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# From Bystanders to Core Participants? A Literature and Data Review of Self- Funders in Social Care Markets

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This is an interim report, presenting the findings of a realist synthesis of the literature and analysis of secondary data, and has not been peer reviewed. The final report from the research projects will be peer-reviewed prior to publication.

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## Executive Summary

This report provides a new analysis of the estimated numbers of people who are self-funding their social care and support, together with the reflections from a realist literature review examining how local authorities are meeting their Care Act responsibilities to self-funders. The analysis is part of a programme of NIHR funded research at the University of Birmingham under the title of 'Shifting Shapes', exploring how local authorities are meeting the requirements of the 2014 Care Act to shape markets and deliver better personalisation of care. The research is ongoing and it would be premature to offer firm conclusions at this stage, not least because there have been major delays in the implementation timetable of the Care Act and a climate of uncertainty surrounds the future of adult social care.

Most of the literature on self-funders is not empirically testing market shaping and personalisation, so much as providing critical insight to the challenges of Care Act implementation. Self-funders have long been regarded as residing on the side-lines of the social care market; however, it is increasingly clear that their presence can both distort markets and ensure markets' viability. Failure to recognise their importance in this dynamic could be highly damaging for all users of social care services and for local authorities attempting to shape markets and optimise personalisation outcomes.

Self-funders are increasingly acknowledged within the social care discourse, but even so it is striking how little is known about this important population, and how they remain relatively invisible. Information about self-funders is scant; the numbers of people paying for care are not known with any precision but are derived from estimates with considerable variation. Similarly, the experiences of self-funders are not routinely captured through large data sets and monitoring such as happens with publicly funded adult social care users.

The term 'self-funder' can be used to refer to a variety of situations, but in this report we use the term primarily to describe people who pay for their own care and support entirely from their own resources. We do not use it to refer to people who are using a Direct Payment or Personal Budget after meeting local authority eligibility criteria for social care; and neither do we use it to describe people who use their own funding to 'top up' their care home fees. However, we are aware that the lines between these different types of funders are increasingly blurred. Our focus is on self-funders aged 65 or over, as the prevalence of self-funding in working age adults is known to be very low and data is particularly poor on this group.

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In Section 1 of the report we examine the data that are available on people paying for care, based on publicly available datasets; we also consider other evidence provided by analysis of responses to a Freedom of Information Request. We consider the data on estimates of numbers of people paying for care both in residential care and in their own homes. The most recent data from the UK Household Longitudinal Survey (UKHLS) provides particular insight on the numbers of people who say they are paying for home care where 6.4 per cent of people aged 65+ report they are paying for care. This is true of around twice as many women (8%) as men (4%). This would suggest a UK-wide estimate of 380,000 people, which is higher than previous estimates. The Health Survey for England (HSE), for example found 4.8% of those aged over 65 reported paying for care at home.

There is an increasing likelihood of paying for care with advancing years, while married couples are least likely to pay for care and those who are widowed are generally the most likely. There are some surprising associations with housing tenure, and the highest rates of paying for home care are found among private tenants, with older people who own their homes outright the least likely to pay for care. It is likely that the latter group are generally more affluent and have better health status than other groups of older people.

Information from a Freedom of Information (FOI) request to local authorities in 2014 on estimated numbers of self-funders suggests 465,000 self-funders in England. Adjustment of the figures to allow for extreme outlier figures produces an estimate of 350,000 people paying for care in their own homes or residential care. It is also estimated that there are one and a half times as many people paying for care at home as there are paying for residential care. The overall figures derived from the most recent sources can be summarised:

- 380,000 people living in UK private households and paying for home care and related services (UKHLS);
- 230,000 people living in private households in England and paying for home care (HSE 2014);
- 350,000 self-funders (care homes and home care) in England (FOI request of LAs with large range of uncertainty).

The analysis of estimates of prevalence of self-funding provides important context to understanding the importance of this group of people in the care market.

Section 2 turns to explore the relatively thin literature on self-funders and to consider whether and how this knowledge influences and informs local authorities' market shaping behaviours. We adopt a realist review methodology to identify and analyse the literature,

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much of which is descriptive and analytical rather than evaluative. Of 85 items included, only 15 were empirical in nature, and just 10 had been peer reviewed.

The realist review approach is theory-driven and seeks explanations to understand the mechanisms by which interventions produce different outcomes. For the Shifting Shapes programme overall we have developed a set of 'programme theories' about how market shaping might work through particular mechanisms and planned outcomes. These are conceptualised in three categories:

- Care as a market: what is the underpinning theory about the operation of quasi-markets in a care setting that supports market shaping and personalisation as intervention mechanisms?
- Supply and demand: what are local authorities expected to do to shape care markets and support personalisation and what is the expected response from providers?
- The active consumer: what assumptions about the behaviour of individuals and families using care services are embedded within the market shaping logic?

In this paper, with its focus on self-funders, we have concentrated more on some aspects of the theory map than on others because of their particular relevance. Thus, we examine:

- Market limitations.
- Personalisation.

And 'rival framing' theories:

- Constraints on local authority market shaping.
- And lack of tools for people to make effective choices.

In the literature on self-funders, it is the rival framing theories which predominate in analysis and commentary. However, much of the literature either pre-dates the 2014 Care Act, or was produced soon after. Furthermore, the delay in implementing the Care Act inevitably means that the literature is likely to be biased towards more critical analysis.

Our analysis cannot, at this stage of Care Act implementation, provide any definitive conclusions on whether market shaping and personalisation have been effective in achieving better outcomes for self-funders. However, we are able to offer detailed insights and understandings to the explanatory context surrounding implementation of the Care Act. We

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have explored and highlighted the multiple challenges and tensions in bringing about the transformation of care and support. Future introduction of a capped cost model could have significant implications for the stability of the care market, and in reducing the monopsony power of local authority purchasers.

In conclusion, the future challenge for research and practice is to consider what market shaping and personalisation objectives and outcomes will look like in a context in which the Care Act is only partially implemented. It is inevitable that uncertainty about the next steps will cause some blight to local progress and preparations, but the wider question is whether, regardless of the decisions made about personal responsibility for funding care in old age, self-funders can continue to be treated as bystanders in the social care market. It is clear that the presence of self-funders shapes and re-shapes the social care market in ways which have a profound impact on the care system, and they can no longer be seen as incidental to the operation of adult social care.

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## Introduction

The University of Birmingham has been commissioned by the Department of Health and Social Care to undertake two major linked research projects into the implementation of the 2014 Care Act (Great Britain Parliament, 2014), focusing particularly on ‘market shaping’, and ‘personalisation’. The combined project, known as *Shifting Shapes*, has a number of related components to address the central aims of understanding whether local authority market-shaping activities are providing a choice of good quality, cost-effective, information and care provision; and doing so in ways that support personalised services, delivering individual choice, control and good care outcomes.

A central dimension of the *Shifting Shapes* project explores the experience of people who are self-funding their social care and support. This includes what local authorities are doing to shape the provision of services, information and guidance for people making vital care choices; whether people who are self-funding are able to access care and support that facilitates quality, choice and control, and the impact on self-funders of the delay in the full implementation of the Care Act. These questions will all be examined through fieldwork in 8 local authorities in a later phase of the project. At the outset of the research, secondary data analysis and literature searches were undertaken to provide background and context to the research, and the self-funder aspects of that work are presented in this report.

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## Background and Context

Before exploring the literature, we begin by setting out the background and context of the Care Act 2014. The Act is widely viewed as the most significant piece of legislation in social care for decades and consolidates and replaces numerous earlier Acts that built up incrementally. It creates new duties for local authorities and their partners, and new rights for people who use services, and for their carers. It was seen as a particularly significant piece of legislation for self-funders as it created a duty for local authorities to provide information and advice to people who were funding their own care. It also introduced a cap on the financial liability of self-funders, although that has not been implemented. At the present time, the 2014 Care Act remains the only current expression of policy on adult social care in England, and its requirements continue to direct local practice.

The Act has a number of underpinning objectives and principles, reflected in the creation of new duties on local authorities around care and support, and particularly to:

- promote individual wellbeing;
- prevent needs for care and support;
- promote integration of care and support with health services;
- provide information and advice; and
- promote diversity and quality in provision of services.

Part 1 of the Act addresses the legal framework for providing adult social care in England. The general responsibilities of local authorities set out in sections 1-7 embody the aspirations and objectives that were originally outlined by the Coalition Government in the 2012 White Paper (Department of Health, 2012). The paper set out a 'vision for care and support' in these terms:

Our vision is one that promotes people's independence and wellbeing by enabling them to prevent or postpone the need for care and support. We will also transform the system to put people's needs, goals and aspirations at the centre of care and support, supporting people to make their own decisions, to realise their potential, and to pursue life opportunities (p.18).

Two central aspects of the Care Act were a new duty placed on local authorities to 'shape' care markets, and a requirement to support individual choice and control within the broader wellbeing duty, which is referred to by the term 'personalisation' in the [Care Act statutory guidance](#).

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The funding of social care, and measures to protect self-funders from potentially catastrophic care costs, had been on the political agenda for several years before the Care Act. The Dilnot Commission's review on fairer care funding had been published in 2011, concluding that the system for adult social care funding in England 'is not fit for purpose' (Commission on Funding of Care and Support, 2011). In place of the 'confusing, unfair and unsustainable' system, the Dilnot Commission recommended capping the lifetime contribution to adult social care that any individual would need to make at between £25,000 and £50,000, and proposing that '£35,000 is an appropriate and fair figure' (p. 5).

The response from the Government to the Dilnot recommendations came in February 2013 when the then Health Secretary announced that a cap of £75,000 would be introduced, alongside an increase in the means testing threshold from £23,250 to £123,000 (Department of Health, 2013a). People requiring permanent residential care would remain responsible for their 'living costs' (as opposed to care costs), meaning that even after reaching the threshold for state support, people would contribute 'around £12,000' a year to general living costs.

The 2014 Care Act duly incorporated the cap on care costs (set initially at £72,000) and expected implementation to commence on 1 April 2016. From this date, local authorities would be required to establish care accounts for adults meeting eligibility criteria for care, but whose financial assets were above the means testing threshold, in order to keep a record of total accrued costs, and their progress towards the cap.

However, following the 2015 General Election and a change of administration, the incoming Conservative government announced a change in the timetable with implementation of part 2 of the Act postponed until April 2020 (this included both a postponement of the cap on care costs and also changes to the capital limits and means test).

The unexpected General Election of 2017 signalled some further changes to adult social care (Henwood, 2017a). The Conservative Manifesto (The Conservative and Unionist Party, 2017) made no mention of the delayed Care Act or the provisions for the cap on care costs, but rather stated:

(...) we will introduce a single capital floor, set at £100,000, more than four times the current means test threshold. This will ensure that, no matter how large the cost of care turns out to be, people will always retain at least £100,000 of their savings and assets, including value in the family home (p.65).

With no indication of a cap on costs, and with the new threshold being *lower* than the one set out in the postponed Care Act, far from being welcomed, the manifesto position created

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confusion. For the first time the manifesto also stated that in future, means testing for home care would be undertaken on the same basis as for residential care (i.e. taking the value of property including capital assets into account wherever care is provided). The Prime Minister announced a 'clarification' of the policy just days later; stating that there would 'be an absolute limit on what people would need to pay' (Henwood, 2017b). With the outcome of the election resulting in a minority Conservative government, the way forward on social care remains uncertain.

The context to any discussion of the implementation of the Care Act in general, and in respect of the measures addressing paying for care in particular, is therefore one of considerable ambiguity and confusion. The Care Act had appeared to offer a firm foundation for adult social care for a considerable period ahead, and particularly so in creating major consolidation of many years of complex incremental law development. However, the reopening of the debate about paying for care, the lack of political consensus on the way forward, and the apparent abandonment of implementation plans for part 2 of the Care Act, once again creates major uncertainty. This is the case not only for people – and their families – who are users of long term care, or likely to be so in future, but also for local authorities who were preparing for a new role in facilitating the operation of individual care accounts and implementing the capped cost model.

Self-funders are often peripheral to debates about care. Their exact numbers are not known, and their experiences are not captured in large data sets such as the Personal Social Services Adult Social Care Survey. This report goes on to look at the existing state of knowledge about self-funders and their engagement with the care market, highlighting key themes from the literature. It begins by looking at existing data on the prevalence of self-funding.

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## Section 1: Data on the Prevalence of Self-Funding

'Self-funders' is a term which is now in more frequent use in relation to social care for older adults; it is also a term which is often used to refer to a range of different circumstances and situations. In this report we use the term primarily to describe people over 65 who pay for their care and support entirely from their own resources; we are not describing people who have a Direct Payment or Personal Budget as a result of meeting eligibility criteria for local authority social care, and neither are we referring to people who 'top up' the costs of residential care from their own resources. Increasingly, however, the lines between these types of self-funder are becoming blurred and those responsible for social care policies and practice need to be cognisant of their impact on all of these groups.

One of the key characteristics of self-funders is their relative invisibility compared to people who use publicly funded care services. Some of them may be known to the local authority, but their numbers and needs are not systematically recorded as those of local authority funded care recipients are. Nor do they complete the Personal Social Services Adult Social Care Survey to give their account of the quality of care, if using only self-funded services. This section considers the data that are available on self-funders and focuses on the prevalence of people paying for their social care as indicated by publicly available datasets in addition to analysis of a pre-existing Freedom of Information request.

It is important to note that whilst data on self-funding amongst over 65s is known to be incomplete, even less is known about working age adults who self-fund their care. They are not included in the data sets that we report on below. Laing Buisson's annual report on care for working age adults notes: 'With the exception of acquired brain injury and substance misuse, nearly all funding of WAASC [working age adult social care] services for younger adults with learning and physical disabilities and mental health needs comes from public funds' (Lang, 2016, p. 21). For this reason, the report focuses on self-funding amongst over 65s, although the need for work to understand the experience of the small group of younger self-funders is recognised.

For home care, the numbers of people paying for care are derived from the Health Survey for England and the English Longitudinal Study of Ageing. That is, those in households with different kinds of care arrangements, some of which they may be paying for. Estimates tend to be in the order of between 150,000 – 250,000 depending on the particular definitions used (for the 65+ population) in past analysis. This number would equate to only around 2% of those aged 65 or older. However, our new analysis of more recent data suggests a much higher proportion of people are self-funding.

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For those in care homes, it is possible to make estimates at the local authority level by looking at the number of residential beds (available from the Care Quality Commission, CQC), likely occupancy levels, and numbers that are funded by the NHS. That tends to generate estimates of around 40-45% of beds being fully self-funded, or around 170,000 for England as a whole (Putting People First Social Care Consortium, 2011). We understand that CQC's Provider Information Collection will, in the near future, provide data relating to the CQC-registered providers' views on the proportion of home care activity that relates to self-funders.

We provide further details on such estimates below, and take forward new analysis based on data from the latest UK longitudinal study, and from a set of Freedom of Information requests sent to local authorities in 2014.

### Cross-Sectional Micro-Data on Self-Funders

This review offers the opportunity to update the limited existing knowledge on self-funders. The most recent addition to our knowledge comes from the UK Household Longitudinal Survey (UKHLS), often called *Understanding Society*. In the most recently available data (in mid-2018 that is wave 7) there are new questions of relevance. For wave 7 (with interviews taking place mostly during 2015 and 2016) the UKHLS asked questions about paying for social care (defined in the survey as help with a list of activities of daily living, such as bathing and eating). The sample was people living in private households in the UK, and the relevant questions were asked of those aged 65 or older. An advantage of this study is that it has a generous sample size, including close to 9,000 full interviews with people aged 65 or older. This provides confidence in the reliability of the responses recorded, although the precise question wording should also be considered for the validity of the replies.<sup>1</sup> Appendix 2 to this report gives more technical details of the definitions and measures used.

People paying for care were defined as those who said they paid for all or some of their care, but only where that payment came from their personal income or assets, and not from a Direct Payment or Personal or Individual Budget from the local authority. This can be a

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<sup>1</sup> The question used in UKHLS wave 7 was adapted from Blake et al., (2010) 'Social Care for older people aged 65+, questionnaire documentation'. <http://www.natcen.ac.uk/events-and-training/our-events/events/launch-of-new-survey-question-module/social-care-questions-for-over-65s>. It asks: "Do you or your spouse {if HHGRID.LiveSp = 1} / or your partner {if HHGRID.LiveWith = 1} pay or give any money for the help given by [SCPayCodeA] ? Please include any payments made for this care, even if not made directly to the care provider." Respondents are then classified as self-payers if *any* of the money paid comes from 'My own personal income, savings, pension or benefit (such as Attendance Allowance)'.

complex area and people are not always sure if they are ‘self-funders’ if they use money from their Attendance Allowance (AA), for example, to pay for care. However, the questions asked about money from personal resources and defined that to include AA. Similarly, some people using Direct Payments or Individual Budgets may describe themselves as self-funders because they are making their own care arrangements. The relevant questions however are based on people’s payment arrangements, and not on how they describe themselves.

Among people aged 65 and above, 6.4 per cent of those living in private households were paying for care (Table 1). Women (eight per cent) were about twice as likely to be paying for care as men (four per cent), although this partly reflects a higher average age profile for women compared to men. At a UK level, these proportions of the older population would indicate around 380,000 people living in private households and paying for home care. This is rather higher than past estimates have tended to suggest. This may reflect the inclusion of those ‘topping up’ payment for care, as well as those paying for all of their care. Other differences could relate to the broad coverage of the relevant questions, which could include paying for cleaning and the work of a council ‘handyman’ for odd jobs rather than care *per se*. Controlling for age, women were still somewhat more likely to be paying for care (see **Error! Reference source not found.1**).

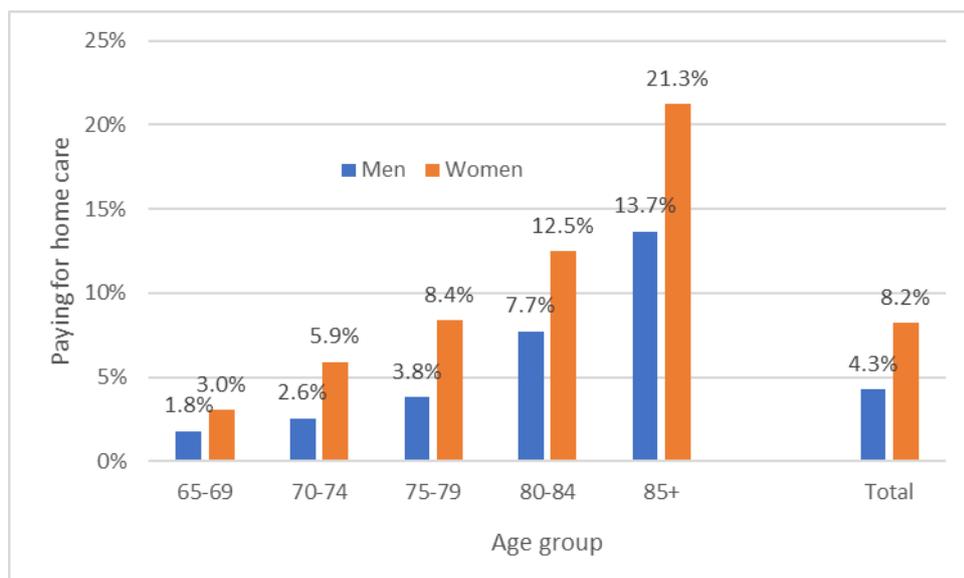
**Table 1      Paying for Home Care by Age Group**

Cell percentages

	<b>65-69</b>	<b>70-74</b>	<b>75-79</b>	<b>80-84</b>	<b>85+</b>	<b>All aged 65+</b>
Paying for home care	2.4%	4.3%	6.3%	10.5%	18.2%	6.4%
Base (unweighted)	2,953	2,704	1,331	1,079	784	8,851

Source: analysis of UKHLS wave 7.

**Figure 1**      **Paying for Home Care by Gender and Age Group**



Source: Analysis of UKHLS wave 7.

**There were also strong links between paying for care and relationship status, as only 4 per cent of those living with their spouse were paying for care, compared with 10 per cent for those with a different marital status. Those who were married (and living with a partner) were least likely to be paying for care, as low as 3 per cent for men and 4.8 per cent for women, which probably points to the importance of mutual support and co-dependency of older couples caring for one another or to the generally higher living standards of those within couples (see**

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**Table 2      Paying for Home Care by Age Group, Gender and Marital Status.**

2). There are some complex interactions between age group and marital status, although it seems that bereavement is associated with higher rates of paying for care, compared to other groups who live alone

**Table 2 Paying for Home Care by Age Group, Gender and Marital Status.**

	65-69	70-74	75-79	80+	All aged 65+
<b>Men</b>					
Single	1.9%	7.0%	[5.4%]	[10.3%]	5.0%
Married	1.2%	1.9%	3.3%	7.8%	3.0%
Divorced	2.8%	4.5%	[7.7%]	[12.9%]	5.1%
Widowed	10.0%	4.3%	4.4%	15.7%	11.3%
<b>Women</b>					
Single	0.0%	2.0%	[10.7%]	22.4%	9.7%
Married	3.3%	3.4%	4.8%	13.2%	4.8%
Divorced	3.0%	11.5%	12.5%	8.8%	7.5%
Widowed	2.6%	10.1%	12.6%	18.3%	13.8%
<b>Bases</b>					
<b>Men</b>					
Single	104	76	41	41	262
Married	1,039	998	451	500	2,988
Divorced	133	103	32	34	302
Widowed	66	94	85	244	489
<b>Women</b>					
Single	63	63	30	69	225
Married	1,080	850	355	256	2,541
Divorced	247	167	75	59	548
Widowed	216	352	260	658	1,486

Source: Analysis of UKHLS wave 7. Percentages in [ ] are based on fewer than 50 actual cases and so may be unreliable.

Higher rates of paying for home care were strongly associated with increasing age, which tends to affect other associations between different individual characteristics. For instance, those with a car, or still in paid work, or having gained a degree, were less likely to be paying for care, but this reflects their spread towards the lower end of the post-65 age distribution (i.e. on average they are younger).

**A person's ability to pay may also affect their actual spending, and one way of considering relative affluence is through housing tenure. As we show in Table 3 Paying for Home Care by Age Group and Housing Tenure.**

3 for those aged 65+ the highest rates of paying for home care were found among private tenants, with 8.1 per cent paying for some care. Social tenants and those paying off mortgages (a diminishing group across the older age bands) were the next most likely to be paying for any care. Those who were outright home owners had the lowest rate of paying for care (5.5 per cent). This may be reflecting a better state of health among this group, who on

most measures tended to be the most affluent of the older group, and with a more fortunate life history (Pollock, 2007).

**Table 3 Paying for Home Care by Age Group and Housing Tenure.**

	<b>65-69</b>	<b>70-74</b>	<b>75-79</b>	<b>80+</b>	<b>All aged 65+</b>
<b>Housing tenure</b>					
Own	2.2%	3.7%	5.7%	12.8%	5.5%
Mortgage	1.7%	5.1%	13.3%	21.0%	6.0%
Social rent	3.2%	5.9%	3.5%	12.6%	6.2%
Private rent	3.6%	5.9%	10.5%	16.9%	8.1%
<b>Bases</b>					
Own	2,092	2,079	1,000	1,419	6,590
Mortgage	290	156	60	62	568
Social rent	412	338	198	286	1,234
Private rent	70	112	79	244	505

Source: Analysis of UKHLS wave 7.

As its name suggests, the UKHLS is conducted across the whole of the UK, whereas some other sources are restricted to England (particularly The English Longitudinal Study of Ageing, ELSA; and The Health Survey for England, HSE). Rates of self-funding were seemingly higher in England (6.7 per cent) compared with Wales (5.9 per cent) Scotland (4.6 per cent) and Northern Ireland (4.5 per cent) but the differences were small. Even so, the Scotland:England difference was large enough, and based on sufficient cases, to be statistically significant ( $p < 0.05$ ). This difference, with fewer self-payers in Scotland, may well be reflecting free personal care provision in Scotland

People receiving Disability Living Allowance (DLA) were rather more likely than average to be paying for care, as 11 per cent did so, but as many as 20 per cent of those receiving Attendance Allowance (AA) were paying for care.

It is also possible to look simultaneously at a number of characteristics, using a multivariate statistical procedure known as logistic regression. The results of a logistic regression analysis are shown in Appendix 2. The results indicate that: older age is strongly associated with paying for care; men are less likely to pay for care than women; and single adults living alone are rather more likely to be paying for care than those in couples. There was also some evidence that those living in Scotland were less likely to be paying for care. Having controlled for age, gender and some locational factors, there were no longer any statistically robust association between paying for care and housing tenure, nor living in a rural area.

Results from the UKHLS may be compared with those of the Health Survey for England (HSE), which has included questions on paying for care in a run of recent surveys (care is defined in the questionnaire as tasks of daily living such as getting out of bed and bathing). Again, attention is restricted to those aged 65 or older, who are asked the relevant questions. Results for the UKHLS, even restricting analysis to only include England, appear somewhat higher than for the Health Survey for England in 2014.<sup>2</sup> Either the UKHLS is giving higher results because of its different sampling approach, or there has been a considerable increase in prevalence since the last reported HSE figures from 2014 (a period of continuing austerity in public and especially local government finance), or the questions are identifying somewhat different definitions of what counts as self-funding (e.g. the HSE only includes informal care of 20+ hours in the past week). Such large differences are more likely to be due to the latter two explanations, rather than sampling issues, but it is not possible to break down precisely where such differences have arisen.

**Table 4 Paying for Home Care by Age Group: Surveys and Years Compared.**

<b>Results for England</b>	<b>65-69</b>	<b>70-74</b>	<b>75-79</b>	<b>80+</b>	<b>All aged 65+</b>
<b>UKHLS 2015-17</b>	2.7%	4.3%	6.4%	14.8%	6.7%
<b>HSE 2014</b>	1.2%	1.9%	4.5%	11.8%	4.8%
<b>HSE 2013</b>	1.8%	1.9%	4.1%	10.6%	4.5%
<b>HSE 2012</b>	0.8%	2.7%	4.0%	12.0%	4.8%

Source: Analysis of UKHLS wave 7 and HSE 2012-14.

### Local Authority Numbers – Response to a 2014 Freedom of Information Request

In 2014, a series of Freedom of Information (FOI) requests were made for unknown purposes under the name 'Adam Wallace' to local authorities in Britain on the topic of social care. Part of the four-part request was to ascertain for each Local Authority 'What are your working estimations of how many 'Self Funders' are in your Council area...'.<sup>3</sup> Responses to

<sup>2</sup> The HSE questions ask separately about 'Whether respondent or partner pays for formal help provided through LA' and 'Respondent or partner pays for formal help not provided through LA (20+ hours in last week)'.  
<sup>3</sup> A follow-up question probed for the budgets of self-funders, but few Local Authorities were able to provide sensible data for this question.

these FOI requests have been published on the *What do They Know* (2014) website. We are unsure how this data was used by the initiators of the FOI request, and cannot locate anywhere it has been analysed and published. We have therefore collated this relatively raw information, and report on the results. It is likely that the numbers here are underestimates of current levels.

**Of the 152 bodies responsible for social care provision in England, seven (five per cent) did not respond to this particular FOI request. Another 56 (37 per cent) replied to address certain questions but could not provide any information about self-funders in their locality. If we were to assume that the non-responders and those unable to answer were drawn at random from the group of 152, then the data provided would be consistent with an England estimate of around 465,000 self-funders (see**

**Table 5 Estimated Number of Self-Funders in England.**

5).

Given that local authorities will be most familiar with those using their own services (and taking account of the likely uplift in self-funders since 2014), this number should be regarded as an under-estimate. It is possible to consider that estimates are subject to a degree of sampling error, and we should account for that variability in how we treat the data, as we indicate in Table 5. This generates a range of estimates from 350,000 up to 580,000. There are some extreme values in the dataset that look, in a few cases, to be rather high and which have a disproportionate effect on the overall numbers. If we remove those outliers, then the figure for self-funders in England looks to be around 350,000.

**Table 5 Estimated Number of Self-Funders in England.**

Grossed-up numbers

<b>Naïve weighting of responses</b>	<b>Adjusting for statistical variability</b>	<b>Removing 5% outliers from LAs</b>
465,000	350,000 – 580,000	350,000

Analysis of set of FOI requests.

Responses from local authorities frequently did not specify whether their self-funder estimates were based on those people paying for home care and/or residential care. However, where (some) local authorities in this request *were* able to break down their figures into those in care homes and those living in the community, there tended to be about 1.5

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self-payers in the community for every 1 who was a self-funder in a care home. This contrasts with other evidence where a 1:1 ratio is more likely.

Overall, we may summarise these aggregate results as follows:

- 380,000 people living in UK private households and paying for home care and related services (UKHLS wave 7);
- 230,000 people living in private households in England and paying for home care (HSE 2014);
- 350,000 self-funders (care homes and home care) in England (FOI request of LAs with large range of uncertainty).

There are strengths and weakness of each of the different kinds of estimates produced. The UKHLS has a very large sample size. It also uses recommended approaches to ask about paying for care. However, it is based on a panel (albeit re-weighted) and there is only one wave of data to analyse. The HSE gives relatively stable figures from a number of survey years but has a somewhat smaller sample size in each year, so overall estimates may be less reliable, particularly when made for smaller sub-groups. Finally, the two surveys ask about paying for care in different ways, although both employ a relatively nuanced approach.<sup>4</sup>

This brief overview of the data on numbers of self-funders in England, and the basis for estimated figures, provides an important context to our subsequent understanding and analysis of the size and significance of this group of people in the care market. We turn now to explore the literature on self-funders and to consider how this knowledge influences and relates to the market shaping roles and responsibilities of local councils.

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<sup>4</sup> We also note that in 2016-17 the Family Resources Survey included new questions in this area, asking: Does your household pay for or contribute to the cost of home care services provided by professional health or care workers for someone in your household? INTERVIEWER: Home care services include medical treatment and therapy and also help with daily tasks such as meal preparation, laundry, shopping, transportation and companionship. Only include home care services provided to someone because they have a long-term physical or mental ill-health or disability (or problems relating to old age). 1. Yes / 2. No.

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## Section 2: Self-Funders and the Care Market: Evidence from the Literature

The second half of this report presents a realist review of the literature on self-funders and their experience of engaging with care markets. The literature on people funding their own social care and support ('self-funders') is of relatively recent origin and is still developing. Much of the literature is 'grey' rather than academic or empirically based. As such, the search strategy took an inclusive approach and incorporated the maximum number of sources rather than focusing only on peer-reviewed, academic outputs.

### Realist review methodology

Online literature searches were undertaken using broad terms of 'self-funders'; 'care'; and 'England' from 2000-2017. This identified 101 items; targeted searches were also undertaken to capture 'grey' literature, and particularly to pick up online commentary and analysis, and this identified a further 11 items. All references were captured using EndNote and duplicates and misidentified references were removed, leaving a total of 85 items (see Appendix 1).

Data extraction sheets were designed by the project team for use across the literature reviews, and a separate sheet was completed to chart each item. The charting process is of value in enabling comparison of key dimensions within and between different studies and pieces of literature. The self-funder literature is diverse in character, but much of it is not primarily academic in nature, and is primarily descriptive and/or analytical rather than evaluative, and therefore tends to develop the theoretical framework, rather than test it. Table 6 below summarises the source types identified. The type of material identified most frequently was classified as 'reports', which includes academic research reports, but also reports of studies undertaken by charities, or special investigations of specific aspects of the care market and self-funders' experiences. The next two most frequently identified types of literature can be seen as journalistic analysis and commentary, reported in magazine articles (typically in the social care trade press), or via website articles and blogs. Of the 85 sources, ten of these were peer-reviewed and 15 were based on the results of empirical investigations.

**Table 6 Literature by Source Type (n=85)**

Book	Briefing	Bulletin	Chapter	Circular	Guide	Journal	Letter	Magazine	Report	Statement	Toolkit	Web page
1	8	1	1	1	5	10	2	12	34	1	1	8

In exploring the literature we have adopted a 'realist review' approach, following the model described, for example, by Pawson *et al.* (2005), and by Pearson *et al.* (2015). Pawson *et al.* described the approach as one that:

seeks to unpack the mechanism of how complex programmes work (or why they fail) in particular contexts and settings (2005, p..S1:21) (Original author emphasis).

A realist review is theory-driven; Pearson *et al.* state that the primary goal of such an undertaking:

is explanation-building, aiming to produce a contextualised understanding of the mechanisms by which interventions produce different patterns of outcomes. (2015, p.578)

As developing concepts, it is likely that there would be a range of opinions as to what market shaping and personalisation aim to achieve, along with the actions needed to achieve these aims. A realist review attempts to uncover and question these expectations.

Within the realist method the identification and refinement of propositions about how any given programme should achieve its intended outcomes are identified as 'programme theories', described by Pawson *et al.* as:

the theories, the hunches, the expectations, the rationales and the rationalizations for why the intervention might work (2005, p.S1:26).

Consequently, this realist review stands in distinction to Baxter and Glendinning's (2014) scoping review of the literature on self-funders which provided a broad mapping of what is known about the self-funding population, and highlighted gaps in the evidence base including the relevance of market shaping to self-funding. Indeed this realist review seeks to address precisely these deficits in knowledge and is focused on revealing the nuances in the concepts of market-shaping and personalisation through looking specifically at self-funders.

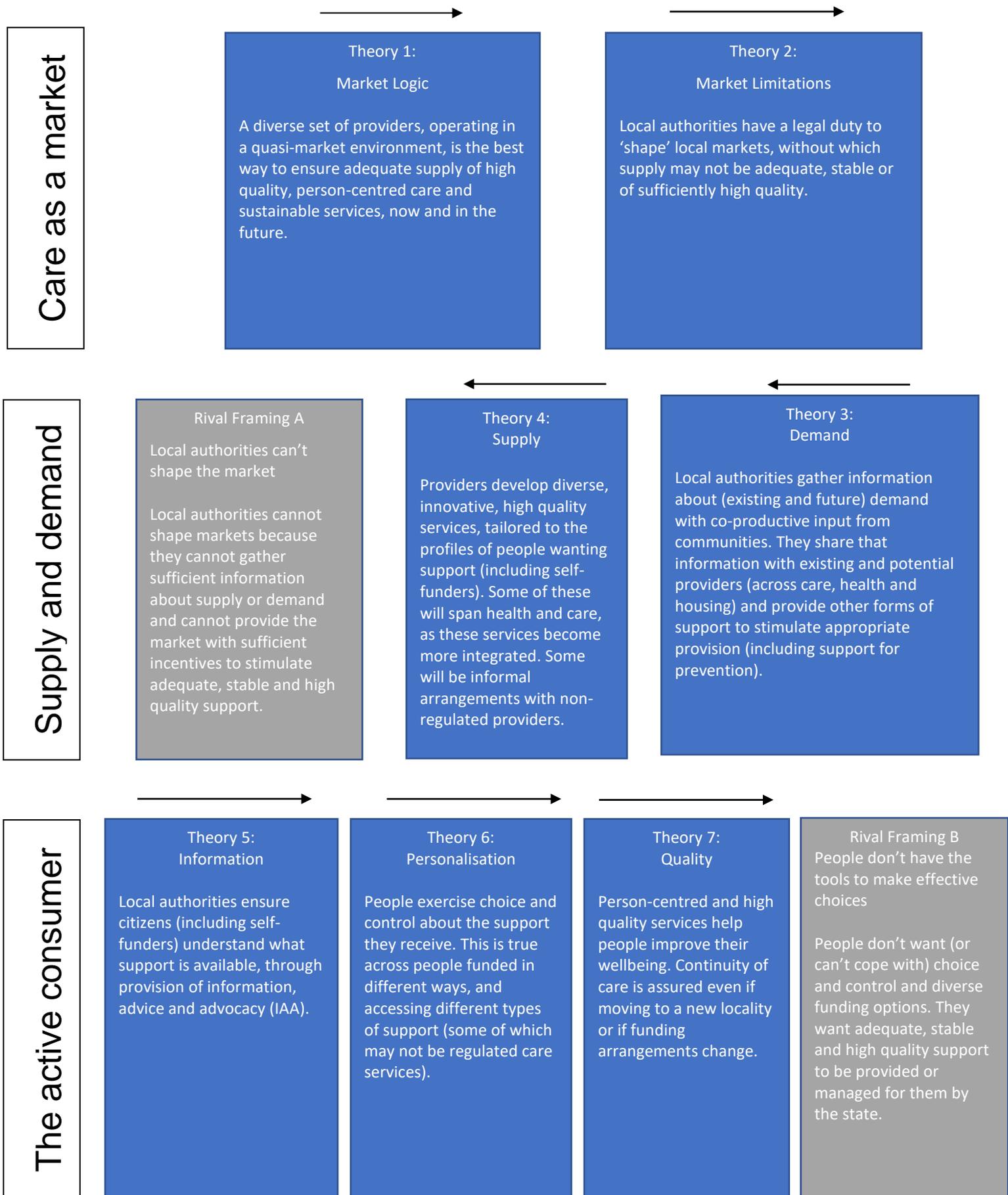
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This review is focused on developing and, where appropriate, testing the theory map developed by the broader *Shifting Shapes* project. Figure 2 below sets out the programme theory map for the whole project which links contextual factors to a set of mechanisms and planned outcomes. These programme theories are presented within three categories:

- **Care as a market:** what is the underpinning theory about the operation of quasi-markets in a care setting that supports market shaping and personalisation as intervention mechanisms?
- **Supply and demand:** what are local authorities expected to do to shape care markets and support personalisation and what is the expected response from providers?
- **The active consumer:** what assumptions about the behaviour of individuals and families using care services are embedded within the market shaping logic?

For the current paper, with its focus on self-funders, some aspects of the theory map are of more relevance than others. In particular, theories 2 and 6, and rival framings A and B are particularly significant. We explore these in greater detail in the sections that follow.

**Figure 2 A Programme Theory Map for Market Shaping and Personalisation**



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## Theory 2: Market Limitations

This theory focuses on the limits of markets within a social care setting, in which supply and demand may be misaligned, and the duty of local authorities (assigned by the Care Act) to 'shape' local care markets. The limitations of the market, without local authority involvement in shaping, are frequently expressed in terms of the exploitation of self-funders. Campbell, for example, draws attention to findings from work by Age UK (Lowe, 2016) highlighting the declining numbers of residential care beds which results in private funders facing a 'raw deal' and 'sharp practice' when attempting to negotiate fees (Campbell, 2016).

Growing numbers of older people face increasingly high care home fees to subsidise the lower fees paid by councils for those who cannot afford to pay, a leading charity has warned (2016).

Age UK described this situation whereby self-funders are effectively 'paying the price' for a failing care system. As Campbell highlights, the charity also pointed to the particular vulnerability of privately funded care home residents, especially at a time of shortages of supply, who lack security of tenure. Such insecurity can be expected to both constrain the ability to negotiate with the market, but also to limit residents' willingness to complain or object to the conditions they face. The Competition and Markets Authority (CMA) study into the care homes market has similarly drawn attention to the vulnerability of self-funders and their need for enhanced consumer protection (CMA, 2017).

The privatisation of social care provision has been developing rapidly over the past three decades, but as Hudson argues, there are widespread concerns both about quality and sustainability of supply:

The big private care providers are based upon such fragile and high-risk investment models (designed to maximise short-term financial returns) that they are at risk of market failure. There has already been one spectacular such failure – Southern Cross in 2011 – and a recent survey of local authorities reveals that most are expecting further failure in the coming year (Hudson, 2016).

Changing the nature of the market, and the experience of self-funders, has direct implications for the role of local authorities, and Hudson argues that the very qualities that are needed to manage change and shape markets have tended to be stripped out in 'reducing bureaucracy' and seeking savings during continued austerity pressures.

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Without the intervention of local authorities to shape the market, the limitations of supply and understanding of the customer base arguably impacts not only on actual and prospective self-funders, but also on providers. Baxter's (2016) reflections on the findings of a scoping review on self-funders and social care, for example, observe:

If providers, especially home care providers, are to diversify to meet the demands of the self-funding market, they need a thorough understanding of who their purchasers are, as well as the types of services they want to purchase. These services will not necessarily be the same as those commissioned by local authorities on behalf of personal budget users. (p.189)

In 2011 the House of Commons Committee of Public Accounts undertook an investigation of user choice and competition in care markets (Great Britain House of Commons Committee of Public Accounts, 2011). In addition to the responsibilities and duties of local authorities, the Committee argued that the Department of Health needs to have effective oversight of the care market to protect the interests of both social care users and of taxpayers:

The Department has nothing in place to oversee the market at the local level to avoid certain providers becoming too dominant in a region. It must specify what market share at the local level is acceptable, what arrangements will be made to keep market shares of large scale providers under review, and what additional powers it requires in case it needs to intervene to prevent a provider becoming dominant (p.5).

The Care Act was in part a response to this perceived failing with new requirements around local authority responsibilities for market shaping. However, the Act's focus on markets only at the level of individual local authorities means that there is still a gap around understanding and managing care markets within and between regions.

The National Audit Office (NAO) also investigated user choice and provider competition in care markets, drawing attention to the highly varied nature of the care sector which ranges from large national care home providers, to small businesses and sole traders (National Audit Office, 2011).

Market conditions are similarly varied, and range from areas where a single provider has a large market share which may extend well beyond the boundary of one single local authority, to areas where there is virtually no provision at all. The extent to which the Department and local authorities are actively engaged with remedying market problems and developing the provider side is, however, very mixed. (p.26)

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The 2017 CMA inquiry into residential and nursing care homes for older people was driven in part by widespread concerns that high fees for self-funders were cross-subsidising inadequate fees from local authorities for publicly funded residents (CMA, 2017). Indeed, their final report did find that this was the case: ‘on average a self-funding resident is paying over £12,000 a year more than an LA to have a place in the same care home’ (CMA, 2017, p. 40). The CMA noted that such practices were occurring despite the fact that providers acknowledged ‘that the costs of LA and self-funded residents are very similar’ (CMA, 2017, p.39). Whilst most homes continue to provide support to both publicly funded and self-funded clients, there is evidence that investment in new care home provision is increasingly targeted at self-funders rather than local authority-funded places (CMA, 2017, p. 100).

The sustainability of the care market depends critically on profitability for providers. However, the impact of pressure on local authority budgets and continuing austerity has had a polarising impact on the market, with wide-ranging implications. Analysis by the County Councils Network and LaingBuisson (2015) explores the issues and points to the consequences of councils using their bulk-buying power.

All of the major care home groups with high exposure to council funded residents have seen a continuing fall in operating profits as a percentage of revenue, over recent years while the profitability of care home groups focused on private pay has typically been increasing, stable or, at least, more stable. The growing level and extent of cross-subsidy is now unsustainable in many areas, and a direct consequence of insufficient funding for social care (p. 3)’

Data from 12 councils participating in the study indicated that self-funders typically pay a 40% premium for residential and nursing care, compared with the usual cost rate for care arranged and funded by local authorities.

The importance of self-funders to care market sustainability was underlined in the profitability analysis of the sector undertaken by the CMA. Thus, whilst overall the sector is ‘just able’ to cover its operating costs and capital, this is *not the case* for providers primarily serving state-funded residents.

Our analysis shows that while many can cover their day-to-day operating costs, they are not able to cover any additional investment costs. This means that while they might be able to stay in business in the near term, they will not be able to maintain and modernise facilities, and eventually will find themselves having to close, or move away from the LA-funded segment of the market. (CMA, 2017, p. 13).

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To the extent that the state of the market and its precarious sustainability are the result – at least in part - of Councils setting their fees for care homes too low, local authorities are arguably failing to address fully the requirements and implications of their market shaping role in relation to the whole of the local care market, and particularly in the longer term. This much has also been acknowledged in principle in the Government’s response to the CMA report (Department of Health & Social Care, 2018), which stated:

(...) care capacity should be planned to meet the needs of all service users, which in line with local authority market shaping duties means that local authorities pay a reasonable, sustainable rate to providers (para 2.4).

The Government’s response to the CMA further underlined that future care proposals will consider fundamental issues facing the care system, ‘including the future sustainability of the market, capacity planning and market shaping responsibilities’ (Department of Health & Social Care, 2018, para 2.9).

## Theory 6: Personalisation

Another theory from the broader programme theory map which has particular salience for self-funders is that which relates to the personalisation of care services. Exercising choice and control over the nature and manner of care and support is, as outlined previously, at the heart of the Care Act reforms intended to maximise individual independence and well-being. There is considerable consensus on the principles and aspirations of personalisation. A joint statement by the then Department of Health *et al.* (2010) commented that:

Giving people control of their own resources and determining how their needs are met is transforming social services. Services are being personalised. Many people will want to organise all their support and services themselves, based on good information. Others will want help from peers and user and carer-led organisations. However, many will want social work support to manage risks and benefits, and to build their self-esteem and aspirations, so that they can take control or make difficult decisions. (p.3)

Significantly, in considering the future role and contribution of social work to personalisation, the statement also suggested that the development of information, advice and advocacy, together with support planning and brokerage may mean:

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(...) new roles for social workers alongside services led by people using services and their families. This may include services for people who fund their own social care. (p.4)

It needs to be recognised that in the majority of local authorities, the proactive offer of support and care planning for self-funders would be completely revolutionary. The impact of the Fair Access to Care (FACS) eligibility framework (Department of Health, 2002) which allowed local authorities to set eligibility for care at one of four levels (Critical; Substantial; Moderate, and Low) encouraged inconsistent and arbitrary eligibility thresholds around the country. The role of the local authority effectively became one of gatekeeping, and determining simply whether or not a person could receive care and support. By contrast, the establishment of a national eligibility threshold was seen to represent a different model of assessment (Department of Health, 2013b):

The future system will place more emphasis on the role of the assessment process in supporting people to identify their needs, understand the options available to them, plan for meeting care needs and for caring responsibilities and reduce or delay needs where possible) (para 1.8).

Statutory guidance and regulations described the assessment and eligibility process as one of the most important elements of the care and support system, emphasising that decisions about eligibility should be made only after completion of assessment, and that similarly the assessment of financial means should *follow* the needs assessment and not affect the local authority's decision to carry out an assessment (Department of Health, 2014). Guidance for Health and Wellbeing Boards and Commissioners issued by OPM and SITRA (Miller, Bunnin, & Rayner, 2013) argued that commissioners:

should treat self-funding as another type of self-directed support, and aim to enable a social care market that works well for all. This should include enabling all who use social care (whether self-funded or state-funded) to contribute to shaping the market to better meet their own needs (p.5).

Support for people funding their own care and support might come from various sources; but the skills and abilities required are usually seen as ones that self-funders and their family members might struggle to muster for themselves. Hart (2014) has drawn attention to the disadvantages for self-funders unfamiliar with the care market, and contrasts the approach with the market management required:

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Relatives are commonly undertaking their own needs assessment, arranging care and making the purchasing decisions, while having little or no understanding of the care market. Given their lack of experience in care commissioning they are probably not the right people to do this, particularly at a time of crisis (Hart, 2014).

The Care Act envisaged that self-funders who had been assessed for care and had started the clock on their care account could choose (for a fee) to have help from the local authority in arranging their care. As we have outlined previously, the cross-subsidisation that typically occurs by charging self-funders a higher rate than is usually secured by local authority commissioners, could create some contradictory pressures. The Care Act offered the prospect of a different position for self-funders in which they were not simply left to their own devices, as has often been the experience to date. The delay in implementing part 2 of the Act means that at the present time the actual consequences for self-funders remain uncertain and largely untested.

However, some of the literature paints a more optimistic picture about the ability of self-funders to secure care of their choosing. For example a study (Mangano, 2016) found family carers demonstrated:

ability to gather and use information to select providers and negotiate with them; they have exerted (or are exerting) at least some degree of choice and do not feel that the support purchased (and for which their relatives or they themselves pay out-of-pocket) is the outcome of chance or someone else's decision (...) Study participants' ability to be active in the social care market sounds positive for the implementation of the arrangements envisaged by the Care Act 2014 (p.162).

This finding was based on a small number of interviews with family carers rather than people accessing services and stands in contrast to the wider literature which underlines the difficulties and bewilderment of self-funders attempting to navigate the care market (CMA, 2017; Henwood, 2009; Hudson & Henwood, 2009; Putting People First Social Care Consortium, 2011). However, the study intimates that choice could potentially be supported and would benefit from further exploration.

Other research evidence on the factors associated with greater personalisation in services have underlined the issue of scale. Needham *et al.* (2015) examined the role and contribution of micro-enterprises and found they were able to offer more personalised support than larger providers, particularly for home-based care. These organisations may be particularly important for people funding their own care and support:

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Micro-providers market themselves through word-of-mouth and local networks within the localities in which they operate, providing services for self-funders and people with direct payments. They struggle to get local authority referrals or to support people on managed personal budgets (p.21).

In addition to out-performing larger organisations, micro-providers were also judged to offer better value for money, and lower cost was not associated with lower quality service.

The reality of personalisation may have a different meaning when comparing care staff and people who use services. Thompson *et al.* (2015) explored the experience of nurses in care homes, and particularly the impact of multiple source care funding on their recruitment and retention:

Findings suggest that participants are uncomfortable with the business aspects that funding issues bring to their role. The primary difficulties faced are: tensions between care and funding; challenges associated with 'selling beds'; and coping with self-funding residents' changing expectations of care (p.171).

Moreover, study participants identified a disparity between the expectations of self-funding residents and those of care professionals regarding quality:

While participants value a service based on care, they felt that self-funding residents look for more tangible signs of quality (p.173).

Examples were given of residents wanting demonstrable quality in their environment, and:

Participants also suggested that self-funding residents and their families are preoccupied with staff availability and attentiveness (p.173).

Participants indicated that the expectations of self-funders had an impact on their relationship with care staff as they could 'become more demanding'. These findings are based on the reflections of a small number of respondents (thirteen nurses from seven nursing homes in the North East of England), and further investigation of perceptions and attitudes would be needed to explore how widespread these are in other settings and locations. However, it would be surprising if residents paying often very large sums of money for their care did not feel that they should have comfortable and pleasant surroundings, or that they should be entitled to a certain level of care. Thompson *et al.* (2015) observe that participants:

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perceive a tension between the culture of nursing which is based upon the provision of an equitable care service that promotes residents' independence and the expectation of residents to be provided with a tariff-related hospitality service. (p.175)

Other research has indicated that people paying for their own care are often unable to judge quality and tend to assume that higher cost is associated with higher quality. The CMA review, for example, found people unsure what questions to ask or how to judge the care homes available to them, and tended to make decisions 'based on look and feel' (CMA, 2017, para 9.48). It is unsurprising therefore that people paying for their own care would be particularly sensitive to what they perceive as poor quality either in terms of material surroundings or the level of service delivered.

A recurrent theme in much of the literature on personalisation concerns the scale and nature of the cultural change that will be required from local authorities and from providers if services are to offer genuine choice and control. Guidance on market shaping produced by the Institute of Public Care (Oxford Brookes University Institute of Public Care, 2016), for example, observes:

Commissioners concerned with shaping the market will want to work with providers to ensure that the needs of people who use services are matched by the supply of services. Those involved in the assessment, support planning and review process will need to take a strengths-based approach underpinned by good local knowledge. For some this will require a change in organisational culture.

And

Across the sector, there needs to be greater ambition to realise the benefits offered by personalisation. Offering people the same services, but just with different methods of payment, is not personalisation (p.2).

As the IPC also observe, the challenges that can come with shaping the market may be considerable and the increasing significance of individual purchasing is likely to reduce the purchasing power and ability of the local authority to negotiate on price, quality and level of service:

Transaction costs may increase as a result of the growing number of people purchasing their own care. All of these are transitional issues as the power dynamics shift away from local authorities towards people who use services and their carers (p.12).

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There is an assumption that individual purchasing (through direct payments) will be an empowering experience for people, without acknowledgment of the well-documented difficulties that self-funders experience when trying to use individual purchasing as a lever for market power, and typically finding they lack meaningful choices or negotiating opportunities.

Guides and briefings from SCIE (Social Care Institute for Excellence. Association of Directors of Adult Social Services. Department of, 2009) and Think Local Act Personal (TLAP) in partnership with Voluntary Organisations Disability Group (VODG) (Think Local Act Personal & Voluntary Organisations Disability Group, 2014) emphasise the challenges of making personalisation a reality, but also the benefits of doing so. There is a recognition that the interests of people funding their own care and those of people using personal budgets, will be similar and will 'often mean a need for innovative services which better respond to individuals' purchasing decisions' (SCIE *et al.*, 2009, p.2).

The changes brought by the Care Act aim to put self-funders on the radar of local authority commissioners, where they may have previously been absent. In part personalisation requires local authorities to address universal services for all residents within their area, and in relation to market shaping,

This means working collaboratively with partners and with providers to influence the health and wellbeing of communities and ensure better access to an improved range of services and supports for personal budget holders and self-funders (SCIE *et al.*, 2009, p.3).

Guidance from TLAP (2014) similarly addresses the requirements for 'making it real' for personal budgets and self-funding. The primary means for achieving this end and maximising choice and control are seen to reside in appropriate information and advice (which we explore more fully below).

### Rival Framing Theories

The programme theory map (shown on p.25) drew attention to two rival theories which challenge the scope for the theories to operate in the way that the map sets out. Rival Framing A is concerned with constraints on local authority market shaping; Rival Framing B addresses the limits faced by people – especially self-funders – who lack the necessary skills and resources to achieve choice and control. We turn now to explore these in greater detail.

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## Rival Framing A: Constraints on Local Authority Market Shaping

The concerns over risks of market failure and provider collapse have been explored under 'market limitations' above, however, the constraints on market shaping are wider than this. Of central importance is the overall shortfall in funding for social care. The crisis in funding became increasingly apparent during 2016/17, and culminated in the March 2017 budget with the Chancellor committing an extra £2 billion of funding spread over three years, with half available in 2017/18. However, pressures on funding and rising demands on social care provision continue to dominate the discourse. The Association of Directors of Adult Social Services, for example issued a statement highlighting the ongoing challenges:

ADASS has repeatedly warned government that funding reductions in social care would lead to fewer people getting less care, provider failure, and would impact on the NHS. It is equally the case that much needed investment in prevention, digital technology and wellbeing services is taking place against a back-drop of years of cuts to adult social care and wider council services. This represents a vicious spiral (ADASS, 2018, p. 7).

ADASS stated that "at least £2bn is needed by 2020 just to stabilize the market and to enable key statutory responsibilities to be fulfilled", and it is this apparent scale of underfunding which dominates any discussion of the social care market. 'Key principles' of the future of care outlined by the Secretary of State include recognition of the need for a sustainable funding model, 'supported by a diverse, vibrant and stable market' (Hunt, 2018).

The current debate is often dominated by a sense of crisis, but the enduring nature of the challenges to be addressed around securing a sustainable model of funding social care is likely to mean that the issues will continue to be major concerns for any government in both the short and longer term.

### Market Oversight and Understanding Self-funders

A further constraint on local authorities' market shaping activity is the relative absence of meaningful market oversight. The National Audit Office (NAO) (2011) has explored the importance of building market oversight capability, and the need to deal with potential market or provider failure. This has implications both for local authorities, but also for the Department of Health and Social Care, and the NAO comments that both:

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need to know what a successful market looks like, have a strategy for monitoring the care market against this (including knowledge of self-funders), and for intervening, where necessary, to make sure outcomes are delivered and users' and public funds are used efficiently. (p.28)

Although the NAO investigation is a few years old, and pre-dates the Care Act, the conclusions of the analysis and the importance of market oversight are of continuing relevance and importance. Hudson (2016, p 16) observes that the direction of policy has largely been an attempt to regulate the market, 'rather than shape, or reshape it'. Proposals in the CMA (2017) report on care homes that the CQC should be given a role in relation to the oversight of local authority commissioning were not picked up in the Government's response, although more guidance on this may be forthcoming (Department of Health & Social Care, 2018).

Central to poor market oversight is the lack of detailed knowledge of self-funders' characteristics and requirements. Local authorities' inadequate understanding and information about the numbers and needs of self-funders reflects their failure – for the most part – to engage with this part of their population. A toolkit developed by IPC (2015) on understanding the self-funding market was aimed at addressing precisely these inadequacies that prevent local authorities shaping local markets and supporting self-funders. The state of knowledge about what care and support self-funders purchase and why is also poor. Baxter (2016) for example, reports that very little is known about self-funders: '...local councils are often not aware how many people fund their own home care or residential care in their areas' (p.187).

This lack of awareness and understanding of self-funders by many councils can have significant consequences. Ensuring that self-funders are able to make the best choices for their needs and personal situations matters not only at the level of the individual, but also from the local authority's perspective. If people make poor choices, particularly in terms of financial planning, they are more likely to run out of money faster and to fall back on local authority support. Indeed, the first that local authorities know of the existence of self-funders is often when they are notified by care homes that a resident can no longer pay their fees (by which time they will have spent below the threshold at which they would qualify for help).

Analysis by the Local Government Information Unit (LGIU) has highlighted the 'potential financial liability' which self-funders represent for local authorities (Carr-West & Thraves, 2011; Carr-West & Thraves, 2013). Awareness of the risks appears to have increased: in 2011 only 39 per cent of local authority respondents knew how many self-funders in their area fell back on state funding, but this had apparently risen to 59 per cent of councils by

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2013 (Carr-West & Thraves, 2013). It is estimated that around a quarter of self-funders do indeed run out of money and require local authority support, and clearly this represents a significant financial risk for councils (at a cost of £425m in 2011-12 in England, for example).

Analysis of local authority readiness for part 1 of the Care Act by the NAO drew attention to findings from the 'stocktake' exercises undertaken by the then Department of Health together with the Local Government Association, and Association of Directors of Adult Services (National Audit Office, 2015). The stocktakes found local authorities increasingly identified uncertainty about demands from self-funders (and from carers) 'as the greatest risks to implementation' (p.19). The NAO (2015) commented that demand from self-funders is uncertain, particularly from those in the community; while the uncertainty and lack of detailed research on the self-funder population which characterises most local councils, is also true nationally.

The then Department of Health based its own estimates on existing research and survey data and did not undertake any further primary research. Guidance to local authorities suggested that where no better data exists locally, councils should assume that the number of self-funders using homecare is the same proportion as those in residential care. The NAO (2015, p. 28) found that more than half of councils who provided estimates (54%) adopted this assumption. As we highlighted in part 1 of this paper, this is likely to be a highly conservative assumption as the latest figures on people paying for care suggest the numbers paying for care at home are considerably higher than those paying for residential care.

Another survey of local authorities undertaken in 2016 found more than a quarter (27 per cent) reporting 'insufficient data about whether the supply of social care in their area could meet demand' (Cameron, 2016). The survey found variable market awareness and understanding, with some local authorities doing better than others in trying to find out more about local market conditions and self-funder behaviour. Clearly, many local authorities are uncertain how best to collect the necessary information:

Many respondents acknowledged that their understanding of the self-funded market was particularly low, and explained that this was due to a lack of time and resources available to gather information. Some councils pointed out that because self-funders pay for their care privately, normally without any involvement from their local authority, providers are under no obligation to share their data, and are often reluctant to do so (Cameron, 2016, p.20).

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## Cap on Care Costs and Market Impact

The shelving of implementation of part 2 of the Care Act has left considerable uncertainty about future arrangements for self-funders. It is highly likely in the future that there will be some variant of a cap on care costs and shared responsibility for funding between the state and individuals. Indeed, the previous Secretary of State alluded to the difficulties of achieving a sustainable funding system and the implications for 'the debate we need to have with the public on the challenges of sourcing additional social care funding' (Hunt, 2018). Any changes in the model of support for self-funders could bring profound changes to the care market. Analysis indicates that growing polarisation of the market is apparent:

with many providers focusing almost exclusively on the self-funder market. This is resulting in a shortage of places for council placements and fee levels that increasingly councils cannot afford. (County Council Network and LaingBuisson 2015, p.3)

That analysis argued that in future it was likely that the Care Act would create a series of ramifications within the care market, in particular:

- Self-funder fees would fall to some extent because of increased transparency associated with care accounts (which would see self-funders informed about the usual cost rate paid by their local council). This would be likely to affect behaviour and encourage self-funders to ask the council to arrange their care or could give self-funders greater leverage to negotiate fees. This, in turn, 'could have a severe negative impact on the profitability of providers' (p.4).
- At the same time, polarisation between publicly and privately funded care would be likely to increase, weakening councils' position and necessitating them paying higher fees 'to sustain a functioning market and prevent provider exits' (p.4).
- Local councils and NHS partners would find it increasingly difficult to arrange care at market discounts, or at all. This would increase costs but could also lead to further increases in delayed hospital discharges, with consequent pressure on acute hospital services.

This scenario indicates the complexity of the environment of social care provision and the relative inability of local authorities to shape the market when supply is short and demand

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high. The reliance on cross-subsidisation from self-funders has been crucial both to provider sustainability and to councils being able to continue to pay below market rates for care.

The analysis is also reinforced by other commentary (Lloyd & Independent Age, 2013), for example also explored cross-subsidisation in the residential care market, and pointed to future risks that councils 'will be strongly incentivised' (p. 14) to reduce their usual cost rate to the minimum possible which will force self-funders who become eligible for council support nonetheless to use 'top ups' from their own resources. Allan *et al.*'s (2017) study of the differences in residential care fees between local authority funded places and self-funders suggests that those local authorities with the greatest 'market power' have the largest differences. Market power refers to the extent to which the terms on which care and support are purchased can be influenced and is theorised by Allan *et al.* (2017) to have both demand and supply aspects. In terms of demand, this is related to the number of local authority funded residents as care home providers will be more dependent on the local authority. In terms of supply, the more providers that operate in an area will increase competition and theoretically allow local authorities to drive down costs (Allan *et al.*, 2017, p. 5-6).

As we have pointed out previously, the shortfall in funding for local authorities was one of the main justifications for delaying implementation of part 2 of the Care Act, and indeed was the focus of lobbying by the Local Government Association (LGA), among others (Local Government Association, 2015). While arguing that this did not signal a reduction in the support of the LGA for the Care Act reforms, it reflected a growing concern that the reforms could not be implemented when the current system was under-funded and on 'such an unstable foundation' (p. 1).

If we are faced with a choice between reforms and system sustainability we must prioritise the latter. Continuing with the cap on care, without funding for mainstream social care, risks putting even more pressure on a system which might then fail to deliver the care that people need, risking the quality and safety of services which millions of people rely on every day (Local Government Association, 2015, p.2).

The significance of this rival framing (which highlights the limits of local authority market shaping), and its prevalence within the literature, points to the concerns and challenges around the constraints on local authorities. Lack of information or knowledge of both demand and supply factors is critical, and so too are the financial difficulties around historic and continuing under-funding. Frequently, the literature provided an appraisal as to how well local authorities are able to respond to the demands of market-shaping, in addition to exploring how providers have been affected by constraints on local authority budgets.

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However, gaps in knowledge were also indicated. As Baxter (2016) commented in reviewing the literature, 'we found no evidence about the impacts on self-funders of market-shaping and commissioning' (p.188). At the same time, however, cross-subsidization has been (and continues to be) a critical factor in shaping markets.

As the literature demonstrates, many of the problems with the market have been hidden or deflected by the existence of self-funders who have effectively (and usually unknowingly) subsidised council funded care. Hence, as the title of this report emphasises, self-funders are not passive bystanders on the periphery of local authority market shaping, but a key influence on the shape and viability of the local care market; self-funders are arguably continuing to bear the consequences of wider under-funding. The impact of any alternative model will need to be assessed not only in terms of the fairness for individuals and sustainability in the long term, but also for the potentially unforeseen consequences in further destabilising the care market.

We turn now to consider rival framing B, which emerged as the most frequently identified theme across the theory map, and which again offers a perspective that challenges the core objectives of market shaping and personalisation embedded in the Care Act.

### **Rival Framing B: Lack of Tools to make Effective Choices**

As we have explored above, access to information, advice and advocacy (IAA) is key to the achievement of personalisation (theory 6); conversely, shortcomings in IAA threaten to undermine the exercise of choice and control and to constrain the delivery of personalisation.

This was the most frequently identified theme in mapping the theories across the literature. However, there is considerable repetition and cross-referencing in the literature and the key issues explored in more depth through analysis or research were relatively few. The main dimensions are examined in greater depth below.

### **Choice in the Social Care Market**

As the literature demonstrates, critical analysis of the particular difficulties confronting self-funders in the social care market have highlighted the problems for people not knowing where to turn for help, or indeed the nature of information and advice that they might require. The operation of a market is typically characterised as people understanding their own requirements and preferences, and consumer power is associated with efficiency, choice

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and quality, or what has been termed the 'voice, choice and exit' framework (Farrell, 2010). In exploring the meaning of choice in elective health care, Exworthy and Peckham (2006) observe that:

The exercise of choice by patients is mediated by knowledge, resources, family circumstances, residential location and the availability of alternative providers. (p.268)

Very similar issues can be identified in respect of choice in the social care market. Baxter and Glendinning's scoping review of self-funders found evidence less of well-informed consumers choosing to buy care that best meets their requirements, than of uncertainty and lack of meaningful choice (Baxter & Glendinning, 2014):

Self-funders often approached their local authorities as the first point of contact for advice but could feel disadvantaged by their perceived unwillingness to help. (p.i)

Miller *et al.* (2013) point out that evidence indicates few people plan ahead and many therefore make decisions at times of crisis.

This can lead to a lack of consideration of alternative options and premature use of residential and nursing home care. Pressure on hospital beds and lack of access to re-ablement can mean that many people, who could, with additional support, continue to live in their own homes, end up in residential or nursing home care instead. This can lead to a loss of independence and self-funders paying for more expensive types of care than they actually need (p. 17).

Henwood & Hudson's (2008) analysis of the position of self-funders in respect of eligibility criteria for social care in 2008 identified the relative invisibility of self-funders, and the limited response to their needs which was typically expressed in 'signposting' to other (mainly third sector) sources of information. The question of offering assessment of needs to people who were self-funding was rarely raised, and the study found people 'steered towards residential care with haste and before other options had been explored' (p.8). Once self-funders were admitted to a care home, lack of on-going contact or review by local authorities was also the norm.

It might be thought that people in a position to fund their own care and support will have the greatest choice and control available, but Henwood and Hudson (2008) remarked:

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In practice, the study found that self-funding people on the contrary were often the most disadvantaged and isolated in the whole system. Rather than making active choices, many appear to end up in their situations as a matter of chance (p.9)

### Information, Advice and Advocacy

Additional analysis provided further insight to the issues around IAA, and underlined that despite some improvements, practice in the provision of IAA was highly variable, information was often written for professional rather than lay audiences, and people's specific needs 'require more than just an information bank' (Hudson & Henwood, 2009), and the advice and advocacy components of IAA are more often absent. More recently, consumer research carried out by CMA as part of their care homes market study 'found that people felt that the support and advice provided by LAs can be both variable and limited' (CMA, 2017, p.123).

Exploration by Henwood of the journeys made by self-funders also found that experience of signposting was rarely positive (Putting People First Social Care Consortium, 2011), and typically involved being 'passed from pillar to post' (p.48). The lack of guidance available for people undertaking 'journeys without maps' had profound consequences for self-funders:

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 (...) 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 (p.50).

The Care Quality Commission (2009) has acknowledged that 'people who pay for their own care are often poorly served', often being left to their own devices and not knowing where to go for information or advice at a time of pressure or stress and when making life-changing decisions. While acknowledging that there is good practice in some councils, CQC comments that this is 'sporadic' rather than universal, and needs to change. The CMA consumer research indicates little apparent change or improvement has been achieved in recent years; many people were unaware of the information and advice available to them, or felt that what was available was limited:

The research also found that many self-funders stopped communicating with LA social services once they realised that they were not eligible for funding (and that

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they thought social workers stopped communicating with them at this point too).  
(CMA, 2017, p.126)

In addition to information and advice about care and support options that might be available and how to access them, self-funders need independent financial advice if they are to make the best choices and to make best use of their resources. As we explored earlier, local authorities also have an interest in ensuring such advice is available because of the implications of people depleting their savings and falling back on state funding. Evidence from the Local Government Information Unit indicates that information and advice is often not provided at the right time, is not sufficiently tailored to the needs of self-funders, and council information often does not signpost people to independent financial advice (Carr-West & Thraves, 2011). In 2013 the LGIU observed that some local authorities had made significant improvements in financial information and advice services available to self-funders, but there was still a long way to go (Carr-West & Thraves, 2013). Improving such support is seen to make sense both for self-funders, *and* for councils, as they argue:

Improved access to independent financial information and advice can help older people remain in a care setting of their choice, and local government to reduce the £425m cost in England of people who fund their own residential care and fall back on state funding. Improved support for self-funders helps older people to live out their lives in a manner of their choosing. To achieve this, while saving money, is an opportunity that councils should seize (p.7).

Financial advice for people who are self-funding is not only about financial products and planning, but also support in understanding and negotiating care contracts, as Hart (2014) points out, for example, when people are entering residential care:

The professional support provided at this time usually consists of information and advice, not the commercial elements of purchasing care, such as securing a good price on the placement. People often believe high costs mean high quality. And once the placement is made, self-funders and their relatives often feel trapped financially with little or no commercial leverage. It is common to see contracts signed enabling the provider to increase fees between 7 and 9 per cent a year (Hart, 2014).

The findings from the CMA care homes market study further reinforced conclusions on the difficult circumstances in which people make choices about entering permanent residential care, particularly when those decisions are made under time pressure and with no previous experience (CMA, 2017). Not only is care typically a distress purchase, but it is often made with insufficient knowledge or understanding of costs. The CMA found most provider

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websites, for example, failed to provide any indication of the weekly fees charged to self-funders, or to set out additional costs such as deposits and upfront payments, or charges for 'extras' which people may have thought would be included. This lack of transparency makes it more difficult for self-funders to compare the real costs of different homes, and leads to people making choices they may not have done with full information available to them.

It is rare for people to choose to move homes once they are resident, not least because of the upheaval and distress involved. But this exposes self-funders to additional vulnerability:

This means residents are potentially susceptible to price rises and changes in service once they have lived in a home for some time, and are less able to do anything in response. There may also be less willingness to challenge the care home over potentially unfair contracts and practices. The personal impact on residents if a care home asks them to leave can also be much greater than in other markets because of the stress and potential health effects on them. (CMA, 2017, para 11.2)

The additional work required from councils to deliver their responsibilities to self-funders may be considerable, not least with 'hard to reach' parts of the self-funder population. Research has found, for example, that one of the reasons people become self-funding, and often do so without approaching the local authority, is because they don't want to share information about their financial circumstances or prefer to manage their affairs privately (Baxter, 2016; Putting People First Social Care Consortium, 2011).

Another important, but under-explored, dimension of information and advice for people funding their own care arises in respect of those who are employers of support workers. Ekosgen and Breakthrough UK (2013) point out that relevant information tends to be targeted at Direct Payments recipients rather than self-funders, 'despite the fact that the issues, decisions and challenges that they face will in many cases be very similar' (p. 43).

It is important to point out that the majority of the literature reflecting Rival Framing B (lack of tools to make effective choices) was written either before the Care Act, or in the immediate aftermath, and to a certain extent it might be argued therefore that the empirical literature reviewed is indicative of the issues and concerns that the Care Act was intended to remedy. The extent to which the situation has changed is uncertain although the latest findings from the CMA have once again emphasised familiar concerns and issues. Furthermore, the delays in full implementation of the Care Act (i.e. the provisions that relate particularly to self-funders), mean that the position of self-funders is far from resolved. Indeed, it is highly likely that the delays have reduced the pressure to address these long-standing issues that have been demonstrated in the literature and to ensure adequate information, advice and

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advocacy are available to all self-funders. The leverage that would have been provided by the need to establish care accounts, and the incentives for self-funders to make themselves known to their council to trigger their account, have been removed, at least for the time being. Far from being able to exercise real choice and control, it is likely that most self-funders continue to be stuck in a limbo where their options are often limited and a matter of happenstance rather than design.

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## Conclusions

This paper has combined quantitative data analysis with a realist review of the literature to build understanding of the levels of self-funding and the issues facing self-funders within the wider context of understanding market shaping requirements. As we have commented, the data presented here, from the most recent wave of the UKHLS, produces somewhat higher estimates of numbers of self-funders than past surveys, but has a reliable sample base and draws on long experience on how to ask questions concerning social care. Data from local authorities also tends to be at the top end of previous estimates, and is likely to underestimate the true extent of self-paying. Not all local authorities were able to provide an estimate of the number of self-funders within their area and this further demonstrates that little is known about how many people pay for care and the type of support they receive. The partial implementation of the Care Act and the rescinding of the introduction of care accounts means that uncertainty as to the number of people self-funding their care is likely to remain.

The realist review of the literature was undertaken to focus on the self-funder aspects of market shaping and personalisation. It is important to understand that the theory map is not linear, and the theories are not mutually exclusive; different aspects of theories may apply at different times, and particularly components of theories emerge in various contexts. However, the 'rival framing' theories generally offer a counterpoint that challenges the theory of how market shaping is supposed to operate. It is these rival framings that are most prevalent in the self-funder literature and which underline the limits of market shaping and personalisation impacting on self-funders.

There are two key caveats that need to be stressed, and which have been alluded to earlier in the analysis. First, a great deal of the literature identified pre-dates the 2014 Care Act, or was produced soon after; moreover, the delay in implementing part 2 of the Act necessarily means that analysis is more likely to be biased towards more critical or rival framings. Second, and related to this, the majority of the literature develops the theories rather than actively tests them. Indeed, in exploring the literature, it was difficult to identify examples of analysis that tested the theories; and only 15 of the 85 literature items were seen to do so through empirical exploration. Even these examples were largely concerned with pre-Care Act parameters, or with the first phase reforms of the Act.

As Pawson *et al.* (2005) explored in developing a realist review methodology:

Realist review does not provide simple answers to complex questions. It will not tell policy-makers or managers whether something works or not, but it will provide the policy and practice community with the kind of rich, detailed and highly practical

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understanding of complex social interventions which is likely to be of much more use to them when planning and implementing programmes at a national, regional or local level (S1:21).

The analysis of the literature around self-funders and adult social care undertaken for this report has provided particular insight to the explanatory context around the implementation of the Care Act, and the implications for people funding their own care. Identifying and understanding specific mechanisms and outcomes has been more limited and constrained for the reasons outlined above. The review has also – unlike many other realist reviews – not been concerned with a specific intervention or service delivery model, but with a much wider and more fundamental shift in the model of adult social care. Because of changes in the timetable for implementing the Act, we are – at this time – unable to answer the central question of whether local authorities’ responsibilities for market shaping are successfully delivering enhanced personalisation, choice and control for people funding their own care. What the scrutiny of the literature *does* reveal are the multiple challenges and obstacles to this transformation, and the inherent contradictions and tensions in the role and responsibilities of local authorities in implementing the Care Act. In particular, in seeking to manage the market, and to implement the capped cost model of care, the market is likely to become destabilised and the monopsony power of councils considerably reduced.

The literature has also provided detailed understanding of the situation of self-funders and the problems they face in securing personalised care and support for themselves. A key test for the implementation of the Care Act is whether future analyses will indicate the experience of self-funders is qualitatively different and better. How this can be judged, and the specific questions that need to be asked, have been significantly informed by this review and its consideration of the theory map. Locating the situation of self-funders within the wider context of the logic and limitations of the care market has advanced our understanding of self-funders and their experience.

Going forward, the challenge for both research and practice is now to consider what market shaping and personalisation objectives and outcomes will look like in a context in which the Care Act is only partially implemented. It is inevitable that uncertainty about the next steps will cause some blight to local progress and preparations, but the wider question is whether, regardless of what happens politically, and what decisions are made about personal responsibility for funding care in old age in particular, self-funders can continue to be treated as bystanders in the social care market? What is obvious is that the presence of self-funders shapes and re-shapes the social care market in ways which have a profound impact. They can no longer be seen as incidental to the operation of adult social care, but as integral to it.

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## Appendix 1: Self-funder literature

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## Appendix 2: Technical details

### Key variables used in quantitative analysis

#### UKHLS (*'Understanding Society'*) wave 7.

The scope of the questions extends to this set of possible provision (from Socialcare\_w7.Scpaycodea/b):

- 11 the home care worker, home help or personal assistant
- 12 the member of the reablement or intermediate care staff team
- 13 the occupational therapist, physiotherapist or nurse
- 14 the voluntary helper
- 15 the warden or sheltered housing manager
- 16 the cleaner
- 17 the council's handyman
- 18 the other help you receive

Sample selected where g\_dvage >= 65 (people aged 65 and over) and where g\_ivfio == 1 (full interview conducted with respondent).

Results weighted by g\_indinub\_xw (cross-sectional adult main interview weight).

Dependent variable PAY4CARE derived as:

```
generate PAY4CARE = 0
replace PAY4CARE =1 if (g_anypaya==1 & g_howpaya1==1) | (g_anypayb==1 &
g_howpayb1==1)
```

#### Health Survey for England 2014

Sample selected where Age35g >= 17 (aged 65+).

Results weighted by wt\_int (HSE 2015 Weight for analysis of core interview sample).

\* Some element of self-funding.

```
generate selfFund = -8
replace selfFund =1 if anypay == 1
replace selfFund =2 if anypay2 == 1
replace selfFund =3 if (anypay == 1 & anypay2 == 1)
label variable selfFund "Whether paying for some element of care"
label define selfFund -8 "Others aged 65+" 1 "Paying for LA care" 2 "Paying for other care" 3
"Paying for LA & other care"
label values selfFund selfFund
```

The full files, which are SPSS format, are available for download at: <https://osf.io/k9v3q/>.

Logistic regression analysis of those who self-fund (UKHLS wave 7)

The Table below presents the key coefficients from a logistic regression analysis with a number of key variables included.

	B	Sig.	Exp(B)
<b>Country</b>		.095	
Wales	-.104	.639	.901
*Scotland	-.416	.043	.660
Northern Ireland	-.577	.117	.561
<b>Age group</b>		.000	
**70-74	.581	.001	1.788
**75-79	.906	.000	2.474
**80+	1.675	.000	5.337
<b>Housing tenure</b>		.307	
Owned with mortgage	.186	.441	1.204
Local authority rent	-.125	.347	.883
Private rented	.263	.193	1.301
<b>**Male</b>	-.472	.000	.624
Rural areas	-.121	.286	.886
<b>**Single adult</b>	.679	.000	1.971
Constant	-3.677	.000	.025

Note \* p<0.05; \*\* p<0.01.