



Putting **People First**
Transforming Adult Social Care

People who pay for care: quantitative and qualitative analysis of self-funders in the social care market

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Foreword

Both the Government's *Vision for Adult Social Care* and the new social care sector partnership agreement *Think Local, Act Personal* recognise the importance of working in future to support all people who receive social care, including those who fund themselves.

The two reports contained in this document provide the latest position on self-funders. The first, *Estimating the number and distribution of self-funders of care in England* is a quantitative analysis of the number of people who self-fund. The second *Journeys without maps* is a qualitative analysis of the current experience of a sample of self funders.

Whilst the number of self-funders remains difficult to quantify, it is clear that they represent a very significant and growing proportion of 'users' of care and support services. Councils and providers must give greater focus to the needs of this growing group, particularly given the evidence regarding the absence of information, advice and support identified in the M. Henwood report *Journeys without maps*.



Jeff Jerome
National Director Social Care Transformation

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1 Background

In 2010 the Putting People First Consortium commissioned two studies concerning people who fund their own social care and support.

Estimating the number and distribution of self-funders of care in England is a quantitative study from the Institute of Public Care at Oxford Brookes University. This report:

- Estimates the numbers of older people who pay for registered social care in England,
- Explores future trends in self-funding,
- Discusses the emerging task towards self funders for councils.

Journeys without maps: The decisions and destinations of people who self fund is a qualitative study from Melanie Henwood Associates. This report was jointly commissioned by the Putting People First Consortium and SCIE. The report:

- Tracks the journeys of those who self fund their care and support through a series of interviews with a sample of providers of care, service users and carers.
- Explores the decisions people make, how and why they make them, and the consequences of those decisions.
- Concludes that there is a paucity of help and information available to those who self fund.

2 The Policy Context

A *'Vision for Adult Social Care'*¹ confirms the importance of councils recognising and working with all who receive social care support whether by funding their own care provision, being in receipt of direct payments or those on whose behalf the council purchases services. The Vision emphasises three key points about universal access to services.

"Whether they receive a direct payment or fund their own care and support, people should have access to a service that meets their needs".

"To have real autonomy and choice people need information and advice.. people funding their own care have a particular need for information and guidance to help plan how their care needs are met.".

"Our vision looks out to strong communities, not up to the state – to a big and open society... The increased use of personal budgets preferably as a direct payment, alongside people funding their own care, will be a catalyst for change".

The new partnership agreement between councils and the care sector "*Think Local, Act Personal*"² reiterates the requirement for good information but also proposes a sector wide role for councils to determine whether services are delivering appropriate outcomes, avoid risk and ensure people have the opportunity to make choices over, and have control of, the care they receive.

¹ *A Vision for Adult Social Care: Capable Communities and Active Citizens*, Department of Health, 16th November 2010

² *Think Local, Act Personal: Next Steps for Transforming Adult Social Care*, Putting People First, published 4th November 2010. <http://www.puttingpeoplefirst.org.uk/ThinkLocalActPersonal/>

“Councils and providers need to demonstrate the difference being made to someone’s life. This can be done by putting in place independent processes to check that outcomes are achieved and publishing the results. As part of this, it will be important to include an understanding of the experience of local people who self-fund their care and support”.

“Risk management and protection/safeguarding should be addressed in a balanced way across all sections of the community, avoiding an approach that views people in receipt of social care funding as most at risk”.

“In parts of the country, people eligible for ongoing funding from the council may comprise only a minority of those using care and support services. A whole community approach is therefore essential to help all people exercise choice and control”.

3 The self funder market

Most commentators agree that in both the short and long term the number of self funders of care will grow. The numbers of people who self fund their care provision is primarily influenced by the relationship between state funding and individual wealth.

Therefore, numbers may rise through: tighter eligibility criteria, increased charging, less state funding of community organisations, more people having direct payments and through people who are eligible, topping up their provision from their own, or their families’, means. However, an increasing number of people who currently self fund their care home placements, may cross over to being council funded if the value of their investments diminish or through increased longevity and spending down capital assets.

In the longer term occupational pensions and the value of housing equity held by many older people is likely to take large numbers out of state funding at the current thresholds. For example, by 2030 a third of Herefordshire’s population will be aged at least 65, and over with well over 80% being home owners³. Changes in the capacity or location of families to offer care to their older relatives may also promote an increase in those who fund their own care and support.

However, estimating the precise numbers of self-funders is an inexact science for a variety of reasons. For example:

- Providers are an obvious source of data, however, many are unable or unwilling to provide information on the numbers of people who self fund.
- Many people might receive quite high levels of care from (usually) non registered providers, often described as offering ‘help around the house’, where neither the purchaser nor the provider views the service as ‘care’.
- Some people are in receipt of council funded services, but top this up through informal care or buying additional hours from registered providers. Consequently, there can be some element of double counting.
- With the use of direct payments, some people will organise and pay for their care themselves, but be funded by their council. Providers may not always be able to identify which care is self-funded and which is funded by the state.

³ Source: POPPI

There are also issues concerning the use of national published data, e.g. not all residents in the younger adult homes category are under 65: and not everyone in older people's homes are aged 65 and above. In addition, the Department of Health does not have data available on the numbers of care home residents fully funded through NHS continuing care. From IPC's projects with councils concerning self funders, it was found that NHS funded continuing care can account for up to one-third of all nursing home beds in one district council.

4 Executive Summary

4.1. Estimate of care home self-funders

Using data from the Care Quality Commission (CQC) on the total numbers of places in registered care homes; of local authority funded places, and of NHS funded placements, along with regional data on vacancy rates collected by Laing and Buisson, IPC estimates that around 170,000 places are self-funded, representing 44.9% of the 378,053 registered care home places in England. The proportion of self-funded places in residential care homes is 39.6%, and 47.6% in nursing homes.

4.2. Estimate of home care self-funders

The English Longitudinal Survey of Ageing (ELSA) includes questions relating to help with care and where people get it from. Applying the proportion of people aged 65 who pay for care to the total older population in England indicates that there are an estimated 168,701 older people paying for care.⁴ The number is projected to increase to 249,298 by 2030, if the proportion of the older population that pays stays the same. If support with instrumental activities of daily living⁵ is included, then the estimated total number rises to 271,536 in 2010 increasing to 400,658 by 2030.

4.3. Value of the market for privately funded care

Applying the Wanless Review's methodology, combined with data from the English Longitudinal Survey of Ageing and Laing and Buisson, IPC estimates that the total size of the self-funded care market is significant:

- The home care market has grown from an estimated £510 million in 2002-2003 to £652 million in 2010 and the
- Care home market for older people in England is estimated to be £4.9 billion.

Both estimates exclude people who 'top-up' a council funded care home place. Assuming 23% of council placements are topped up by third party payments, this could represent an additional £1.15 billion.

4.4. Providers' concerns

Whilst greater choice through a growth in the number of self funders and an increase in those with direct payments / personal budgets would appear to be good news for providers, but there are a range of experiences:

- There are clearly challenges associated with managing a market that comprises a large number of individual purchasers as compared to large contracts with local councils.
- Providers vary in their understanding and engagement with the self-funder market; for some it is core business, while for others it remains marginal.

⁴ Katz S. Downs TD, Cash HR, et al (1970) Progress in the development of the index of ADL. *Gerontologist*, 10:20-30, 1970

⁵ Lawton, M.P., & Brody, E.M. (1969) Assessment of older people: Self-maintaining and instrumental activities of daily living, *The Gerontologist*, 9(3), 179-186.

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- Some providers distinguish between self-funders and those using Direct Payments/personal budgets, and may favour the 'pure' self-funder as a target market because of their greater purchasing power.

4.5. The journeys of people who self-fund

The majority of people do not think ahead or plan for the possibility that they may need care and support. Therefore, when a crisis occurs they are not prepared for remaining in their own home and decisions are made swiftly and often by families that a move to a care home is appropriate.

Both providers and people funding their own support reported that decisions were often made in hospital at a time of crisis.

Time and again, people described the struggle to obtain appropriate information, advice or advocacy to help them in making life changing decisions. The challenge for local councils is that many people simply do not think of approaching them for help in part because of lack of knowledge, while others are deterred by the perceived stigma of state services. Of those who do approach the local council, but are ineligible for help because of their financial assets, the experience was of little information being offered and 'signposting' to other sources of support was usually negative. The most frequent experience was of people being given a list of care homes and left to find their own way. Having sufficient resources to be self-funding is not, of itself, any guarantee that people will have greater control over their situation, and choices are often absent.

4.6. The task ahead

There are a range of activities that councils can undertake to both help self funders, and improve their performance and their understanding of the market:

- If councils are to be able to play an effective role in shaping the local care market they need to better record their contacts with all people requesting care and support. By ensuring that customer facing staff are recording all contacts (and providing people with accessible, accurate and appropriate information and advice) councils can monitor the current self defined needs of self-funders and the nature of these contacts.
- Councils need to work with providers to raise awareness of the changing market, and to influence the development of services to meet the needs of self-funders and people using Direct Payments. Providers are also an important source of intelligence about the size and characteristics of the local self-funding market.
- The numbers of people who have spent their financial resources and move from self-funding in care homes to requiring state funded support are of particular concern to councils because of the financial implications. Authorities need to monitor this closely. However, they can also maximise the income of self-funders by ensuring that they are receiving benefits to which they are entitled and are in receipt of independent financial advice in managing their resources. Providers can be a good source of information if people are expressing concern about their funds becoming depleted.
- Most authorities provide some basic advice and information to self funders. However the evidence indicates that this is most frequently just a list of care homes and other social care services. Not only do people need better information but also to have access through a variety of mediums to match people's preferences (such as electronic information; telephone support, or face to face).
- Self-funders often struggle to navigate the care pathway, and to understand the financial implications of different options. People need help to assess the suitability and quality of the care options available to them and it is important that both national (CQC) and local information and data are designed to meet these consumer requirements.

Estimating the number and distribution
of self-funders of care in England –
a quantitative study from the
Institute of Public Care at
Oxford Brookes University

December 2010

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1 Introduction

1.1 Purpose of the study

The purpose of this study is to estimate the numbers of older people who pay for their own social care in England, future trends in self-funding, and the likely impact of future levels of equity on the older people's population in terms of self-funding. It has been prepared for the National Director for Social Care Transformation by the Institute of Public Care at Oxford Brookes University as part of a wider programme of work on the development of the social care market.

The work has been carried out in parallel with a qualitative study, by Melanie Henwood who is retrospectively tracking the journey into self-funding of a sample of self-funders in three geographical areas. This will look at how these people came to pay for their own care, the advice and information that was available to them, and what they would do differently, knowing what they now know.

This study was limited in its focus to older people (as the largest group of self-funders and the group for which data are most easily available), and self-funders receiving registered care in care homes, and people who pay for their own home care. However, there is a considerable degree of self-funding in mental health, and to a lesser but still significant extent, in learning and physical disability, that it would be useful to explore in the future.

1.2 Background

Preliminary discussions with other experts in the field emphasised that estimating the numbers of self-funders is a fairly inexact science in a number of ways:

- The the only people who really know who self-funds are providers and there is no central repository for this information. In the home care market, there is no requirement for registration which would provide a route to capturing data in the number of self-funders. IPC has found that at a local level, care home and home care providers are frequently either reluctant or unable to provide accurate data on self-funders.
- Many people might receive quite high levels of care from (usually) non registered providers, people they describe as offering 'help', where neither the purchaser nor the provider describes what is purchased as 'care'. This is where, what Forder¹ calls, 'domestic support' may shade into 'care' over time.
- Some people may receive state provision, but either they or their relatives top this up through informal care or through buying additional hours from registered providers. Therefore, there can be some element of double counting.
- With the introduction of direct payments and personal budgets, some people may organise and pay for their care themselves, but be funded by their local authority. In past projects, IPC has found that providers may not always be able to identify which care is self-funded and which funded by the state.
- Finally, there are a number of people who move out of the UK retiring abroad: the Institute for Public Policy research (IPPR) estimated there were over one million UK pensioners living abroad in 2006. A significant number of these are likely to pay for care in their new country of residence.

¹ Forder J (2007) *Self-funded social care for older people: an analysis of eligibility, variations and future projections*, PSSRU Discussion Paper 2505, PSSRU and CSCI.

1.3 IPC's approach

There were a number of component parts to the study which are described below. Having reviewed previous attempts to estimate how many people pay for their own care in England, IPC obtained data from the Care Quality Commission (CQC) and Laing and Buisson to calculate an estimate of the number of older people paying for a care home place.

In order to estimate the numbers of people who pay for home care, IPC used data from three national surveys: the English Longitudinal Study of Ageing (ELSA Wave 3, 2006-2007), the British Household Panel Survey, and the Health Survey for England 2000 which contain a range of questions concerned with paying for care or help in the home. The results of the Life Opportunities Survey have not yet been made available. These survey results were then applied to population projections to generate a range of estimates for the numbers of people paying for their own home care.

The results of these first two elements of the study were used to update the analysis in the Wanless Review of the likely impact of future levels of equity on the older people's population in terms of self-funding.

The quantitative work was supplemented by telephone interviews with providers and representatives of provider umbrella groups to test the findings from the data analysis. In addition, an analysis of local authority responses to the Annual Quality Assurance Assessments' question about services provided for self-funders in 2008-2009 was conducted.

1.4 Acknowledgement

We are grateful to Nick Miller and colleagues at the CQC for their help in providing data for the analysis of self-funders in care homes.

2 Previous studies of self-funding

In contrast to publicly funded care, there is a lack of reliable data for the total private expenditure on care homes and self-funded domiciliary care². This leaves any estimate of the total self-funding population and associated private expenditure on social care as, at best, a well-informed indication. Forder³ estimates that 13.2% of all older people receive funded care services (care home or community-based care), of whom one-quarter (25%) are fully self-funded (See Table 1).

Table 1 Service recipients aged 65+ by type of care and funding – England

	LA supported care		Self-funded only, not LA funded		Top-up funding on LA funded care		Private pay – any	Total
	000s	%	000s	%	000s	%		
Community based care	606	81	145	19	154	21	40	751
Care homes	199	63	118	37	70	22	59	317
Total	805	75	263	25	224	21	46	1,068

Source: Forder, 2007

² Wanless D (2006) *Securing Good Care for Older People: Taking a Long-term View*, London, King's Fund.

³ Forder J (2007) *Self-funded social care for older people: an analysis of eligibility, variations and future projections*, PSSRU Discussion Paper 2505, PSSRU and CSCI.

According to Forder, private expenditure committed to full self-funded social care is substantial and is likely to form around 30% of the total spend. When local authority charges and top-up expenditure are added, total private expenditure on social care for older people is estimated by Forder to be in the region of £5.9 billion, about 50% of all expenditure on personal social care for older people.

Out of a total of 317,000 care home placements, 37% were estimated by Forder (2007) to be fully self-funded arrangements (Table 1). This proportion has remained more or less stable over recent years. The Office of Fair Trading's report into care homes for older people in the UK⁴ found that 32% of residents were self-funding. Wanless (2006) estimated that between one-quarter and one-third of care home places are wholly privately funded, while Laing and Buisson estimated that 41% of care home places for the elderly and physically disabled in the UK were fully self-funded in 2009⁵, equivalent to £5.4 billion of the total care home market of £13.2 billion.

There is very limited evidence available about the total amount paid in top-up fees: Forder (2007) estimates 22% of local authority placements are topped up by third party payments, compared with the OFT's estimate of 24% (2005). The results of recent surveys undertaken for Laing & Buisson (2009) indicate that rates of top-up funding may be as high as 28%. Broadly speaking, it is likely that nationally about a quarter of care home placements are topped up by third party payments.

Research in 2002⁶ (Netten et al.) on the financial status of older people in residential and nursing homes found that most self-funding residents had enough assets to last for several years before they had spent down to the means-testing capital threshold. Overall, nearly two-fifths had assets *in excess* of £100,000, although one-third had total assets of £60,000 or less.

There is relatively little information about the market for privately purchased home care, either in terms of hours bought, or amount spent. The data available usually relate to *all* home care, not just that for older people. The data also tend to include self-funded care provided by local authorities and independent agencies, and not payments to care workers directly employed by the older person. 'Self-funded' in these studies almost always refers only to care which is wholly privately funded; it does not include local-authority funded home care for which the means-tested recipient pays a part-contribution through charges.

Forder (2007) estimated that of 751,000 older people receiving community based care: 145,000 (19%) paid for their own care, and 154,000 (21%) topped up local authority provided care. Usually the additional amount of care purchased is modest at around 4 hours a week, although some older people buy a lot more. This contrasts with the OFT report (2005) which indicated that 35% of council supported people also received private third-party payments.

There is uncertainty about whether the volume of home care purchased is growing or declining⁷. Two surveys undertaken in 2004 by the UK Home Care Association (UKHCA) found a decline in the number of privately purchased hours of home care in England⁸. This result was unexpected, given both the ageing population, and the tightening of local authority eligibility and funding criteria, which would be expected to increase the amount of privately purchased home care.

⁴ Office of Fair Trading (2005) *Care Homes for Older People in the UK: A market study*. London: Office of Fair Trading.

⁵ Laing & Buisson (2009) *Care of Elderly People: UK Market Survey 2009*, London.

⁶ Netten, A., Darton, R. and Curtis, L. (2002) *Self-Funded Admissions to Care Homes. A report of research carried out by the Personal Social Services Research Unit, University of Kent on behalf of the Department for Work and Pensions*, Department for Work and Pensions Research Report No. 159.

⁷ Laing & Buisson (2005) *Domiciliary Care Markets 2005*, London: Laing & Buisson.

⁸ McClimont B, Grove K (2004) *Who Cares Now? An updated profile of the independent sector home care workforce in England*, Carshalton Beeches: UK Home Care Association. www.ukhca.co.uk/pdfs/whocaresnow.pdf

3 How many self-funders are there in care homes?

3.1 Estimated number of self-funders in care homes in England

Using data from the CQC on the total numbers of places in registered care homes at 30.9.09, the total number of local authority funded places, and the total number of NHS funded placements, along with regional data on vacancy rates collected by Laing and Buisson, we have estimated the total numbers of full self-funders in England in Table 2.

Table 2 indicates that an estimated 169,748 or 44.9% of all care home places in England are occupied by full self-funders. The proportion of self-funded places in residential care homes is 39.6%, and 47.6% in nursing homes. The technical appendix provides details by local authority. However, there are a number of data issues which are discussed below in more detail.

Table 2: Estimated number of people who pay for their own care home place in England based on data from CQC and Laing and Buisson

	A	B	C	D	A-B-C-D=E
Type of home	Total numbers of places available at 30.9.09	Vacancy levels	Local authority funded placements	NHS funded placements	Number of self-funders by each local authority
Residential care home	187,330	18,809	93,247	1,118	74,156
Nursing care home ⁹	179,393	17,830	75,521	673	85,359
Total	378,053	37,749	168,768	1,788	169,748

Note: The sum for column A does not agree between the total number and the numbers of people in residential and nursing care. This is because there are some undefined places in the CQC data - it is therefore correct. For this reason the totals in column E also do not agree, and this is once more correct.

Column A in Table 2 includes the total number of places available in registered care homes at the end of September 2009. This is a dataset held by CQC which is available for councils on a regular basis on the CQC website. IPC looked at the data relating to homes in the older people category determined from national minimum standards applied in most recent inspection. However, not all residents in the younger adult (YA) homes category are under 65: and not all residents in older people (OP) homes are aged 65 and above. Some homes at 30.9.09 will have been in the process of re-registration / suspended / about to expand with new places / have recently expanded, but these cannot be identified from the CQC data.

Column B uses data from Laing and Buisson who gather data and publish regional occupancy rates from providers.

Column C includes data from the CRILL (Capturing Regulatory Information at a Local Level) returns at 30.9.09 held by CQC. We have used the data on the numbers supported in care homes from inside and outside the area. So for example some local authorities on the edge of London have relatively high

⁹ Nursing home: this category includes any home with one or more beds designated for nursing. Not all beds in all homes will be nursing beds – some will be for personal care.

proportions of people funded by other local authorities in care homes in their area. The CRILL forms do occasionally overstate numbers – councils have not counted those in the homes but those with recurring care booked in the homes.

Some councils may well also have included some self-funders and some residents who are in fact fully funded by a PCT (both are excluded from what is asked for in the CRILL return); and also understate numbers – some councils failed to match correctly / at all with CQC data and may have occasionally reported residents as still in homes which have been re-registered following a change of ownership

Column D uses the data available from the NHS Information Centre's PSSEX1 report 2008-2009 on Section 256 NHS fully funded residents of care homes. It is possible that there is some under-reporting – some local authorities had nothing recorded under this heading. The data will principally be for: *post hospital discharge* - it is not clear how many such beds are jointly paid for under s.256 arrangements; and some *continuing care*, probably mainly for older people, those with a learning disability, and other long term specialist conditions. The Department of Health did not have data available on the number of people in all NHS continuing care funded places in care homes. From IPC's work in one local authority, we have found that NHS funded continuing care can amount to up to one-third of all nursing home beds in one district council.

In addition, there will be some places funded by Welsh and Scottish councils (particularly near the Welsh and Scottish borders) which the CQC data will not pick up.

4 How many self-funders of home care?

Three national surveys contain questions relating to payment for care or help: the English Longitudinal Survey of Ageing (Wave 3) or ELSA, the British Household Panel Survey, and the Health Survey for England¹⁰. To estimate the numbers of people paying for personal care at home, we extracted the proportions from each survey (broken down by age group and gender) and applied them to national population projections from the POPPI database (see full details in Appendix 1). These are reported on the following page:

4.1 ELSA

ELSA Wave 3 (2006-2007) is the most recent of the three surveys and also covered the largest number of respondents. In ELSA Wave 3, respondents were asked a number of questions relating to help with care and where they get it from:

- Respondents were asked whether they have difficulty with a range of activities including:
 - moving around the house?
 - washing and dressing?
 - eating and preparing meals?
 - shopping for groceries?
 - work around the house or garden?
 - making telephone calls?

¹⁰ The National Centre of Social Research is launching a set of new model questions in November 2010 for use in national surveys such as the Health Survey for England 2011. The questions will cover respondents' need for social care services and how they pay for them.

- managing money such as paying bills or keeping track of expenses?
- taking medicines?

This is followed by a question about who, if anyone, helps with these activities including ‘home help or care arranged privately’. We looked at the responses that covered the Activities of Daily Living (Katz scale)¹¹: moving around the house, washing and dressing, eating and preparing meals, and the wider range of activities which roughly corresponds with the Instrumental Activities of Daily Living (Lawton-Brody scale)¹².

Tables 3 and 4 below present the percentage of the population and the estimated current and projected total for England that pay for these kinds of home care.

Table 3: % of those 65+ paying for help with moving, washing & dressing, eating & preparing meals (all 3 variables above)

	65-69	70-74	75-79	80-84	85+	Total
Men	0.53	0.56	0.51	1.45	2.26	0.82
Women	0.61	1.15	3.42	3.16	9.31	2.87
Total	0.57	0.87	2.18	2.40	6.86	1.96

Source: ELSA Wave 3

Table 4: Applied to the POPPI Figures (ELSA - paying for help with moving, washing & dressing, eating & preparing meals (all 3 variables above))

Males	2010	2015	2020	2025	2030
65-69	6187	7502	6816	7476	8539
70-74	5417	5948	7279	6656	7333
75-79	3819	4268	4771	5894	5428
80-84	7446	8445	9863	11,255	14,035
85+	8875	11,180	14,188	18,188	22,602
Total	31,076	36,011	39,601	43,752	48,814

Females	2010	2015	2020	2025	2030
65-69	7642	9306	8486	9256	10,664
70-74	12,472	13,525	16,559	15,170	16,606
75-79	31,426	33,656	36,898	45,448	41,898
80-84	23,343	24,155	26,727	29,761	36,944
85+	74,517	82,021	92,309	109,029	130,256
Total	137,625	153,003	164,945	180,187	200,484

¹¹ Katz S. Downs TD, Cash HR, et al (1970) Progress in the development of the index of ADL. *Gerontologist*, 10:20-30, 1970

¹² Lawton, M.P., & Brody, E.M. (1969) *Assessment of older people: Self-maintaining and instrumental activities of daily living*, The Gerontologist, 9(3), 179-186.

The ELSA figures indicate that there are an estimated 168,701 older people paying for care to help them with the activities of daily living in England, and that the number is likely to increase to 249,298 by 2030, if the proportion of the population that pays stays the same.

If the instrumental activities of daily living are included, then the estimated total number rises to 271,536 in 2010, increasing to 400,658 by 2030 (see Tables 5 and 6).

Table 5: % of those 65+ paying for help with moving, washing & dressing, eating & preparing meals, shopping & work around the house, answering the phone & managing money, taking medicines.

	65-69	70-74	75-79	80-84	85+	Total
Men	0.53	0.74	0.77	2.17	3.95	1.18
Women	0.92	2.29	5.31	6.90	13.5	4.73
Total	0.74	1.57	3.38	4.81	10.20	3.16

Table 6: Applied to the POPPI Figures (ELSA - paying for help with moving, washing & dressing, eating & preparing meals, shopping & work around the house, answering the phone & managing money, taking medicines.)

Males	2010	2015	2020	2025	2030
65-69	6187	7502	6816	7476	8539
70-74	7158	7860	9619	8795	9690
75-79	5767	6444	7203	8898	8196
80-84	11,143	12,638	14,760	16,844	21,003
85+	15,512	19,541	24,798	31,790	39,504
Total	44,718	51,821	56,987	62,960	70,244

Females	2010	2015	2020	2025	2030
65-69	11,526	14,035	12,798	13,960	16,083
70-74	24,835	26,933	32,974	30,207	33,068
75-79	48,794	52,256	57,290	70,565	65,053
80-84	50,970	52,744	58,360	64,984	80,668
85+	108,054	118,935	133,853	158,099	188,879
Total	226,818	252,161	271,843	296,964	330,414

The figures indicate that the proportion of people paying for help with both the activities of daily living (ADLs) and the wider instrumental activities of daily living increases steadily with age. There is also a striking difference between the proportions of men and women paying for care: the proportion of women in the total female older population paying for care is consistently higher than the proportion of men across all age groups. In terms of ADLs, the proportion of the older female population paying for help is overall four times higher than the proportion of men. It seems likely that this is a reflection of the higher numbers of single older women: older men are more likely to have access to informal care from a spouse or partner and may therefore be able to avoid paying for home care. However, there may be other factors at work which would be useful to explore.

5 British Household Panel Survey (BHPS)

The British Household Panel Survey includes a question about whether: home help, and meals on wheels are paid for, or provided by social services/NHS, along with a range of other health related services such as chiropody.

Applying the proportions from the survey results indicate that there are a total of 276,083 older people paying for home help or meals on wheels in 2010 which will increase to 410,481 in 2030, assuming the proportion of the population paying remains unchanged (see Tables 7 and 8).

The total figure is remarkably close to the ELSA estimate. However it should be noted that the BHPS data covers households in England, Wales, Scotland and Northern Ireland and the questions differ from those in ELSA. Again there is a marked difference between the proportions of older women and men paying for help, although not as large as that in the ELSA Wave 3 data.

Table 7: % of those 65+ paying for home help or meals on wheels (variables RHLSVCF or RHLSVBF =2)

	65-69	70-74	75-79	80-84	85+	Total
Men	0.25	0.6	1.08	1.33	10.47	1.92
Women	0.8	1.33	2.03	6.9	14.34	4.24
Total	0.56	0.99	1.61	4.32	12.88	3.21

Table 8: Applied to the POPPI Figures (BHPS - paying for home help or meals on wheels)

Males	2010	2015	2020	2025	2030
65-69	2918	3539	3215	3526	4028
70-74	5804	6373	7799	7131	7856
75-79	8088	9039	10,102	12,480	11,496
80-84	6830	7746	9047	10,323	12,873
85+	41,116	51,796	65,731	84,263	104,710
Total	72,762	84,319	92,724	102,444	114,296

Females	2010	2015	2020	2025	2030
65-69	10,022	12,204	11,129	12,139	13,987
70-74	14,424	15,642	19,151	17,544	19,205
75-79	18,654	19,977	21,902	26,977	24,870
80-84	50,970	52,744	58,360	64,984	80,668
85+	114,777	126,335	142,181	167,936	200,631
Total	203,321	226,039	243,681	266,200	296,185

6 Health Survey for England 2000

This survey is now somewhat dated, however the sample size was almost as large as that used by ELSA. The questionnaire asks if the respondent has used private domestic help in the last month. The total estimate is considerably higher than for the other two surveys: 337,715 in 2010 and 508,607 in 2030 (see Tables 9 and 10). This is the broadest question of the three surveys and clearly will have included people who have a cleaner, but have no need for care or support. The differences between men and women vary across the age groups. The wording of the question may be important in explaining this contrast with the other two surveys.

Table 9: % of those 65+ paying for private domestic help

	85+	80-84	75-79	70-74	65-69	Total
Men	4.34	2.42	4.48	3.59	3.93	3.85
Women	2.05	6.35	4.99	7.12	2.80	4.00
Total	2.52	5.23	4.79	5.65	3.36	3.96

Table 10: Applied to the POPPI Figures (HSE - paying for private domestic help)

Males	2010	2015	2020	2025	2030
65-69	45,875	55,629	50,543	55,433	63,316
70-74	34,726	38,129	46,666	42,667	47,007
75-79	33,551	37,493	41,906	51,771	47,685
80-84	12,427	14,094	16,461	18,784	23,423
85+	17,043	21,470	27,247	34,928	43,404
Total	145,903	169,077	185,932	205,421	229,187

Females	2010	2015	2020	2025	2030
65-69	35,078	42,714	38,951	42,487	48,950
70-74	77,216	83,738	102,521	93,920	102,813
75-79	45,853	49,107	53,837	66,312	61,132
80-84	46,907	48,539	53,708	59,804	74,238
85+	16,408	18,061	20,326	24,008	28,682
Total	191,812	213,244	229,888	251,132	279,420

To summarise, the three surveys are all slightly different in terms of sample, questions and purpose. Reviewing the three, it seems that the ELSA Wave 3 questions best capture the data we are seeking to obtain. However, both the Life Opportunities Survey and the Health Survey for England 2011 will provide useful data to update these results.

The technical appendix provides details of the estimated numbers paying for home care by local authority using the ELSA percentages. These estimates do not make any allowance for differences in wealth and deprivation between authorities which may affect the actual numbers, and should therefore be treated with caution.

7 Size of the market for privately funded care

To estimate the size of the market for privately funded home care, we have adopted Poole's methodology which draws on work by Carol Jagger and colleagues for the Wanless Review. Poole uses data on the estimated numbers of people in five different dependency groups, and assumes a time input per week for each group to calculate the total number of hours provided per week. Using the hourly rate provided by Laing and Buisson, she then calculates total annual expenditure on privately funded home care. We have adopted a similar methodology using data from ELSA on the proportion of people in each dependency group paying for personal care (see Table 11). This has been applied to current population projections, following the same number of hours per week for each of the dependency groups, and multiplying by the latest figure for hourly rates from Laing and Buisson in their 2009 report.

Table 11: Estimated size of self-funded home care for people aged 65+

	Dependency group			All
	Group 0	Groups 1-3	Group 4	
Number of recipients	17,427	75,720	75,720	168,867
Input per recipient (hours per week)	2.9	3.7	8.4	
Total hours per week (thousands)	50.5	280.2	636.0	966.7
Total annual private expenditure at £12.98 per hour (£million)	£34.1	£188.9	£429.3	£652.3

IPC's calculations indicate that the estimated total size of the home care market has grown from £510 million in 2002-2003 to £652 million in 2010. However, this masks a lower overall number of people estimated to be paying for home care compared with the Wanless review. This reflects the use of different datasets.

The total size of the self-funded care home market for older people in England is estimated to be £4.9 billion (see Table 12). This compares with Laing and Buisson's 2009 estimate of £5.4 billion which covered the whole of the UK and included elderly and physically disabled placements. Given these differences in coverage, the two estimates appear reasonably close.

Table 12: Estimated size of self-funded care home expenditure for people aged 65+

	Residential care home	Nursing home	Total
Estimated number of self-funded places	74,156	85,359	169,748
Weekly average cost ¹³	£482	£684	
Total annual self-funded expenditure (£million)	£1,858.6	£3,036.0	£4,894.6

It should be noted that both estimates exclude people who pay a contribution towards or 'top-up' a local authority funded care home place. As mentioned earlier, Forder (2007) estimates that 22% of local authority placements are topped up by third party payments, compared with the OFT's estimate of 24% (2005). Assuming the rate is 23%, this could represent self-funding by an estimated 168,768 people towards part of an additional £1.15 billion (see Table 13).

Table 13: Estimated size of partial self-funded care home expenditure for people aged 65+ including local authority element (assuming 23% of local authority funded places are topped up)

	Residential care home	Nursing home	Total
Estimated number of partial self-funded places	21,447	75,521	168,768
Weekly average cost ¹⁴	£482	£684	
Total annual care home expenditure where partial self-funding occurs (£million)	£537.5	£617.8	£1,155.3

¹³ Laing & Buisson (2009) *Care of Elderly People: UK Market Survey 2009*, London.

¹⁴ Laing & Buisson (2009) *Care of Elderly People: UK Market Survey 2009*, London.

8 Future trends in self-funding

8.1 Views of providers umbrella groups

A series of interviews were conducted with umbrella groups representing different elements of the care industry to explore what data they had on self-funding and how they thought it would develop:

- **ECCA** – the English Community Care Association which represents small, medium and large independent care providers.
- **UKHCA** – the UK Homecare Association which is a professional association of home care providers from the independent, voluntary, not-for-profit and statutory sectors.
- **Ceretas** - Formerly known as the British Association of Domiciliary Care or BADCO, Ceretas is the professional association dedicated to individuals working in Home Care.
- **National care forum** – which represents the interests of not-for-profit health and social care providers in the United Kingdom.

The most recent data available from the UKHCA based on a sample week in September 2008 indicated that 21.4% of the total care hours were purchased by self-funders. Most of the groups had no data and one commented on the difficulty of obtaining information on self-funding from providers.

Three of the four interviewees expect the volume of self-funding to increase over the coming years due to a number of factors, but particularly the combination of demographic trends and the effect of cuts in the public sector which are expected to result in more people falling below the FACS eligibility criteria and deciding to pay themselves (or third parties) for a care home place. Those interviewed also mentioned the impact of personal budgets and direct payments which could turn everyone into a self-funder in terms of their relationship with a provider, and potentially result in more topping up by people with a personal budget.

A couple of interviewees commented on a north-south divide in self-funding with a greater number and proportion of self-funders in the south reflecting the greater wealth of the south of England.

In terms of the overall market, a number of possible trends were mentioned:

- An increase in the market to provide domestic support – ‘that bit of help’ around the edges of care which enables people to continue to live independently in their own home.
- An increase in NHS continuing care as a result of older people having to wait till a crisis, due to tighter FACS eligibility criteria, resulting in hospital admissions and then NHS continuing care.
- Rising user expectations leading to greater demand for flexibility in how and when care is provided.
- Increasing numbers of people crossing the threshold from self-funding to local authority funded care due to increased longevity and rising care home fees.
- More effective marketing by providers which could increase self-funding overall, or only increase the provider’s market share.

8.2 Interviews with Providers

Interviews were conducted with a small sample of care home and home care providers to obtain data on self-funding and explore their views of current and future trends. There was considerable reluctance among providers to respond to requests for interviews and data which reflects the difficulty of obtaining good data in this field.

Reported rates of self-funding from the care home providers ranged between 30% and 45%; and for home care providers the range was between 6% and 25%. One provider commented that it was difficult to be sure to what extent home care was self-funded rather than paid for through self-directed support.

All providers thought that there were a growing number of self-funders: one home care provider had experienced a doubling of the number of self-funders between 2008 and 2010. However, most providers did not think that the upward trend was very strong. Several commented on the impact of local authority budget cuts, policies to avoid the use of residential care, and downward pressures on price.

Providers also mentioned demographic trends, personal budgets, increasing use of NHS continuing care, and the need for more flexible and varied services (such as gardening, chiropody and hairdressing) as factors affecting the market for self-funded care.

9 Update of Wanless vignettes

The background paper by Teresa Poole for the Wanless Review of Social Care¹⁵ provided example financial profiles of four single people aged 65+ as vignettes to illustrate the impact of current care home charges on their available assets. We have updated these four vignettes, applying average residential care home fees of £482 per week (according to Laing and Buisson), single person's State Retirement Pension of £95.25 per week, lower rate Attendance Allowance of £47.80 per week, occupational pension in two examples, and personal allowance. State pension, occupational pensions, personal allowance, and care home fees have all been assumed to rise by 3.1% per annum in line with the Consumer Price Index.

The box below gives the financial profiles of the four single people aged 65 and over. The Tables in Appendix 2 roll the scenarios forward to identify the point at which each person would cross the threshold of the upper tariff for local authority funding of their care home placement. The four vignettes have followed the approach of those in Poole's paper, taking person B as representative of a median position for an older person moving into a care home.

¹⁵ Poole T (2006) *Private Expenditure on Older People's Social Care*, Background Paper for Securing Good Care for Older People, London: King's Fund Wanless Social Care Review.

Example financial profiles of four single people aged 65+

Person A

Net housing wealth: £200,000

Savings: £30,000¹⁶

State pension: £95.25 per week

Occupational pension: £120 per week

Attendance Allowance: £47.80 per week

Person B

Net housing wealth: £170,000¹⁷

Savings: £18,750¹⁸

State pension: £95.25 per week

Occupational pension: £70 per week¹⁹

Attendance Allowance: £47.80 per week

Person C

Net housing wealth: None

Savings: £30,000

State pension: £95.25 per week

Occupational pension: None

Attendance Allowance: £47.80 per week

Person D

Net housing wealth: None

Savings: £18,750

State pension: £95.25 per week

Occupational pension: None

Attendance Allowance: £47.80 per week

From the Tables in Appendix 2, it emerges that Persons C and D would both be eligible for local authority within the first year, while Person B would reach the threshold during year 10 of their stay in a care home, and Person A would reach the threshold in year 14.

¹⁶ Average saving of person aged 55+ is £33,000 according to Birmingham Mid-shires.

¹⁷ Halifax House Price Index – Average property price in 2010.

¹⁸ Median average saving for person aged 75+, Aviva Annual Retirement Report, Feb 2010

¹⁹ Median average occupational pension for single pensioner, Pensions Policy Institute, 2008/09

10 What services do local authorities provide to self-funders?

10.1 Research

In the previous sections, IPC has sought to estimate how many people are paying for their own care in England. This section, looks at what services local authorities provide to people who pay for their own care, using the data held by the Care Quality Commission from each local authority in response to the AQAA self-assessment question 9GN097. This asks: 'Please describe services that are provided for self-funders in 2008-9 considering use of community or residential services'. A full list of responses for 2008-2009 was obtained.

The aim of reviewing this information was to draw out the extent to which local authorities actively identified and engaged with self-funders in their areas. The review of responses focused on specific references to information, advice, assessment and signposting as the most common forms of service provided. In addition to this, there were some specific examples of services provided. The responses provided a 'snapshot' of what authorities offer (different councils may offer the same services, but some may not have specified everything available to self-funders while other have given a fuller more detailed picture).

A small number of responses for Councils from the following year, 2009-10, have been included to highlight any significant changes in the information provided. These Councils have been chosen based on the information provided for 2008-9.

10.2 Analysis

Of the 152 Councils that responded, only three authorities mentioned a figure for the number of self-funders in their areas which appeared to relate to self-funders in care homes (Lambeth, Thurrock, and Wakefield). IPC are also aware of three other authorities that have commissioned work to estimate the numbers of self-funders in their area. The responses confirmed the impression that the great majority of local authorities currently have little information about the numbers of people who pay for their own care.

Two-thirds (67%) of local authorities mentioned assessment for self-funders. All self-funders are entitled to an assessment of their need for social care and this should precede any financial assessment.

With regard to the specific services offered, 91% of local authorities mentioned the provision of information as a service to self-funders; and 84% mentioned the provision of advice.

A relatively small number of authorities (39%) mentioned signposting to other services, advice or providers, and just over half (58%) of Councils mentioned other services and activities provided to self-funders, such as joint commissioning, financial advice, hospital and emergency support, voluntary and provider support. The next section provides details of a number of specific examples arranged thematically.

10.3 Specific examples

10.3.1 Financial advice

A number of authorities undertake assessment and review of the financial circumstances with self-funders. Gateshead, Leicestershire and North Lincolnshire provide benefits advice in independent care homes. Herefordshire, Dudley and North Somerset provide welfare benefit checks and financial assessments for self-funders and in Middlesbrough, everyone over 70 has their health and social care needs assessed. Bournemouth described work in progress to identify self-funders who may run out of funds, and provision of financial advice through the voluntary sector.

10.3.2 Hospital and emergency support

Authorities including Bath and North East Somerset, Cheshire, Cheshire West and Chester, Derbyshire and Surrey have teams working within local hospitals to provide support and advice for older people leaving hospital care. Windsor and Maidenhead offers discharge planning for those leaving hospital.

Some, such as Dorset, support voluntary organisations in providing this function.

East Sussex and Northamptonshire offer some care and support to people leaving hospital. Enfield offers a Home from Hospital service free for six weeks.

Somerset offers Rapid Response and Initial Response services free to self-funded users for a period of up to two weeks to help them in crisis or to return home from hospital.

10.3.3 Information and advice

Southend has established a social care access team established to provide advice and support to self-funders. In Manchester all residents are supported in self-assessment of care and writing support plans and organising support.

Kinston-upon-Hull is working on a universal information and advocacy service with NHS partners and Bradford provides joined up information together with the PCT. Essex has a telephone helpline for people looking for, or in residential care. In Havering, care home owners are invited to update the number of beds available daily on the council website

10.3.4 Voluntary and provider support

Funding for voluntary sector support and advice is provided by a number of Councils, including Bristol, Bromley, Harrow, Hounslow, Reading, Rochdale, Sheffield, and Tower Hamlets. Gateshead has contracts with voluntary organisations to provide advice and low-level brokerage. In Lambeth, low-level preventative services are funded through third sector providers.

Enfield, Rutland, Southwark and Trafford fund the local Age Concern to provide a range of financial support and general advocacy services to self-funders. In Wandsworth, Age Concern has been commissioned to support people to arrange care packages. The Council also supports other voluntary groups.

East Riding of Yorkshire Council has jointly designed a website with the voluntary sector to provide information to self-funders on community services. Stockport funds an information line run by the voluntary sector.

10.3.5 Other services

Calderdale and Doncaster provide support services to self-funders at home, regardless of their income. Self-funders have access to the same level of service as non-self funders in Kingston on Thames, Kirklees and Knowsley. In Herefordshire self-funders can access all community-run projects and get access to Council social and leisure facilities.

Derby offers a subsidy for community-based services for all users on a sliding scale. North Tyneside has a maximum charge of £99 for non-residential services. Cumbria: all residents are entitled to be placed in residential care under the council's rates, allowing the council to review when assets may reduce.

Lincolnshire and Windsor and Maidenhead offer a deferred payment scheme for people who fund themselves.

Luton offers 6 week service reviews for self-funders moving into care, with annual reviews thereafter.

Solihull is one of the authorities which has introduced a brokerage service which self-funders are eligible to use. Swindon also has an in-house brokerage team which self-funders can use. Durham offers support self-funders choosing a home or community service. In Islington, if assessed as requiring residential or

nursing care, self-funders have the same access to the resource team to help identify care and have continued care management during this time.

In Staffordshire and Surrey, community equipment is provided free to self-funders. Telford and the Wrekin offers free equipment and meals to self-funders regardless of their means. Surrey and Stockton-on-Tees offer telecare to self-funders. Manchester, Wiltshire and Wokingham offer reablement services to self-funders. Wokingham offers free respite care.

Blackpool and Gateshead are two of a number of Councils which provide reviews to self-funders when visiting others in the same care home.

A review of selected 2010 responses is provided in Appendix 3.

10.4 Summary

The responses provided by local authorities to the specific CQC question vary greatly, and there are clearly gaps. Nevertheless, the information offered does point to a significant level of support for self-funders across most authorities, with a number providing innovative and inclusive support for this group.

In 2009-2010 the responses were notable for a greater emphasis on voluntary involvement, and the provision of more information in the form of web support or improved leaflets. This suggests that services may be in the process of being revised across a large number of authorities as financial pressures increase.

The AQAA return does not ask specifically what work local authorities are doing to establish how many self-funders they have, but it is striking that only two authorities mentioned that they had undertaken this work.

11 Conclusions and further work

This report has covered a wide range of aspects of self-funding by older people in England. The technical appendices present the estimated number of people who pay for all of their care in a care home in each local authority in England. The size of this market is now a significant part of the total care market. Self-funding in care homes represents an estimated £4.9 billion with additional top up funding for more than an estimated 168,000 local authority sponsored places. Self-funding of home care represents an estimated £652 million.

In the future self-funding of care will be subject to a number of factors pulling in different directions as Table 14 suggests

Table 14: Examples of influences on the volume of self-funding

More self-funding	More publicly funded care
Reductions in public sector expenditure	Reduced value of assets such as property or shares
Increased equity	More older people
More older people with occupational pensions	Pressure on NHS to move people swiftly out of hospital
Tighter eligibility criteria or changes in the basis of funding care	Higher prices for care
Migration to other countries	

Based on the vignettes, it seems likely that most single older people could fund their care home costs for as long as they are likely to need it, although it is not clear what impact the recession may have on this capability. However, there will continue to be people who do not own their own home, and others who share it with a spouse or partner for whom local authority help with funding will be required.

There are also other factors to take into account, such as the degree to which extra care housing and assistive technology might influence the self-funding market. For example, if people can invest in extra care as a property based approach to retaining their equity whilst at the same time receiving relatively high levels of care, this is likely to have a significant impact on the demand for care home provision.

The analysis of the AQAA forms indicates that most local authorities provide some basic support to self-funders in the form of advice and information, but few appear to have much information about how many self-funders they have or are in contact with. The examples cited in this report illustrate that there is scope to provide a much broader range of services to help people who pay for their own care.

Estimating the numbers of people who pay for their own care is subject to many caveats and health warnings, largely the result of the lack of data and difficulties around definition. However, the introduction of a set of new model questions covering self-funding in the forthcoming Health Survey for England should provide a useful opportunity to compare findings and revisit these estimates. In addition, there are a number of areas where further work may be of value:

- The material in this report has been produced using national data and prevalence rates and a reworking of previous estimates. It would be valuable to be able to cross check this against registered providers actual number of self funders in a sample of local authorities.
- Older people's assets are changing rapidly, in terms of pensions and equity. It is likely that there is a much wider distribution of wealth from richest to poorest than would have been the case twenty years ago. It would be valuable to compare these factors against the estimates in numbers in order to explore the impact these factors may have on the future numbers of self funders.
- Anecdotally, local authorities report an increase in self-funders running out of money in care homes. It would be valuable if some of this material from around the country could be pulled together in order to explore the impact this is having on publicly funded care, and to produce an estimate of how this might impact over the next couple of years.
- Little is known of migratory patterns within the UK, and between the UK and other countries. Does the flight from London of older people reflect their preference or a lack of resources in the capital to support older people? Are older people increasingly rejecting a move to the coast or country? Are more people moving abroad in older age to countries with better or cheaper health and care, or for other reasons? What might be the impact of migration and second home ownership in the West Country and South coast of England? All of these factors may have a significant impact on self-funding and care provision, yet there is an absence of data on their current or likely future impact.

Appendix 1

HSE

Count of Everyone aged 65+ in the Survey

	85+	80-84	75-79	70-74	65-69	Total
Men	322	207	290	251	280	1350
Women	1222	520	441	351	286	2820
Total	1544	727	731	602	566	4170

Count of those paying for private domestic help (variable uosph = 1)

	85+	80-84	75-79	70-74	65-69	Total
Men	14	5	13	9	11	52
Women	25	33	22	25	8	113
Total	39	38	35	34	19	165

% of those 65+ paying for private domestic help

	85+	80-84	75-79	70-74	65-69	Total
Men	4.34	2.42	4.48	3.59	3.93	3.85
Women	2.05	6.35	4.99	7.12	2.80	4.00
Total	2.52	5.23	4.79	5.65	3.36	3.96

Applied to the POPPI Figures (HSE - paying for private domestic help)

Males

	2010	2015	2020	2025	2030
65-69	45,875	55,629	50,543	55,433	63,316
70-74	34,726	38,129	46,666	42,667	47,007
75-79	33,551	37,493	41,906	51,771	47,685
80-84	12,427	14,094	16,461	18,784	23,423
85+	17,043	21,470	27,247	34,928	43,404
Total	145,903	169,077	185,932	205,421	229,187

Females

	2010	2015	2020	2025	2030
65-69	35,078	42,714	38,951	42,487	48,950
70-74	77,216	83,738	102,521	93,920	102,813
75-79	45,853	49,107	53,837	66,312	61,132
80-84	46,907	48,539	53,708	59,804	74,238
85+	16,408	18,061	20,326	24,008	28,682
Total	191,812	213,244	229,888	251,132	279,420

ELSA

Count of Everyone aged 65+ in the Survey

	85+	80-84	75-79	70-74	65-69	Total
Men	177	276	391	538	569	1953
Women	333	348	527	611	652	2475
Total	510	624	918	1149	1221	4428

Count of those 65+ paying for help with moving around the house (variable hehphpr = 1)

	85+	80-84	75-79	70-74	65-69	Total
Men	4	4	1	3	3	15
Women	25	11	12	6	4	58
Total	29	15	13	9	7	73

% of those 65+ paying for help with moving around the house

	85+	80-84	75-79	70-74	65-69	Total
Men	2.26	1.45	0.26	0.56	0.53	0.77
Women	7.51	3.16	2.28	0.98	0.61	2.34
Total	5.69	2.40	1.42	0.78	0.57	1.65

Applied to the POPPI Figures (ELSA - paying for help with moving around the house)

Males

	2010	2015	2020	2025	2030
65-69	6187	7502	6816	7476	8539
70-74	5417	5948	7279	6656	7333
75-79	1947	2176	2432	3005	2767
80-84	7446	8445	9863	11,255	14,035
85+	8875	11,180	14,188	18,188	22,602
Total	29,181	33,815	37,186	41,084	45,837

Females

	2010	2015	2020	2025	2030
65-69	7642	9306	8486	9256	10,664
70-74	10,628	11,526	14,111	12,927	14,151
75-79	20,951	22,437	24,599	30,299	27,932
80-84	23,343	24,155	26,727	29,761	36,944
85+	60,110	66,163	74,462	87,950	105,072
Total	112,210	124,748	134,484	146,912	163,461

Count of those 65+ paying for help washing and dressing

	85+	80-84	75-79	70-74	65-69	Total
Men	0	2	1	0	0	3
Women	12	3	5	1	3	24
Total	12	5	6	1	3	27

% of those 65+ paying for help with washing and dressing

	85+	80-84	75-79	70-74	65-69	Total
Men	0	0.72	0.26	0	0	0.15
Women	3.6	0.86	0.95	0.16	0.46	0.97
Total	2.35	0.80	0.65	0.09	0.25	0.61

Applied to the POPPI Figures (ELSA - paying for help with washing and dressing)

Males

	2010	2015	2020	2025	2030
65-69	0	0	0	0	0
70-74	0	0	0	0	0
75-79	1947	2176	2432	3005	2767
80-84	3697	4193	4897	5589	6969
85+	0	0	0	0	0
Total	5685	6587	7244	8003	8929

Females

	2010	2015	2020	2025	2030
65-69	5763	7017	6399	6980	8042
70-74	1735	1882	2304	2111	2310
75-79	8730	9349	10,250	12,625	11,638
80-84	6353	6574	7274	8099	10,054
85+	28,814	31,716	35,694	42,160	50,368
Total	46,514	51,712	55,748	60,900	67,759

Count of those 65+ paying for help with eating & preparing meals (variable hehpdr =1)

	85+	80-84	75-79	70-74	65-69	Total
Men	0	0	0	0	1	1
Women	9	1	2	0	1	13
Total	9	1	2	0	2	14

% of those 65+ paying for help with eating and preparing meals

	85+	80-84	75-79	70-74	65-69	Total
Men	0	0	0	0	0.18	0.05
Women	2.7	0.29	0.38	0	0.15	0.53
Total	1.76	0.16	0.22	0	0.16	0.32

Applied to the POPPI Figures (ELSA - paying for help with eating and preparing meals)

Males

	2010	2015	2020	2025	2030
65-69	2101	2548	2315	2539	2900
70-74	0	0	0	0	0
75-79	0	0	0	0	0
80-84	0	0	0	0	0
85+	0	0	0	0	0
Total	1895	2196	2415	2668	2976

Females

	2010	2015	2020	2025	2030
65-69	1879	2288	2087	2276	2622
70-74	0	0	0	0	0
75-79	3492	3740	4100	5050	4655
80-84	2142	2217	2453	2731	3390
85+	21,610	23,787	26,771	31,620	37,776
Total	25,415	28,255	30,460	33,275	37,023

Count of those 65+ paying for help with moving, washing & dressing, eating & preparing meals (all 3 variables above)

	85+	80-84	75-79	70-74	65-69	Total
Men	4	4	2	3	3	16
Women	31	11	18	7	4	71
Total	35	15	20	10	7	87

% of those 65+ paying for help with moving, washing & dressing, eating & preparing meals (all 3 variables above)

	85+	80-84	75-79	70-74	65-69	Total
Men	2.26	1.45	0.51	0.56	0.53	0.82
Women	9.31	3.16	3.42	1.15	0.61	2.87
Total	6.86	2.40	2.18	0.87	0.57	1.96

Applied to the POPPI Figures (ELSA - paying for help with moving, washing & dressing, eating & preparing meals (all 3 variables above))

Males

	2010	2015	2020	2025	2030
65-69	6187	7502	6816	7476	8539
70-74	5417	5948	7279	6656	7333
75-79	3819	4268	4771	5894	5428
80-84	7446	8445	9863	11,255	14,035
85+	8875	11,180	14,188	18,188	22,602
Total	31,076	36,011	39,601	43,752	48,814

Females

	2010	2015	2020	2025	2030
65-69	7642	9306	8486	9256	10,664
70-74	12,472	13,525	16,559	15,170	16,606
75-79	31,426	33,656	36,898	45,448	41,898
80-84	23,343	24,155	26,727	29,761	36,944
85+	74,517	82,021	92,309	109,029	130,256
Total	137,625	153,003	164,945	180,187	200,484

Count of those 65+ paying for help with moving, washing & dressing, eating & preparing meals, shopping & work around the house, answering the phone & managing money, taking meds.

	85+	80-84	75-79	70-74	65-69	Total
Men	7	6	3	4	3	23
Women	45	24	28	14	6	117
Total	52	30	31	18	9	140

% of those 65+ paying for help with moving, washing & dressing, eating & preparing meals, shopping & work around the house, answering the phone & managing money, taking meds.

	85+	80-84	75-79	70-74	65-69	Total
Men	3.95	2.17	0.77	0.74	0.53	1.18
Women	13.5	6.90	5.31	2.29	0.92	4.73
Total	10.20	4.81	3.38	1.57	0.74	3.16

Applied to the POPPI Figures (ELSA - paying for help with moving, washing & dressing, eating & preparing meals, shopping & work around the house, answering the phone & managing money, taking meds.)

Males

	2010	2015	2020	2025	2030
65-69	6187	7502	6816	7476	8539
70-74	7158	7860	9619	8795	9690
75-79	5767	6444	7203	8898	8196
80-84	11,143	12,638	14,760	16,844	21,003
85+	15,512	19,541	24,798	31,790	39,504
Total	44,718	51,821	56,987	62,960	70,244

Females

	2010	2015	2020	2025	2030
65-69	11,526	14,035	12,798	13,960	16,083
70-74	24,835	26,933	32,974	30,207	33,068
75-79	48,794	52,256	57,290	70,565	65,053
80-84	50,970	52,744	58,360	64,984	80,668
85+	108,054	118,935	133,853	158,099	188,879
Total	226,818	252,161	271,843	296,964	330,414

BHPS

Count of Everyone aged 65+ in the Survey

	85+	80-84	75-79	70-74	65-69	Total
Men	172	225	279	334	394	1404
Women	286	261	344	376	502	1770
Total	458	486	623	710	896	3174

Count of those 65+ paying for home help (variable RHLSVBF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	10	3	3	0	1	17
Women	37	10	6	2	3	58
Total	47	13	9	2	4	75

% of those 65+ paying for home help (variable RHLSVBF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	5.81	1.33	1.08	0	0.25	1.21
Women	12.94	3.83	1.74	0.53	0.6	3.28
Total	10.26	2.67	1.44	0.28	0.45	2.36

Applied to the POPPI Figures (BHPS - paying for home help)

Males

	2010	2015	2020	2025	2030
65-69	2918	3539	3215	3526	4028
70-74	0	0	0	0	0
75-79	8088	9039	10,102	12,480	11,496
80-84	6830	7746	9047	10,323	12,873
85+	22,816	28,742	36,475	46,759	58,106
Total	45,855	53,138	58,436	64,561	72,030

Females

	2010	2015	2020	2025	2030
65-69	7517	9153	8347	9104	10,489
70-74	5748	6233	7631	6991	7653
75-79	15,989	17,123	18,773	23,123	21,317
80-84	28,292	29,277	32,394	36,071	44,777
85+	103,572	114,001	128,300	151,540	181,044
Total	157,286	174,860	188,508	205,928	229,124

Count of those 65+ paying for meals on wheels (variable RHLSVCF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	10	0	0	2	0	12
Women	8	9	2	3	1	23
Total	18	9	2	5	1	35

% of those 65+ paying for meals on wheels (variable RHLSVCF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	5.81	0	0	0.6	0	0.85
Women	2.8	3.45	0.58	0.8	0.2	1.3
Total	3.93	1.85	0.32	0.7	0.11	1.10

Applied to the POPPI Figures (BHPS - paying for meals on wheels)

Males

	2010	2015	2020	2025	2030
65-69	0	0	0	0	0
70-74	5804	6373	7799	7131	7856
75-79	0	0	0	0	0
80-84	0	0	0	0	0
85+	22,816	28,742	36,475	46,759	58,106
Total	32,212	37,329	41,050	45,353	50,600

Females

	2010	2015	2020	2025	2030
65-69	2506	3051	2782	3035	3496
70-74	8676	9409	11,519	10,553	11,552
75-79	5330	5708	6258	7708	7106
80-84	25,485	26,372	29,180	32,492	40,334
85+	22,411	24,668	27,762	32,791	39,175
Total	62,339	69,304	74,714	81,618	90,812

Count of those 65+ paying for home help or meals on wheels (variables RHLSVCF or RHLSVBF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	18	3	3	2	1	27
Women	41	18	7	5	4	75
Total	59	21	10	7	5	102

% of those 65+ paying for home help or meals on wheels (variables RHLSVCF or RHLSVBF =2)

	85+	80-84	75-79	70-74	65-69	Total
Men	10.47	1.33	1.08	0.6	0.25	1.92
Women	14.34	6.9	2.03	1.33	0.8	4.24
Total	12.88	4.32	1.61	0.99	0.56	3.21

Applied to the POPPI Figures (BHPS - paying for home help or meals on wheels)

Males

	2010	2015	2020	2025	2030
65-69	2918	3539	3215	3526	4028
70-74	5804	6373	7799	7131	7856
75-79	8088	9039	10,102	12,480	11,496
80-84	6830	7746	9047	10,323	12,873
85+	41,116	51,796	65,731	84,263	104,710
Total	72,762	84,319	92,724	102,444	114,296

Females

	2010	2015	2020	2025	2030
65-69	10,022	12,204	11,129	12,139	13,987
70-74	14,424	15,642	19,151	17,544	19,205
75-79	18,654	19,977	21,902	26,977	24,870
80-84	50,970	52,744	58,360	64,984	80,668
85+	114,777	126,335	142,181	167,936	200,631
Total	203,321	226,039	243,681	266,200	296,185

Appendix 2 – Vignettes

Person A: Reaches threshold of £23,000 during year 14.

Year	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Assets															
Net Housing Wealth	200000														
Savings	30000														
Total Asset	230000	217455	204469	191029	177123	162735	147853	132461	116545	100089	83078	65495	47324	28547	9147
Income															
State Pension	4953	5107	5265	5428	5596	5770	5949	6133	6323	6519	6721	6930	7145	7366	7594
Occupational Pension	6240	6433	6633	6838	7050	7269	7494	7727	7966	8213	8468	8730	9001	9280	9568
Attendance Allowance	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486
Total Income	13679	14026	14383	14752	15132	15524	15929	16345	16775	17218	17675	18146	18631	19132	19648
Total Asset + Income	243679	231481	218852	205782	192255	178260	163781	148806	133320	117307	100753	83641	65955	47679	28795
Expenditure															
Personal Allowance	1160	1196	1233	1271	1310	1351	1393	1436	1480	1526	1574	1622	1673	1725	1778
Care Home Fees	25064	25816	26590	27388	28210	29056	29928	30826	31750	32703	33684	34694	35735	36807	37912
Total Expenditure	26224	27011	27823	28659	29520	30407	31320	32261	33231	34229	35258	36317	37408	38532	39690
Total Asset Left	217455	204469	191029	177123	162735	147853	132461	116545	100089	83078	65495	47324	28547	9147	-10895

Person B: Reaches threshold of £23,000 during year 10

Year	1	2	3	4	5	6	7	8	9	10	11
Assets											
Net Housing Wealth	170000										
Savings	18750										
Total Asset	188750	173605	157939	141735	124979	107654	89743	71228	52093	32318	11884
Income											
State Pension	4953	5107	5265	5428	5596	5770	5949	6133	6323	6519	6721
Occupational Pension	3640	3753	3869	3989	4113	4240	4372	4507	4647	4791	4940
Attendance Allowance	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486	2486
Total Income	11079	11345	11620	11903	12195	12496	12806	13126	13456	13796	14146
Total Asset + Income	199829	184950	169558	153638	137174	120149	102549	84354	65548	46114	26031
Expenditure											
Personal Allowance	1160	1196	1233	1271	1310	1351	1393	1436	1480	1526	1574
Care Home Fees	25064	25816	26590	27388	28210	29056	29928	30826	31750	32703	33684
Total Expenditure	26224	27011	27823	28659	29520	30407	31320	32261	33231	34229	35258
Total Asset Left	173605	157939	141735	124979	107654	89743	71228	52093	32318	11884	-9227

Person C: Reaches threshold of £23,000 during 1st year.

Year	1	2
Assets		
Net Housing Wealth	0	
Savings	30000	
Total Asset	30000	11215
Income		
State Pension	4953	5107
Occupational Pension	0	0
Attendance Allowance	2486	2486
Total Income	7439	7592
Total Asset + Income	37439	18807
Expenditure		
Personal Allowance	1160	1196
Care Home Fees	25064	25816
Total Expenditure	26224	27011
Total Asset Left	11215	-8204

Person D: Reaches threshold of £23,000 during 1st year.

Year	1
Assets	
Net Housing Wealth	0
Savings	18750
Total Asset	18750
Income	
State Pension	4953
Occupational Pension	0
Attendance Allowance	2486
Total Income	7439
Total Asset + Income	26189
Expenditure	
Personal Allowance	1160
Care Home Fees	25064
Total Expenditure	26224
Total Asset Left	-35

Appendix 3 Review of AQAA 2010 responses

A brief review of the AQAA responses provided for 2010 against the responses from previous years.

In the 2009 return **Bournemouth** described work in progress to identify self-funders who may run out of funds and to provide timely financial advice through voluntary sector. The response for 2010 does not refer to this project but it does mention the introduction of better information for self-funders across the authority. The 2010 return mentions continued funding for an Age Concern Community Support Centre, which highlights the variability of the information provided in these responses as it seems likely that the authority had offered support in 2009 but had omitted to mention this.

In its 2009 response, **Croydon** mentioned the development with the PCT and voluntary organisations of a social enterprise to provide advice, info, equipment and services retail, with online access planned and a retail function to be added. The 2010 response from Croydon notes that the 'trading ability' for some service is well advanced but gives little detail of progress.

The 2009 response from **Cumbria** mentions the offer to provide a residential care home place for self-funders under the Council's negotiated rates with providers. The response notes that this helps the Council to plan for depleting assets and benefits reviews. The 2010 response for Cumbria does not refer to this. It describes how the Council is working with third sector organisations to ensure that self-funders get appropriate up-to-date advice when considering purchasing their own support.

Kingston-upon-Hull mentioned in 2009 the advice available through the Council's website and Age Concern. The Council mentioned work with corporate and health colleagues to develop a universal information, advice and advocacy service to bring information on services to mainstream portals. The 2010 return mentions a draft customer strategy to provide multiple information routes, suggesting incomplete progress on this plan. The 2010 return mentions work with providers to identify self-funders to offer them support and advice.

Manchester mentioned access to advice and support to write care plans, as well as preventative and reablement services available to self-funders. It noted that just over a quarter of referrals to its 'short-term team were self-funders. The 2010 response from Manchester notes that 1.98% of people in care homes are self-funders and that all are offered reviews to ensure they have access to good quality information. The Council has set up a web-based information system and continues to offer free reablement. The Council is confident that it offers good support to self-funders.

The 2009 response from **Norfolk** mentions comprehensive advice and support for all residents regardless of their means, including from a range of voluntary organisations. Mentoring is provided for self-funders seeking to design their own care and a care arranging service was signposted for launch in 2009-10, working with existing self-funders to aid its design. The return for 2010 states that self-funders contacting the authority are directed to Care Connect, a Council agency. The Council has improved leaflets and planned to launch a universal information system. The Council also plans to launch a Freeview channel offering a range of information.

Solihull in 2009 mentioned signposting for self-funders to a range of voluntary organisations to provide information and advice, including the funding of a service from Age Concern to provide information on specific services and support for self-funders. The Council was planning to introduce a brokerage function in September 2009 to provide more flexibility for social workers to support a range of clients including self-funders. The 2010 return mentions assessment and support for self-funders, including information and advice.

Southampton mentioned plans in 2009 to develop a low level brokerage, advocacy and support team for self-funders to help identify what services to commission in the longer term. The 2010 response from Southampton mentions assessment and care management services offered to all and refers to support provided by the CAB. The Council also refers to changes in its funding policy which have resulted in more people becoming self-funders. The Council has provided each of these people with a care management review and support in using a personal budget.

Journeys without maps:

The decisions and destinations of
people who self fund – a
qualitative study from
Melanie Henwood Associates

December 2010

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Finally, I am extremely grateful to Linda Christie who transcribed many hours of interviews with great efficiency and unfailing good humour.

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Journeys Without Maps:

The decisions and destinations of people who self-fund

Executive Summary

- 1 A qualitative investigation commissioned by the Putting People First Consortium has been undertaken by Melanie Henwood to retrospectively track the journeys undertaken by people who self-fund care and support, and to explore the decisions they made and the consequences of those decisions in terms of destinations. A central part of the study was to understand the nature and sources of advice and information that people had access to in making their decisions.
- 2 The study had two stages, the first involving face to face interviews with key providers of social care services and support to explore perceptions and understanding of the self-funder market, and also to facilitate access to people who are self-funding for the retrospective tracking. The second stage involved interviews with 30 people who were either using services they were paying for themselves, or were the carers (family members) of people in this situation. Most of the interviews were face to face, but some of those with carers were conducted by telephone.
- 3 The three stages of interviewing provided an opportunity to triangulate information, and to explore recurrent themes and perceptions. A number of key messages can be highlighted:

The Provider perspective

- 4 Providers are of various degrees of sophistication in their understanding of and engagement with the self-funder market; for some this is core business, while for others it is still marginal. Some are deliberately developing a business model to reduce reliance on local authority work and develop new relationships with individual purchasers. Others start from a different place of having little in the way of private business.
- 5 While self-funders often subsidise the residential care market, the opposite can be the case in domiciliary support and can mean that private requests are turned down because of the absence of sufficient business volume, or conversely can mean that private payers benefit from a large volume of work being conducted in an area which allows accommodation of individual requests.
- 6 Providers are disadvantaged by a lack of good intelligence on the self-funder population, compared to publicly funded clients. However, this picture is changing and improving with new quantitative data becoming available both about people privately purchasing services, and the workforce providing these.
- 7 The self-funder population is diverse and there are points on a continuum between the 'pure' self-funder who choose to purchase services; those who become self-funding by default (through the impact of means-testing and social care eligibility criteria); and people who are self-funders through using personal budgets/Direct Payments. Some providers distinguish between these different types of self-funder and may be primarily interested in the pure self-funder because of their greater average purchasing power.
- 8 There is a spectrum of spending by self-funders from people who are just buying domestic or cleaning services, to high net worth individuals who effectively buy live-in staff. For some providers it is a good market strategy to accept people seeking more modest help because this can build over time to more intensive support and personal care.

- 9 Providers recognise that the 'typical' self-funder is someone who has experienced a crisis necessitating action, rather than someone who has made planned and positive choices. In such situations people are rarely well-informed about either what they need or what is available to support them.
- 10 Initial approaches to providers are often made by adult children or other relatives, and they often don't know what it is they are looking for, beyond a general idea that they need some help.
- 11 People find their way by various routes. Some are sign-posted to providers by local councils but the approved provider list is a matter of contention among providers because it excludes some providers, and people seeking help may wrongly believe that the list may offer some guarantee of quality, or that only those businesses on the list should be trusted.
- 12 People need not only information about how to find the right support and services, but also access to independent advice, advocacy and brokerage. This is something that is typically absent for self-funders, even if they manage to secure assessment of their needs. Many people have a good understanding of their own needs or the difficulties they are confronting, but much less idea of what solutions are available and how they might gain access to them. There are some independent care advisors emerging, but this is a fledgling market and there is currently no accreditation for advisors, and some who present themselves as 'independent' are also acting as providers of direct services and may therefore have vested interests.
- 13 While recognising the importance of self-funders to their business, providers are also concerned that the journeys of self-funders are too often guided by happenstance rather than by clear information and advice.

Decisions and Destinations: the self-funder experience

- 14 Interviews with self-funders invited people to tell their personal stories about their journey – how had they reached their particular destination and what were the critical points along the way? In almost every situation it was clear that people had not made their choices in a planned and deliberate way. People generally do not think about their encroaching old age or believe they will need care or support until something happens.
- 15 Being widowed or experiencing a sudden change in health were the key factors that were likely to lead to a change in living arrangements or the need for support. This was particularly the case when people were geographically distant from close family members and concerned that they were becoming too much trouble.
- 16 Having decided that something needed to change, some people are able to be systematic in looking for the right solution for their needs (putting their name on the waiting list of sheltered housing or care homes for example), and were wary of making the wrong decision in haste. In such situations people often chose a level of support that was greater than their current needs (such as in choosing residential care), but did so either because they were not aware of alternatives or because they wanted residential provision to provide them with companionship and security.
- 17 Many people described a range of coping strategies whereby they 'managed' before it became apparent that something more was needed. Typically this coping involved a combination of family, friends and other informal support – these arrangements could be very successful, but were also very fragile and could break down.
- 18 For the majority of people, the transition to using support or moving into a care environment is not something that happens gradually or as the result of considered planning. Most of those interviewed described a sudden and at times catastrophic change that had largely taken decision making out of their hands.

- 19 Major life changing decisions were often made on the basis of little information; people had little idea about where to seek such information or advice.
- 20 Approaching social services for help was something that was not considered by most, or it was seen as something negative to be avoided or treated as a 'last resort'. Those who *did* contact their council typically described being given 'a list' of care homes and nothing more. A minority of people had found their way to other sources of information (such as through Counsel and Care) and reported a more positive experience of advice and information that addressed their particular circumstances. In meeting their responsibilities to provide universal information and advice councils should recognise that people need to be able to access information and advice through a variety of accessible and non-stigmatising routes which offer different models and styles to match people's preferences (such as electronic information; telephone support, or face to face). On the basis of people's reported experiences it is doubtful that the local authority is the organisation best placed to provide such flexible and independent advice when they are simultaneously acting as gatekeepers to limit publicly funded support.
- 21 People with close family were often able to ask family members to help in identifying a suitable care home or to undertake visits on their behalf. For those without family members the process was more difficult and worrying.
- 22 People typically described a 'check list' of features they wanted from support, and anywhere that ticked most of the boxes would be acceptable. Once the decision to move into a care home had been made people generally described it positively or with a degree of resignation – there was no alternative and they had to make the best of it.
- 23 People were in a variety of financial situations and for many there were significant worries about the sustainability of care arrangements and the depletion of savings. None of the people who were self-funding had received independent financial advice on paying for care; some had a vague knowledge about the rules around financial contributions for residential care, but typically this was something that was left to others to handle (with many having Power of Attorney arrangements in place with relatives). For some people there was a profound sense of 'powerlessness' and lack of control over their own financial resources, coupled with some real fear over what would become of them if their savings ran dry.

Carers' Journeys

- 24 Interviews took place with a number of carers and family members – primarily these were adult children of older people needing care and support, but some were spouse carers. They were generally approached to provide insight in situations where a person who was self-funding was unable to participate in interviews, but carers also had their own stories to tell and their own journeys in trying to navigate the self-funding world.
- 25 Carers largely reinforced the themes already identified, but they also revealed a level of concern and anxiety that was rarely articulated by people who were self-funding, perhaps because the implications of situations were more evident to family members than to the person themselves.
- 26 There was a strong reluctance to approach social services – typically a relative was averse to doing so or did not see the relevance to their own situation. Carers often identified the considerable stigma that still attaches to the idea of social services involvement for many older people and were keen to avoid such a situation if at all possible. Those that *did* approach social services reported largely negative experiences in which the *first* and often *only* question they were asked was about their relative's financial status.
- 27 The experience of sign-posting was rarely positive; with people describing being 'passed from pillar to post' and endlessly encountering people whose sole job appeared to be to pass them onto someone else. Only one person had a positive experience of being signposted to a care navigator who had helped them to find appropriate support.

- 28 The attempt to identify suitable care and support on behalf of a relative was often difficult with carers having little idea of how to go about getting appropriate advice or information. 'Getting a list' of care homes from social services was viewed with derision for its lack of value in indicating which care homes were better or most appropriate to the needs of a loved one.
- 29 Some younger carers who were computer literate had accessed the regulator's reports on care homes and tried to interpret the meaning of ratings in practice and to use this in informing their choice of home. The changes to the quality rating system have created some uncertainty while a new model is developed, and it will be vital that what emerges as the alternative is easily accessible and meaningful. Those carers who did not have access to electronic material relied frequently on visits to potential care homes and making judgements based on impressions and appearance.
- 30 Crisis situations were often exacerbated by NHS pressures to empty hospital beds, putting excessive demands on relatives to find a care home within a matter of days (and with no opportunity to explore other options).
- 31 Financial matters were a dominant concern for relatives and carers who were generally better informed about how financial assessment operated and when and how the local council might contribute to the costs of care. People's information on such matters was typically gathered from the national press and from consumer programmes on television and radio. Independent financial advice on care matters was rarely mentioned and was not something people were generally aware of.
- 32 Fear of what might happen when money runs out was also a major concern for carers, particularly for people whose relative was living in a care home which was more costly than would normally be acceptable within local authority contracts. Trying to calculate how long savings might last was a recurrent concern, with some carers thinking they may need to persuade relatives to 'trade down' to smaller rooms to keep things going, and others who had access to their own resources being prepared to make up any necessary shortfall.
- 33 Some carers were continuing to support very dependent relatives at home and wished to continue to do so as long as possible, while recognising that the arrangement was precarious and very demanding, and while the situation was just about manageable in the short term, it was not clear how long this could be sustained. Indeed, it was apparent that a crisis or sudden deterioration in health would seriously compromise carers' capacity and could lead to the collapse of arrangements.
- 34 The experience of supporting relatives and trying to help them find their way as self-funders had opened the eyes of many carers to the reality they faced and made them think more about their own future as they grew older. Many reflected on the unfairness of the current system which was seen to provide little or no help to people with modest savings.

Conclusions

- 35 The experiences of people who are self-funding, and of their family members, are complex and varied. For some people, having adequate financial resources had enabled them to make considered and deliberate choices about the type of support they needed and wanted. For others, decisions had been accelerated or necessitated by changing circumstances and they had little control over subsequent developments. In making vital (and often life changing) decisions, people are most likely to consult family and friends. Almost nobody identified social services as a source of information or advice, and people who *did* have contact with their council often had a negative experience that focused solely on their financial status rather than their needs for care and support. Informal information, word of mouth, and reputation were the most significant factors influencing people's decision making and destinations. This picture is depressingly similar to the findings in earlier research and indicates the considerable challenges that have still to be met by many local authorities in developing their universal offer of information and advice for everyone in need of care and support.

- 36 Almost nobody thinks very much in advance about what they might do if they need care and support. People typically cope until a tipping point is reached, and at that stage decisions often have to be made quickly and with little information to inform major decision making.
- 37 It is clear that having sufficient resources to be a self-funder does not automatically give people greater control over their situation, and meaningful choices are often lacking. While people have few expectations of their local council to provide them with any help, they also have little idea of where else to go for guidance in navigating the complex world of care and support. There was a profound sense throughout the project of people undertaking major life journeys without the benefit of maps to guide them, and with no clear sense of their destination. In many ways people who were self-funding were considerably disadvantaged, relative to people qualifying for publicly funded support, by not having access to independent assessment of their needs (as opposed to their means), or to clear information about their options, and care advocacy to help them in achieving their preferences. For people who were without a close family member to help them on their journey, the options were fewer still and the path a lonely and bewildering place to navigate.

Supporting People Who Fund their Own Care

1 Introduction

- 1.1 In 2009 a two part study was commissioned by ADASS, SCIE and JRF examining information, advice and advocacy for people who fund their own care. The study led to two reports: a literature review across a range of policy, research and developmentⁱ, and a preliminary exploration of national organisations involved in providing information and advice around social care support.ⁱⁱ The two complementary pieces of work produced consistent conclusions, and highlighted four key themes:
- The issue is complex and multi-faceted and even definitions are unclear.
 - Performance and provision are highly variable across the country.
 - The position of self-funders is of increasing significance, but exhortation alone is likely to be insufficient to ensure the needs of this group are addressed.
 - The evidence base on self-funders is weak.
- 1.2 Following discussion of the findings with key stakeholders it was agreed that further investigation was required. A retrospective qualitative study was developed to explore the experiences and stories of people who are self-funding. The core purpose of the study was to examine:
- How and why did people make the choices they did?
 - What information and advice was available to help them to do so?
 - Would they have made different choices with different information or advice?
- 1.3 The study had two stages. The first part involved interviews with key providers of social care services and support in order to explore perceptions and understandings of the self-funder market, and also to provide access to a sample of people who are self-funding for the retrospective tracking stage of the study. The second stage identified around 30 people who were self-funding and living in a variety of situations, from those still managing largely independently, to people receiving home care or other support, people living in assisted living and sheltered housing, and people living in residential and nursing homes. Most interviews were undertaken face to face, but a number were conducted on the telephone (particularly with family members) where the practicalities of visiting people in a number of different parts of the country were not feasible. Visits were undertaken to a number of locations including London; Surrey; Hampshire; Northamptonshire; Nottinghamshire and Oxfordshire. Interviews were digitally recorded and subsequently transcribed. All interviews were conducted on the basis of confidentiality and we do not identify any of the individual respondents in this report. All fieldwork took place between July and October 2010.

Policy Context

- 1.4 The significance of support for people who fund their own care needs to be understood within the wider context of the transformation agenda in social care as set out in *Putting People First* in 2007ⁱⁱⁱ. The first phase of transformation covers the period from April 2009 (when the Adult Social Care Reform Grant was first allocated to councils) to April 2011. In 2009 ADASS, LGA and the Department Of Health worked in partnership to develop a set of milestones against which progress with delivery might be judged. Five key priorities were agreed for phase one:
- Transformation developed in partnership with existing service users (public and private), their carers and other citizens.

- A process is in place to ensure that all those eligible for council funded adult social care receive a personal budget via a suitable assessment process.
 - Partners are investing in cost-effective preventative interventions which reduce the demand for social care and health services.
 - Citizens have access to information and advice regarding how to identify and access options available in their communities to meet their care and support needs.
 - Service users experience a broadening of choice and improvement in quality of care and support service supply that can meet the aspirations of all local people (whether council or self-funded) wanting to procure social care services.
- 1.5 Against each of these priorities milestones were identified for April 2010, October 2010 and April 2011. By April 2010 all councils should have had “a strategy in place to create universal information and advice services”, and by October 2010 this should have been translated into having “put in place arrangements for universal access to information and advice.” This ‘universal access’ should be available to *all* citizens whether they are using publicly-funded services or organising their own support through personal budgets or self-funding. A working paper for the Transforming Adult Social Care Programme Board has identified ‘a core spine’ in terms of the content of national information in relation to adult social care (across the dimensions of information, advice and advocacy).^{iv}
- 1.6 How are councils progressing with this agenda? A review carried out by Opportunity Links in June 2010 focused specifically on progress with implementing information and advice services. It identified “considerable variation” across the country:
- 12% of local authorities stated they are fully delivering information and advice services.
 - 40% do not have an information strategy in place (the milestone for April 2010), and 16% were not yet at the planning stage.
 - Two thirds of local authorities have identified a delivery model.
 - More than half (56%) had not yet started delivering their services or related activities such as training, marketing and evaluation.^v
- 1.7 These findings paint a similar picture to that previously revealed by self-assessment reporting.^{vi} Both rounds of self-reporting (October-December 2009, and January-March 2010) indicated that fewer than 60% of councils reported they had a strategy for universal access to information, support and guidance for adult social care. Between the two rounds of self-reporting the proportion of councils indicating that they *were* including all citizens (i.e. including self-funders) in their strategy rose from 55% to 74% , but over the same period there was a fall in the numbers helping voluntary organisations and other partners to provide universal information (a drop from 89% to 86%). Clearly, there is still considerable work to be completed in developing strategies and putting arrangements in place if subsequent milestones are to be attained.
- 1.8 It is possible, perhaps even likely, that during the early months of 2010 some councils adopted a ‘wait and see’ approach in the lead-up to the general election. The uncertainty about the outcome of the election and whether that might signal a change of policy direction could have caused some degree of planning blight around the further implementation of the transformation agenda. It is helpful, therefore, that the coalition Conservative-Lib-Dem Government moved relatively quickly to emphasise their continued commitment. In July 2010 it was announced in a written parliamentary statement that a Commission was to be established on the funding of care and support, with a white paper to follow in 2011. Moreover, it was stated that the recommendations of the Commission “must also be compatible with the Government’s vision for care and support – supporting personalisation, prevention and partnership, and offering protection for people.”^{vii} This re-statement of core policy around adult social care underlined the continued importance of councils achieving the milestones for the transformation agenda.

- 1.9 In November 2010 the Department of Health published ‘a vision’ document for consultation, setting out “A new agenda for adult social care in England.”^{viii} In many ways this document restated the importance of taking forward the reforms that have already begun, emphasising the rollout of personal budgets, and devolved decision-making within a framework of seven principles (prevention; personalisation; partnership; plurality; protection; productivity, and people). The vision also reiterated the importance of information and advice as “a universal service” for everyone – whether using a personal budget or their own funds, and recognised “that people funding their own care have a particular need for information and guidance to help plan how their care needs are met.”^{ix}
- 1.10 Alongside the vision paper, the Department of Health also issued a further consultation on proposals for an outcomes framework in adult social care,^x and “a new approach in which councils are in the lead, the role of the regulator is refocused, and Government Departments are enablers.” The new ‘permissive collective’ approach to outcomes that is proposed is concerned with “describing the ends, not quantifying the means”, and is to be achieved by the removal of national performance management, targets and annual assessment of councils by the regulator (the Care Quality Commission). The proposed approach centres around a single set of agreed data requirements (the Quality and Outcomes Data Set), and outcome-focused measures to allow local interpretation of data and achievements. The focus of the consultation is on four domains for social care outcomes:
- Promoting personalisation and enhancing quality of life for people with care and support needs.
 - Preventing deterioration, delaying dependency and supporting recovery.
 - Ensuring a positive experience of care and support.
 - Protecting from avoidable harm and caring in a safe environment.
- 1.11 It is not yet clear how the wider roles and responsibilities of councils might fit within this new framework. It is possible that universal services and support for people who are self-funding *could* be accommodated within this model, but there is a risk that it will focus too narrowly on ‘service users’ – i.e. people who meet council eligibility criteria, rather than *all* people who use care and support.
- 1.12 Around the same time that the Department of Health papers were issued, a new sector-wide partnership agreement was also published (*Think Local, Act Personal*) which also addressed the next steps in transforming adult social care. The agreement built on learning from implementing *Putting People First* over the past three years and focused on areas where further action is required. In particular, the agreement underlined the connections between preventative, community-based approaches and personalised care and support. The local leadership roles of councils was emphasised in supporting the development of local resources and opportunities “regardless of how they are paid for or who provides them.” Ensuring that all people have the information and advice they need is part of this role and should include help for people “to make the best use of their own resources to support their independence and reduce their need for long term care.”^{xi}
- 1.13 It is against this emerging policy background that the current study was undertaken. We begin by exploring the perceptions and understanding of the self-funding market among some of the key providers of services and support.

2 The provider perspective

Understanding the market

- 2.1 The self-funding market in social care and support is of growing importance. This is driven by two inter-related trends. First, more people are finding themselves as actual or potential self-funders both because they may hold assets above the means-testing threshold, but also because of rising eligibility levels which exclude people from help organised by social services. Second, many providers are actively seeking to develop the self-funding market as an alternative to reliance on council contracts at a time of increasing economic austerity, as these respondents commented:

“(...) a number of our members now, given the difficulties with local authorities and the tightness of money, would actually prefer to work with and for individuals rather than going through the local authorities.”

“...their self-funder market is the thing that makes their business sustainable, because they're under-funded by the local authority commissioned work.”

- 2.2 At present providers who can be seen as ‘more able’ in their level of sophistication are deliberately developing a new business model that reduces their reliance on local authority work (or indeed reliance on block contracts with a single local council). Some providers do not yet fully understand or welcome the way the market is developing and the importance of establishing new relationships with individual purchasers (whether these are people who are self-funding, or those using personal budgets). Even if most providers were to recognise the wisdom of such a model, not all are able to develop it with equal success. In particular, the need to address marketing and promotion is something to which many have had to give little consideration when their business has been virtually guaranteed by a monopsony commissioner. As this provider described, working with local authority contracts can carry particular frustrations, but it also has obvious benefits:

“The majority of our work is still local authority contract driven (...) in some ways it is easier to deal with a local authority where you've got blocks of work or frameworks of hours, because you have density of volume coming through.”

Whereas, when dealing with private payers, none of this is true and a private client may have particular requirements that do not necessarily fit with other provision:

“and the challenge (...) is that you get the single enquiry private self-funded market.”

- 2.3 From a provider perspective the situation can be very different between residential services and domiciliary. It is widely recognised that self-funders effectively subsidise publicly funded clients, although this has often been far from transparent (particularly for the people who are self-funding). However, in the domiciliary setting subsidies can work in the opposite direction; the financial viability of a contract will be influenced by volume, as this major provider described :

“I guess the cross-subsidy element is if you get one contact here for a private client (...) because you've got carers in the vicinity and they're being paid a rate to do all this work, you can quite easily accommodate that need (...). So there's a lot of private pay work that we can't take on because you haven't got the coverage or volume of work because private pay work doesn't come in a kind of block combination.”

- 2.4 For providers who have a relatively small private client business segment these issues may not be a consideration, but others are likely to see both the opportunities that a private market offers and the costs of *not* pricing this segment differentially, as this person remarked:

“I think that they will eventually start wising up to the fact that they are being asked to deliver services that are different and, in some instances, more expensive than what the council procures

to. But, of course, we are starting from the base where many agencies don't have much in the way of private patient business."

- 2.5 However, as yet there is little evidence that providers are pricing their domiciliary services differently for the private and public markets. There is some expectation that this may change in the future, but much depends on the size of the private market and providers' level of understanding of it. It is clear that the self-funder market is very diverse:

"And how you reach them and how you approach them can be quite different as well, how you market yourself to them (...) Some just have a private need and they come to you from word of mouth or reference, and (...) there's a whole range of different services: it can be companionship; it can be someone who is recovering from a hip operation; it can be somebody who needs shopping, someone to take them to the theatre. So we have a whole spectrum in our business from the high net worth individuals – you know Lord and Lady whatever – who we're caring for down to someone who previously had a package of care from the local authority but is now funding it themselves, and you have a multitude of different services needs."

- 2.6 In addition to questions around the pricing of services, there are wider issues about general provider awareness and understanding of the self-funder population. Some providers are only too aware that "there is very little hard and fast intelligence", and contrasted this with the data available on publicly-supported clients. However, it was also recognised that this is work that is developing and that information *is* gradually improving (and the minimum data set developed by Skills for Care was identified as one such area). Further work has been undertaken by the Institute of Public Care to estimate the numbers and distribution of self-funders in England (also published in this volume),^{xii} and a major quantitative study has been commissioned from the National Centre for Social Research by Skills for Care. The latter piece of work will report in 2011 and will quantify both the size of the privately purchased home care market (whether funded through Direct Payments or self-funded), and the size and nature of the workforce providing it.^{xiii} Even if quantitative information about self-funders improves, some respondents emphasised that what is needed is 'the richness of information' to understand the motivations behind the decisions of people who are self-funding. One of the objectives of this piece of work is to provide some illumination of these issues, and these are explored in greater depth in Sections 3 and 4.

Defining 'self-funders'

- 2.7 As we highlighted in our earlier review of the literature, the definition of self-funders is not entirely straightforward, is in many ways subjective and includes a continuum of arrangements.^{xiv} This conclusion was further reinforced by the current research. A respondent described an apparent 'softening of our self-pay market', whereby more people are becoming self-funders as a result of means-testing rather than "by virtue of personal choice." In addition to the 'pure' private payer who is buying care and support services with their own money, there is an increasingly grey area, or points on a continuum, which also encompasses people who are emerging as private payers by means of personal budgets, as this respondent observed:

"I find it very difficult to distinguish between those two, to be honest (...) I will often say, if I talk about self-funders, I mean people who are either paying for it with their own money or because they have been given money (...) I'm really talking about people who haven't got an intermediary purchasing care on their behalf."

- 2.8 Another respondent commented that because of the roll-out of personalisation:

"sooner or later everybody will be in the self-funder market (...)and I think also it starts to get everybody orientated in businesses to understand that their customer is the person who they work for, not the commissioning manager in the local authority."

- 2.9 Another provider similarly remarked that the experience of working with ‘stand alone self-funders’ provided a model of care that could inform the approach to personalisation:
- “..people are asking for what they want and we’re providing the service to make a difference (...) so we’ve used quite a lot of that thinking to sort of shape our thinking of what personalisation could be for an individual.”*
- 2.10 Such an approach will be increasingly important as personal budgets continue to develop (while recognising as the Audit Commission has cautioned that some councils will need to make significant efforts to achieve the milestones on local targets).^{xv} The role of councils as commissioners is also changing, and new contracting methods for people using personal budgets are emerging in place of existing block contracts (including collaborative commissioning between people using personal budgets, and outcomes-based contracts for example).
- 2.11 While there may increasingly be a blurring of boundaries between people who are self-funding and those who are not, and the benefits of having direct purchasing power may be spread more widely, it was also recognised by providers that there remain some significant differences between self-funders and people using personal budgets. A small independent sector provider was particularly forthright in his views and believed that personal budgets would drive increasing fragmentation of the market and that some providers would only want to work with clients who were genuinely self-funding. However, this would not be a realistic position for most providers, and such a perspective was not widespread.
- “So we are going to start to look at personalisation and say well we can only take so many people on because we can’t afford it (...) I can see some businesses saying well, we won’t do personalisation; it’s not a viable business model (...) you will have companies that will say we do not deal with personalisation because you haven’t got the money.”*
- 2.12 Another respondent observed that “self-funders are the original personal budget holders, aren’t they?” Certainly, personal budgets and Direct Payments *should* equip more people with purchasing power, and the emphasis of the transformation agenda is to ensure that there are components of the system that are universal and everyone uses, nonetheless, it is hard not to conclude that there will be an emerging hierarchy of purchasers in social care which could lead to self-funders being paradoxically both the most sought-after clients, but also in many ways the least well-served.

The self-funding journey and experience

- 2.13 Independent care providers, and bodies representing such providers, have relatively little hard market intelligence about people who are self-funding. This is an area in which evidence is often replaced by anecdote. Nonetheless, the anecdotes reveal a considerable degree of consistency. Typically, providers first encounter the self-funder as someone who has experienced a crisis which necessitates decisions being made about what to do next, rather than someone who has actively planned and made positive choices about their care and support, as this respondent observed:
- “So it may have been a critical incident like the loss of a partner but it might not be a need – totally physical need – it might be for company, it might be a fear of being in the house by yourself and those sorts of things. So I think there’s a real need for richer type data around motivations and also whether motivations help you in terms of your decision making.”*
- 2.14 The fact that people often seek help for themselves or a family member at a time of crisis (“*they’re largely making a fairly urgent or emergency purchase*”) also means that they may not know what it is they are looking for, or what might be available. This reflects the generally low awareness and understanding of the nature of social care across the population, and as this respondent described, “*people tend not to come with a shopping list*”, rather “*I need somebody to come and tell me what’s possible, because I have no idea.*”
- 2.15 This was a picture that was widely recognised and sketched out time and time again by

interviewees, as these comments highlight:

“I think often people are working in a crisis situation, so a critical incident, a fall, a stroke, something that’s produced ‘I can’t live in this house any more’. And then, of course, what people do is they then make decisions about care but they’re not necessarily informed decisions, and they certainly aren’t decisions that are taken with a view to things like re-ablement.”

“It’s a wide range of crises, like somebody coming out of hospital or somebody having a fall at home and now wants to go into residential care, or a family member moving away who was providing care.”

- 2.16 A provider of private residential care described how 60-70 per cent of all their admissions come via acute hospitals. In such circumstances there is little or no consideration of options; rather, a ‘tipping point’ is reached by an event that leads to hospitalisation and from there to permanent residential care.

“The single thing that we know above all else is that they come to us primarily as a consequence of a health crisis rather than a plan.”

- 2.17 In such circumstances people may make decisions in haste and without good knowledge or understanding of the options. As this person remarked, the issue is not just about what services are available, but also about properly understanding the needs of the person for support:

“I think often people are working in a crisis situation (...) and then, of course, what people do is they then make decisions about care but they’re not necessarily informed decisions, and they certainly aren’t decisions that are taken with a view to things like reablement (...) so there’s a whole raft of information needs.”

- 2.18 The crisis admission picture contrasts with the position of a minority of self-funders who *have* made an active decision and have planned their care decisions, as this provider described:

“At the very, very top, there will be a tiny percentage – and I’m not sure I can actually identify it in percentage terms – but let’s say probably under 5% of our beds, and probably nearer to 2 or 3 - where you’ve got people who have made a choice to spend their money and bypass all sort of local authority and other advisers, and approach us directly.”

- 2.19 It may be that this is also indicative of a changed role for care homes, particularly for people who are self-funding. A decade or so ago it was less unusual for people to make their own arrangements to enter a residential home with low or minimal care needs, and to see this primarily as a housing choice if it offered them a lifestyle of their choosing. There are plenty of anecdotes of people moving into residential homes (and even nursing homes) in previous years who would have still been driving their own cars, and for whom the care home was more akin to living in a hotel where they had company if they chose it, their meals and laundry taken care of, and the security of not being alone if anything should go wrong.

- 2.20 The overall dependency levels of people living in residential or nursing homes have been rising. In part this reflects later admissions of publicly-funded residents, and the consequences of raising the threshold of eligibility criteria. Several respondents remarked that this trend creates a barrier to self-funders choosing to enter care homes because it is apparent that these no longer offer ‘a balanced community’ of people at different levels of dependency, and many residents will be in an end of life care situation or will have advanced dementia (we return to this theme later in the report).

- 2.21 The consequence is that people’s duration of using services is now shorter than in the past; the intensity of activity has increased with more admissions. People are less likely to spend a lengthy period as residents, as one director of services described, *“the average length of stay of our frail elderly non-dementia is under a year.”* The emphasis on supporting people to live in the community is one which commands widespread support; however, it also means that residential care is rarely seen as a positive choice. An independent care home director observed:

"I think we would see that publicly funded people are being rationed access to care. I could argue that some of that must be good for maintaining independence but I also think that we're now getting people coming in too late in the life course to get a reasonable benefit (...) I mean they're basically coming in to die."

And another remarked:

"Care homes are perceived as the worst possible thing that could happen, to be avoided at all costs."

2.22 Such developments raise important questions about the role of residential care and quality of life.

Navigation

2.23 As indicated previously, very often it is the adult children of an older person who make the initial inquiry about support. Sometimes this is for personal care, but it is also often for lower levels of support such as help with housework, gardening etc. Indeed, some providers of social care and domiciliary support acknowledge that accepting customers seeking domestic support is a good business strategy because a relationship can be established which provides a platform over time to develop a more intensive or personal service.

"And sometimes we start with just domestic care because that's all they come to us for, but in that way we can establish that we're reliable, and they like our people and we turn up and so on, and then they get sort of progressively..."

And as another commented:

"There's a spectrum of budget spend - so you move from the high net worth individuals to actually you've got people who are looking to pay for a far more modest cleaning service, and it gets you in. And as they get older, there's a requirement then for personal care and other things to creep in."

2.24 With the raising of eligibility thresholds such 'low level' help has virtually disappeared from publicly funded support. This is also evident where people who approach home care agencies or umbrella bodies for such agencies report:

"that they have been directed to us by the local authority (...) where the message has been 'well you don't qualify for help from us'."

And:

"..you probably end up with your local authority and then get turned away (...) and I think that constitutes a fair bit of the referrals and that problem that people don't actually know where to start."

2.25 For some people there is also something of a stigma attached to approaching social services (as we explore further in sections 3 and 4), and many self-funders will totally by-pass this route if they believe that they are unlikely to qualify for any help because of the level of their assets. As this independent adviser described, for example:

"There are a lot of people that won't touch Social Services (...) I had one potential customer and I said something about Social Services and she just turned around and said 'with all due respect, we won't be using Social Services', and put the phone down. So that was it."

And another observed:

"Because [self-funders] haven't engaged with statutory providers in the past, they are quite reluctant to get information or advice on things like this (...) because a lot of that goes to society's view about care and how you're in a way giving up, or you can't manage things, and people don't want to draw attention to that."

"I think we are still very much in the shadow of the workhouse in some ways, and yet, you know,

nothing could be further from the truth in terms of what happens now.”

People’s needs for information are not just around how to find their way into the system, but also with what is available for their particular situation. As some respondents highlighted, people who are self-funding risk not having a proper assessment of their needs, as this person remarked:

“there’s also proper assessment required, because I do think assessment is an area where self-funders are very badly served.”

- 2.26 Without such knowledge and support people end up making decisions which may not meet their particular needs, but offer a solution to their immediate situation. In so doing, other options are closed down and people’s opportunities to maintain their independence for example may be compromised and prematurely closed off, as this person observed:

“...some people might, for example, want a very intensive reablement package or they might want to buy in some convalescence, or they might want to buy in some support services to stay where they are, but they’re never given those sort of option appraisals at the time of assessment (...) People don’t know what’s out there (...) when people are making decisions about care (...) they’re people in a crisis and they know what everybody else knows – which is very little. And that’s the basis on which care is commissioned.”

Information and Advice

- 2.27 People who don’t qualify for support from social services are often left to find their own way in a bewildering environment where they have little idea of where to begin. For some people this can lead inappropriately or prematurely to residential care because of lack of awareness of alternatives:

“People are going into care homes because they didn’t realise that there were all these options that they could stay home, and they’ve never heard of things like telecare and dom-care and live-in care (...) There’s so many alternatives now that they don’t know about, so they’re being forced down a road because they’ve heard of residential homes and nursing homes and that’s all they know.”

- 2.28 People seek different levels of information and advice, and while some will want detailed help for a specific situation, others will be seeking broad reassurance. This may especially be the case when children or other relatives are contacting an information or advice service about the well-being of a parent, particularly if they are concerned about the risks that are being taken in enabling that person to continue living independently, and especially if they live at some distance from the parent.

- 2.29 Some broad signposting of self-funders by councils is clearly taking place, with people being referred to agencies or given a list of approved providers they might want to consider. However, such lists may be very limited, out of date and fail to reflect the range of services that people may wish to buy, as these comments highlight:

“At the moment approved provider lists are generally shut; they only represent providers willing to trade with the council, that the council is willing to trade with and has done some checking (...) and they become more and more out of date, and the innovative provider who wants to do something different – I mean, the last place to go for innovation is a local authority contracting department!”

And

“The approved provider list – it’s a bit naughty, because you may have perfectly good providers who are not approved providers and they will just refer people to someone off the list (...) there is this mindset that says approved provider, there is some sort of accreditation process, but that’s rubbish – you have to tick hundreds of boxes (...) but it’s not about quality at all.”

- 2.30 People who are involved in providing information and advice to people using social care recognised the frustrations for self-funders trying to get information, and the difficulties of negotiating access with some local authorities. As this advisor described:

"(...) at the time I didn't know how to apply for Attendance Allowance, so I've been to see the Money Advice Unit at Social Services who must be the most protected group of people I've ever come across! Social Services wouldn't give me the number; they said 'Oh we can't refer you directly'. It's like a secret mafia, you know, it's unbelievable. And in the end I pushed and pushed and someone did give me the number but said 'Don't tell them I've given you the number.' I mean, this is a public service!"

- 2.31 For people who are under pressure or struggling to make sense of their situation, having to grapple with bureaucracy is extremely challenging and it isn't surprising that people give up if they can't easily find their way into the system. Several respondents described how despite being knowledgeable about social care because they worked in the sector, they *still* found it difficult to find their way:

"When I phoned yesterday for something, and I got put through to completely the wrong department (...) but they just wanted to get rid of me, you know, they didn't want to answer the question."

- 2.32 Another respondent who was involved in providing information recognised that anyone who reaches them has probably already been passed from 'pillar to post' and exhausted all other options such that a place which might ideally be the first port of call is actually "almost the last resort."

- 2.33 The role of the local authority in providing information and advice can take different forms with councils either providing information and support directly or commissioning others to provide it. While many councils have websites that provide information and signposting, some are also taking on a wider advice role which can be problematic. Several respondents expressed their unease, for example:

"The first thing to say is it should be independent, and there is a real grab going on within local authorities to take over the information/advice functions (...) I don't think they should have a role in advocacy and advice."

And another observed:

"The question is how do you ensure that people get the advice, so you have to really push it from a number of different directions. Whether the local authority is the best place for an organisation to do it is questionable actually."

- 2.34 A model such as that offered by FirstStop and Counsel and Care was viewed by some as the way forward:

"[they] are particularly well placed, because they are one of the few organisations that did advice and casework rather than just information. And hopefully, through that they've established a really clear understanding about what some of the issues are and can develop a bespoke response."

- 2.35 It is not only broad information and advice about what support is available that people need, but also assessment of their own situation and consideration of all the available options. In practice, people are rarely experts in social care and have poor information and knowledge on which to base their decisions. The idea of 'care advocacy' and ensuring that people are supported in accessing the care that best meets their needs is generally something "that the self-funder doesn't get." As this person observed:

"I think the word 'abandonment' is strong, but I think in my experience (...) there is a relative abandonment of self-payers. Once you've had that means test that says you're over the threshold and you're on your own."

- 2.36 Several respondents highlighted the apparent lack of independent advisors who can help people to navigate their route (in a way similar to independent financial advisors). This is an area where services are beginning to emerge, but this is on a small scale and there is currently no accreditation for advisors. Some respondents emphasised the need for a wide range of responses:

“..this is potentially a huge market (...) and what I think we need to do is to create a pluralist market in the information/advice services, as long as it is quality-assured and as long as people can have absolute assurance that it is independent (...) you do need more than information (...) what you need is somebody who can go through and give you option appraisals.”

And

“I think there always will be room for lots of providers of advice (...) but you need the sort of high volume people to direct to the specialist people.”

- 2.37 As we have already explored, many people who may need information and advice are in a life-changing situation. The decisions they make will have far-reaching implications and may result in a change of residence or permanent admission to a care home. Clearly, in addition to providing information about the financial implications of any decisions, many people will also need support with the practical and emotional consequences. One such independent care advisor described how they had developed the concept for a service, which they had originally assumed would simply be about assisting people to relocate:

“I realised that nobody was doing it just for older people. And even though some would profess to do it for older people, it was still with an estate agent’s hat on, and it became clear that there was nobody doing it with a social care hat on.”

“People had problems with the whole kind of relocating bit, but actually they didn’t want to relocate, they wanted to stay in their own homes, and had they known what support was available in their homes they wouldn’t have wanted to move.”

- 2.38 Several respondents emphasised the importance of trying to get people to think about the future, and their potential care needs, at a much earlier stage of life. For most people, the likelihood of needing some level of care as they age is something they simply do not consider until it becomes a pressing reality:

“...pretty much everybody, even as they get into quite advanced age, doesn’t take seriously the fact that they are old (...) Nobody plans (...) they’re simply not going to confront those demons until they have to.”

- 2.39 The need for people to have financial information and advice has been identified as a critical gap, and this is of particular concern “because of the evidence that significant numbers of people make both poor care and financial decisions without access to this information and advice.”^{xvi} The Putting People First Social Care Consortium has issued a document providing core information about personal finances and care costs for the public for the use of local authorities and third sector organisations in raising public awareness and signposting to further information (such as to the Society of Later Life Advisers – SOLLA).^{xvii} The importance of such information and advice was underlined once again by the findings from the current study which highlighted the absence of such financial knowledge or understanding for many people who are self-funding.

- 2.40 Just as there is widespread ignorance about how the social care system operates, there is often considerable surprise and alarm when people *do* need care and support and then discover that they will have to pay for it (or make a significance contribution to costs). Respondents commented on the need to “*incentivise people to think about these decisions sooner rather than later,*” and underlined the importance of the Commission on the Funding of Care and Support addressing such issues for the whole population, and to consider the need for appropriate products and advice for people who will not qualify for publicly funded support. Some financial products already exist that enable people to limit their liability and make arrangements for their care while still protecting the majority of their capital (such as through an Immediate Needs Annuity), but awareness of these arrangements is low and people have been reluctant to buy financial products when future arrangements and responsibility for long term care have continued to be contested and uncertain, as this person observed:

“If the Commission does what we hope and expect it will do, it will say very clearly, for the foreseeable future – and it’s a long future – Government will only be able to do this bit. In which case you need (and hopefully they’ll also be saying we’ll help you to do this) to provide for that in some way.”

- 2.41 Ensuring that self-funders receive appropriate financial advice is also of potential importance to councils who may otherwise have to deal with the consequences of people in residential care who run out of money (often the first time that councils become aware of their existence). Running out of money can clearly be a worry for people who are paying for their residential care, as respondents recognised:

“Most of the people who are approaching the situation are aware that there is a limit and might not know exactly what it is but they know the money is running out. And their main concern is if they suddenly have to be funded by a local authority, are they going to move them?”

“I would imagine that the two years before you actually run out are fraught with horrendous psychological concerns, thinking (...) what’s going to happen?”

As the interviews with people who are self-funding, and with their carers indicate in the following sections, this latter comment proved to be particularly prescient.

Conclusions

- 2.42 This brief overview of the reflections of providers on the self-funding market has highlighted a number of themes. A prime purpose in contacting key service providers was in order to find a way of identifying and approaching people who were self-funding. At the same time, it was also an opportunity to explore providers’ understanding of self-funders. It is clear that providers vary in their sophistication and understanding of the private pay market – for some it is core business, for others it is more marginal. Moreover, it is evident that this is a market that is changing and evolving as more people are defined as part of the ‘self-funding’ population. This includes people who have their own resources and have never approached the local authority for help; those who *have* sought help but been told that their needs don’t meet eligibility criteria and/or that their assets place them above the level where they can receive public support, and finally, there is a newly emerging ‘quasi self-funder’ in the form of people who are receiving Direct Payments/personal budgets and are effectively commissioning their own care and support. The prime focus of this study is with the two former groups and not with people using personal budgets; however, it is recognised that many of the issues will be common across these groups and it is important that there is shared learning.
- 2.43 Providers are disadvantaged in their capacity to understand and work with the self-funder population by the lack of good market intelligence. However, both quantitative and qualitative information is accumulating and within the next year there will be considerable improvements in understanding both the self-paying population and the workforce that is employed by some sections of this population.
- 2.44 The appeal of the self-funding market to providers is affected by many variables. It has long been the case that private business in the residential sector allows providers to cross-subsidise publicly funded clients; however, in domiciliary services the economics are rather different depending on both volume and location of clients. For individual self-funders this can create significant impediments to accessing services or finding them at an affordable rate (particularly in rural and remote areas).
- 2.45 Self-funders cover a broad spectrum both in terms of their needs and the nature of support they wish to purchase. Some who start by buying domestic support may go on to access personal care, and the potential of a market strategy that starts from people needing modest levels of help is recognised by some providers who wish to be able to offer the full spectrum of support and ensure continuity of service.

- 2.46 The 'typical' self-funding person that providers encounter is someone who needs care and support as the result of a crisis, rather than someone who has planned their care or is gradually extending the type of support they receive. In a crisis or emergency situation there is rarely the opportunity for people to carefully consider their options or be fully informed about what these might include. This is especially true when people do not have access to expert and independent assessment of their needs. There is an emerging market in independent care advocacy aimed at the self-funding market, but this is unregulated and the independence of some service providers is doubtful.
- 2.47 It is also clear that many providers express considerable concern that the journeys of self-funders are too often guided by happenstance. In such circumstances the experience can be one where despite having personal assets, people experience little control over their situation and rarely approach care and support in a planned manner or as a positive choice. It is to explore these personal journeys, the decisions made and the destinations reached, that we now turn.

3 The decision making and destinations of people who self-fund

Background and Introduction

- 3.1 The focus of this stage of the study was to explore the journeys undertaken by people who were funding their own care and support – how they had gone about accessing services; what advice and information had been available to them and what destinations they had reached. As we discussed in an earlier report, councils have some obligations towards people who fund their own care.^{xviii} Guidance issued by the Department of Health on the Community Care Act 1998 was explicit that the duties of local authorities include the following:

“Local authorities are under a legal duty under the NHS and Community Care Act 1990 to assess the care needs of anyone who, in the authority’s view, may be in need of community care services. It is the Department’s view that the law does not allow authorities to refuse to undertake an assessment of care needs for anyone on the grounds of the person’s financial resources, e.g. because they have capital in excess of the capital limit for residential accommodation. Even if someone may be able to pay the full cost of any services, or make their own arrangements independently, they should be advised about what type of care they require and informed about what services are available.”^{xix}

- 3.2 More recently, guidance on Fair Access to Care issued in 2002 reiterated that:

“An individual’s financial circumstances should have no bearing on whether a council carries out a community care assessment or not. Neither should the individual’s finances affect the level or detail of the assessment process.”^{xx}

- 3.3 The latest guidance on eligibility criteria (2010) was issued in the light of the recommendations from the CSCI review *Cutting the Cake Fairly*, and was similarly clear that:

“An assessment of the person’s ability to pay for services should therefore only take place after they have been assessed as having eligible needs. A person’s ability to pay should only be used as a reason for not providing services in circumstances where a person has been assessed as needing residential accommodation, the person has the means to pay for it and if the person, or someone close to them, is capable of making the arrangements themselves.”^{xxi}

- 3.4 The guidance also underlined that eligibility should be placed ‘within a much broader context’ of

place-shaping and promotion of well-being that offered some level of support to all:

“For example, people who do not meet the eligibility threshold should still be able to expect adequate signposting to alternative sources of support.”^{xxii}

3.5 Moreover:

“All individuals, whether or not they are funding their own care, can benefit from effective information, signposting and support planning (...) councils should consider how they can work to support high quality outcomes for all their citizens, including those funding their own care and support.”^{xxiii}

3.6 The importance of ensuring that people who fund their own care are not excluded from access to assessment, information and support planning was underlined by the findings of CSCI.^{xxiv xxv} Where people are screened out prematurely, or not given adequate signposting to other sources of help there are significant risks that prevention and reablement opportunities are not addressed, with increased likelihood of people needing higher levels of support further down the road.

3.7 It is clear from the content and tone of guidance and other commentary that it is not the intention of policy that people who fund their own care and support should be left to find their own way. However, there is evidence that councils have historically adopted a range of positions towards this group of people, ranging from denial of any support, to minimalist support and – in a minority of cases – a structured strategy to ensure that self-funders are given appropriate information and support.^{xxvi} The indifference towards self-funders that has characterised the response of many councils needs to change in fulfilling the requirements of the transformation agenda for social care. Whether the experiences of people who are self-funding indicate that this *is* happening is the focus of this section of the report.

3.8 As described previously, interviews with service providers were used in part to provide access to people who self-fund their care and support. This was not a straightforward process; some of the providers operate on a national basis and it was necessary to identify some specific areas or services to focus on. In doing so we were also concerned to cover a range of locations and parts of the country. We were reliant on the service provider being able to identify potential participants for the study. We wanted to speak to people using a range of services, from domiciliary support to sheltered housing, assisted living, and residential care. This also meant that some of the people concerned would be too frail or would have levels of cognitive impairment that would prevent them participating directly. Where this was the case interviews were undertaken with family members (see Section 4). There were also some instances where people who had been identified as ‘self-funding’ turned out to be using Direct Payments, which were not the prime focus of this study.

3.9 A consent form was developed which explained the purpose of the research and gave assurances about confidentiality. Some people, but very few, were reluctant to become involved and declined to participate. This was to be expected given that these are private matters and it may have seemed intrusive and personal to be asked questions about how and why people have made their decisions. However, sufficient numbers of people *did* agree to take part, and we are extremely grateful to them for their time and for allowing us to gain a glimpse of their world. Most of the people interviewed were female, and all were elderly; the youngest was 71 and the oldest was 93, with most aged over 80.

Thinking ahead?

3.10 In all interviews people were invited to tell their stories and to explain how they had made the decisions about care and support that they had. In almost every situation it was evident that people had *not* made their choices in a deliberate and planned way. Most people just get on with living their lives on a day to day basis rather than thinking about the longer term, as the following comments illustrate:

"It was something I never thought about (...) that there would come a time when I wouldn't be able to look after myself."

"My plan was to stay at home (...) I've got a beautiful house, but I was getting to the point where I couldn't get up and down stairs safely by myself."

"I couldn't see myself getting old and decrepit."

"I'd never thought about it, you see."

- 3.11 Some people acknowledged that they thought ahead in terms of practical arrangements such as making their wills or "arranging for my burial with my solicitor," but did not think about whether they might need care or support in the future, at least not while they were able to manage without anything ("I was doing everything."). This was especially the case where people had been married and living as a couple where they were able to provide mutual support:

"No, it happened to other people (...) I mean, you carry on as if you're going to live together forever."

"Well not before, certainly not before my husband died (...) no, we hadn't talked about 'the future'."

- 3.12 A minority of people *had* planned ahead. One person described how the lease on her flat had been due to end when she was 83 and she had thought that by the time she reached that stage she would move to a care home. At the time, this had been many years in the future:

"When you're young 83 sounds like ancient (...) and then when you are there, you're alright, and so I thought well, I don't really think I need to go into a home really do I? (...) I wasn't ready to go into one."

- 3.13 In this particular situation, this had been the beginning of a period of ongoing uncertainty about what to do for the best which remained unresolved and was a matter of some worry and distress.

Making a Change

- 3.14 Being widowed, or experiencing a deterioration in health were identified as significant factors that can precipitate a change in living arrangements or need for support. Where people were living at some distance from other family members this often compounded the situation and brought a realisation that something needed to change. Many people commented on how they had become concerned that they were putting their adult children "to a lot of trouble", and taking up a great deal of their time if they needed to visit more frequently. For some, the obvious solution was to move nearer their children, either to supported housing or into residential care, as this person described:

"So I was 80, just nearly 80 when I came, yes (...) I just sort of said to my daughter, look, have you got any small flats or something [near you]?"

- 3.15 In such circumstances where people had decided they needed to move but there was no actual crisis necessitating that they did so immediately, several described putting their 'name on the waiting list' until the right vacancy became available. At the same time, however, it was also recognised that a decision had to be made, and it was better for some if they were able to make it for themselves sooner rather than later:

"You know when you're getting on – you've got to make a decision and that's it, or else somebody else can make it for you!"

- 3.16 Where people had time to make their decision they described being able to approach it methodically – researching various options before committing themselves, and being aware of the need to 'get it right'. For example, as this person recalled:

"But what I decided was that if I was going – I had already moved twice in 5 years – and I thought when I move now I want to try to find somewhere where I can be settled and not have to move

umpteen times.”

This was viewed as a particularly positive feature of schemes where sheltered housing, assisted living and nursing home provision were all located on the same or linked sites, which gave people the security that if their needs increased over time they could still be cared for without another major change. There was also a strong sense of needing to move ‘at the right time’ rather than leaving it until it was too late, as this person described when recounting her move into a warden controlled flat:

“And I don’t think you should be too old before you move. Because now some people are coming in at 85, which I think is a bit old (...) I would say 80 is the limit; you can do it a bit before, but not too early (...) but luckily I did it at the right time I think.”

And as another in a similar situation observed:

“I did feel quite strongly that if I left it much longer I would not be fit and able to do it myself, because I was getting a bit tired. Well, no – I truly was very tired (...) But I had also witnessed other people leaving it too late and not being able to cope with their moves.”

And

“My experience had taught me that if you’re going into a home, you shouldn’t leave it too long. There are a lot of adjustments to be made when you go into homes.”

- 3.17 Some of those interviewed who had decided to move into care homes had clearly done so at a stage when they needed little actual ‘care’, but felt the need for additional security, companionship or to be ‘looked after’. The latter was a particular consideration for people who had often had extremely hard lives and had looked after elderly and other relatives and had reached the point of needing some rest and support for themselves.

Crisis management

- 3.18 In Section 2 we highlighted how interviews with service providers identified that it is often a crisis that triggers people into using services or moving to a care home. This picture was reinforced by the interviews with people who are self-funding. For the majority of people the transition to using support or moving into a care environment is *not* one that happens gradually or as a result of considered planning. Most people who were interviewed described a sudden, and at times catastrophic, change that had largely taken decision making out of their hands. One woman described how she had been coping at home following a hip replacement and her son had been in the process of installing a walk-in shower to make her life easier, when she had experienced a break-in and burglary while she was asleep,

“And it just seemed to knock everything on the head you know (...) and the next thing I knew I was installed in here.”

- 3.19 Another person also recounted how she had been in hospital and was getting ready to return home:

“They were just getting me fitted up for living at home when I had a fall and I split my head open (...) and then I sort of transgressed down to this state. It made a difference; if I hadn’t have split my head open, I don’t quite know what would have happened to me.”

- 3.20 One of the oldest interviewees described how she had been living independently in her own home - well past her 90th birthday - when she lost the use of an arm and found herself discharged from hospital to a care home where she didn’t want to be and which was unsuited to her needs:

“I just suddenly deteriorated and had to come into a home (...) but I wasn’t too happy there; it was a nice home, there was nothing wrong with the home but most of the occupiers had dementia (...) and I’ve got most of me marbles I think! (...) I had a relative and I think she didn’t want any responsibility so she whipped me in there without any thought for me.”

- 3.21 Fortunately this person was able to move to another home when a vacancy became available. Several other people also described moving to a care home directly from hospital “because something had to be arranged” and they were under pressure to move:

“In the end I was in hospital for about ten days and then they said ‘well, you’ve got to go.’ (...) so I came here.”

“They let me stay in the respite centre for a little while (...) well, you knew your options really. You either stayed at home or you came into a home; there aren’t any other options if you can’t cope by yourself.”

“I think perhaps it was one of those cases where I’d got to be got somewhere and that was the only one available at the time.”

- 3.22 The youngest interviewee (aged 71) had been living in a nursing home for six years following a stroke, and described the events that had led to his admission and which still caused great distress:

“I was in hospital a few months; they told me I’d had a stroke (...). The hospital said I couldn’t stay; I had to come out and they wouldn’t let me go home because I wasn’t capable of looking after myself; I said I wanted to go home and they said we can’t discharge you for that, we can only discharge you to a nursing home.”

- 3.23 This person was unable to care for himself and hadn’t been able to walk since the stroke. However, he clearly felt that he had no control over his situation and what had happened to him subsequently; he had not been able to exercise any choice, didn’t want to be in the care home and was clearly unhappy, harbouring hopes that somehow there would be a change in his circumstances and he could return to some independence:

“I’m still sort of living in cloud cuckoo-land, and think maybe I might start walking again despite what they’ve said.”

The journey

- 3.24 How people made the choices they did and what help they had in doing so were important issues to explore. Most people described various coping strategies whereby they had managed for a period of time before it was apparent that other help was needed. Typically this involved a combination of family, friends and other informal support. People described how these arrangements worked for them, for example:

“I’ve also got a ‘treasure’, if you know what a treasure is! And she’s worked for me for 28 years – all my life I’ve had cleaners.”

Over time such arrangements can evolve and develop from simply housework, and into practical and even personal help:

“A couple of years ago I had pneumonia and I wasn’t well and so forth, and she came in at weekends you know (...) if I wanted extra I think that she would come.”

- 3.25 Other people described how the person who they employed to do their ‘shopping and cleaning’ also started to do other things for them:

“She was good; she gave me a shower twice a week, and washed my hair for me. And when she first started to help me she said, ‘you tell me what you want me to do; I will do anything’, and she would.”

- 3.26 People explained how they got to know people who could help them through their social networks and communities (particularly the church). In one instance it was this cleaner/carer who helped the person decide to move into a care home (“she said she felt that I couldn’t do any better than this.”). A person living in a sheltered flat described how she had found her cleaner through other people

living in the development:

"I've got X, she comes and does a bit of cleaning (...) she's only got two of us left now, I think she would give it up but she says she doesn't really like to because she looks on us more as friends."

- 3.27 Such arrangements can be very successful, but they are also extremely fragile. For people who are largely or solely reliant on the help, advice and kindness of someone who is partly a 'friend' but is paid for their service, there is a high degree of uncertainty and vulnerability. The arrangement has no contractual basis and can break down; there is scope for exploitation, and there is considerable potential influence over the decisions people might make, even though they may have no expertise or real knowledge in this area. Family members were the major source of help people identified, but it was often to avoid such help becoming too much that people decided to change their living arrangements. For people who are elderly, many of their friends and family are similarly aged which restricts how much support they can be expected to offer, as this person recognised:

"The thing is that most people who would be willing to help are people who've got so much to do anyway, and most of them are elderly (...) which is the problem with my brother and his wife. They would do it; they would do anything for me, but sometimes I say 'no, that's enough', because they're getting to the stage now where it's a bit of a struggle for them to get upstairs in their own house."

- 3.28 While people described how they appreciated the help from their family, they were also very concerned not to become a burden, as these comments highlight:

"What I wanted to do was to be within easier reach of the two boys (...) but I don't want to be so near to either of them that I have to be invited to Sunday lunch every week."

"You see I sold my house so that I could come into care because I've got two sons (...) and I didn't think it was fair on them."

"I don't expect any of the kids to come into me because they've got their own lives to lead."

"So I came here [from hospital], not with the idea of staying forever, but I decided (...) that for the sake of both my sons (...) for their peace of mind, they know I'm safe here."

- 3.29 For people who have no children or partner to offer support it was recognised that relying on neighbours and friends was unsustainable, as this person described:

"I wasn't prepared to be in that place by myself (...) I've got a brother in Scotland and that's it, so I really had no option."

Information & Directions

- 3.30 Having made a decision that a change in living arrangements was needed, how did people go about finding out what was involved and what they might need to do? In talking to people about their experiences it was apparent that major life changing decisions were often made on the basis of little information, and people had little idea about where to seek such information or advice, as the following comments illustrate:

"Well, to tell you the truth, I began to dither, to know what to do."

"I were not sure, you know, I thought – I don't want to do the wrong thing, it's a big decision."

"Well, I'd always sort of thought it was a nice home, but I didn't know much about it, not had much experience of homes."

- 3.31 The idea of approaching an organisation such as Social Services for advice or help in this situation was something that was simply not considered by most, as this person remarked:

"No, I'm afraid, you know having spent my life making my own decisions, I tend not to seek advice."

And as another person also remarked about what they might have done differently:

“Oh I’ve got no idea; I don’t know (...) I’m afraid I’m very independent. I don’t know what I would have done.”

3.32 Some people took a different approach:

“I rang up [the Council] and asked them to send me a complete list of all the care homes in [this area]. I hadn’t realised how many there were (...) and on paper evidence we boiled them down to about half a dozen.”

And as another person described:

“So I decided to start looking and in fact I got a few telephone numbers and saw some adverts and things (...) then I was sitting in the doctor’s waiting room one day and looking at Saga magazine, and I had a pencil and paper in my bag and I wrote a few things down, and I thought, well, we’ll start here.”

3.33 Another described how moving into a home was primarily a practical decision because the alternative was less appealing:

“It was going to cost me more in many ways to have permanent help [at home], and also a consideration was that you can’t rely on one person. I mean if someone lets you down then where am I? (...) and also, I wouldn’t want somebody messing about in my kitchen!”

3.34 The first port of call in exploring options was usually family members and people described undertaking visits to care homes or sheltered accommodation either with family members, or with them doing so on their behalf in order to find somewhere suitable, for example:

“We boiled it down to those [homes] that were handy for my son and daughter in law’s house (...) and one Sunday we came up and I joined my son and his wife and we went around all these nursing homes.”

“Well, I’d got [my son] to go and look at places, and he phoned me one Sunday morning and he said ‘at last I’ve found the place’, because he had looked at so many and he thought they were terrible. And I said ‘okay then, I’ll come and see it’, and he brought me here, and I liked the look of it.”

And

“Well, I got a list of all the care homes and I had one friend that was very good to me and she took me round, and we went round to visit some of them.”

3.35 Others referred to undertaking research about homes via the internet:

“Well the reputation [of this home] was so good, and a friend of mine, her husband is a computer expert and he went on the [internet] to read about this place and he said it was three star.”

3.36 While several people described approaching social services and being given a list of homes, no one recalled being given any further information or advice, or being signposted towards other sources of help. For some people having to find their own path came as a shock:

“When you’ve got the money to pay, you’ve got to pay yourself and (...) they knew I could afford to pay (...) I thought they would take me round to see some of the places, but they wouldn’t.”

3.37 In fact, on this occasion a person described having had some help from social services “but it was accidental”. A social worker who had been involved in conducting an assessment had taken the initiative to call in to a local home that he thought might suit the person and had picked up a brochure, “so when he was passing he said ‘I thought this might interest you’, so inadvertently he helped me.” Such support from a social care professional was exceptional, and no other person interviewed had a similar experience.

3.38 Once somewhere suitable was identified people generally made an immediate decision and decided against looking at other options. For such a major life decision this is in some ways surprising, but this needs to be viewed in context. People who are making such decisions are doing so when they have already accepted that a change is inevitable; having done so the issue is then about finding somewhere that will be 'acceptable', rather than somewhere they actively wish to live.

3.39 For people who do not have immediate family to help them in making decisions about the future, the situation can be very difficult. Trying to find out about what options might be available and to investigate them is demanding and worrying. One person described the various things that she had considered:

"So I thought, well what do I need? And also, if I'm going into a home, what sort of home should I go into? Should I go into a home in London where my friend is nearby, or should I go down to Brighton because it's by the sea?"

3.40 In this situation the person thought her best option was to move into sheltered housing but she had been unable to find anywhere suitable. Some of the places that she liked were run by charities that had policies about eligibility based on religious grounds that excluded her, while others could only offer studio accommodation rather than the one bedroom unit that was wanted. The result was that she remained in limbo on a waiting list for suitable accommodation but was becoming more and more pessimistic that anything would ever become available (particularly as the providers of sheltered schemes had advised her that that people moved into studios to await the availability of a larger unit, so one bedroom sheltered flats rarely became available to people who were not already resident). The result for this person was an impasse where she felt sure she should be moving to different accommodation with some support, but she simply did not know what to do for the best "so, I've come back and dithered ever since." At the same time, the person recognised that she might have only a limited window within which to make a decision and thought that sooner or later needing help would be inevitable:

"I think eventually what will happen is that, if I live as long, and you can't blind yourself to it, you're going to have to have help because you revert back to being a child you know, I realise that."

3.41 Almost all the interviewees recognised that moving into sheltered housing or residential care was a major decision and one that they needed to get right. Some people had checklists of things that they wanted in any new situation, for example:

"I didn't want to be upstairs. I wanted a door where I could walk out to the garden, you know, sort of thing. And there were quite a few things I wanted (...) and unless you're going to do something like this, what was the point of moving?"

3.42 Almost none of the people who had moved into a care home or sheltered housing said that they were unhappy about the choices they had made, and most described their decisions positively, or at worst with a degree of resignation. Almost everyone who was interviewed was remarkably sanguine about their situation, and even those who had needed to make major adjustments in their living arrangements and to move from their own homes to residential care viewed it as just something they had needed to do, rather than it being a major trauma or source of distress. At one extreme were comments such as the person who remarked:

"Well I frequently say that it's one of the best things I've ever done coming in here (...) nothing to worry about now."

And

"I felt when I'd made the decision, I felt that it was the right one because in a place like this there's always somebody around."

3.43 Others were clearly bearing an unhappy situation with some stoicism. For example, this person observed that while he was content with his choice of care home, his days were very long:

“My day consists of ‘killing time’ essentially; you know, whatever I say about it. Killing time, yes.”

Similarly, another person remarked:

“I consider I’m very lucky for my age (...) oh, I don’t get melancholy; I just wish things weren’t as they are, but they are (...) so no good moaning is there?”

“I mean, if I hated it I wouldn’t be here, I would have moved on (...) but you don’t know what – out of the frying pan into the fire.”

“And I do look at life like that, you know, you’ve got to get on with things, not expect somebody else to do it for you. So there you go.”

- 3.44 The most negative comments were made by someone who would have much preferred to be living in a flat or supported accommodation and whose frustration was evident. In having to rely on other people for help he described a situation that was made worse by the attitude of some staff members:

“Everything they do here is not for your benefit, it’s for theirs – what makes it easier for the carers; I think they are probably all the same these homes.”

Paying for Care & Financial Advice

- 3.45 As we have already discussed, the term ‘self-funder’ covers a wide range of scenarios. Not surprisingly, therefore, the people who were included in the research sample also represented a range of circumstances and a variety of financial situations. There are national rules on charging for residential care and as of April 2010 this means that people with capital over £23,250 must meet the full cost of their care. People with capital between £14,250 and the upper limit must make a contribution from both capital and income to the costs of their care, while no contribution is made from capital below £14,250 (although income is still contributed).

- 3.46 For many people – particularly those living in care homes - awareness of their finances and concern about what might happen in the future, were significant worries. The following comments were typical of many:

“What terrified me more than anything else, was the cost of these things (...) I was horrified! I suppose I hadn’t stopped to think.”

- 3.47 Others also remarked that they were paying more than £200 a day for their care and were concerned that this would rapidly deplete their savings:

“I’ve got to be very careful [that] I’ve got enough money to get through.”

- 3.48 Most of the people who were paying for residential care had sold their homes in order to do so (although one still owned the property and was paying for her care from her savings, with her house still available to be sold “if the worst comes to the worst”). Many of these did not know the detail of their financial situation and simply left this to other people to manage on their behalf, and several mentioned Power of Attorney arrangements either with family members or solicitors (“my son deals with most of my financial things”). For some people, the management of money had become an issue of contention.

“I’ve got a relative who got to be my Power of Attorney, even though I said I didn’t want one (...) that’s caused me an awful lot of problems (...) I’ve had my head screwed on ok all my life, it’s horrible to feel that somebody else is messing around with your bank accounts (...) I don’t think she would rob me of a penny, but it’s just the inconvenience.”

- 3.49 This person – living in a care home - also thought that their savings had already dropped below £14,000 but did not know who he should contact about the situation or whether he would get any

help. While people often did not know in detail the state of their remaining assets, there was a concern about what might happen when their money ran out. One person was particularly concerned because of the discussion about the national financial deficit and the impact that the public expenditure review might have on councils' ability or willingness to meet costs:

"What concerns me is (...) I pay [for the care home] until my savings have disappeared almost, and then I was interviewed by Social Services to make a record of what I'd got and how long it was likely to last, and then it would be topped up by the council tax. But now with the problems that we've got with budget cuts and so on, what do I do if they don't want it any more?"

3.50 What was striking about these situations was the level of worry that it was causing the elderly person, and the apparent absence of anyone who might be able to allay their fears or give them reliable advice.

3.51 Another person similarly remarked on fears about what would happen in the future, but was in the happier position of being reassured by her family:

"Well I talked it over with [my son] and I said 'my money is not going to last very long in a place like this.' And he said 'well we are going to pay for it between us, and we will ask Social Services to pay for some of it, why shouldn't they?'"

Conclusions

3.52 This section has explored the experiences of people who are self-funding and using a variety of forms of social care and support. The picture that emerges is a complex and varied one; for some people having adequate financial resources had enabled them to make considered and deliberate choices about what sort of support they might need. For others (the majority), decisions had been accelerated or necessitated by changing circumstances such that things happened *to them* over which they had limited control. In making their decisions people are most likely to consult with family and friends, and to get help from these sources with finding out additional information. Almost nobody identified social services or any other organisation as a source of information. Informal information, word of mouth and reputation were far more significant in influencing people's destinations and decision making. It was striking that the experiences of people who are self-funding seemed to have changed little since previous research undertaken in 2007 which found people who were self-funding being "steered towards residential care with haste and before other options had been explored."^{xxvii}

3.53 It is clear that almost nobody thinks very much in advance about what they might do if and when they need care or support. Most of the people who were interviewed were in their 80s and had only needed help in relatively recent times. Because they had been coping until there was a sudden change in social support or a tipping point was caused by a change of health status, they had convinced themselves that they were – if not immortal – then certainly not needing to make plans for their 'old age'. As many observed ruefully, this was something that happened to other people, not to them. If older people are unlikely to think about their future care needs, it is even less likely that younger people give the matter much consideration; although some of the family members and carers who had seen the difficulties their parents experienced may have been forced to confront the realities for themselves.

3.54 It was difficult for some people to recall the chain of events leading up to their current situation, or to be clear about when things had happened and what they had thought about it at the time. Where people were too frail or confused to be consulted about events and their self-funding journey, interviews were instead undertaken with family members. While many of these confirmed the themes that have already been highlighted in this section, they also introduced some further dimensions. It is to the experiences and insights of family members that we now turn.

4 Carers' Journeys

Introduction

- 4.1 Interviews also took place with a number of family members and carers. These were mainly adult children of older people needing care and support, but some were spouse carers. Carers were approached partly to provide insight to situations where a person who was self-funding was unable to participate in interviews, but carers also had their own stories to tell and their own journeys in trying to navigate the world of self-funding. In many ways the themes that emerged from these interviews reinforced those already identified. However, they also revealed a level of concern and anxiety that was rarely articulated by people who were self-funding, perhaps because the implications of situations were more evident to family members than they were to the person themselves.
- 4.2 In all the interviews undertaken carers indicated real concern for the wellbeing and security of their family member, and compassion for the difficult situations and poor quality of life which many of those relatives faced.

The stigma of social services

- 4.3 Most of the carers were very clear that they and – more importantly – their relatives, were either reluctant to approach social services or did not, for a variety of reasons, see the relevance of that service to their own situation. The following comment was typical of many:

"I don't particularly want Social Services – or rather, Mum and Dad don't particularly want, it's about them not about me – Mum and Dad don't particularly want Social Services coming in and saying what they already know."

- 4.4 For this person, both he and his parents were only too aware that they had significant and increasing needs for support and could see not value in Social Services coming in simply to provide confirmation:

"...and then saying, 'well actually we can arrange it for you but you're going to have to pay for it'. And I think Mum and Dad's view is that actually they are compos mentis and Mum particularly knows what help she needs."

- 4.5 In such situations family members were reluctant to force relatives into accepting something that they were uncomfortable with, and were concerned that as far as possible they should support their relatives "to be in control of their own destiny" and make their own decisions. The issue for most people was not a reluctance to pay for the support they might need, but to have any involvement with social services:

"I think their perception of social services is that it is almost a point of last resort."

Another person similarly remarked:

"But I suppose a lot of people associate social services with when you're really down and out."

And indeed some very elderly people had good reason to have this perception:

"Well I suppose my mother's generation, there's still some knowledge of the workhouse."

- 4.6 The reluctance of some other people to involve social services was less to do with the perceived stigma than it was with previous experience as self-funders, for example:

"I wasn't desperate to have social services in here (...) I've been through this process, a very similar process with my father-in-law, and it seemed to me (...) when he called them in, I mean they

seemed to be more preoccupied with how much he'd got than what the problem was, and I wasn't happy to have all those people crawling all over the house."

- 4.7 People who had made contact with social services were generally disparaging about the experience, and similarly recounted how an assessment of their means seemed to be the dominant consideration:

"[a friend] made enquiries [for me] with social services but he very soon realised that they – I've got a few coppers more than £23,000 – and they really didn't want to know."

And as another person also recalled:

"So I rang social services and said could they help me with this, and the first thing that they said to me was 'does your father own more than £23,000?' That was the very first question before they said anything else or if they could help."

Another person who had tried to find a suitable care home for her mother:

"They just said 'oh, she's self-funding' that was it, you know (...) somebody did come out from social services. She came out to see Mother and to make an assessment. We never heard anything more."

- 4.8 Some other people were offered assessments by social services, but these were often viewed negatively or rejected out of frustration. The benefits that an assessment might offer in terms of identifying someone's particular needs and matching these to available services did not appear to be explained. Rather, people perceived 'assessment' as something bureaucratic and unhelpful, as this comment underlines:

"At one point I got someone offering to do a carer's assessment on me. And I was jumping up and down in fury by then, so what I didn't need was a carer's assessment! I don't need another assessment; I need some help."

- 4.9 Not surprisingly, when people had negative experiences of this nature they then recounted how they were very unlikely to approach social services on future occasions, and ended up often feeling "very jaundiced about the organisations because nothing seemed to apply in our case." Frequently this left people with nowhere else to turn for help or advice and information, a point we return to later in this section.

Navigation

- 4.10 Just as the previous sections have described crises triggering people becoming self-funding for care and support, carers described a similar trajectory. Typically there was a realisation that things could not continue the way they were either because carers were unable to cope with increasing needs, or because of an event that led to a hospital admission and the need for subsequent ongoing support. In such circumstances carers described how they set about trying to find a suitable care home, for example, but did not know how to go about getting appropriate advice or information that would inform their decisions, as this person described:

"And we had a chat to a lady from social services who wouldn't give us any specific advice about a care home, but we played a game called 'go through the list', and if she shook her head it wasn't a good one, and if she nodded it was a good one, but she 'couldn't possibly comment'."

Another carer described a similar experience of being given a list and left to find their own way:

"They say they can't tell you which ones are the best. You get a list and they refer you to looking up online at, you know, what the reports say."

- 4.11 When decisions had to be made in a hurry, trying to make the right judgement was more difficult and often upsetting. This carer recalled the experience when her father had been admitted to hospital

following a stroke:

"...and then they said 'there's nothing more we can do for him; you must get a nursing home' (...) this was extremely difficult (...) I was fairly distressed about the fact that they gave us ten days to get him out of there."

- 4.12 Some carers were able to undertake their own research on behalf of elderly parents, and explored the ratings of services by CSCI (as it then was) or CQC. One carer described how he had become attuned to interpreting the reports:

"We went through that and I got to the stage where I could tell by how many pages it had whether it was good or bad. The more pages, the worse it was!"

Others were less convinced that the reports told them anything meaningful on which to base a decision:

"I think a lot of those, well it's very difficult to assess from them because a lot of the assessment is a box-ticking exercise. It doesn't really tell you how they treat people, or [if there are fewer] facilities but there are, you know a couple of really dedicated staff which may be better than somewhere that's got more."

- 4.13 For carers who were less technologically able, or wanted to look behind the reports, the task of finding out about care homes was an arduous one that involved visits to as many places as possible, with little knowledge of what to look for beyond the obvious signs, as this person described:

"And I had gone round them all and been totally disappointed with all of them (...) places that were nearby. And I went to view them all and the majority of them were just, you know – it's awful, you go through the door and you are nearly knocked back. And I couldn't put my mother in somewhere like that."

- 4.14 The typical carer journey was a lonely one where people were unsure of how to go about finding appropriate and good quality care, and where the difficulties were compounded by the need to do so quickly. A carer described how as soon as she realised that her parents would be self-funding for any help they received, she believed there was no point in trying to organise it through social services:

"I thought, well you know, social services – by the time they've done their assessments and everything else, it would take forever, so I was trying to go direct to the agency. But a lot of them, because we're in a rural area, a lot of them really aren't interested in coming to somewhere a bit out in the sticks."

- 4.15 Some interviewees described a real sense of embattlement in their dealings with social services, and an apparent tension between social workers and social services management, where social workers tried to 'stick their neck out' to get the best result for someone (such as when their money was running out), rather than being driven solely by financial pressures.

- 4.16 It is evident that navigation is about far more than simply finding out what services are available – are they able to meet the particular needs of a person, and – as in the situation above – are they prepared to meet those needs wherever that person is located? Simply having the resources available to purchase care is no guarantee either that the most appropriate care can be found, or that the purchaser is in control of what help they can get and when.

- 4.17 Many of the people who were self-funding would be described as middle class, articulate and educated. Some had run successful businesses and been used to organising their lives and had demonstrated considerable personal resources and confidence. Even so, the social care world was one that was unfamiliar and confusing, and decision making was therefore far from easy. As these carers described the dilemma:

“Here I was in a completely unknown and new situation as far as I was concerned, so I had got no idea what steps I should be taking with local authorities or social services or anybody. I hadn’t got a clue.”

And

“If we decide to go down the residential care route, you do feel a bit kind of on your own. It’s not that I want somebody to tell me what to do, but, yes – you are in a mass of statistics and names and numbers and trying to find the right place isn’t easy.”

- 4.18 All of the carers who were interviewed had views about how things could be better organised and navigation made easier. Some people identified ‘a single point of contact’ as something that would be particularly beneficial. This was seen as something that probably should not reside either with the NHS or with social care given the potential for cost-shunting and territorial disputes, and the inappropriateness of ‘gatekeepers’ giving out information, but there were also concerns about locating such a role within the third sector, for example:

“There are an awful lot of charities and organisations who are only too keen to help. Unfortunately what they do and how they do it isn’t particularly clear (...) there are all sorts of people (...) but there is no clear path as to this is what you need to do.”

And

“And so I was going round and round in circles. I’d got lots of people very kindly on the phone referring me to someone else, and them referring me to someone else.”

“And there seem to be an awful lot of people whose entire role is pushing you to someone else. Sort of passing the buck on, and not so many people actually doing anything.”

“One of the things that really, really annoyed me when I was looking, trying to find someone to come in to help because we had reached a little bit of a sort of hiccup and a crisis point, was that I kept getting referred to everyone else.”

- 4.19 Another carer similarly made a plea for the personal touch with information and knowing where to go to access it:

“Somebody to physically come and discuss the situation or information to be sent that we could (...) and a contact that we can speak to and discuss problems (...) somebody who can actually talk you through the various things that are available, so that you can decide which course you want to take.”

- 4.20 The sense of isolation and having to seek out information rather than being able to easily access it was uppermost for many, and was “very wearying” as this person remarked:

“I just think there is something dramatically wrong with the system. And if you want to find out anything, you’ve got to find everything out yourself.”

And as this person observed:

“It would have been nice if they [social services] had come, and they’d explained to her the options and, you know, we really feel that you might benefit from this path or that path.”

- 4.21 In retrospect people wished they had known how the care and support system worked before they had to find out in the middle of trying to manage a traumatic or urgent situation. One person thought that “some sort of information could be sent to all households”, but in reality it is unlikely that people take much notice of generic information *until* it is relevant to their lives.

- 4.22 Concerns about what to do and how best to make decisions were particularly uppermost in people’s minds when they were thinking about the future and the uncertainty of what might lie ahead:

“And what we haven’t got at the moment is the answer to ‘what’s the next step that we take?’ (...) You know, ‘this is how you do it, this is how you access this; these are the services that can help

you, these are the ones that can't.' That would be great."

And

"It is quite clear to me (...) I know it's a situation that will undoubtedly get worse (...) I've no doubt that some time in the coming months I'm probably going to have to make the decision about whether my wife should remain here or not."

- 4.23 But such decisions would be far from easy, and many carers (themselves elderly) were struggling to cope with the pressures, as this person acknowledged:

"To be frank with you, I mean I'm not sure where I am. I mean, it's taken me all the time, energy and effort to get in place the things I have got in place."

- 4.24 One carer described being given another contact number by social services, without any information about who the number was for or what they might be able to offer ("we can give you a number to ring"). However, this turned out to be a service commissioned by the council to provide advice and brokerage, which was able to identify information exactly tailored to her needs, and provided in a helpful and sensitive manner. The carer's positive experience of this service was in stark contrast to everything else she had encountered:

"And she was very compassionate, very kind. She knew exactly what I required and, true to her word, by the Wednesday morning a dossier arrived on the doorstep with three care homes that I could visit immediately [she had arranged] I could go to, and about another three that had a little waiting list but she suggested I might also like to go and see."

- 4.25 This service and personalised support was greatly appreciated by the carer but this help had not been easy to find, and the impression was that social services had passed on the phone number with reluctance rather than seeing it as a key element of their signposting responsibilities.

Financial and Legal Matters

- 4.26 Financial matters and concerns about money were a dominant theme for relatives and carers. Unlike most of the people who were self-funding and who had a vague knowledge of how financial assessment was undertaken or how the local authority might be able to help and in what circumstances, their carers and families were generally well informed (or had acquired expertise through the experience). As this person observed, such knowledge was picked up along the way and could be very useful:

"Things like 'Working Lunch' and things like that on the TV, and 'Money Box', and all those sort of things; you pick these things up and you know that there's some limit at which somebody else has to pick up the bill."

- 4.27 The impression that some people acquired about how and when the local council might 'pick up the bill' was not always accurate, and the reality could be more of a challenge, as this person discovered:

"So you think, oh that's going to be great – Mum's only got that much money now so no trouble at all. But then the council are involved and they then started referring to this third party who was going to pay the difference. And I thought 'oh that's nice, who's that?' and they said, 'you!' (...) and it was something like £180 a week!"

- 4.28 By trying to find the most suitable care homes for their relatives to move to, carers were usually making arrangements where charges were significantly in excess of the fees that their local council would normally meet. In the case above where a shortfall was identified it was reported that the council had told the family that another option would be to move the resident to a cheaper home, and indeed the way this was communicated appeared to be a 'threat' to do just that. Having already seen some of the other homes on offer and been unimpressed by their quality, the relatives refused

this option. In this situation there was considerable correspondence about what would happen next, and the carer was an articulate and determined person who was able to challenge the system and not give up easily:

“They did say it was above the price band, but we had another review and, good on the lady that did it, she said it would be detrimental to my mother to move. And with me and my letters and all the rest of it, and I eventually found someone higher [in the organisation] who I suppose didn’t really want to be bothered, and they said ‘Okay, we’ll pay’.”

- 4.29 However, even in this situation the family were left in a position of uncertainty where they were afraid to ask questions and unsure if the council was ‘picking up the tab forever or just until the end of the month’. The process from the time the family had advised the council that their relative was approaching the financial limit and an offer being made was a long one, and in part it appeared to them as a process of attrition where they had to keep to their position in order to get any response. It was recognised by this family that other people would find such challenge a considerable struggle, as they remarked:

“I can just imagine for other people, it’s difficult to get the information. And you do have to be quite resolute. I would imagine – say a couple living together and one of them is in very ill health, or not good health and needs to go in, it would be a nightmare (...) the eyes are on the budget and not on the person.”

- 4.30 Another carer whose mother had entered a nursing home was similarly worried about how long the money would last and how to slow the rate at which it was being spent:

“My brother worked out she had four and a half years (...) that’s a big worry. That’s something I need to do. I mean we were hoping that, for a start, she might move into a single room rather than the suite [she has at the moment] (...) it’s awful to think we’ve just got a time limit, you know.”

- 4.31 Another carer was supporting both of her very elderly parents in her own home and had resisted looking at residential care because she was so concerned about the consequences of money running out:

“Well no, because to be honest with you there wasn’t enough for them [both] to go into a private home. They would have gone through it by now at the price they all are (...) initially anyway (...) they had more than £23,000. Not a huge amount. They wouldn’t have gone without each other, so you’re talking about a double whammy here. And although I know one can get help it’s fairly minimal I think. So it just simply wasn’t an option.”

- 4.32 And yet another carer whose mother had moved into a care home was in the position of knowing that there was a significant amount of money available:

“My father was very prudent and, you know, they had a property. Well, when she came to us because she couldn’t manage on her own, she sold her property and that’s...I just put that into a pot for her care.”

This person recognised however, that the funds were finite but hoped that they would outlast her mother:

“I’m lucky that she has the means to be cared for. It won’t go on forever; it can’t go on forever, but I think as she is very elderly and has been very poorly (...) we shall probably get through. But, you know, if this had happened in her 70s – no way.”

- 4.33 Carers and family members were in the invidious position of hoping their loved ones died before their money ran out. Indeed, carers often expressed the wish that they would prefer for it ‘all to be over’ for the sake of the quality of life of their relative.

- 4.34 None of the people interviewed had sought or received independent financial advice specifically relating to their care situation. Some had been given general information through their council at the

time of the financial assessment, although this wasn't always accurate or helpful:

"We decided what a load of rubbish! You know, we wanted to believe him because what he was saying was to our advantage, but when we tried to follow through it was a load of rubbish (...) he said 'can I see the bank statements?' and 'she's entitled to this and she's entitled to that, and entitled to something else.' And she was entitled to nothing!"

- 4.35 All the carers had Power of Attorney arrangements to facilitate them supporting their relative and managing finances on their behalf. One person had made arrangements following the discovery of 'Solicitors for the Elderly' which he had found particularly helpful. Other financial help, such as Attendance Allowance was often discovered by chance rather than as the result of accurate information or advice.

Conclusions

- 4.36 The experiences of carers were remarkably similar. To a lesser or greater extent all had found themselves struggling to find their way in a system of which they had little or no prior knowledge, and where the pathway was by no means clear. Experiences of contact with social services were primarily negative – focused principally on assessing the financial means of the person needing care, or were frustrating in failing to offer any clear information or advice and referring them elsewhere to other organisations which often in turn passed them on again. On many occasions people felt that they had to learn to play a 'game' in their dealings with the council – either to get information that was of value, or to persuade the council to accept financial responsibility when assets had been spent down. Moreover this was a game where the rules were hidden and apparently fluid. For people who were unskilled in such negotiations, or lacking in the time or other resources to engage in them, the process was bewildering and frustrating.
- 4.37 Being issued with a list of possible care homes was often the sole information that people were given, and of itself such a list was of limited value. People had little knowledge or expertise with which to judge the respective merits of one home over another or to interpret inspection reports, and although some people acquired knowledge rapidly (not least by undertaking personal visits), this was an uncertain science and one that was only viable for carers living in some proximity to the person needing support. Finding out how to navigate the system was all the more difficult when people were responding to the immediate demands of a crisis and having to make decisions in a hurry.
- 4.38 People acquired knowledge and information from various sources but typically these were informal and relied on word of mouth and reputation, rather than the result of clear sign posting. A minority of people had found their way to specialised advice (such as through Counsel and Care or local advocacy and brokerage services) and these were highly valued. However, for the most part these services were more apparent by their absence in people's lives than by their presence. While it was common for people to make Power of Attorney arrangements to better support a relative and handle financial matters, no one had taken independent financial advice or was aware of specific financial products that might be of benefit to their situation.
- 4.39 Not surprisingly, most carers viewed the future with some trepidation and concern. Where people were endeavouring to support someone at home they were doing so in situations that were often precarious and where increasing dependency would – sooner or later – be a tipping point, with the likelihood of residential care becoming necessary. In such situations some people were desperate and had no clear idea of what to do for the best. For carers already supporting someone in a residential situation the predominant concern was around whether people would outlive their savings and what might then happen.
- 4.40 As with the experiences of people who were self-funding, carers and family members were often isolated and poorly equipped to make important decisions about care and support. Having financial resources was no guarantee of itself that people were able to secure the best or most appropriate care and support or know how to access it.

5 Conclusions

- 5.1 This qualitative study of people's experiences of self-funding has revealed a picture in which there are many features that give cause for concern. Many of the emerging conclusions have been highlighted in the course of the report, and this final section does not repeat all of these, but does underline the major issues arising. In implementing the transformation agenda of Putting People First councils have been required to meet a number of key delivery milestones. All councils should already have a strategy and arrangements in place for universal access to information and advice services; by April 2011, the public should be informed about where they can go to get the best information and advice about their care and support needs. On the basis of the evidence of the current research, meeting this target will be challenging for many councils. Moreover, it is not enough that information and advice should be 'available', but it needs also to be relevant, accessible and timely – and satisfying those requirements will be considerably more demanding.
- 5.2 Few people – whether self-funders themselves or members of their families – have good awareness or understanding of how to go about getting information or advice on care and support. Most people consult with family and friends for advice, and gather information from informal sources, by word of mouth and reputation. For people who do not have close family members who can help them, or worse have relatives who have no wish to be involved, the process is even more challenging and stressful. In such circumstances it is not surprising that many people ignore the reality of their position and their increasing need for support until such time as a crisis in their health or a sudden change in their ability to remain independent forces a change of tack. Decisions were typically made as a matter of urgency and in practice people had little control over their situation and meaningful choices were often lacking.
- 5.3 Some people made use of the internet and the quality ratings of the regulator (CQC) to inform their decisions. However, under new arrangements the Care Quality Commission stopped awarding quality ratings on 30 June 2010 and ceased the process of key inspections that would result in awarding a quality rating from that date. A new information system is being developed to address the quality of adult social care and to "provide information about the quality of registered services for people who use and commission them, to help them make choices and decisions." Work is also taking place with the Social Care Institute for Excellence to develop the concept of 'excellence' in quality ratings (which a provider would have to apply for).
- 5.4 A consultation on the CQC proposals for quality information is expected in 'winter 2010/11' but had not appeared at the time of writing (December 2010), and the cessation of the quality ratings system in advance of the development of a new model has been the focus of criticism.^{xxviii} The reduction in the amount of information being collected by CQC, and the emphasis in the new outcomes framework on 'essential standards' and 'risk-based inspection' could prove to be a retrograde step. It is essential that any new system of regulator judgements is readily accessible and understandable if it is to be of value to self-funders, carers and other people using care and support in making informed choices.
- 5.5 For most people in this study, contacting social services or the council for help or information would be anathema. The image of social services is such that for many people – particularly for those who are elderly – there is considerable stigma in approaching them for help. Furthermore, while people have little knowledge of how the social care system operates, most *do* have a general awareness that if they have any savings and own their own home they will have to pay for care and support. Armed with this information people may see little added value in approaching social services only for this to be confirmed. The experiences of people who took part in this study provided recurrent evidence that their low expectations were repeatedly reinforced.

- 5.6 The most frequent experience of people who *did* approach the council for help was to be provided with a list of care homes and other social care services. It would be very generous indeed to interpret such a list as an offer of information and advice. Councils should also play a part in signposting people towards other organisations that *can* provide such help, but again the overwhelming experience of most people was merely of being ‘passed from pillar to post’. In the single instance where someone was referred to an organisation that could provide tailored advice and information, the process of referral was handled poorly and a contact number passed on with apparent reluctance. Some people had found their way to other sources of specialised information (such as through Counsel and Care) and these were highly valued for their relevance and courteousness, particularly when contrasted with less favourable experiences of trying to access help or information. There is a pressing need for a range of independent and high quality information and advice services, together with individual advocacy and brokerage support, that can be easily accessed and does not require people to navigate multiple portals before arriving at the right place.
- 5.7 Despite all the emphasis of policy guidance on assessing people’s needs *prior* to looking at their financial means, many people had negative experiences of the opposite situation. It appeared to be commonplace that people would be asked about their financial situation at the outset and effectively told that no help was available if their assets were above the means testing threshold. Perhaps as a result of this experience the idea of ‘assessment’ was one that many people regarded with negative connotations; none of the people who were self-funding, nor their family members, had an experience of assessment that focused on identifying their needs for care and support, how best these might be met and what options were available.
- 5.8 It is possible that the term ‘assessment’ is inadequate to convey to people anything positive or to encourage them to go through the process in the hope of getting some help or useful advice. Similarly, those involved in providing assessment rarely seem to offer this as anything helpful concerned with identifying people’s needs rather than with identifying them as ineligible for help. In the absence of needs assessment people have inadequate knowledge about what support might be available to them and how to access it. People who could benefit from reablement and prevention services are at risk of missing such opportunities and being directed instead towards permanent residential care which might otherwise be avoided or deferred.
- 5.9 Councils that take on the responsibility for providing information and advice themselves, rather than ensuring that it is provided as part of a wider strategy, are likely to struggle to reach key audiences who are unlikely to access information from this source. Furthermore, the independence of information and advice provided in this way is also dubious, and there are dangers in trying to accommodate this function with one that is essentially providing a gatekeeper to limit access to publicly funded support.
- 5.10 It is also clear that people who are self-funding make major decisions, with consequences for large amounts of personal expenditure, on the basis of little or no independent financial advice. Few people were aware that specialised financial advice even exists in this field, and there is clearly a major task in raising the population’s awareness and knowledge. A similar issue arises in respect of people’s awareness of care and support in general. It was striking that while many older people had made wills and arrangements for their final wishes to be known, and many had made sure that their funerals were already paid for; none had thought about whether they might need care and support and if so what they would want to happen.
- 5.11 The responsibilities of councils to ensure that everyone can access the information and advice they need require a range of approaches if this is to truly be a ‘universal service’, and one that delivers high quality outcomes. Information alone is not sufficient; people also need guidance and support in planning how their care needs might be met, and in making some of the most important decisions of their life. The milestones for delivery of the transformation agenda remain important targets, but it is also vital that these are not seen as something that can be ticked as ‘done’. Rather, these will remain important objectives that need to be refreshed and revisited to ensure approaches are dynamic and delivering the intended outcomes.

- 5.12 Similarly the proposed outcomes framework for social care provides both risks and opportunities. In focusing on localism and a more permissive approach, rather than a top-down and centrally driven model, councils have opportunities to address outcomes that are meaningful to their communities. It will be essential that these, and the parallel Quality and Outcomes Date Set that is envisaged, are sufficiently broadly based that they do not focus only on people currently using social care services under the ambit of eligibility criteria, but that they include *all* people using care and support services, however these are funded.
- 5.13 The experiences of people who are funding their own care and support are complex and varied. In this study, a minority of people had sufficient financial resources and the support of family members to enable them to make considered and deliberate choices about the type of support they needed and wanted. For others, perhaps most, being a self-funder did not automatically mean that they had control over their situation and in practice their choices were few. With little idea of how to go about seeking help to navigate the complex world of care and support, most people were undertaking major life journeys and making significant decisions without the benefit of maps to guide them, and with little clear view of their destination. For people who did not have close family members to help them on the journey, the options were fewer still and the path a lonely and bewildering place to travel.
- 5.14 With the continued roll-out of personal budgets and wider social care transformation, all councils need to address the provision of information, advice and advocacy. There is much in the experience of people who are self-funding that could and should inform this development. Councils should recognise that people need to be able to access information and advice through a variety of accessible routes which offer different models and styles to match people's preferences (such as electronic information; telephone support, or face to face). On the basis of people's reported experiences in this study it is doubtful that the local authority is the organisation best placed to provide such flexible and independent advice when they are simultaneously acting as gatekeepers to limit publicly funded support, and when the involvement of social services is still widely perceived as stigmatising.
- 5.15 Too often the experience of self-funders is still poor, and the impact this has on their lives and decisions has been explored in this report. However, what people need from information and advice services is clear, and where good services exist, people's experiences are altogether more positive and lead to better outcomes. The vision for adult social care emphasises that personalisation should mean "people, not service providers or systems, should hold the choice and control about their care." This report has highlighted the considerable challenges that remain in ensuring that people *are* enabled to exercise autonomy, and that the journey through care and support becomes one that is well charted and clearly marked. Such dimensions must become integral to the key outcome domains being sought in adult social care.

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