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How older people interact with the social care system and market

Report based on qualitative research with older consumers

Prepared for:

Which?

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Contents

1. Executive summary

1.1 Introduction

This research was commissioned to give Which? a better understanding of how older people and their families engage with social care-related decisions and the different pathways that are taken. A broad definition of social care has been adopted in this research to include not just formal care services but also aids and adaptations, housing changes and other types of support.

In July 2018, Collaborate Research conducted a total of 29 qualitative interviews with older people (12 of which also involved a family member) who fit into one of the four cohorts of interest:

- 8 interviews were with people who do not live in age-specific housing or receive domiciliary care but are finding it more difficult to cope at home (cohort 1)
- 8 interviews were with people receiving local authority-funded care[1] in their own (non age-specific) home (cohort 2);
- 8 interviews were with people who live in age-specific accommodation but where care is not provided (cohort 3); and
- 5 were with those who live in supported housing and are receiving some care (cohort 4).

The key questions that this research sought to answer were:

- What are the triggers and prompts for engagement with the social care system;
- How and why do older people identify options and make choices;
- What information or advice have they sought to help with these decisions; and
- To what extent, and in what way, are they considering the potential for their needs to change.

1.2 Key findings

1.2.1 The decision-making context

This is both a broad and complex topic, with a wide range of needs and potential interventions, a mixed provision and funding landscape, and often with very vulnerable older people at the centre.

Each individual case is different, making it difficult to generalise about decision-making processes and pathways. However, a common feature is the close connection between health and social care services from the consumer's perspective, as care and support needs are largely driven by health

[1] The focus just on local-authority funded domiciliary care was due to Which? having previously commissioned research with recipients of self-funded domiciliary care

needs. In addition, families often play a major care and support role, supplementing or replacing formal services.

1.2.2 Engagement triggers and prompts

Early engagement tends to be minimal because of future uncertainty, a range of cognitive biases and also because funded services are by nature reactive. This means that the vast majority of decisions are made at the point of need, and often when there is a crisis at which time decision-making can be extremely challenging. The reluctance of consumers to engage can also result in decisions being delayed beyond the point of need and in acquired products and services going unused.

However, some choices are easier to engage than others because older people can see clear associated benefits and there are fewer negative associations or barriers to consideration:

- More positive engagement with: Bathroom changes, household aids to support independent living, day clubs and organised social activities.
- Reluctance to consider: Personal care and aids that are perceived to be clinical or stigmatising.
- Mixed views on: Moving home and the adoption of technology.

1.2.3 Identifying options and making choices

There was a great deal of variability evident in decision-making pathways, reflective of the unique circumstances of each individual, but also some common themes:

- A number of decisions may be required at any one time to respond to complex needs, as well as iteratively over time as needs change.
- When care, aids and adaptations and housing are local authority-funded there is little *choice* and key skills for a positive outcome are 'knowing the system', advocacy and tenacity.
- Even when consumers are self-financing they are choosing in an unfamiliar market and do not necessarily know the available options or what would be best for them.

There was variability evident not just in the decision-making process but also outcomes, depending on factors including financial resources, decision-making support provided by family members and the publicly funded provision in their area.

A number of barriers have been identified to making good choices and getting satisfactory outcomes. Some of these relate to deficits in consumers' understanding and cognitive biases. However, supply-side or systemic barriers are equally important.

1.2.4 Sources of information and advice

Decision-making regarding housing, care and other interventions can be a struggle for older consumers and their families. This is due to most people's lack of prior experience and the

challenges associated with making good choices when dealing with complex health needs or at times of crisis.

Various public sector and voluntary organisations currently provide older people support in different specific areas but there is no definitive 'go to' place. Consumers are looking for more than information signposting and need high quality, tailored and joined up advice.

Particular areas where there is currently a gap in provision include proactive outreach services, 'whole person' support, support specifically for mental health and wellbeing, and continuing support.

1.2.5 Looking to the future

There is a strong tendency among older people not to think or plan too far ahead because of the uncertainty about future needs and also a reluctance to focus on a potentially negative future.

However, this research suggests that older consumers would consider future interventions that support their independent living arrangements and help them avoid or defer the need to go into residential care. In particular, they would be prepared to consider incremental changes that adapt to changes in needs whilst limiting the risk of upheaval.

Adaptive technology could play a future role for some but it should not be overstated, as there are a number of potential barriers to its adoption and use by older people.

1.3 Conclusions and implications

Providing more support at point of need

Consumers tend not to plan ahead for changing needs (especially care) in later life and it can be very challenging for them to self-serve effectively at point of need. The risk of consumer detriment is currently high, and there is a need for more support to help consumers make the best possible choices at this critical time. Information remedies alone will not be enough to achieve this and a significant gap has been identified in providing holistic guidance.

Addressing supply-side and systemic issues

However, this research has shown that suboptimal outcomes are not just caused by deficiencies in individual consumer behaviour. A number of wider systemic and cultural barriers will also need to be addressed in order to reduce consumer detriment:

- For example, there is evidence of considerable variation in publicly funded provision and issues with speed of response and quality.
- While health and care needs are closely linked there appears to be insufficient service-side integration to enable a joined up response to be provided.

- We have identified a particular gap in services identifying and responding to mental health issues and poor emotional wellbeing, which were prevalent across our sample.
- Currently, families often play a major role in providing care and support. This can be due to inadequacies in formal provision and is not necessarily a situation which is either equitable or sustainable.
- A further systemic barrier relates to the negative associations with a number of age-specific products as well as the provision of care services. This is related to a general stigma about ageing, which forms the cultural backdrop to decision-making.

Encouraging positive preparations

This research also indicates some opportunities. While people are clearly reluctant to plan for their potential future care needs, there are indications that some could be motivated to prepare for a good quality later life. We have seen evidence of this from those in our sample who made decisions more proactively, and pre-crisis, such as moving house or adapting existing accommodation to make it more suitable and future proof. In addition, a number reported that measures they have put in place have improved their quality of life, which again is suggestive of the potential for the right types of interventions made at the right time to make a positive difference.

2. Introduction

2.1 Background

2.1.1 General policy context

The current social care system is already under considerable strain and, with an ageing population, it can be expected to become increasingly difficult for people to access the social care that they require. There is much evidence to support this, including:

- By the Kings Fund and Nuffield Trust in late 2016 which found that local authority budget cuts had resulted in more than one quarter (26%) of older people with care needs no longer receiving public funding[2].
- By Age UK in 2017 which calculated that 1.2 million older people in England with a social care need do not receive the help they require[3].
- By Which? in its estimation that a further 42,000 residential care places could be required in England by 2022 to keep up with demand but only 20 local authorities are set to keep pace with this[4].

There are also additional challenges for consumers beyond funding.

On the supply side, there is evidence of variability in the quality of care, with a fifth of residential care homes and a fifth of home care services in England rated by the Care Quality Commission as inadequate or requiring of improvement[5].

From a consumer perspective, social care decisions can be complex and evidence suggests that consumers rarely consider or plan for social care ahead of need. Instead, decisions tend to be made at times of crisis, under stress and time pressure, and from a point of inexperience, which risks leading to suboptimal outcomes.

For example, recent research commissioned by Age UK[6] found that older people regard it as difficult to plan for the future as their future health and care needs are unclear. In addition, some pervasive

[2] *Social Care for Older People: Home Truths* (Kings Fund and Nuffield Trust, September 2016) - https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Social_care_older_people_Kings_Fund_Sep_2016.pdf

[3] *Briefing - Health and Social Care for Older People in England* (Age UK, February 2017) - https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true

[4] Which? Campaign - as reported in https://consumerinsight.which.co.uk/articles/local-elderly-care-beds

[5] *The State of Adult Social Care Services 2014-2017: Findings from CQC's Initial Programme of Comprehensive Inspections in Adult Social Care* (Care Quality Commission, July 2017)– as reported in https://www.which.co.uk/policy/public-services/3203/beyond-social-care-keeping-later-life-positive

[6] *Financial Resilience During Retirement: Stage 2 Qualitative Research with Consumers* (Collaborate Research for Age UK, January 2018) - https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/money-matters/rb_jan18_financial_resillience_qualitative_research.pdf

barriers were identified to the consideration of social care which contribute to a strong sense of negativity and disempowerment in this area. These include:

- General negative associations with catastrophic needs, poor quality care and neglect;
- A lack of consideration of alternative (e.g. domiciliary care) options to care homes;
- A strong view that the requirement to self-fund is unfair;
- An expectation that the cost burden will be very high if residential care is required, meaning that most people's assets will be quickly used up; and
- A lack of belief that making financial provision will ensure they get better quality and choice of care.

The Government is considering how to ensure that the social care system for older people is fit for the future and a policy announcement on this is expected some time in Autumn 2018.

2.1.2 Which?'s focus on later life consumer issues

Later life consumer decisions and issues are a key area of focus for Which?. Some of its activity in this area includes:

- The creation of soon to be re-launched free website to provide independent information on all aspects of care for older people.
- Campaigning for fairer treatment of care home residents, through the *Care Needs Care Now* campaign.
- The recent launch of a policy report, *Beyond Social Care: Keeping later life positive*, setting out Which?'s insights on how consumers engage with social care, ahead of Government's anticipated publication in the Autumn of a new Green Paper on Social Care in England.

To inform its policy on social care for older people, Which? has undertaken a comprehensive evidence review of consumer engagement with the care market[7] and commissioned additional primary research including a population-wide attitudinal survey and qualitative research with self-funders of domiciliary care.

However, a further gap in evidence has been identified on how specific cohorts of consumers engage with the social care system and market at various stages of their journey, and how this varies according to their different circumstances and needs. Which? commissioned this research to add to its evidence base by addressing this gap.

[7] *Planning and Shared Decision Making in Elderly Care: A Scoping Research Review* (Tay, E. and Massaro, S. for Which?, publication forthcoming in 2018)

2.2 Research objectives

Overall, this research was commissioned to give Which? a better understanding of how older people and their families engage with social care-related decisions and the different pathways that are taken. As the available evidence points to pervasive barriers to planning for care, Which? particularly wanted this research to explore whether there are any products or services that older people are prepared to consider earlier and in a more positive way. In addition, as most existing research focuses on attitudes and behaviour with respect to residential care, this research looks at decisions taken by people who continue to live independently.

There were several specific questions that this research has been tasked with answering, including:

- What are the triggers and prompts for engagement with the social care system;
- How and why do older people identify options and make decisions;
- What information or advice have they sought to help with these decisions; and
- To what extent, and in what way, are they considering the potential for their needs to change.

This research adopts a broad definition of social care to include not just formal care services but also aids and adaptations, housing changes and other types of support. It explores both elements provided and funded through local authorities and those accessed through the commercial market and paid for by consumers. In addition, the role of unpaid support provided by family members and the voluntary sector has also been considered.

2.3 Research methodology and sample

Collaborate Research conducted a total of 29 qualitative interviews with older people who fit into one of the four cohorts of interest:

- 8 interviews were with people who do not live in age-specific housing or receive domiciliary care but are finding it more difficult to cope at home (referred to in this report as cohort 1)
- 8 interviews were with people receiving local authority-funded care[8] in their own (non age-specific) home (cohort 2);
- 8 interviews were with people who live in age-specific accommodation but where care is not provided (cohort 3); and
- 5 were with those who live in supported housing and are receiving some care (cohort 4).

[8] The focus on just local-authority funded domiciliary care was due to Which? having previously commissioned research focused on recipients of self-funded domiciliary care

To ensure that respondents would be able to recall previous decisions they had taken regarding their housing and/or care, we required cohorts 2-4 to have been in their current situation for no more than 3 years.

In addition, a cross-section of consumer characteristics and geographies were represented across the sample, including:

- Both men and women;
- A range of ages above 55 years;
- Different income levels;
- Some people from Black and Minority Ethnic (BAME) backgrounds; and
- People living in a number of locations across England including Greater London, Eastbourne, Yate in the South West, in and around Birmingham, and in and around Newcastle.

The interviews all took place in respondents' homes during July 2018 and the average interview length was 90 minutes. Respondents were able to involve their carer or trusted family member in the interview if they so wished. In total, 12 interviews also included a family member which means that 41 individual perspectives were represented in the research.

The interviews were moderated by Collaborate Research's team of senior qualitative researchers led by Monique Rotik. All of the moderators have extensive experience in conducting research with older people and discussing sensitive research topics including related to personal and financial matters.

Respondents were recruited by expert qualitative recruitment agency, Criteria Fieldwork. People were informed in advance that the research was for Which? and provided an invitation letter explaining the purpose of the research.

2.4 This report

This report draws together the main evidence collected from the four cohorts represented in this qualitative research. It is comprehensively illustrated by verbatim quotes, to reflect the flavour of the views expressed older consumers, and is structured in the following way:

- Section 3 summarises the contextual insights to set the scene and help the reader interpret the sections that follow.
- Sections 4-7 directly address the core research questions:
    - What are the triggers and prompts for engagement?
    - How and why do older people identify options and make choices?
    - What information or advice have they sought to help with these decisions?

- To what extent, and in what way, are they considering the potential for their needs to change?

There is also an Executive Summary that precedes this Introduction, and a final Conclusions section that sets out some implications for Which? and others to consider in response to the findings.

3. Decision-making context

Key points

- This is both a broad and complex topic, with:
    - A wide range of needs and potential interventions:
    - A mixed provision and funding landscape: and
    - Often very vulnerable older people at the centre.
- Each individual case is different making it difficult to generalise about decision-making processes and pathways.
- However, a common feature is the close connection between health and social care services from the consumer's perspective, as care and support needs are largely driven by health needs.
- In addition, families often play a major care and support role, supplementing or replacing formal services.

3.1 Older people have a wide range of care and support needs

A **wide range of care and support needs** were reported across our sample, including related to:

- Managing health conditions;
- Ensuring safety and security;
- Conducting personal and household tasks;
- Mobility around the home;
- Getting out and about;
- Social interaction and wellbeing; and
- Decision-making and administration.

These are not mutually exclusive and a number of respondents had **multiple needs**.

Most of these needs relate not just to age-related frailty but also to associated **health conditions, disabilities** and/or **declining capacity.**

All of those interviewed expressed a strong desire to manage their needs in such a way as to allow them to continue living **as independently as possible** and, importantly, to avoid or defer the need for residential care.

"I'd be alright if I maintain my independence or I had assisted living or something, but I wouldn't want to go into care. Obviously, if I had to, I would have to, but it's not something I would be happy about." (Older person living in non-age specific housing and not receiving care, Eastbourne)

3.2 A vast array of interventions currently support older people

This research was intentionally focused on decisions related to the social-care system, including concerning **aids and adaptations, housing changes and domiciliary care**. Each of these categories spanned an **extensive array of interventions** across our sample:

Aids	• Household aids such as bath chairs, toilet frames, commodes, reclining chairs, specific types of beds, perch chairs, tip kettles, flip taps, grabbing devices etc. • Mobility aids such as sticks, walkers, Zimmer frames, wheelchairs, mobility scooters etc. • Personal aids such as personal alarms, key finders, accessible mobiles etc.
Adaptations	• Bathroom changes, stair lifts, ramps and rails etc.
Housing changes	• Downsizing and different types of age-specific housing (e.g. for the 'actively retired', sheltered, extra care)
Domiciliary care	• Personal care, meal preparation, administering medication, housekeeping, accompanied walks etc.

In addition, **health services** were normally critically important in helping older people to continue living independently given their often multiple and complex health needs. In particular, respondents referred to the contribution of primary health services such as their GP as well as district or community nurses where this service exists. In addition, there were mentions of specific secondary health services such as fall clinics, rehabilitation services and palliative care services.

Another key insight from this research was the central care and support role often fulfilled by **older people's families.** This included undertaking research to inform decisions on interventions, plugging gaps in formal care or acting as primary care givers, and conducting financial administration for their older relative.

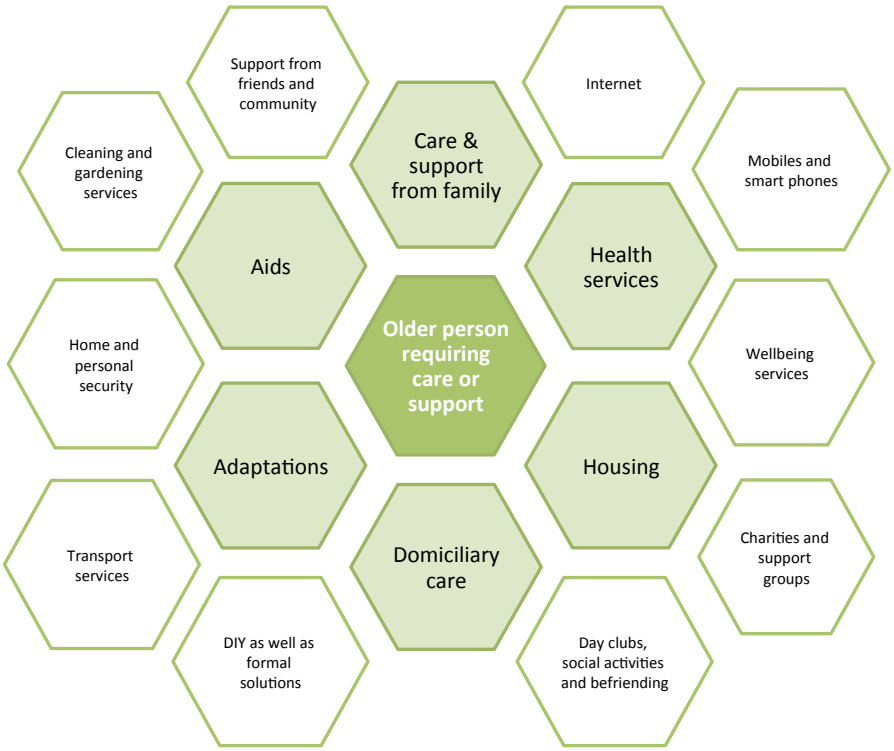
Beyond this, a **range of other interventions** also contributed to supporting the lives of different individuals:

- Day clubs, arranged social activities and befriending services;
- Transport services such as subsidised taxi services and community transport;
- The internet and mobiles for those with access and the skills and confidence to use them;
- Home and personal security systems such as secure entry and emergency pull cords, particularly for those living in age-specific accommodation;
- Cleaning and gardening services;
- Charities and support groups;
- Wellbeing services such as keep fit classes and tai chi; and
- Friends and the wider community, e.g. the church.

A further learning is that some people have applied **'do it yourself' remedies** instead of formal solutions to meet a particular need. For example, some people preferred to have a daily check-in call arrangement with a friend rather than to use a personal alarm.

This whole mosaic of potential interventions is illustrated in Figure 1, over the page.

Figure 1: Range of potential interventions for older people requiring care or support



3.3 Needs are met via a combination of public, private and unpaid provision

Another aspect adding complexity to consumer decision-making in this area is the mixed provision and funding landscape, which includes **local authorities,** the **commercial market** and the role of **unpaid (typically family) care and support**. For example, across our sample:

- People tended to access some aids and adaptations from their local authority if they were eligible but often also purchased their own if they had the means (e.g. if they wanted more choice or there was a delay in local authority provision).
- Some of those who had moved home had purchased privately while others lacked the financial resources to do this and were reliant on local authority or housing association provision.

- With domiciliary care, the focus of this research was on local authority provision[9] but formal arrangements were in many cases heavily supplemented by unpaid care provided by family members.

3.4 The majority with care and support needs are vulnerable consumers

A range of consumer characteristics and circumstances have been represented in this research. However, one common feature is that most respondents could be considered to be **vulnerable.** For example, several reported **mental health issues** or poor emotional wellbeing ranging from mild to severe which mainly related to the experience of dealing with increasing needs and disability. There were also other forms of vulnerability including their **partner dying or going into residential care**, **reduced capacity and/or confidence** in decision-making, and being **housebound or socially isolated**.

"Well, I'm very depressed at the moment. I've had counselling and I've had group therapy. I'm getting over a mastectomy but I'm not saying that's what made me depressed. It was the pills. The pills made me tired and I didn't want to do anything." (Older person living in non-age specific housing and not receiving care, Greater London)

"I have to be housebound, I suppose you'd call it…It's just hit me hardest coming all quickly. That's what it probably is, being [an] active sort of person, now I have to do a lot of sitting about." (Older person living in age specific housing and not receiving care, Newcastle)

This preponderance of vulnerable older consumers is significant because it means that they are less likely to be able go it alone in decision-making and more likely to **require external guidance and potentially also advocacy.**

[9] As mentioned in the Introduction, this is because Which? conducted previous research with self-funders of domiciliary care

4. Engagement triggers and prompts

Key points

- Early engagement tends to be minimal because of future uncertainty, a range of cognitive biases and also because funded services are by nature reactive.
- This means that the vast majority of decisions are made at the point of need, and often when there is a crisis at which time decision-making can be extremely challenging.
- The reluctance of consumers to engage can also result in decisions being delayed beyond the point of need and in acquired products and services going unused.
- However, some choices are easier to engage with than others because older people can see clear associated benefits and there are fewer negative associations or barriers to consideration:
    - More positive engagement with: Bathroom changes, household aids to support independent living, day clubs and organised social activities.
    - Reluctance to consider: Personal care and aids that are considered to be clinical or stigmatising.
    - Mixed views on: Moving home and the adoption of technology.

4.1 Social care-related engagement is almost always reactive

For the vast majority of older consumers represented in this research, social-care related decisions were made **reactively**, having been triggered by a change in their circumstances and needs. Often, such decisions were taken at a time of **health-related crisis** and at which time decision-making was extremely challenging.

However, there was not always a single trigger and in some cases **cumulative factors** contributed to decisions being taken once the consumer reached a tipping point. For example, some spoke of increasingly feeling that they were struggling to cope at home, or about having increasing fears for their personal safety due to progressive health conditions or following the experience of successive falls.

External parties were often the instigator of the decision-making process, and a key influencer, especially at points of crisis such as diagnosis of a serious health condition or fall requiring a hospital admission. For example, in a number of cases a GP referral, hospital discharge process or family members' intervention led to the care or support arrangements being put into place for older people. Formal interventions by primary or secondary care services are by nature reactive and only possible to activate at the point of need.

A **minority engaged more proactively and positively**. This mainly applied to **housing-related decisions** such as moving to a more suitable home or adapting existing accommodation to make it more suitable and future proof. There appears to be a finite window for this type of engagement as most who had made such decisions had fewer or less complex health needs. Obviously, the ability to make proactive decisions of this nature also requires adequate financial resources to be present.

4.2 There are some pervasive barriers to early engagement

A number of barriers to early engagement have been identified in this research, some of which map onto known **cognitive biases and heuristics**.

For example, we found evidence of **fear of regret contributing to inertia**. This relates in part to the **lack of familiarity** with the social care system, as most had no prior experience of making decisions in this area. This led to them worrying about making the **wrong choices**.

A particularly strong example of this was evident in some respondents' strong **attachment to their long-term home**. This contributed to reluctance to contemplate moving because of the expected upheaval of the process alongside uncertainty about whether they would be happy in a new home and potentially new area.

> *"I'd like to stay in this house. It's just that it's very familiar. I've been here for so long. My life has always revolved around South East England."* (Older person living in non-age specific housing and not receiving care, Greater London)

However, improving people's understanding of the care system is unlikely in itself to compel them to engage with it more proactively. We also identified a range of **other pervasive barriers,** including:

- A general **reluctance to focus too much on the future** indicating **present or status quo bias**. This was in part due to the uncertainty about future needs at an individual level, but also because people worried that trying to plan for all possible eventualities outside their control might be counterproductive and could lead to a negative mindset that would detract from their intention to make the best of life now.

> *"You never know what the future brings, do you? The present, we're okay. I'm very much of a 'cross this bridge when we come to it' kind of person."* (Older person living in age specific housing and not receiving care, Birmingham)

- A strong drive to **remain independent** which, for a number of people, acted as a deterrent to seeking help. In some cases, this was linked to an overestimation of one's physical capabilities. It was also related to a desire to avoid becoming reliant on help or aids, which is in part a legitimate concern to avoid becoming over-disabled.

"I didn't want [help] obviously, I wanted to be independent. I still want to be independent but can't be." (Older person living in non-age specific housing and receiving care, Yate)

- Concerns about **costs and affordability** where self-funding. This was particularly true for housing changes, as downsizing does not always mean paying less. It also applied to bigger ticket adaptations such as stair lifts and bathroom changes.

"It's down to the financial thing, isn't it? If you've got the money to have these things that can help you in your everyday life, and to keep you safe, that's great, but if you haven't got the money to do it, then what's the point?" (Family member of older person living in age specific housing and receiving care, Greater London)

- **Negative perceptions of formal care and certain aids**. With care, the initial association tended to be with worst-case scenarios and care homes. Some had also heard negative reports of carers in the media. In addition, there was a reluctance to consider certain aids which were felt to be overly clinical or stigmatising (especially wheelchairs and commodes).

"I've heard horror stories from other people and I know we're lucky to get [the carers] we've got." (Family member of older person living in non-age specific housing and receiving care, Birmingham)

"I hate this damn chair… Do you know what, when you're in a wheelchair people pretend you're not there, its awful." (Older person living in non-age specific housing and receiving care, Yate)

The impact of this general reluctance of consumers to engage can also be that decisions get **delayed *beyond* the point of need** and some acquired **products and services go unused** as people try to manage without them even if they require them.

4.3 Some choices are easier to engage with than others

Some choices are inherently easier to engage with than others, mainly because they are perceived to have **clear benefits** and **fewer negative associations** or barriers to consideration. Once in place, some of these interventions are reported to have had a **marked positive impact** on older people's lives, including:

- Products and adaptations to make **bathrooms easier and safer to use** independently e.g. shower rooms, downstairs toilets, walk in baths, bath and shower chairs etc.

> *"When I'm sitting down, I mean, the shower's above you, and I've thought, 'God, I should have had this before.' It's absolutely wonderful, actually."* (Older person living in non-age specific housing and not receiving care, Birmingham)

- Other **household aids and adaptations that support safety, comfort and independent living and people get the benefit from every day**, e.g. grab handles, rails on stairways, reclining chairs and adjustable beds. Overall, people tend to welcome aids and adaptations that are relatively unobtrusive, easy to use and ideally have good design and aesthetics.

> *"Things that you need every day, that type of help. They put on things to help you to get out of the bed, sort of rails on the side. They're just a little rail that you put underneath the mattress on the side of the bed and everything. Something to sit in the shower, and things like that. Things to pick things up, handy grabber things."* (Older person living in non-age specific housing and not receiving care, Newcastle)

- *"***Day clubs and other organised activities** to provide the opportunity for social interaction and mental stimulation.

> *"There isn't one day when [mum] doesn't go out… she's made a good selection of friends. I think having her stimulated every day is really important as it's kept her 8 years down the line (from Alzheimer's Diagnosis) still really lively, still active and still able to communicate with people."* (Family member of older person living in non-age specific housing and receiving care, Greater London)

On the other hand, evidence from this research suggests that there is a general reluctance to engage with decisions which have **largely negative associations** such as:

- **Formal care**, especially where it involves **personal care,** as this represents a loss of independence and can be seen as dehumanising.

"I don't like people helping me in the shower and washing my hair. I don't like the personal part of it. I can put up with them putting the kettle on for me or hanging my washing out but I don't like personal care, I must admit." (Older person living in non-age specific housing and receiving care, Yate)

- **Aids** which are perceived to be **clinical or stigmatising**. This particularly applies to wheelchairs, commodes and toilet seats but there was also an apparent reluctance to use personal alarms and to have grab rails outside houses as each are associated with being visible markers of old age and frailty.

"I wouldn't have had a wheelchair if I'd have had had my way, because I feel completely out of it then when I'm in it. I hate it." (Older person living in non-age specific housing and receiving care, Yate)

"The toilet seat, at the moment it's in the boiler room. I'm saying I'll try and manage without it." (Older person living in age specific housing and not receiving care, Birmingham)

"We might get [a personal alarm] later. Maybe if there's just one of us. We're fine now." (Older person living in non-age specific housing and not receiving care, Eastbourne)

There were **mixed views expressed about moving house**. Moving to more suitable accommodation (e.g. smaller, single level, closer to family, closer to amenities, with adaptations, with additional facilities and support in the case of age-specific accommodation) can be associated with a **positive future vision** for some people who are still relatively fit and well and have the required financial resources. However, for others, and particularly those who are still living in their long-term home,

there was sometimes a strong resistance expressed to consider moving due to the anticipated **upheaval and loss of familiar environment.**

> *"I've had a few moves since I've been on my own and wasn't scared of moving but a lot of people are really afraid. If they've lived in their house 40-odd years and they're frightened of moving. It's a big thing to move. It's a traumatic thing and they've got all that stuff."* (Older person living in age specific housing and not receiving care, Birmingham)

4.4 Mixed engagement with technology

Whilst not a primary objective, this research also explored engagement with technology to support older people to remain living independently.

We found that some were using 'standard' technologies such as **the internet and mobile phones**, including smart phones.

In addition, there were examples across the sample of the adoption of **age-specific and adaptive technologies**, including:

- Large button mobiles;
- Alarm pull cords within the accommodation and personal alarms;
- Entry security systems including cameras and a bogus call button; and
- Remote monitoring and telecare systems.

In most cases, the decisions to acquire adaptive technologies were ***not* made by the older person themselves but by others,** such as family members or the management of their accommodation. It tended to be these other decision-makers who were most enthusiastic about the technologies. For example, the quote below relates to monitoring technology set up by family members to help an older person with dementia live safely in her long-term home:

> "*We've got cameras. There's like a motion alert, that's one there. The front door is on a motion alert, so as soon as there is a motion there it will bleep our phones, iPads, and we've all got access... The cameras are a peace of mind for us all and I think, personally… so that I can try and get my life back a little bit."* (Family member of an older person living in non-age specific housing and receiving care)

Overall, **some older people were also happy to adopt** technologies and could identify benefits to using them.

> *"Thank god for the internet really, because it's a lifeline. General things you can find out… People who aren't computer literate must be so frustrated."* (Older person living in age-specific housing and not receiving care, Greater London)

However, **others were reluctant** to consider them due to:

- A lack of awareness of what is available;
- Negative associations with certain technologies such as personal alarms, (as reported in the previous section); and
- A lack of interest in new technology generally.

> *"I'm just too old and set in my ways to be wanting to be involved in the new technology. I mean, that's a smart television so, technically, if I had the internet I could switch that on and use that as, like, a computer, you know. I'm not interested."* (Older person living in non-age specific housing and receiving care, Newcastle)

There were also some people who have been **excluded from using technology for accessibility reasons**, including:

- Lack of broadband access at home[10];
- Lack of affordability;
- Lack of skills or confidence in using the technology; and
- Physical barriers to use such as dexterity issues, tremors and visual impairments.

[10] According to an Ofcom report from 2017, 37% of those aged 65+ and 51% of those aged 75 do not have broadband access at home - https://www.ofcom.org.uk/__data/assets/pdf_file/0018/105507/internet-use-attitudes-bulletin-2017.pdf

"The keyboards on an iPhone, they're too small for me. See, I thought I'd be able to get an iPhone, which I did. I thought I'd be able to get Uber, or something like that, as a taxi service. But I can't type the address, or by the time I've typed the address I don't want to go there anyway. So, it's a physical disability that prevents me doing it." (Older person living in non-age specific housing and not receiving care, Greater London)

5. Identifying options and making choices

Key points

- There was a great deal of variability evident in decision-making pathways, reflective of the unique circumstances of each individual, but also some common themes:
    - A number of decisions may be required at any one time to respond to complex needs, as well as iterative decision-making over time as needs change.
    - When care, aids and adaptations and housing are local authority-funded there is little *choice* and key skills for a positive outcome are 'knowing the system', advocacy and tenacity.
    - Even when consumers are self-financing they are choosing in an unfamiliar market and do not necessarily know the available options or what would be best for them.
- There was variability evident not just in the decision-making process but also outcomes, depending on factors including financial resources, decision-making support provided by family members and the publicly funded provision in their area.
- A number of barriers have been identified to making good choices and getting satisfactory outcomes. Some of these relate to deficits in consumers' understanding and cognitive biases. However, supply-side or systemic barriers are equally important. In particular, a number of those who rely on funded services reported issues in dealing with local authorities to get the support they needed.

5.1 Not one common process but some general themes

Overall, social care decisions are perceived by older people and their families to be **very different to other consumer choices**. For example, consumers often had no prior experience of making these types of decisions and the intersection of the social care system, health system and commercial marketplace added to the complexity of decision-making.

Not surprisingly, there was a great deal of **variability evident in decision-making pathways** reflective of the unique circumstances of each individual. The approach of different consumers was influenced by factors such as:

- Their **individual needs**, including how complex these were and whether or not they were at a point of crisis when the decision needed to be taken.
- The **type of choice**, as their decisions could have been related to moving house, introducing domiciliary care or putting in place aids, adaptations or other types of support.
- Their **financial resources**, which had a major bearing on the choices available to them.

However, there were also some **general themes** apparent across the sample:

- This type of decision-making is more accurately described as a **consumer journey** rather than a single process. There were often different stages when decisions were required and iterative decision-making as needs change.
- A **number of decisions** are often required at any one time in order to put in place the mosaic of interventions needed to respond to complex needs.
- **Decisions are typically shared** and the **main decision-makers are often family members** rather than the recipient of the intervention.

There was variability **evident not just in the decision-making process but also outcomes**, depending on factors including financial resources, decision-making support provided by family members and the publicly funded provision in their area.

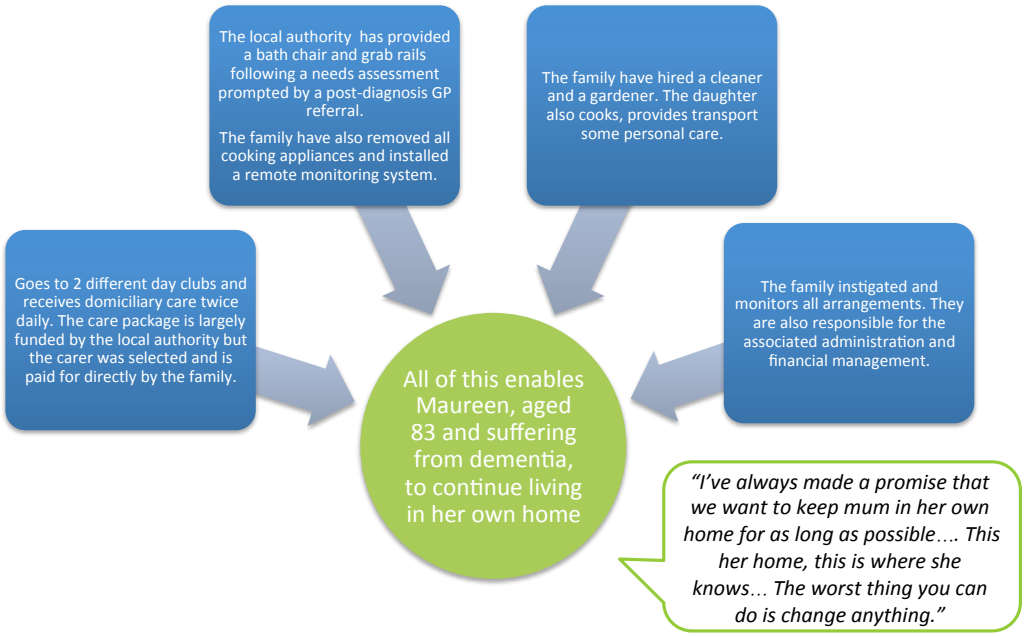
Those who are reliant on local authority funding often felt they have **very limited choice and some described a *"battle"*** to get an adequate response.

5.2 Example pathways

The case studies to follow are designed to illustrate the diversity of consumers' experiences.

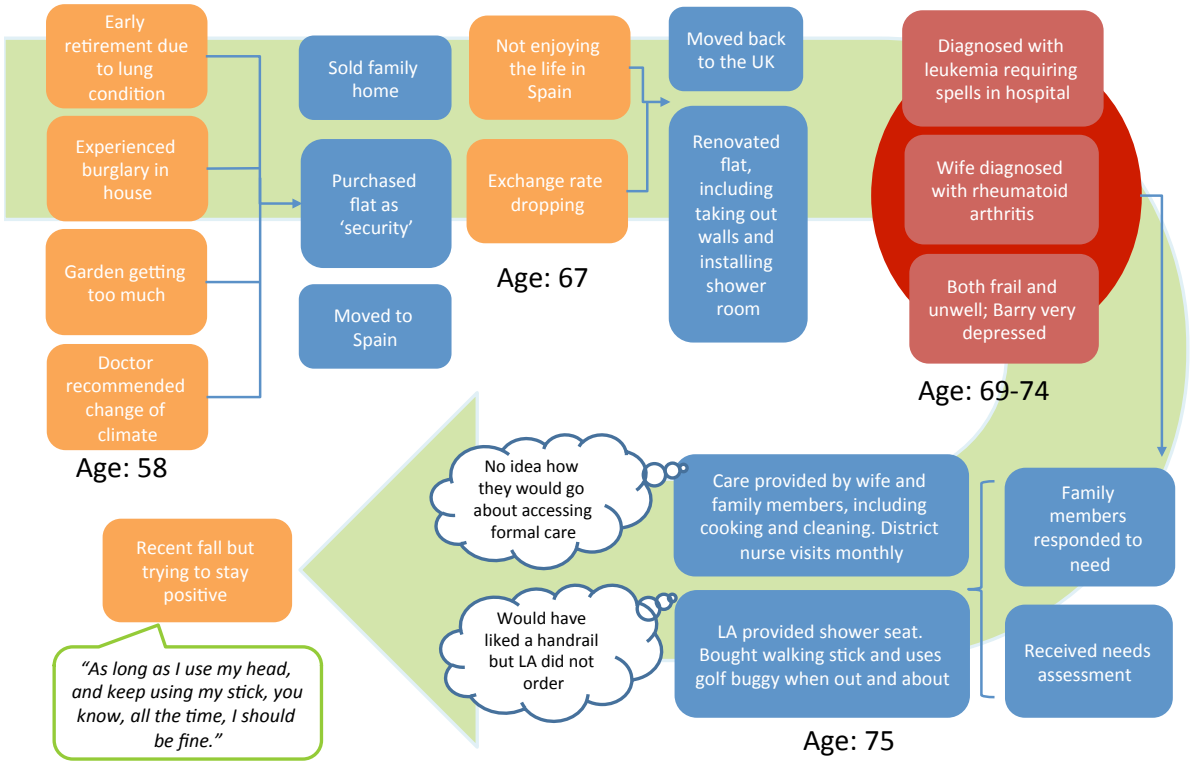
The first example over the page (Figure 2) shows the **range and complexity of decisions** that need to be taken in order to support independent living for some older people. It also demonstrates the **significant role played by some families** in decision-making as well as providing support to maintain arrangements.

Figure 2: Maureen (living in non-age specific housing and receiving care, Greater London)



The second example to follow (Figure 3) shows the **longitudinal decision-making journey** undertaken by some older people, with different decisions made iteratively as their circumstances and needs change. It also highlights the challenge faced by people who need to make **decisions at points of crisis** and how not having any prior decision-making experience can mean consumers **lack understanding of system** and how to get the best out of it.

Figure 3: Barry (living in non-age specific housing and not receiving care, Birmingham)

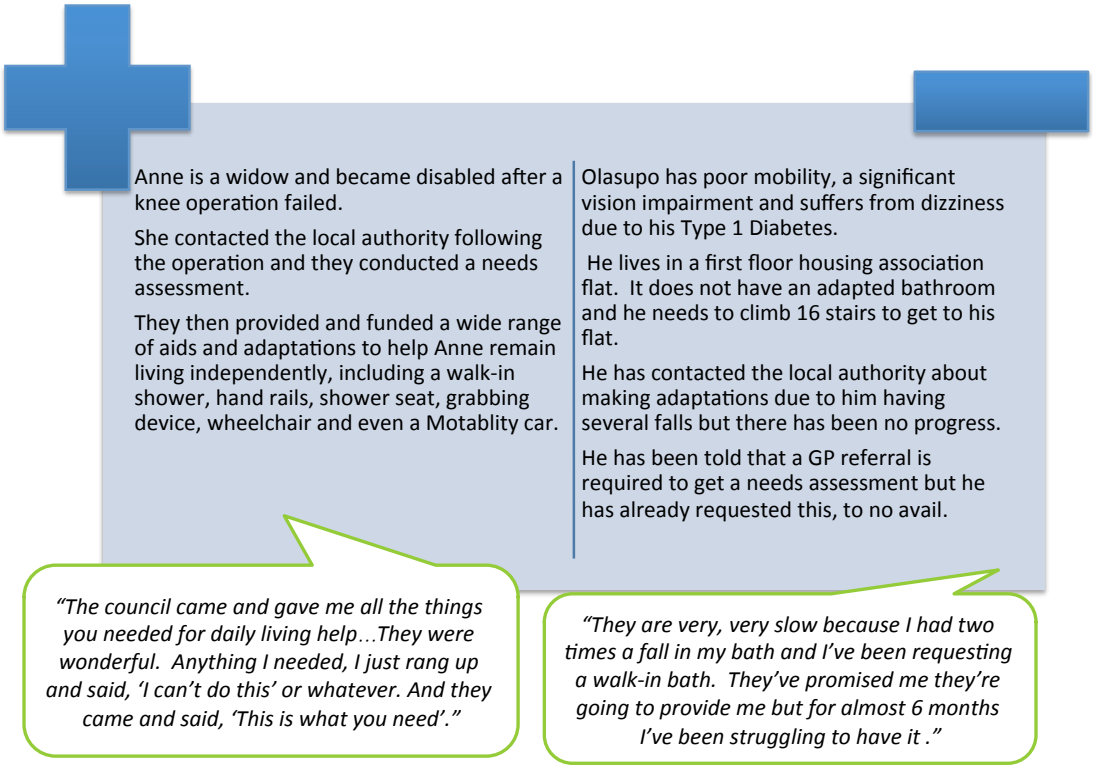


5.3 Decisions on aids and adaptations

There was a **great deal of variability** in the decision-making processes reported for aids and adaptations, as well as in consumers' satisfaction with the outcomes.

The first examples over the page (Figure 4) were each reliant on their publicly funded provision but they received **very different responses from their respective local authorities**.

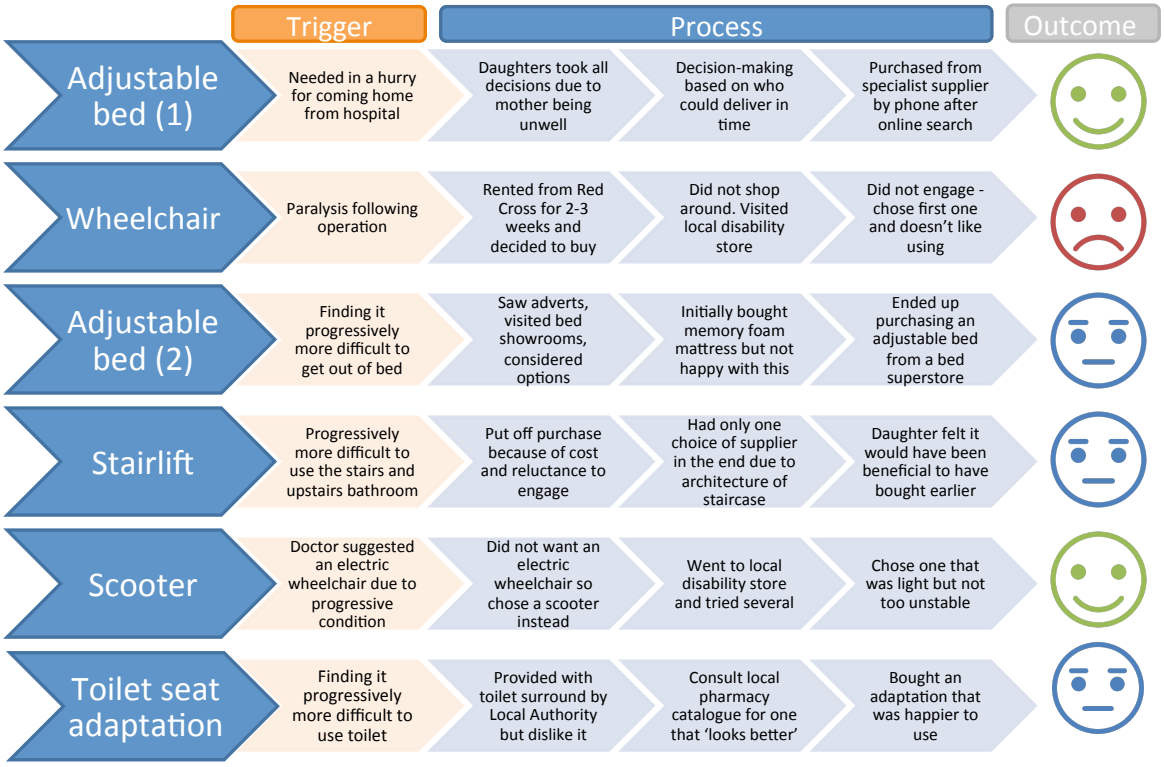
Figure 4: Examples of consumers' experiences with seeking publicly funded aids and adaptations



There was also considerable **variability in the process for choosing self-financed aids and adaptations,** as shown in the examples illustrated in Figure 5. Some of the purchases were made at times of crisis and time critical while others were made due to progressive difficulties rather due to an emergency trigger. For many, decision-making was shared and other family members were the primary decision-makers in some cases due to the health of the recipient. The people making the decisions were not always aware of the range of options available or able to fully compare the market.

In addition, there were **variable outcomes reported**. The timing of the purchase had a bearing on this as well as the extent to which the individual had choice in the solution. However, even where the outcome was satisfactory people were often not happy that they needed the aid or adaptation hence the outcome is scored as neutral rather than positive.

Figure 5: Examples of consumers' experiences in choosing self-financed aids and adaptations



5.4 Decisions on housing changes

As with aids and adaptations, there were a number of **differences in the processes reported among those who have moved home,** and **some were more satisfied than others** with their outcomes.

As previously mentioned, this research intentionally focused on people who had moved to housing which is specifically designed for people over 55 or 60 years. However, it became apparent from the interviews that there was considerable variation in experiences of such age-specific accommodation, including:

- Differences between those who have **purchased privately and others who are renting** from their local authority or housing association.
- Differences between those who have moved into **sheltered or extra care accommodation**, and others whose accommodation is billed as being for those who are **'actively retired'** and more self-sufficient.

- Differences based on variations in **levels of facilities and support available** in the accommodation they have moved to, from very little or no extra facilities or support to extensive communal facilities and an onsite manager or warden service.

Overall, **some consumers were very satisfied** with their choice of age-specific housing which they believe has had a positive impact on their lives. Features that were particularly valued (where provided) included:

- Emergency alarms and a secure entry system;
- Accessible design, with lifts and shower rooms;
- Communal facilities such as gardens, lounge and laundry;
- Social activities and a sense of community; and
- The support provided by the warden or house manager where this service exists.

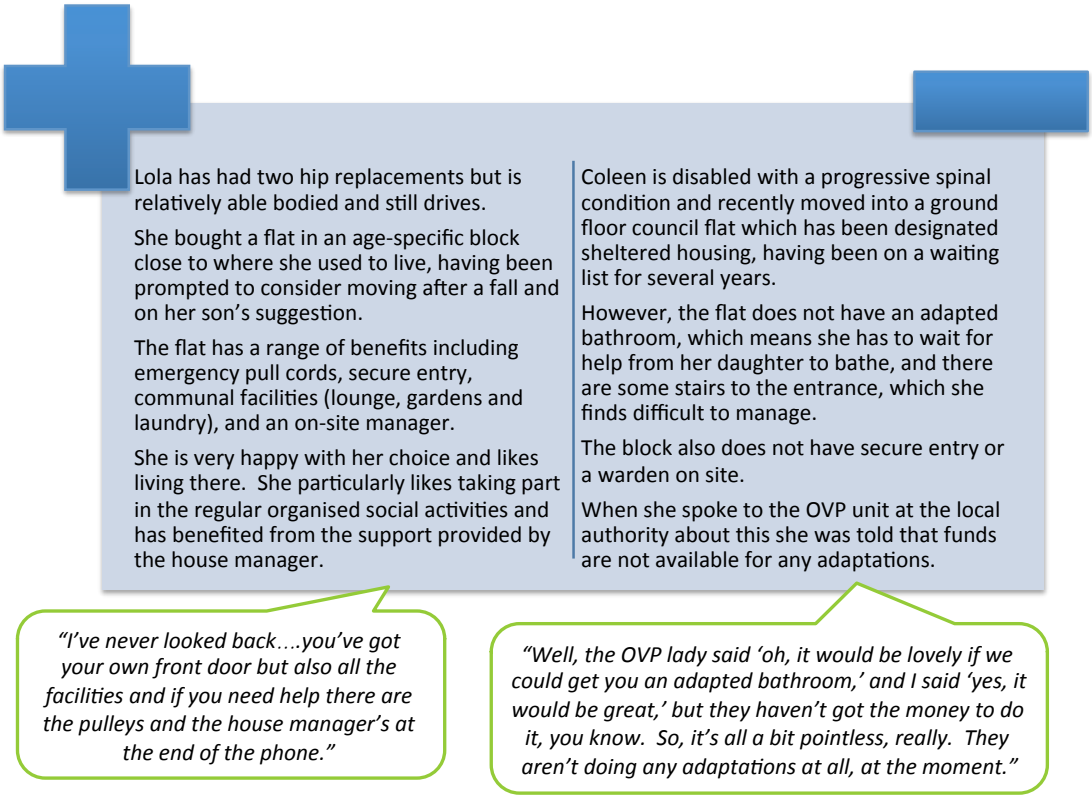
The **support offered by the warden or house manager** was reportedly considerable in some cases:

> *"It's when I've had anything that I've needed. If anybody has a problem with anything to do with the flat. I mean, anything. If your washing machine or your cooker goes, obviously, she might have somebody, I mean, I have telephone numbers. Then, she will tell you or give you their phone number. Anything I've had wrong, she'll come up and have a look. She's very kind, very helpful."* (Older person living in age specific housing and not receiving care, Greater London)

> *"I'm content because the care manager and deputy manager are so good. I receive care on time and if I needed more help they would give it to me immediately."* (Older person living in age-specific housing and receiving care, Greater London – this individual lives in an extra care facility where 24/7 care services are provided on-site)

Those who selected their housing from the private market tended to be more satisfied as they had more choice available to meet their specific needs and preferences. By contrast, some those who have needed to rely on local authorities to provide their accommodation reported shortages in suitable stock meaning they had to wait and make do with housing that did not fully meet their security, accessibility and support needs. These differences are illustrated in Figure 6 over the page.

Figure 6: Examples of consumers' experiences in choosing age-specific housing



A number of those who were renting from **local authorities or housing authorities** also reported that their **warden service had been downgraded or was not meeting their expectations**:

"When I moved in we had a full-time manager which was brilliant. You could talk to her about anything but she would also, if you had paperwork to sort out, she would help you with that… But she's now gone. We've had three different scheme managers since she left and that's in only just over 12 months. They're part-time and basically they don't do the same sort of things that the other lady used to do." (Older person living in age specific housing and not receiving care, Eastbourne – this individual rents from the local authority)

"The warden here is not very helpful. He's supposed to check in on my mum every morning but he's stopped doing that for some reason. Any issues that he's supposed to help with, it's a struggle to get assistance." (Family member of older person living in age specific housing and receiving care, Greater London – this individual rents from a housing association)

However, **even for those who purchased privately, the age-specific housing they chose did not always meet their needs**. Some reported **snagging issues** that they were struggling to resolve with management. Some also worried about **ongoing fees** and whether these would rise and become unaffordable.

"When we came here, there were an awful lot of problems. Bad workmanship. One was unbelievable, one was a water leak. It would take me five or ten minutes to explain it, but it was really bad…. We had to have a new kitchen worktop because they used the wrong type of adhesive, or that's what they were saying." (Older person living in age specific housing and not receiving care, Birmingham – this individual purchased privately)

"Since I've been here, the ground rent and all of that has kept going up every year, which is very wrong. We hope it doesn't go up anymore." (Older person living in age specific housing and not receiving care, Greater London – this individual purchased privately)

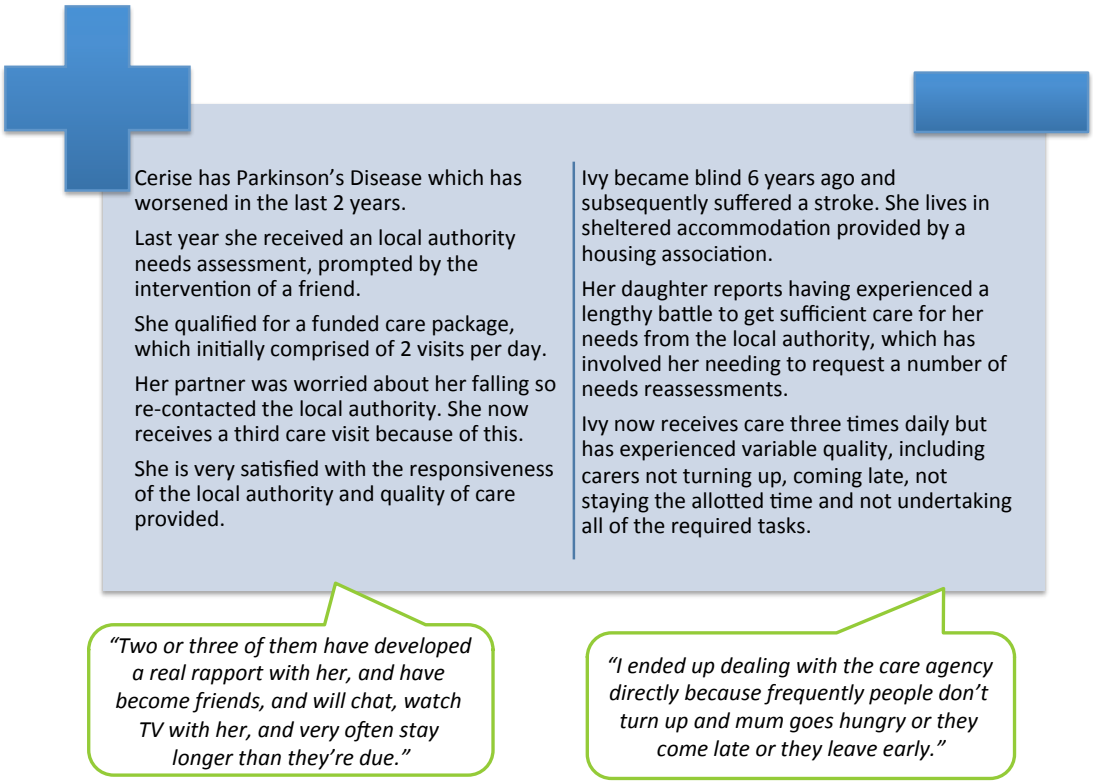
5.5 Decisions on domiciliary care

With respect to decisions about domiciliary care, this research intentionally focused just on people who received local authority funded provision. However, notwithstanding the relatively tight parameters around this cohort, there were differences in people's experiences. These reflected:

- **Variations in the level of provision and eligibility criteria between different local authorities**, indicative of a postcode lottery with 'winners and losers'.
- **Variability also in the quality of care** delivered once arrangements had been set up.

The two illustrative examples detailed in Figure 7 below detail the experiences of respondents living in two different boroughs of Greater London. **One is very happy** with her experience of dealing with the local authority and with the care she now receives. **The other describes a lengthy *"battle"*** to try to get her mother the care she needs due to her multiple and complex health conditions. She feels that the **quality of care being provided is still not satisfactory** meaning that the battle for the family continues. This second case study also indicates that **different skills to other types of consumer decision-making** are required to deal with local authorities regarding care. These include 'knowing the system', advocacy and tenacity.

Figure 7: Examples of consumers' experiences in seeking publicly funded domiciliary care



5.6 Barriers to making good choices

When care, aids and adaptations and housing are local authority-funded there is perceived to be **little *choice*** and key skills for a positive outcome are 'knowing the system', advocacy and tenacity.

Even when consumers are self-financing they are choosing in an **unfamiliar market** and do not necessarily know the **available options or what would be best for them**.

This research has identified both barriers related to the behaviour of individual consumers and wider, systemic obstacles.

5.6.1 Behavioural barriers

Overall, **lack of awareness** across many areas is a major barrier to making good choices. Some particularly **poorly understood aspects** across the sample included:

- The role of local authorities in provision of social care, the needs assessment process and funding thresholds/entitlement (for those without prior experience of this).
- Specific types of products and services such as extra care or assisted living accommodation, more specific aids and adaptations, and additional types of support such as befriending services.
- Additional options available to those receiving publicly funded care including to choose their own carer and pay them directly.

One of the impacts of low awareness is **availability bias**. For example, a number of those making self-financed choices deferred to known options rather than fully searching the market.

Another effect of consumers' lack of understanding is that they are **not well placed to challenge the social care system** if they receive a suboptimal response**.** Low awareness of how publicly funded services work, together with low expectations, meant that consumers in this research tended to be grateful for what they got rather than to question it.

Other behavioural barriers include:

- Lack of interest, confidence or capacity to make good decisions;
- Lack of time to consider options fully or shop around (if the decision is urgent); and
- Lack of decision-making support (for those without involved family members).

5.6.2 Systemic barriers

There are also some significant **systemic barriers**. For example, major adaptations and aids, and housing moves are **not affordable** for a number of people and not all among these would be eligible for publicly funded services.

> *"I would like a stair lift, that's the only thing. If I got a stair lift I would be over the moon, but it's the money."* (Older person living in non-age specific housing and not receiving care, Newcastle)

"We just can't afford that [retirement flat]. It was all, like, the extras that you had to pay, you know, like the upkeep of it, and all things like that." (Older person living in non-age specific housing and receiving care, Yate)

In addition, a number of those who do qualify for public funding reported **barriers in dealing with local authorities** to get the support they need. These barriers apply to all stages of the process, from assessment, determining entitlements through to implementation:

Assessment	• The onus is on the consumer to be aware of the process and apply. • Consumers often perceived (or had been told) that a GP referral would be required to activate the needs assessment process.
Entitlements	• There was reportedly considerable variation in provision and eligibility thresholds across different local authorities in this research. • Care packages were often regarded as insufficient to meet needs by older people and their families.
Implementation	• Some have experienced a lengthy wait to receive aids and adaptations. • A number reported poor or variable quality of the domiciliary care provided. • There is perceived to be insufficient supply of suitable local authority or housing association accommodation for older people.

"I assumed there'd be lots of care available but it was a huge, huge struggle, years and years trying to get the right care because the social services. They try and give you as minimal as possible and then you have to try and prove that she needs more care or more time with the carers because of this reason or that reason." (Family member of older person living in age specific housing and receiving care, Greater London)

"I think it's one of those things, isn't it? As the funding starts drying up, or it's withdrawn, or they're closing that service, and this service, then I think it does get harder to achieve what they're saying is their threshold." (Family member of older person living in non-age specific housing and receiving care, Birmingham)

6. Sources of information and advice

Key points

- Consumers are unlikely to self-serve effectively given their lack of familiarity with these decisions and the challenges associated with making good choices when dealing with complex health needs or at times of crisis.
- Different organisations provide support in different areas but there is no definitive 'go to' place.
- Signposting is not enough and consumers need high quality, tailored and joined up advice.
- Particular areas where there is currently a gap in provision include:
    - Proactive outreach services;
    - Whole person support;
    - Support for mental health and emotional wellbeing; and
    - Continuing support.

6.1 Challenging for consumers to find and make sense of information

Consumers feel that while relevant information is probably out there, it is **challenging for them to find and make sense of**. This is particularly true for those with significant **health or capacity issues**, **no family members to help** with the research, or who are **not internet users**.

Services that would be expected to play a signposting and advisory role - such as GPs and hospitals, and third sector organisations such as Citizens Advice - are perceived to be under **significant resourcing pressure** which impacts their ability to support people who need it.

> *"You used to be able to go to CAB, didn't you? Well, you can't get hold of them, for love or money, anymore…You know, you go to the doctors now and you've only got a 5 minute slot."* (Older person living in age specific housing and not receiving care, Greater London)

There were also a number of reports of **difficulty finding the appropriate place to ask**, particularly within government bodies, and being passed around.

> *"Social services don't get involved. They put it on the family if there's an issue to sort it out. If you don't know how to or can't then they're still reluctant."* (Family member of older person living in age specific housing and receiving care, Greater London)

This contributes to a sense of being **forced to 'go it alone'**, which requires significant time and tenacity, and represents a considerable burden on older people and their families who need to make the decisions.

> *"You're literally diagnosed [with Alzheimer's] and you are on your own. You're given a couple of leaflets, but I thought, 'Okay, what do we do now?'"* (Family member of older person living in non-age specific housing and receiving care, Greater London)

There were reports of finding out things largely **accidentally or through word of mouth**, rather than through more official sources.

> *"I just feel that we're not given all the information that we should be. It's like with the water company, they don't say 'oh, yes, you can get 25% off'. You've got to find this out for yourself."* (Older person living in age specific housing and not receiving care, Eastbourne)

6.2 Different organisations provide support but no one-stop-shop

Some organisations and individuals were mentioned as providing **support in specific areas**. These were mainly **medically-focused**, including district nurses where these existed, palliative care services and charities providing support for specific medical conditions (e.g. Alzheimer's Society, Dementia UK, British Heart Foundation, the Stroke Association etc.). In addition, **Age UK** was mentioned several times and was variously used for help in determining benefits assessments, setting up powers of attorney and befriending services.

While Age UK is probably closest to a 'go to' organisation, people felt that there was no **overarching one-stop-shop to 'guide you through the process'** of responding to later life needs.

"There's no central point that you can to and ask 'right, can you help me with this?' You know, be it a disability matter, be it a getting in the shower, you know, getting up the stairs, anything, the whole, sort of, kit and caboodle, there's nobody you can ask, and you're just pushed through pillar to post about everything, and you find it so frustrating." (Older person living in age specific housing and not receiving care, Greater London)

"There's not one place you can go to, to find help that encompasses anything you need. You know, help with housing, help with mental health, help with benefits, sourcing aids, funding for aids and adaptive technology. Information about, you know, simple things like a handyman to come round and put things up, carers, social aspects, you know, getting out and about, meeting other people." (Family member of older person living in age specific housing and receiving care, Greater London)

6.3 Some particular gaps in information and advice

This research has identified some particular gaps in the information and advice that is currently available:

- **Proactive identification of, and response to, those in need by authorities**. Currently, people feel they are left on their own and that the onus is on them to sort out their issues and initiate contact with relevant bodies.
- **'Whole person' support.** This refers to support that is focused on the individual rather than just their condition, and concerned with all of their needs. It is also seen as important that the support is tailored to individual capability levels.
- **Support for mental health and emotional wellbeing**. This is currently done well in some cases, particularly by palliative care services. However, these findings indicate that many in need lack access to good mental health support, particularly in adapting to new living situations (e.g. carers visiting, loved ones dying or moving away to care homes etc.) or physical restrictions which can have negative impacts on their mental health and quality of life.

- **Continuing support as needs change and evolve**. A number felt that cases are currently closed too quickly and that it can be challenging to receive a reassessment when needs change.

7. Looking to the future

Key points

- The short-term focus of older people and their families is on addressing any current issues and problems.
- There is a strong tendency not to think or plan too far ahead because of the uncertainty about future needs and also a reluctance to focus on a potentially negative future.
- However, this research suggests that consumers would consider future interventions that support their independent living arrangements and help them avoid or defer the need to go into residential care. In particular, they would be prepared to consider further incremental changes that adapt to changes in needs whilst limiting the upheaval that will be experienced.
- Adaptive technology could play a future role for some but it should not be overstated, as there are a number of potential barriers to its adoption and use by older people.

7.1 Short-term priorities are to address any immediate problems

When asked to consider the future, several respondents felt their existing arrangements to be suboptimal. Their focus was understandably on **remedying any issues or problems they were currently experiencing**, such as:

- Managing **physical and/or mental health conditions.**

> *"I keep saying to myself, 'I've got to make myself better. I've got to make myself do things.'"* (Older person living in non-age specific housing and receiving care, Birmingham)

- Sorting out any **housing issues**, such as snagging or lack of required adaptations.

> *"That door has been supposed to be replaced two years ago when I came in, and I'm still waiting. They've now promised me that that's going to be in five weeks' time."* (Older person living in age specific housing and not receiving care, Newcastle)

- Addressing any issues with **poor or variable care.**

"I'm struggling to get the carers to take [mum] out. Even though it's on her billing that she is to be taken out every Friday or whatever, for an hour or two, sometimes they just don't do it. Then they make up an excuse to say, 'Oh, she didn't want to go out,' and I will get a call and I'll speak to my mum and she will say, 'No, I was waiting to go out, I don't why they didn't take me out.' So, it's a constant struggle." (Family member of older person living in age specific housing and receiving care, Greater London)

- Accessing support where needed to help people who wish to have **more social interaction** or to **get out and about more.**

"It would be wonderful if someone could come around and have a chat, have a cup of tea or whatever. I think it means a lot. I mean, you gather that I'm self-sufficient but you can still feel lonely." (Older person living in non-age specific housing and not receiving care, Greater London)

Not all were in a position to help themselves with these issues and **support in these areas is required** too.

7.2 There is a reluctance to think too far ahead

There was evidence of **strong reticence from older people to think or plan too far ahead.** This is not just about being in denial. Not surprisingly, people perceived that it would be difficult for them to plan ahead due to **uncertainty about their future needs**. In addition, they felt that trying to anticipate all eventualities outside of their control may be counter-productive because it **risks making them anxious or depressed**, rather than making most of the here and now.

"I think you've just got to take it as it comes, sort of thing, you know. I think if you planned in advance for (getting worse), you'd, sort of, be a bit of a defeatist. You know, you'd think, 'Oh, it's going to happen so I might as well accept it,' whereas I'm not like that, I'm the other, sort of, way round, you know. I just think, 'yes, if it happens, it happens', but I'm not going to live my life thinking negatively." (Older person living in age specific housing and not receiving care, Greater London)

"I always feel it's being a bit pessimistic if you… start thinking, 'Oh, well, in a few years' time I might have this, and I might have that. I'll have to plan.' You've just got to live your life, wait and see if it happens, and then work round it." (Older person living in age-specific housing and not receiving care, Birmingham)

Overall, there was an understandable preference given to **incremental changes** in response to changes in needs rather than major changes that risk causing upheaval. In addition, people were strongly motivated by a desire to **retain independent living arrangements** and avoid or defer the need to go into residential care.

7.3 Potential for adaptive technology to play a future role for some

While the primary focus of this research was on exploring respondents' personal experiences we also took the opportunity to test reactions briefly to some adaptive technologies that most did not have prior awareness of or exposure to.

We introduced and explained five newer types of adaptive technology – **accessible phones, telecare systems, telehealth systems, smart home automation and memory aids.**

A few had large button mobiles, a couple had telecare systems in their accommodation and a small number knew about and used memory aids. However, there was otherwise **low awareness** of these technologies.

Consumers' in-principle interest in these options was contingent on their perceived **ease of use** and the product being seen to bring **clear benefits**, particularly with respect to enabling safety and supporting people to live independently. **Telecare was of most interest** overall because of the safety benefits and also this because places less onus on the consumer to operate it. Conversely, **smart home automation was least appealing** because it lacked a compelling perceived benefit.

In a real world choice context, **affordability** would of course also be a major consideration, and we did not discuss costs of these technologies in this research.

In addition, some of these technologies (e.g. telehealth and smart home automation systems) **require smart phones with apps to operate them**. Many of our respondents **did not currently have access to these** and some felt that they would not have the necessary confidence to use them.

In addition, as previously mentioned, some in this age group are disinterested **in anything technical** and some people reported that their **technical skills have declined with age**.

On the other hand, as reported in Section 4.4, some older people in this research were using more mainstream technologies, such as a variety of devices to access the internet, and finding these to

have significant benefits. This shows the **potential of emerging technologies to play a positive role** for those older people (and their families) who have the capacity and interest to engage with it.

8. Conclusions and implications

8.1 Conclusions

Consumers tend not to plan ahead for changing needs – especially care - in later life. It can be very challenging for them to self-serve effectively at point of need due to their vulnerability coupled with the complexity of the choices they need to make. The risk of consumer detriment is therefore currently high.

However, this research shows that suboptimal outcomes are not just caused by deficiencies in individual consumer behaviour. There are also number of supply-wide and systemic barriers operating which form the backdrop to decision-making:

- For example, on the supply-side we found evidence of considerable variation in publicly funded provision, as well as issues with speed of response and quality.
- While health and care needs are closely linked, there appears to be insufficient service-side integration to enable a joined up response to be provided.
- In addition, there appears to be a particular gap in the response to mental health and emotional wellbeing issues which were prevalent across our sample.
- Currently, families often play a major role in providing care and support. This can be due to inadequacies in formal provision and is not necessarily a situation which is either equitable or sustainable.
- A further systemic barrier relates to the negative associations with a number of age-specific products as well the provision of care services. This is related to a general stigma about ageing, both felt personally by respondents and in the response of wider society to them.

There are clearly a number of issues that require addressing but also some hopeful signs in this research. While most had not planned ahead, there were a few who had made decisions more proactively and pre-crisis, such as moving house or adapting existing accommodation to make it more suitable and future proof. These measures reportedly had a marked positive impact on the quality of life for these older people and may provide an example for others to follow.

8.2 Implications

Overall, there are three areas where we believe interventions should be considered based on the findings from this research:

- Providing more support at point of need;
- Encouraging positive preparations; and
- Addressing supply-side and systemic issues.

Each of these is explained in more detail in the sections to follow.

8.2.1 Providing more support at point of need

Consumers clearly require help to make the best possible social care choices, and this is particularly if they at a point of crisis or otherwise vulnerable.

Information remedies and signposting will not be sufficient for most and there is a need for holistic and tailored guidance, and potentially also advocacy, to support consumers to achieve good outcomes.

Given the interconnectivity of health and care needs, there is strong case for greater integration of health and social care systems to provide a more joined up and potentially earlier response as needs develop rather than at point of crisis.

However, older people's support needs also extend beyond both health and social care to include decisions related to finances, wellbeing and end of life planning amongst others.

This research indicates that families should be regarded as a target for information, guidance and support alongside the older consumers themselves, given their high degree of involvement in decision-making.

8.2.2 Encouraging positive preparations

Although most older people are reluctant to plan ahead for care and a negative future, a few people in this research have made positive preparations especially with regard to moving home or adapting current housing.

This indicates an area of opportunity. However, evidence on consumers' behaviour suggests that most will not seek out information about making positive preparations for later life unless they are already minded to make changes. Therefore encouragement is likely to be needed to motivate others, for example through proactive outreach by trusted organisations that can provide guidance in this area.

The evidence suggests that there is merit in exploring further the potential for a pre-emptive assessment for ensuring a 'good quality later life', including fit for a lifetime housing and aids/adaptations to support independent living. This could potentially tap into teachable moments when there may be a greater receptiveness to engage.

However, in order to provide relevant advice in this area policy makers will need first to agree what good planning looks like and how people could achieve this in the face of significant uncertainty.

While this research has shown that home adaptations and aids can make a positive impact to people's quality of life, consumers are put off by stigmatising and clinical age-specific products. This suggests that addressing these barriers will also be required in order to motivate people to be more proactive. In particular, this and other research indicates that there is considerable room for improvement in the design and marketing of products that could be of benefit older people.

8.2.3 Addressing supply-side and systemic issues

Respondents' variable experiences of publicly funded social care are suggestive of considerable variability in current provision. Constrained local authority budgets are likely to mean less funding, higher eligibility thresholds, and potentially also slower response times, in future unless these resource limitations are addressed.

In addition, both this and other research[11] shows that the metanarrative around social care for older people, and ageing in general, is almost entirely negative. These negative associations are deeply entrenched and will be difficult to shift. However, we feel there would be value in Which? and others working in this area to begin a conversation on how to change the discourse and response to older people in this area so it becomes more person-focused and enabling. In particular, there is an opportunity to convey a positive vision of what older life with additional needs could look like rather just focusing on addressing the problems.

[11] See, for example:

- *Stereotypes of Aging: Their Effects on the Health of Older Adults* (Dionigi, R. in Journal of Geriatrics, 2015) - https://www.hindawi.com/journals/jger/2015/954027/
- *The Risks of Ageism Model: How Ageism and Negative Attitudes toward Age Can Be a Barrier to Active Aging* (Swift, J. et. al. in Social Issues and Policy Review, 2016) - http://eprints.bbk.ac.uk/21658/6/21658.pdf
- *That Age Old Question: How Attitudes to Ageing Affect Our Health and Wellbeing* (RSPH and Calouste Gulbenkian Foundation, 2018) - https://www.rsph.org.uk/uploads/assets/uploaded/010d3159-0d36-4707-aee54e29047c8e3a.pdf