help this vision to become reality; and what could get in the way)

As explained above, we wanted to capture a variety of perspectives ranging from those of providers and commissioners of long-term care services to those of members of local community groups, older people's networks/clubs and local activists. We encouraged and worked with the local leads to try and support local older people living in care homes to attend. We believe it is a measure of where people are currently at that this was not achieved in any significant degree in any of the sites. It also provided a stark illustration of some of the central messages from the literature review – the lack of a clear voice and low levels of engagement and empowerment among older people with high support needs.

Visit 2

The sole focus of the second visit to fieldwork sites was to hear the voices of older people within residential and other long-term care settings – particularly as it had proved so difficult to engage older people with high support needs in the stakeholder discussions above. We visited people in the following areas and settings:

- Royal Borough of Kingston – two adult placement locations and two care homes;

- Leeds – one extra care housing scheme and two care homes;
- Norfolk – one extra care housing scheme and two care homes;
- Inverness – two care homes.

People were invited to take part in one-to-one and small-group discussions/interviews with members of the fieldwork team through letters distributed directly to residents of homes and schemes which were taking part in the fieldwork, and posters publicising the project.

Standard schedules were developed, covering the same key areas of discussion explored during the first visits (as listed above), to guide the interviews and discussions with older people. This gave us and local participants a clear and transparent structure for our discussions, ensured we were consistent across all areas and 'settings' in what we covered, but also allowed for individual variation and flexibility in how conversations proceeded – according to people's own preference, style and need for support during the discussion. It is important to note here that no one struggled with the discussions, although some of the topics were clearly distressing, uncomfortable at times or difficult to comprehend. Support for participants was prepared if people needed it; and each discussion went at the pace of the person we were meeting with.

Analysis of emerging themes and issues

Following the second fieldwork visit, both locally specific and common findings, lessons and cross-cutting themes (i.e. across the scoping study and fieldwork so far) were identified. This analysis included the levers and opportunities for and barriers to change, as well as detailed messages from participants.

An emerging vision of long-term care was then drafted based on what works and what is important to older people.

Visit 3

Visit 3 was designed to engage with a wider audience and range of stakeholders in each area, through a half-day workshop to share our findings and test the emerging vision, and to develop a

shared vision for how things could change to promote the voice, choice and control of older people with high support needs.

At the same time as testing and shaping this vision, participants were asked to think further about the practical levers for change and improving the quality of life through increasing choice and control; and the barriers which need to be overcome or dismantled in order to achieve this goal.

Table 1 gives the details of the numbers of people involved in different elements of the fieldwork in the four study sites. We have kept confidential the names of the homes and other schemes we visited and the individuals who told us their stories about how they came to be living where they are now and what they would like their lives to be like – now and in the future.

Common messages and themes

Common messages and themes identified from synthesising the detailed analyses from all three visits in the four areas are shown below, as they relate to the themes of voice, choice and control for older people with high support needs.

Our central message, from looking across the fieldwork findings, is that an understanding of and focus on voice, choice and control – on self-determination and independent living – is missing for older people with high support needs. This gap is evidenced at all levels:

- in individual experiences of the support people receive and the options open to them;
- in terms of wider support and commissioning decisions that affect local communities;

- in the research and policy frameworks that influence and guide practice at a local level.

Voice, choice and control

A key theme about what helps, and also what is missing, is the importance of empowering relationships. These lie at the heart of positive social interaction and activity, and are key to enabling voice, choice and control for many of the people we met.

I didn't socialise much, only with my husband [who died], but I knew if I came here I would need to change and I did and it's been good.
(Care home resident, Kingston)

This is related to the impact and sense of loss that people experience if they are alone and do not have even 'just one person' in their lives. In these situations the potential role and impact of advocacy is striking, but also missing for most people we met.

We found that in most areas and in the majority of cases, direct payments and individual budgets are not well understood and in some cases unknown – mainly through assumptions made by others that older people with high support needs could not cope with the complexity and responsibility involved.

We found this ironic given that the majority of people we met were already dealing, and in some cases coping incredibly well, with enormous change, complexity and responsibilities – and would prefer to have more direct control and a sense of purpose and responsibility in their lives. They may need additional support in order to take up these responsibilities, but at present no one is really exploring the possibilities or resolving the practicalities involved in making this happen.

Table 1: Fieldwork – numbers involved by area and activity

Site	Stakeholder meetings	Discussions with older people	Local feedback and discussions	Total
RB Kingston	25	25	12	62
Leeds	15	19	5	39
Inverness	19	15	12	46
West Norfolk	26	25	7	58
Total	85	84	36	205

No one at a local (or at a national) level seems to be grasping the full implications and impact of demographic change beyond what this might mean for 'the funding issue'. We believe this impact needs to be taken into account in local commissioning and investment strategies, and that there is a need for a different vision for long-term care to guide plans that ultimately affect us all. We are not just talking about 'someone other' when we talk about long-term care; this is potentially about all of our futures and all of our lives.

It's difficult to say what we will all want in 20–30 years' time.

(Stakeholder attending workshop in Norfolk)

Specific messages about voice

- The impact that the skills and attitudes of managers and staff have on older people and their families is immense. They can make both positive and negative differences.
- Positive examples still tend to be professionally dominated, e.g. personalised care plans rather than person-centred support/life planning which is led by the person and their views of what is important to them, not just what is important for them.

Staff know what I like and don't like.

(Care home resident, Leeds)

There was a meeting the other night. Some people talked but nothing special. Would be able to talk better on a one-to-one basis.

(Care home resident, Inverness)

- The absence of a strong and influential voice for older people with high support needs in care homes and in alternative supported living arrangements including extra care and adult placement schemes was striking.

I wouldn't tell anyone if I was depressed – just get on with it – which happens quite a lot.

(Care home resident, Inverness)

- Alongside this central message was the importance placed by the people we met on listening to and understanding their own unique and personal views, preferences and opinions – and the need for this to be actively encouraged and supported in the first place.
- There is a great need for empowerment and involvement of residents – in big and small decisions.

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

(Care home resident, Leeds)

- There is a related need to recognise much more clearly the impact of disempowering relationships, which have wide-reaching consequences for older people who live in situations where their voices are effectively 'managed' by others. Often this arises as a result of other people's concerns and anxieties for them. For example, some staff felt that older people would not want to come to a meeting, or attend an interview or small-group discussion because 'they are too tired', 'it is too taxing for them', or 'they really wouldn't be interested'. We found that such comments were always refuted by the older people concerned, who expressed a keen desire to be included and involved.
- As a result, staff need to be actively encouraged to develop different relationships with older people who have high support needs – to move away from traditional notions of 'looked after' or 'cared for' towards a more enabling role that promotes inclusion and citizenship.
- The role of and need for advocacy and access to specialised support, including counselling and assistance with communication

impairments/support needs, emerged as significant gaps.

Everyone died – I could have done with a counsellor.

(Care home resident, Norfolk)

- The link between voice and inclusion was clear. Often care homes are isolated from the communities in which they are located, but would benefit greatly by being more connected. Increasing inclusion of older people who live in those homes is about practical as well as philosophical values and approaches, e.g. the need for accessible transport so people can get out and be included in local community activities/opportunities.
- The vast majority of the people we met with were very appreciative of the time and interest taken in listening to their views, experiences and hopes for the future, including the ideas shared about how life could change not only for themselves but for others sharing the same home environment. While this may be a reflection of the lack of voice experienced by older people within long-term care settings, it also suggests that opportunities to improve this situation would be warmly welcomed by many people in these situations. We observed time and again the positive effects of older people living in care homes coming together to share their views, concerns, anxieties and ideas in a free and open way – as well as the limited opportunities for many people to do so.

Oh, did you think that? I did too and I thought I was alone in thinking it.

I've lost the ability to communicate as there's no one with the same interests here as me.

(Discussion between care home residents, Kingston)

Specific messages about choice

- The way that most participants and respondents think of choice is by equating it to 'What's on offer now?' (vis-à-vis options/alternatives for support/care).
- For older people living in care homes, 'choice' is most often equated with choice over food/meals, what time you get up, and what time you go to bed.
- With regard to 'What's on offer now?', many people equate this to money or resources available and in particular to what people can afford. In other words you can only choose if you have personal resources to draw on (people assumed especially in the fieldwork that self-funders have more choice, which was not borne out either in the scoping study or in the shared experiences of older people in the four localities).
- There is a significant lack of choice and support/information to make decisions (i.e. exercising choice), especially when a decision to move is being or needs to be made. People described being rushed into decisions at times of crisis or high stress. The lack of planning at an individual level was also a common factor here, and on reflection (in the conversations we had with people) this was seen to have impacted on them in a big way, directly leading to restricted choice and limited control.

I came here eight years ago. My sight was deteriorating, bad arthritis, wasn't coping – my social worker bullied me into coming here.

(Care home resident, Kingston)

- The range of 'what's on offer now' is limited, being a mixture of insufficient alternatives being available (e.g. individual budgets and circles of support) and limited availability in local facilities including both extra care housing developments and long waiting lists for good (and often bad) care homes.

Without some kind of compulsion/real motivation, nothing will change.

(Stakeholder attending workshop in Kingston)

- Choice should be widened out as far as possible – there is a need for an atmosphere of continually looking at where and how this could be expanded.
- There is a significant lack of innovation, especially related to different and more community-based options and solutions.

Irrespective of where long-term care is provided, it has to be more person-centred with innovative, creative approaches involving family, friends, neighbourhood projects etc.

(Stakeholder attending workshop in Leeds)

- There is a huge lack of knowledge about processes and criteria involved when decisions to move are being made. People do not know what is involved, they do not know what ‘the deal is’, and they have little help to navigate their way through this.
- There is a huge feeling that it is always a one-way move – unless you get ‘moved’ out later to somewhere else of a similar nature (i.e. it is not your choice that this happens, nor when this happens).

I had to sell my flat to pay for X care home so now I haven't got any choice – this is my home because it's all I've got left.

(Care home resident, Kingston)

They sold my house to pay for my care home – now money all gone and I get supported care.

(Care home resident, Norfolk)

- There is a strong perception that your choice and control reduce significantly when moving to a care home, which may be exacerbated by the feedback we received that it is most often other people who make the decision in the first place. This loss of control then often continues once the move has been made.

I didn't know about the home but it was my daughter enquiring about it previous to that. She had enquired in other homes but found this one more acceptable for me.

(Care home resident, Inverness)

- Very negative perceptions about this sector generally persist, including poorly rewarded and motivated staff, and a recognition that this limits choice and honest, open dialogue about what is involved for everyone.

Specific messages about control

- We need to support people's aspirations and needs and build options for support and care around this.

It would be great if we could use some of the fee we pay for our own leisure, maybe have someone for two hours each week to do what we want with us – take me out on the bus, sort out my wardrobe.

(Care home resident, Kingston)

- Training is needed in key areas for staff, e.g. dementia care, communication, emotional support, recognition and support for mental health support needs. There is a great need to spread good practice in a much more assertive way (for example, dementia care mapping is still very limited and not well understood – should this be a core skill for all staff working in care homes?).

I would like the care assistants to talk to me when they come to care for me.

(Care home resident, Norfolk)

- Risk aversion comes from all places and perspectives, not just staff or the system but from relatives and families too. This has a very limiting effect on personal control, and ultimately how you and others see your life and future life chances.
- Much more open communication is needed, especially around areas such as end-of-life wishes. We heard a strong message that things have been improving in relation to end-of-life choices and control – about death and dying – although there is still a lot more to do here.
- There is a need for staff from different agencies to join up more – good examples of working well emerged when this happens (e.g. improving end-of-life care).

Chapter 5 sets out a vision for a different future for older people with high support needs, based on what people told us is most important to them. It also considers the notion of what this 'vision' entails for different people and why it appears to be so difficult for people to envisage a different kind of future or life either for themselves, or for others in the case of families, commissioners, providers, policy-makers, researchers and commentators.

We start to explore how these barriers might be addressed by setting out a potential agenda for change to achieve this vision in Chapter 6.

5 Building a vision for the future

Common messages and a vision for a good life

The fieldwork findings and common messages provide us with insight as well as detailed feedback from older people about what constitutes ‘a good life’ when you need a lot of support in your everyday life.

The most commonly mentioned areas include:

- people knowing and caring about you;
- the importance of belonging – and relationships and links to local communities within this;
- being able to contribute (to family, social and community life, and communal life too) and being valued for what you do;
- being treated as an equal, as an adult;
- respect for your routines and commitments;
- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with;
- having and retaining your sense of self, your personal identity – including being able to express views and feelings (self-expression);
- your surroundings – those that are shared and those that are private;
- getting out and about.

Following conversations with local stakeholders, the project team and the advisory group, we built upon these initial themes to develop a way of capturing and illustrating these key elements of a good life.

This became the Keys to a Good Life framework. All those involved in this work believe that adopting this framework could help to change how we all think about the long-term care of older people.

This change would involve a significant move towards thinking explicitly about what older people who need a lot of support in their lives would like their lives to be like and about the support that they told us would help them to experience this. This is a completely different approach to the current debate within Government and across the sector about the future role and funding of long-term care where discussions are not only dominated about who pays for what, but shaped by questions that explicitly lead people to have that discussion rather than a broader debate about what needs funding in the first place.

The six keys within this framework are captured in the bunch of grapes illustration in Figure 4.

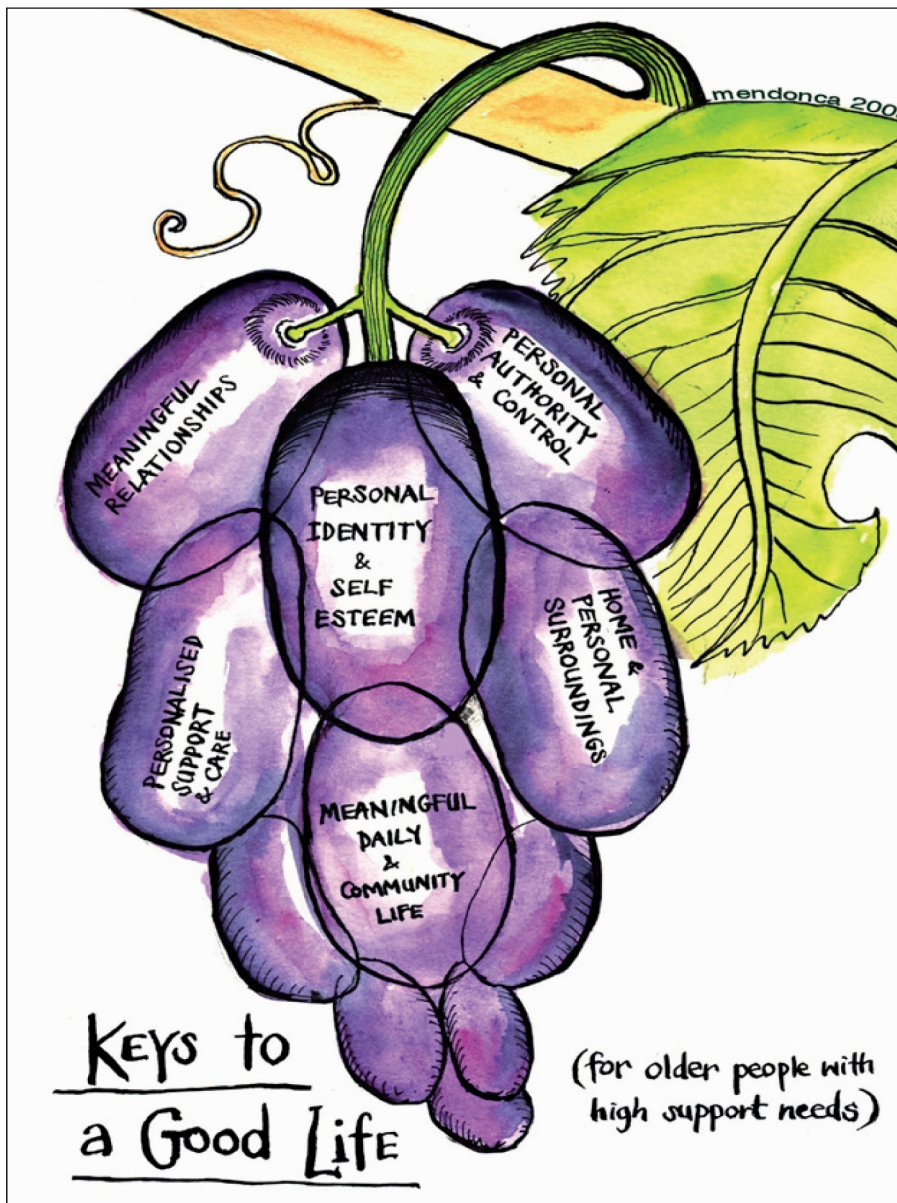
Using this picture to illustrate the keys to a good life was a deliberate choice for capturing and sharing what older people with high support needs have told us is important to them about where and how they live their life. Those who have seen and responded to us about this image have said how they have appreciated the use of a picture that is not about ‘frailty’ or ‘need’ or ‘care’, but about one of the good things in life – wine! We need to remember this in thinking about the use of powerful and positive images to influence and bring about change in our attitudes, behaviours and the decisions we make about long-term care moving forward.

An explanation of the characteristics or features of these six keys is set out below.

Personal identity and self-esteem

- This is the central, underpinning element or key to a good life.

Figure 4: 'Keys to a Good Life' for older people with high support needs



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- Self-expression – being able to express what is important about you, your views and beliefs and being able to trust that you will be heard, understood and valued – is crucial for self-determination, choice and control.
 - Having a voice or say over what happens in your life, any support you need, and leading decisions that are made follows from this.
 - People knowing you and respecting you – whatever makes you ‘you’ – taking account of your culture, race, language, beliefs, history and present situation.
 - Others in your life knowing the real you, your skills, talents, gifts and experiences.
 - Having and retaining your ‘sense of self’ – self-knowledge and awareness.
- Meaningful relationships**
- Having people in your life who really matter to you.
 - Being able to choose who is in your life.
 - Maintaining close and other important relationships.
 - Feeling connected with those around you.
 - Developing new relationships and friends.

- Respect for your sexual life, identity and relationships.

Personal control and autonomy

- Having control over personal decisions including where you live, who you live with, how you live.
- Having support to enable you to make the decisions that matter to you.
- Feeling in charge of your life; and having the support you need to live your life.
- Having control over personal finances, and help to manage them from people you choose and trust.

Home and personal surroundings

- Having choice and control over your immediate physical environment, including the way you get about and where you get about to, space and other access issues.
- Having choice and control over your own personal/private space.
- Having a say in the type and range of communal spaces available to meet with friends and family – not just within your immediate home environment but in your surrounding neighbourhood as well.
- Feeling safe, secure, warm and comfortable.

Meaningful daily and community life

- Feeling valued and belonging.
- Having a purpose and a role and continuing to contribute to family, social, community and civic life.
- Being able to get out and about and take part in local community and civic life as usual.
- Exercising your right to vote, and having support to do this if you need it.

- Being able to volunteer, and also to receive volunteer support.

- Maintaining friendships and contacts from your own chosen, as well as your local, community(ies).
- Choosing how you spend your time and who you spend your time with, including support if you need it to pursue your own personal interests.
- Having help to plan, make plans and see them through.

Personalised support and care

- Having choice and control over the support you need (in order that all of the above happens, in the way you want it to happen).
- Being able to choose who supports you.
- Being able to access the kind of support that is important to as well as important for you (small details as well as the larger aspects).
- Having access to support that helps you to maintain your own physical, emotional and mental health and well-being – including at times when you are not able to do this yourself.

These two latter points include equal access to universal services as well as the more specialist support that people may need to manage specific conditions or situations.

Experiences of building a vision

We discovered that it is extremely difficult to have conversations about a vision for the future when talking with and about the experiences and aspirations of older people with high support needs, especially those who currently live in residential or nursing homes.

This became evident during the fieldwork and also in our wider conversations with the advisory group and sounding board, and in the responses to the Call for Information in the scoping study.

[There is] *Some difficulty in going far beyond tweaking what's there already – difficulty in imagining radical new approaches.*

(Stakeholder discussions in Kingston)

On the other hand, those involved in local discussions about future visions identified a range of wide-reaching and tangible goals:

A world where asking people what they want and what they want to achieve, and then working with/supporting them to achieve this/provide this is the norm.

As wide a choice as possible and the support to make that choice.

Same standards as for younger or disabled people.

Range of accommodation available and better/increased use of technology to help provide care and promote independence.

(Participants at stakeholder discussions across all four areas)

Through detailed reflection and discussion with these different 'project stakeholders' we identified some of the key barriers that prevent these conversations at an individual and local level, and those blocking the way to having a different national debate about long-term care. We believe all three levels need attention in order to shift us all closer to older people's vision for a good life if you need a lot of support.

A vision and plans for individuals

Individually, thinking about what could be different and how you want your life to be can be difficult if you are in this situation now, and you (and others) have very low expectations about what is feasible or possible. It was extremely hard for many of the people we spoke with to imagine how things could be different in their lives – even though it was clear to us that many people would like their lives to be very different from how they are now. In addition, if you are unwell, or experience fluctuations in your physical or mental and emotional health, it can feel distressing, without the right kind of support and

encouragement, to have conversations about the future. We learnt that many people are desperate to have these conversations, and have plenty of ideas about how small but essential areas of their life could be improved with little, if any, additional resource. Very few older people involved had experienced this kind of support, or been engaged in these kinds of conversations.

Thinking about the future or a vision of your own future can also be difficult if you are not in this situation, i.e. when the emphasis is on planning ahead for a time when you might need support in the future. Few of us want to think about the need for care and support for ourselves. This is in spite of the feedback we had from many of the people we spoke with who believed that planning ahead would have helped them enormously, especially when the time came for difficult decisions to be made (although these difficult decisions were in part due to the lack of opportunity or alternatives for support on offer).

These difficulties were echoed in discussions with representatives at a national level (the sounding board) when participants shared their assumptions (shown below) about what the research would have found. The fact that most people at this level believed our findings would be negative (regarding the voice, choice and control of older people with high support needs) indicates to us that expectations need to be shifted wholesale before you can start to build a vision for a different, better life, and therefore for long-term care.

[There's a] *Fear culture – 'don't want to be a trouble maker'.*

Feeling of helplessness – 'nothing can change'.

Isolation in care homes and extra care.

Feeling of powerlessness, self-imposed? Imposed by others!

Low expectations of residents.

Lack of choice.

Reluctance to plan; lack of info and advice to help plan – or is v patchy; lack of advice and assessment at crisis point.

Not going to happen to us.

Confusion and worry about funding.

Local visioning (e.g. for local communities and populations)

Locally, these conversations about a vision can be difficult because of the narrow view of possible options and possibilities that commissioners and providers consider for this population of older people. Many organisations are still commissioning very traditional models of support that reflect deeply embedded assumptions and beliefs about what's 'appropriate', practical and affordable. These assumptions need to be openly discussed in order to widen choice, increase control and strengthen voice.

Many people believe that extra care housing is the solution for developing an alternative model to traditional residential care. We visited (and the scoping study provided examples of) extra care housing developments which are indeed providing an alternative model of support. We also encountered large-scale building developments of often 100 or more 'units' with one care provider, locked into a contract that tenants or occupants have to buy into, thereby offering little or no choice or control about what support you are able to access in order to go about your independent life. While the concept of having 'your own front door' as a central feature of independence is well known and widely accepted, there are other more fundamental aspects of voice, choice and control that this model does not on its own guarantee. As the full scoping study indicates, there are many definitions and different types of extra care housing schemes being developed with as yet relatively little evidence that captures the direct experiences and satisfaction of those who move and live there.

Evans and Vallely (2007, p. 8) define extra care as 'housing with full legal rights associated with being a tenant or homeowner in combination with 24-hour on-site care that can be delivered flexibly according to a person's changing needs'. Other definitions have been more specific about the nature of support available, such as ERoSH: 'Extra care housing schemes provide 24-hour support, meals, domestic help, leisure and recreation facilities and security' (EroSH, 2005, p. 6).

Tinker et al. suggest, 'This inability to arrive at a clear definition concerning the features that actually comprise extra care housing is indicative of the diversity of provision, the design differences between schemes, [and] the varying emphases that individual schemes have' (Tinker *et al.*, 2007, p. 42). They conclude that there remain many unanswered questions about extra care housing options. This is reinforced by Croucher *et al.* (2006), who note that there is only a small body of empirical evidence from the UK to illustrate how well different schemes actually work.

In terms of choice and control over options and opportunities for support, the sounding board participants felt that we would have found the following:

People want to live in their own homes as long as possible.

How to manage with housing – question about preparation; concerns about relocation.

Special concerns about ethnic minority groups.

'No choice' for older people [or] care staff.

Everyday life choices made by others – when to get up; eat; etc.

'Disconnect' between what people get and what people expect.

Poor choice 'but a caring environment that looks after me'.

Poor understanding of what 'choice and control' means among older people.

Where is the voice for older people? (a few people who speak 'on behalf' of all).

People have voices. No one listening.

Lack of engagement with people with dementia.

A small number of responses to the Call and our stakeholder discussions have highlighted the

importance of the limited and patchy examples of good practice that do exist around citizenship and empowerment for this population of older people. These examples are so few in number, limited in their scope and of such variable quality that we believe that they miss the essence of independent living and are unlikely to bring about widespread change on their own.

A national vision

Nationally and societally, conversations about a vision for a good life can be difficult because there is currently no visible discussion going on around rights, equality and opportunities for this population of older people. We hope that the recent, increased focus on the need for a human rights perspective on elder abuse in different institutional settings will help to address this gap (British Institute of Human Rights, 2006). The current focus, however, remains the provision of care by professionals and providers and the need for additional resources – rather than the range of people, possibilities and hopes for a different future that need resourcing.

A number of ‘project stakeholders’ at both local and national levels have shared with us that this was the first time they had been engaged in such discussions in relation to long-term care (for older people) or about the population of older people with high support needs. It is not surprising then that the sounding board expectations of what we would have found in this work highlighted the need for and lack of understanding about human rights, a rights-based approach, and wider systemic issues about the system of care available to and experienced by older people with high support needs.

Human rights ignored.

System not working.

*Any clear mechanisms for having a voice?
Problems with access to homes.*

*Things not there – needs-wise for older people
and their carers, e.g. flexible support.*

*Evidence not what policy-makers want to hear
– will accept message when factors converge.*

Economics shapes care.

*Barriers by care home managers to
engagement – assumptions.*

*Need to redefine what we mean by
independence – can be supported to be
independent.*

It is interesting that, alongside these conversations, there have been (at least) two other national debates or funded discussions taking place around long-term care. These have focused almost exclusively on the affordability of and future funding for long-term care:

- The Caring Choices initiative, a coalition of 15 organisations from across the long-term care system, sought to gather information and views from older people, carers and others with direct experience of the systems on how care should best be funded in the future (Caring Choices, 2008). The focus in this series of regional workshop discussions focused almost entirely on questions of who should pay what amount in order to cover the increasing costs of care for older people in Britain in the future. It did not include wider issues of choice, control, inclusion or even what was being paid for in respect of long-term care. Out of the 728 participants who completed a survey responding to these key questions only 22 per cent were older people and of these only a small minority included older people living in care homes or in transition involving a move to a care home (approximately 5 per cent).
- The Government’s discussions on the Department of Health’s Green Paper on the long-term funding of social care (due to be published in early 2009) has been driven by demographic forecasts and assumptions about the nature of intensive support the increasing numbers of older people (especially those aged over 85) will require in the future. At present these discussions are focusing on forecasts and projections that predict that future generations of older people will want and access the same kind of support that is available now. This is precisely the type of

expensive support that older people have told us that they do not want, as it offers a narrow and limiting range of options for support, and does not enable them to participate in family and community life as an equal and valued member of society (a key government commitment set out in the *Independent Living Strategy* published by the Office for Disability Issues in March 2008).

In 2006, the Office of the Deputy Prime Minister produced an online paper that accompanied the launch of Sure Start to Later Life (Social Exclusion Unit, 2006). This paper, *Making Life Better for Older People: An Economic Case for Preventative Services and Activities*, suggested that reducing rates of institutionalisation by just 1 per cent could achieve a £3.8 billion saving to the Exchequer.

While there are different opinions about the validity of this claim (see www.ripfa.org.uk/evidenceclusters/displayCLUSTER1.asp?catID=6&subcat=1) there is also little evidence to suggest that this could not be achieved if commissioning patterns, government policy and innovations in practice development focused their attention on widening 'what's on offer' (rather than the offer, which the above two initiatives are focused upon) to meet the needs and aspirations of older people with the highest level of support needs. Much more needs to be done to invest in broadening these options out, involving older people in their development, engaging other public services beyond social care, evaluating their impact, and using the Keys to a Good Life as the underpinning values and principles to guide practice in this area.

Barriers to achieving the vision

Recognising that barriers to independent living exist for older people with high support needs is critical. If these are not acknowledged, they will persist and older people's vision for their own life will not be achieved.

This section captures the barriers that project stakeholders consistently identified throughout this work which prevent older people with high support needs from having a voice, and in particular an influential voice. This summary also includes

their sense of what would be different for older people if these barriers were overcome, and older people's voices were being heard and acted upon – an agreed essential first step towards realising this vision. Chapter 6 develops these messages more clearly as a call for wide-ranging and radical change within and across all public services including the long-term care sector.

Increasing the influence of older people's voices in their own support

Barriers include:

- the invisibility, isolation and 'societal neglect' of older people with high support needs;
- loss of and low self-esteem, confidence and expectations (possibly as a result of the above);
- very low awareness of and understanding about – and possibly lack of support for – an independent living ethos for this population of older people;
- power differences where other people are deemed to know best and are in charge of key decisions and resources;
- lack of knowledge and skills to act and behave differently, and absence of training and support to change.

What would be different with/through an influential voice?

- An informed, empowered voice acting at different levels which is heard by those around you.
- Higher visibility and participation in key discussions about key decisions affecting your own future.
- Person-centred and self-directed support will be the norm.
- Society is more older people friendly and influenced by individual passions and interests, not just costs.

- Older people are recognised and engaged as part of the solution, not just a problem.
- Feeling as a provider that you are doing something more worthwhile.
- There would be a proper user-led organisation for older people with high support needs.
- Policy and practice would actually reflect what older people (with high support needs) want.
- Older people would be more integrated into the wider community, more visible, more integrated.

Increasing the influence of older people's voices in commissioning and providing services/support

Barriers include:

- the way commissioning and delivery work now;
- what gets commissioned;
- attitudes towards and resulting features of this population group.

What would be different with/through an influential voice?

- Older people are treated as equal partners, involved from the very beginning.
- Wider, more imaginative and flexible services.
- Focus on outcomes.

Increasing the influence of older people's voices in national policy and wider society

Barriers include:

- direct and indirect ageism (and other forms of discrimination);
- the agenda is set by Government (Treasury) and those who have the ears of Government;
- practical issues have become barriers, because of the above and because it is not straightforward, fast or inexpensive.

What would be different with/through an influential voice?

- Government would be doing consultation differently – they would be co-producing policies and strategies in this area with older people with high support needs.

The vision for a different model of long-term care which is presented in this report is predicated on a wide range of other people accepting that there is a need for fundamental change from the current situation.

This requires significant cultural as well as structural changes to the current system of long-term care. In taking this debate forward, with older people who need a lot of support at the centre of the debate, we cannot yet be certain how this future model will look, what it will consist of, or what it will cost. We believe we are so far away from having this dialogue that the first major investment we need is in building consensus for a new direction of travel. We cannot continue as we are at present; discussions about changing the system based on 'who pays for what' is not enough. We have to combine these different approaches into a completely different discussion and set of developments – based on older people's vision.

The focus in our final chapter is on building consensus for radical change that goes beyond structural reform, to embrace wider societal attitudes as well as public policy, service attitudes and deep-rooted beliefs that impact on the life chances of, as well as quality of life for, this excluded population. Chapter 6 introduces the need for an agenda for change to drive future policies and strategies designed to achieve structural improvements that deliver choice and control for older people with high support needs.

6 Creating an agenda for radical change

Developing an agenda for change

Chapter 5 emphasises the need for a strong vision. Chapter 6 expands this message, and argues for a multifaceted set of approaches to sharing, exploring and embedding this vision. We also point to the need for strong leadership at all levels, to steer change through that will ensure the vision becomes reality, not yet more rhetoric that disengages, alienates or excludes the very people it is trying to benefit.

Across all strands of this work, there has been a steadily growing recognition and a sense of collective responsibility (and dismay and frustration) about the status quo regarding long-term care. Those involved in different aspects of this work agree that this situation is not acceptable and has to change. There is a strong feeling that we need to work much more collaboratively across different interests, perspectives, sectors and positions to radically improve the life chances of older people with high support needs. And for this to happen, things have to change radically, not just be tweaked. This covers the bigger picture of widespread and societal, not just systemic, ageism – and the capacity and willingness of both families and communities to be part of this collaborative change.

This area is complex and wide-ranging. It touches different and competing agendas and interests, many of which are economically more powerfully and societally easier to engage with than the need for us to change the way we think about extreme old age, frailty and the current model of residential care.

It is extremely difficult to engage all the players and interest groups to have this conversation about a different vision for long-term care, based on older people's own aspirations and choices. It is particularly hard to have a discussion about aspirations for a good life in the face of technical and global forecasts around demographic

change and affordability. Big numbers mask these underlying but fundamental issues of life chances, personal choices, power and control for this population of older people. The increased emphasis on personalisation and citizenship enshrined in the *Independent Living Strategy* (ODI, 2008) and *Putting People First* (HM Government, 2007) may help to unblock these conversations, but only if it is made explicit that older people who live in care homes or other supported living arrangements are part of this policy picture.

Overwhelmingly there is a feeling that the root cause of the mismatch between what people want and what people get is societal. As mentioned in Chapter 5, a number of participants told us that this was their first opportunity to come together, step back and reflect on the current situation, the wider context of system reform, and the barriers as well as opportunities to fundamentally transform long-term care so that it more closely reflects what older people with high support needs told us matters to them. If this is the first time this has happened for people heavily involved in these debates and services, it illustrates how far we have to go to create a pressure and momentum for change within as well as outside the 'system'.

We believe, therefore, that more still needs to be done in presenting these key messages and older people's vision for a different and better life; and in formulating and agreeing an agenda for radical and sweeping change. This needs to be framed as a debate that is not about long-term care but about our future lives and life chances.

Rather than presenting a series of well-formulated, specific actions to achieve this vision for long-term care, we first set out the recurring and consistent messages from different project stakeholders about the need for a broader debate about the current imbalance of power and lack of ambition nationally, in order to transform the system that supports older people with high support needs.

This gives us three broad areas for consideration, which we follow with potential areas for action (using the Keys to a Good Life framework) to improve the life chances of older people with high support needs. We end this chapter by considering models for addressing and achieving cultural change within care systems and societally.

What needs to change?

We identified three clear directions from project stakeholders about addressing the current imbalance of power and lack of ambition that exists nationally about and for older people with high support needs.

The need for a much clearer steer towards, and action to deliver, independent living and equal access to self-directed support

This spans a number of different aspects, including the need for revisiting some of the language and terminology used to explain developments typically associated with ‘personalisation’ and ‘transformation’. This includes increased control over your entitlement to resources associated with state-funded support but also retaining control over your own resources and ‘purchasing power’. This also includes supported decision-making, person-centred support planning and increased access to information, advice, advocacy and peer- or user-led support.

A central goal or outcome for individuals is autonomy – having power over your own life and choice and control over any support you need in your life. A key message here is the need to understand that losing your autonomy is the same thing as losing your humanity. Many of the messages and experiences shared through this work were indeed about just that: older people no longer being seen as or feeling themselves to be their ‘essential selves’ (Scourfield, 2007); no longer able to express themselves; no longer active, equal and valued citizens. That is a loss of humanity. Services and support which do not enable older people to hold on to their unique sense of self and their humanity are therefore dehumanising, not just disempowering.

The Keys to a Good Life framework was seen as a useful one for exploring these issues,

illustrating what is important (e.g. capitalising on the powerful impact that visual images such as the bunch of grapes – and others – can have) and identifying priority actions at all levels – from person-centred approaches at an individual level to national campaigns to combat ageism experienced on a societal level (see potential areas for action outlined in Figure 5).

Changing the system for long-term care needs to involve a completely different approach towards, attitudes about and relationships with older people with high support needs

We need to reinstate the notion and importance of citizenship and human rights for older people with high support needs, especially for those who live in residential and nursing homes for whom this is seen as obsolete or irrelevant. This is essential for achieving the Government’s stated vision of equality for all disabled people by 2025; and so that all disabled people and all older people are seen, treated and are able to participate as full and equal citizens, not ‘residents’.

Need to treat older people in care homes as EQUAL ADULTS.

Including a focus on choice and control, and access to high quality support for older people who need intensive and end-of-life treatment/care

The Keys to a Good Life framework can be used not only for underpinning human rights and combating ageism, but also to promote physical, mental and emotional health and well-being among older people with high support needs.

While we would stress that this is not a medical ‘model of care’, it is essential to see and respond to the specific needs and conditions that older people with high support needs might have or develop in a personalised and enabling way. This is about more than dignity and respect. It is about equality of treatment and access to quality services that maximise mental, emotional and physical health, including increased knowledge and skills in supporting people with specific conditions (including the dementias) and at the end of their life. This includes a much greater emphasis on and equal access to physiotherapy, physical exercise

and rehabilitation. As part of these, support should be available to assist older people, their families and staff to learn how to manage (not avoid) risk effectively.

In our view then, the Keys to a Good Life can help keep people, organisations and departments focused on what is important in all of this – it is a vision of how life can be and what is important in life. It is not about services or care systems per se. It could, however, be developed to create an agenda for change as well as working on an individual level to help personal support planning stay focused on the outcomes and differences that matter most to older people.

Potential areas for action (to bring about wider change)

The table set out in Figure 5 includes the potential areas for action to bring about wider change that were identified by project stakeholders. This illustrates how they relate to the six keys to a good life and the three levels of change required to achieve these.

Building consensus by making strong connections

The areas for action presented in Figure 5 are in outline form. While they reflect the consensus reached with project stakeholders concerning the need for radical change, they need to be refined, shared and built upon with a range of other interest groups and a much wider range of stakeholders in order to fully develop an agenda for change that can move forward.

The following areas are those where strong links need to be made and initial discussions held to ensure this work becomes embedded within existing and planned developments already agreed in this arena. This work on embedding older people's vision for long-term care needs to explicitly include the 420,000 older people who currently live in residential and nursing homes, as well as identifying the span of options and opportunities for independent living that also need to be developed, and increased, for future generations of older people with high support needs.

First, in taking these next steps it will be important to link with and incorporate the messages and lessons from other work commissioned by the Independent Living Committee at the Joseph Rowntree Foundation, and the work on independent living and older disabled people which is being taken forward by the Office for Disability Issues. The latter includes the Government's commitment (from the *Independent Living Strategy*) to develop a Regional Action and Learning initiative on achieving independent living with and for older people with high support needs. The links between this study on older people's vision for long-term care and the Regional Initiative on independent living need to be clarified. For example, the Keys to a Good Life vision that has emerged from this work provides an important visioning tool for the Regional Initiative; and the Action and Learning Initiative provides essential testing ground for the vision.

There is also a need to make strong links between future developments following on from this study and current programmes that are focused on improving the quality of life for care home residents now. These include the My Home Life programme; the Department of Health's Dignity in Care initiative; the use of the Eden Alternative to bring about cultural change within specific home environments; and the development of extra care housing facilities and other designs for supported living arrangements that offer an alternative to traditional forms of residential care.

Strong connections also need to be made with the concurrent debates on long-term care referred to in Chapter 5, namely the Caring Choices campaign and the Green Paper developments on the future of social care.

There are important messages both from the fieldwork and the scoping study for inspection and regulation, not least the need to concentrate collective energies on increasing the voices of older people with high support needs in all aspects of their own support and care; in the development of options and mechanisms for exercising choice and control; and in commissioning decisions that affect local communities, families and individuals who need a lot of support in their lives.

Figure 5: Potential areas for action

Vision of a good life for older people with high support needs	Changes at an individual level that older people, families, staff and others can make to achieve this vision	Changes to services and systems of support that commissioners and providers can make to achieve this vision for local populations and communities	Changes at a national policy or societal level that will create or support a fundamental shift from what happens now, to achieve this vision
<p>1 Personal identity and self-esteem</p> <p>2 Meaningful relationships</p> <p>3 Personal control and autonomy</p> <p>4 Home and personal surroundings</p> <p>5 Meaningful daily and community life</p> <p>6 Personalised support and care</p>	<p>Human rights better understood (and applied)</p> <ul style="list-style-type: none"> The Keys are the starting point for ensuring greater awareness of and attention to every older person's right to a good life and a sense of their own unique contributions (raising self-esteem and personal identity is key to self-determination, choice and control) <p>Practical mechanisms that facilitate voice and deliver choice and control</p> <ul style="list-style-type: none"> Empowering older people to speak out and up Normalise person-centred planning and user-led approaches Individual budgets are part of this but not enough on their own Develop key messages and practical tools that promote life planning to help overcome the fear of 'dependency' (loss of choice and control), to enable people to plan ahead, make personally positive and timely decisions, and protect their personal identity and self-esteem Better information and advocacy – and access to it Advocacy needs to be non-directed, and more available/accessible Older people choosing and employing their own personal assistants supported by flexible employment practices and continuity of response Staff, families, all of us will be building in time to listen/communicate with people 	<p>Commissioners and providers talking directly to older people with high support needs</p> <ul style="list-style-type: none"> The voices of older people with high support needs being heard directly in research and other commissioning activities Build capacity of older people to be involved – and also build up older people's organisations which are increasingly led by older people (not paid staff alone) <p>Demonstrate that locally the vision is being embedded, with agreement from all partners/providers about what this means in practice</p> <ul style="list-style-type: none"> Vision needs to be translated into practical plans and locally agreed targets through Local Area Agreements, e.g. 35 agreed targets which are resourced Greater awareness of human rights and their enforcement among older people and support staff Promote policies and good practices that illustrate how to embed voice, choice and control for this population Develop joined-up systems of support (not just the social care system) that stop people falling out of options/opportunities for independent living at certain ages <p>Older people involved in every local decision-making process</p> <ul style="list-style-type: none"> Include the 50+ population Commitment to consult (?work with) minimum number of older people with high support needs (must be diverse) 	<p>Shift from professional gift model to a citizenship model</p> <ul style="list-style-type: none"> Services/budget owned by older person rather than gifted by professionals/agencies This will achieve better value from taxation Shifting societal expectations and attitudes <p>Focus on understanding ageism and a rights-based approach</p> <ul style="list-style-type: none"> Need a shift away from the current world – where there are two worlds of policy: older people; everyone else Anti-ageism campaign – hard-hitting, awareness-raising, focusing on equal access – real focus on changing social attitudes towards older people but alongside tackling wider social issues of inequality/equality Ensure budget related to need not age Security of tenure wherever you live Improve regulation <p>A commissioner with vision: every older person matters</p> <ul style="list-style-type: none"> Political and financial commitment Action to raise expectations of current generation of older people with high support needs, and those of the people around them Top-down and bottom-up pressure for social change including human rights for older people

Vision of a good life for older people with high support needs	Changes at an individual level that older people, families, staff and others can make to achieve this vision	Changes to services and systems of support that commissioners and providers can make to achieve this vision for local populations and communities	Changes at a national policy or societal level that will create or support a fundamental shift from what happens now, to achieve this vision
	<p>Older people with high support needs sitting on and actively contributing to panels, planning forums, advisory groups</p> <ul style="list-style-type: none"> • People will know what co-production is and what it looks and feels like • Older people will be doing it together, asking ‘what do you want and how can we make it happen?’ • Peer support and peer-led developments enable older people with high support needs to do this <p>Good management and leadership</p> <ul style="list-style-type: none"> • Evidence of a belief that change is required • Shift in power balance • Change to risk management (not avoidance) policy and practice • Promote policies and good practice that illustrate how to embed voice, choice and control for this population • Work together and not undermine each other – be honest about vested interests so they can be addressed – at every level: individuals, organisations • Ask when does an individual professional lose sight of the person they are trying to help, e.g. through fear of losing job? 	<ul style="list-style-type: none"> • Greater awareness and education (not just through ‘information and advice’) for older people and professionals regarding possibilities and options • An influential collective voice will encourage personal and individual voices to flourish • Promote and enforce the right to multidisciplinary assessment and independent advocacy and threshold/transition to long-term care including ‘check in’ questions for initial and ongoing assessments/ reviews (e.g. ‘would this be the only or the best option/ outcome if this person was 20?’) <p>A broader range of different things being planned and designed, commissioned and provided</p> <ul style="list-style-type: none"> • Commissioners opening up potential/creative ideas for new services • More investment in third sector • Learn from personalised support plans to inform population and practice-based commissioning • Critically review what is currently available for older people and what they actually end up with against younger people with same level of support needs • Focus on commissioning enabling environments in extra care housing and other models of housing support • More needed on investment in change/supporting change and human resource issues (not just ‘training’) • Sharing good practice – agreeing and identifying this with older people 	

Achieving radical change

We know from the literature and our own and others' observations in this work that cultural change is one of the hardest things to achieve, especially on a grand scale. The 'change literature' published on public sector reform since the late 1990s has indicated that such programmes have a tendency to revert to structural reorganisation (sometimes referred to as 'reconfiguration') as the main mechanism for delivering complex change agendas. Attitudinal change is a much harder nettle to grasp.

Some of the outline areas for action in Figure 5 involve practical, tangible developments that should be relatively easy to introduce, if our earlier points about the need to reach consensus on the need for change in the first place are addressed. Others, however, point to far more complex, subtle and deeply embedded attitudes which impact at a societal and public policy as well as service delivery level. These need a different approach entirely.

We have identified some key lessons for achieving radical and deep-rooted culture change in public policy from a draft discussion paper produced by the Prime Minister's Strategy Unit (PMSU), *Achieving Culture Change: A Policy Framework* (Knott *et al.*, 2008). Despite its draft status, the paper provides a comprehensive overview of the current knowledge base of cultural change and considers how this can be used to inform policy development. One of the key lessons it outlines for policy-making (and therefore for policy-makers too) is the need to better understand the circumstances under which culture change interventions are most likely to be appropriate and effective. This section summarises the key lessons which we believe will help move us closer to older people's vision for a good life if they need a lot of support in their lives.

The PMSU paper particularly emphasises the need for new thinking when change is required which involves a shift away from deep-rooted cultural factors; and sets out a three-pronged but practical approach to implementing culture change policy.

The three key steps are:

- First, identify and define the 'target' populations (for change) combining traditional demographic

or epidemiological profiling with psychological techniques to develop a detailed map of what motivates different people. The reason for this is to understand how different groups respond to policy interventions and how they can be tailored accordingly. This is especially important in this arena given how difficult it has been to engage certain key interest groups (e.g. the care industry) in this work.

- Second, assess the drivers of attitudes and behaviour for each of these target populations. This requires an understanding of the relationship between cultural factors and behaviour in the area of long-term care, using older people's vision for their own support. Where attitudes are strong and entrenched, and where there is a close link between attitudes and behaviours (i.e. what people believe and what they actually do), it is suggested that the policy focus should be on addressing underlying cultural factors (rather than behaviours). Where attitudes are broadly aligned with the desired outcome, but these attitudes are not translating into required or expected behaviours, this suggests the policy focus should be on more traditional behaviour change levers (e.g. enabling, incentivising and encouraging). Where there are gaps in underlying attitudes, values, aspirations and self-efficacy, as well as in actual behaviours (i.e. the likelihood of the desired policy outcome being achieved is low), this suggests the need for a combined approach which addresses both the underlying cultural factors *and* behaviour change through enabling, incentivising and encouraging measures. Whatever the scenario, the timing and sequencing of different interventions will affect their effectiveness.
- Third, map possible policy interventions onto this assessment of the relationship between attitudes and behaviour. There is strong evidence which indicates it is possible to influence attitudes and values through some immediate influences on individuals (i.e. changing societal attitudes through creating opportunities for different social behaviours), as follows:

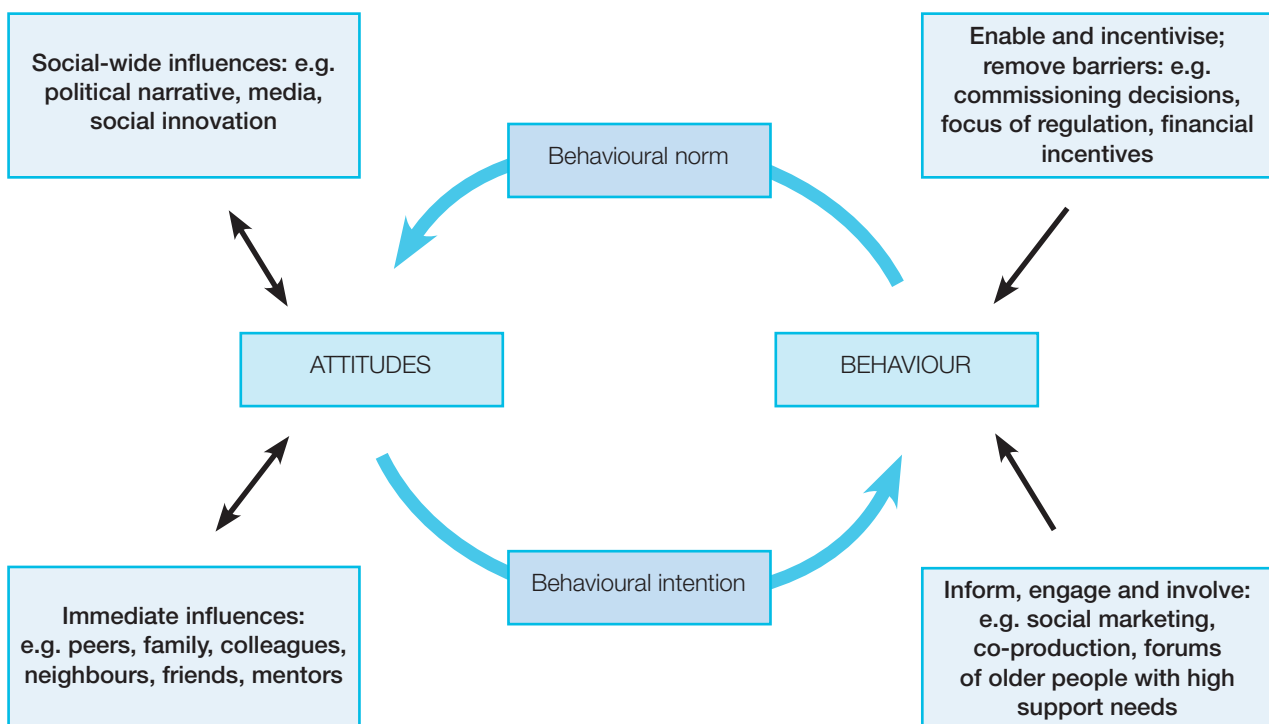
- Mentoring and use of trusted advisers can raise life aspirations for people and help show them pathways for these aspirations to be realised.
- Improving the quality of the built environment such as school infrastructure or neighbourhood regeneration can send a powerful signal to neighbourhoods to raise levels of aspiration.
- creating the conditions for new ideas and social innovation in this area to be developed, nurtured and diffused across society (which would require a much higher and different profile for older people with high support needs and the range of support that they personally prefer, than at present);
- encouraging open debate and dialogue in society, for example by using trusted authority figures to promote attitudes and values, and by building consensus on issues such as shifting the power base away from professionals and others towards older people and increasing the influence of their own voices. This also means recognising the role that peers and well-known and respected organisations can play in leading social norms, and actively engaging these organisations.

These approaches need to be combined with interventions that seek to shift attitudes, values and aspirations at a whole society level. The paper points to the following examples, which we believe can be applied to ‘long-term’ care with the aim of working towards older people’s vision for a good life if they have high support needs:

- consistency of policy narrative that establishes and reflects positive social norms and values in respect of age, ageing, extreme old age, support and independent living;
- signalling these in a coherent manner throughout all policy decisions, and ensuring that Government itself leads by example;

Importantly the culture change framework introduced in the paper recognises the shifting sand of what is and what is not regarded as an acceptable role for Government in creating a pressure for or encouraging such change itself. This is especially important in this context, given current and ongoing debates about the changing

Figure 6: Culture change framework for older people’s vision for long-term care



relationship between ‘the citizen and the state’, especially with regard to the funding of long-term care services we have mentioned earlier.

While there are elements of this framework that are highly relevant and of practical use in moving this whole debate forward, we do believe this needs to be adapted and applied to fit the specific case presented in this report, namely achieving a radical cultural change towards how we all regard extreme old age and older people with high support needs (with a view to then shifting how we view long-term care towards older people’s own vision for the future). The diagram in Figure 6 sets out the framework as presented in the PMSU discussion paper, with some minor adaptation to reflect older people’s vision and the need for radical change to achieve this.

Messages and commitments from sounding board participants

Finally, we set out the final comments and observations that were shared at the national sounding board event, comprising perspectives from people involved in all phases and locations of this work. This gives an indication of the commitment to taking this work forward, and the shared concerns about the scale, nature and complexity of the challenges that are involved. Importantly, however, these messages also contain a strong message of hope, ambition and enthusiasm for change which the project stakeholders want to continue to be involved in. This enthusiasm must be harnessed to ensure that older people’s vision for long-term care – for a better life – does not end at this early stage of development with the writing of this report.

General comments/observations

Powerful and urgent need for a shared, unifying vision of what we’re trying to achieve, with whom, what will be different ... and how to get there.

Need for co-operation and collaboration: we shouldn’t be arguing about this and the right way to do this, we need to be working together to create lasting and real change.

Importance of hope and ambition – mustn’t get weighed down by practical challenges and resistance to change.

Frustration that things haven’t changed/aren’t changing as quickly as we all want them to – and that it’s still too easy for people to dismiss opportunities, aspirations and ambitions when talking about (rather than listening to) older people with high support needs.

We need to ensure that this work adds to the momentum for change, and recognise that we’re not starting from scratch but we do have a long way to travel.

Reflections from tables focusing on national level

It is very difficult focusing on national level without paying attention to or taking account of personal level.

It is also hard to connect the two.

It’s hard to define/agree how, and how best to influence change.

The lack of a voice at a personal level is important to focus on above everything else (but also does need to connect up with policy/strategy/guidance/commissioning in order to ensure this happens).

We need to learn from and connect up different arenas and policy/practice worlds (e.g. age and older people/disability) – a long way apart from each other at present.

Reflections from tables focusing on personal level

We’ve got a very long way to go to making sure this does happen (ie. older people’s voices raised, heard and responded to at every level).

Good practice does exist but is limited and seen as ‘innovation’ rather than standard or the

bare minimum (which is what people feel we should get to).

It's a rights-based issue.

Where good practice does exist it helps to change things for a few, rather than many.

It's easier to think of what needs to change for one person/a few people than it is to think about how to change things for many people (so not surprising that this then gets stuck in terms of good practice).

It's easy to get disheartened too – so we need to design in hope, motivation and momentum.

We need to be careful that in showing what needs to change and why, we don't alienate the very people we're trying to engage and shift; at the same time we must not collude with poor practice, behaviours and attitudes.

Reflections from tables focusing on increasing voice in terms of what commissioners/providers do

The language of the service and policy world is alien to most older people with high support needs, so if we're serious about all of this, we need to adapt our language.

Commissioning decisions and practice needs to be influenced by personal experience and aspiration (i.e. voice) ... we need to translate from the personal upwards and outwards to identify the kinds of services and support that deliver the keys to a good life.

Personal stories can really influence positive change – at all levels but especially at a commissioning level.

Competition for resources, contracts and profile gets in the way of increasing voice (both in terms of commissioning teams, providers and also in terms of lobbying organisations as well).

We must invest more in the use of innovative methods (multimedia) that should support a direct dialogue with older people with high support needs.

7 Conclusion

This study aimed to learn from the experiences and aspirations of older people with high support needs, particularly in relation to the role of long-term care. It identified a clear need to strengthen the voices of older people who need a lot of support and to increase their choice and control over that support.

Older people with high support needs tend to have low expectations of their lives, their surroundings and themselves. As they move into care, they are rarely in control of their own decisions, arrangements and financial transactions. There is a great power imbalance between people receiving support and those providing it.

This lack of a voice is compounded by widespread ageism and stigma associated with extreme old age, frailty and intensive support. This includes ageist assumptions, policies and practices, in services, communities and family life.

Recent policy developments in funding health and social care, such as individual budgets and direct payments, seek to promote dignity and choice. Innovations in independent living enable people who need support to have more choice and control in their lives. Yet these developments have been slow to respond to the varying needs and aspirations of older people.

The Government recognises the challenges and trends associated with an ageing population, but much of the current debate is concerned with problems in social care spending and capacity. It does not explore the varied characteristics, contributions and aspirations of older people. There is a strong need for a more joined-up policy approach in this area.

Debates about long-term care and the population receiving it are dominated by financial concerns. This contributes to older people with high support needs being seen and treated as commodities, not consumers with rights, entitlements or purchasing power.

The current situation is not acceptable. In developing the Keys to a Good Life framework, older people with high support needs have set out a vision for the future. Personal identity and self-esteem are central, underpinning elements of this vision.

Achieving older people's vision involves huge cultural as well as structural changes to the type of support available to older people and how it is funded, commissioned and delivered. Change is needed at an individual level, locally for organisations and teams providing and commissioning support and nationally for public policies, public services and the care market.

At the individual level of older people, their families, care staff and others, human rights need to be better understood and applied. Practical mechanisms are required to facilitate voice and deliver choice and control. These changes would see older people with high support needs actively contributing to panels, planning forums and advisory groups. Good management and leadership can also play a part in shifting the power balance and promoting good practice that embeds voice, choice and control.

Achieving this vision for local populations and communities will involve commissioners and providers making changes to services and systems of support. This means talking directly to older people with high support needs and demonstrating locally that their vision is being embedded with agreement from all partners and providers. Older people should be involved in every local decision-making process. By critically reviewing current practice and opening up to creative ideas, a broader range of support could be planned, designed, commissioned and provided, including enabling environments in extra care housing.

Changes at a national policy or societal level should support a fundamental shift away from the current situation to achieve older people's vision.

This means a move away from a 'professional gift model' to a citizenship model, in which services are truly owned by older people rather than gifted to them by professionals. Large-scale changes in society need to focus on understanding ageism and taking a rights-based approach. Political and financial commitments are needed to back up the belief that every older person matters.

Those involved in the study emphasised the need for all sectors, interest groups, Government and society to work collaboratively to ensure that older people's own vision for their future is widely owned and used to shift long-term care away from the current default model of residential care towards a flexible range of different options and opportunities.

Four key areas are relevant to future progress:

- other initiatives commissioned by the JRF's Independent Living Committee and the work being developed by the Office for Disability Issues on implementing the *Independent Living Strategy* commitments for older people with high support needs;
- existing programmes designed to improve the quality of life for older people who currently live in residential and nursing homes (e.g. My Home Life and the Dignity in Care initiative); and the implementation of the housing strategy for an ageing population;
- concurrent debates surrounding long-term care, not least funding debates and developments surrounding the Department of Health's Green Paper on the future of social care;
- current discussions about changes to inspection and regulation arrangements and areas of focus to ensure that key messages from older people with high support needs from this study are taken into account.

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