

Self-funders: Still By-Standers in the English Social Care Market?

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The Care Act 2014 gave local authorities in England broad duties around wellbeing, and responsibility to ensure the availability of good quality, personalised social care and support services for people who need them. These responsibilities are for all people needing support, whether that is publicly or privately funded. In exercising their duties, councils have a responsibility for ‘market-shaping’: that is, understanding the supply and demand for care, and the types of services and support needed now and in the future, and steering the market accordingly. Changes to the implementation of the Care Act removed some of the levers that might have brought self-funders into the mainstream of local authority responsibilities. This article draws on sixty-four qualitative interviews undertaken as part of a larger study on market-shaping and personalisation of care, and reflects on the experience of self-funders and the approach to them adopted by local authorities and provider organisations. The findings indicate that self-funders are still largely bystanders to local authority market shaping strategies, despite being both impacted by those strategies and significantly influencing the markets in which they operate.

Keywords: Self-funders, personalisation, market-shaping.

Introduction

Throughout the developed world, many countries are struggling with how best to respond to ageing populations and to fund and provide vital care and support services both in the community and in residential settings (practical assistance – with activities of daily living such as washing, dressing, toileting, getting up and going to bed, preparing food and eating – for older people, disabled people, people with mental health problems and people with learning difficulties). These debates have been particularly controversial and unresolved in England, where successive governments have pledged to reform the funding of adult social care, but so far failed to deliver (Henwood, 2019). This is despite the passage of the Care Act 2014, which consolidated previous legislation into an overarching statute, made the promotion of well-being a central principle, and required local

authorities to ensure the availability of a wide variety of good quality, person-centred care and support services for people needing them. The continued challenge of how to pay for care without catastrophic costs falling on individuals was a major issue of contention in the 2019 General Election, as it had also been in 2017 (Henwood, 2019).

The Shifting Shapes NIHR-funded research project at the University of Birmingham focused on English local authority responses to their duty under the Care Act to shape local care markets, and on the requirement as part of their well-being duty to support people to make meaningful choices and to take control of their support arrangements (usually referred to as 'personalisation'). This article draws on findings from fieldwork in eight case study sites and reflects particularly on the important sub-theme of how these responsibilities are being interpreted in respect of self-funders (i.e., people paying the costs of their own social care). The statutory guidance on the Care Act (Department of Health, 2014) was clear that the responsibilities of local authorities for market-shaping were wider than their commissioning role and

[the] ambition is for local authorities to influence and drive the pace of change for their whole market, leading to a sustainable and diverse range of care and support providers, continuously improving quality and choice, and delivering better, innovative and cost-effective outcomes that promote the wellbeing of people who need care and support. (Department of Health, 2014: para. 4.2)

In addition to services arranged and paid for by the local authority itself, the guidance included responsibility for market-shaping around services paid for by direct payments and 'services arranged and paid for by individuals from whatever sources (sometimes called 'self-funders')' (para. 4.5).

The levers to drive this greater engagement with self-funders were in part contained in the new responsibilities that the Care Act would have introduced for local authorities to establish a 'care account' for everyone paying for their own care in order to monitor their progress towards the 'capped cost' contribution of meeting their eligible needs. For the first time, many self-funders would have an incentive to approach their council in order to establish a 'care account', and for local authorities this would require far greater engagement with the self-funding population than was typically the case prior to the Care Act. However, this significant part of the Care Act was postponed from the planned implementation date of 1 April 2016, and remains in abeyance.

Our analysis indicated that the Care Act has so far had limited impact on market-shaping at local level (Needham *et al.*, 2018). The second stage of the project explored market-shaping in greater depth by working in eight case study sites. Our full findings and conclusions are reported elsewhere (Needham *et al.*, 2020), but here we focus particularly on what the case studies revealed around local authority understanding of and engagement with self-funders, and how they are considered within local market shaping and commissioning strategies for adult social care. Ensuring the needs of self-funders are reflected in market-shaping strategies is important as, without this, self-funders face more restricted choices depending on the range and type of providers those strategies support and develop.

Background and context on self-funders

Responsibility for publicly funded adult social care in England resides with local councils, but access to such support is limited both by eligibility criteria (based on levels of assessed

need), and individuals' financial assets and means. The impact of austerity on public spending has been reflected in restricted access to social care, as the Care Quality Commission (CQC) acknowledges in its annual report on the state of care (Care Quality Commission, 2019), and this is compounded by instability of the social care market with residential and nursing home beds falling, and staff churn continuing. The Institute for Fiscal Studies has estimated that overall local authority spending on adult social care fell by 5 per cent from 2009/10 to 2017/18 (Institute for Fiscal Studies, 2019), and funding pressures are repeatedly identified by the Local Government Association, and Association of Directors of Adult Social Services (ADASS). The annual budget survey by ADASS in 2019 (ADASS, 2019) concluded:

There is now widespread agreement that the current situation is not sustainable. This year directors have continued to grapple with the same challenges of rising costs, increasingly complex needs, a fragile provider market and constraints on their ability to invest in prevention. (p.35)

It is against this background that councils attempt to shape local care markets and meet their statutory social care responsibilities. People whose financial assets put them over the threshold for local authority support (currently savings of £23,250, plus the value of owner-occupied housing for people seeking permanent residential care but not for domiciliary care) will usually need to make their own care arrangements. A two-tier system of care exists between publicly and privately-funded people, with the latter largely left to find their own way and pay higher fees for the same care. Although people with greater private purchasing power may have more choices and higher quality services available to them (at a price), we argue that they are also relatively disadvantaged and unsupported in the system lacking the leverage available to local authority commissioners, or the knowledge of how to navigate the market.

Knowledge and empirical understanding of self-funders in adult social care is limited. Although the situation of self-funders has attracted increasing interest and debate over the past two decades, they remain largely invisible. Data about the numbers of people paying for care are imprecise and based on a range of estimates, with considerable variation. Our analysis of the most recent data from an FOI request of local authorities suggests there are 350,000 people in England paying for care in their own homes or in residential care, representing around 35 per cent of all people using adult social care (Henwood *et al.*, 2018).

The literature on self-funders is relatively sparse and – for the most part – non-empirical. In our initial review we identified eighty-five items of literature, but most of these were descriptive and analytical rather than evaluative; only fifteen were empirical in nature and only ten of these had been peer reviewed (Henwood *et al.*, 2018). Such evidence as there is largely pre-dates the Care Act and provides a critical reflection of the challenges facing self-funders in trying to navigate social care (Henwood and Hudson, 2008; Putting People First Social Care Consortium, 2011; Baxter and Glendinning, 2015; Baxter, 2016).

A recent study of people's experiences of finding information about self-funded care is typical in reporting challenges for self-funders seeking care (Baxter *et al.*, 2020):

Older self-funders and those looking for care on their behalf feel relatively unsupported in seeking information and making choices about care. Social capital, in the form of personal experience and discussions with family and friends were key. (p. 470)

As the authors commented, the findings echo those of other research ‘*that suggests an underlying assumption that financial assets and capacity to arrange care are related*’ (p. 471), and that self-funders are therefore typically left to sort out their own arrangements with little information or advice to guide them.

The literature points to challenges and tensions in achieving transformation of care and support, and particularly highlights the limited market oversight of local authorities in lacking sufficient knowledge of the numbers and requirements of self-funders, and how this might impact on market supply (National Audit Office, 2015). In addition, the care market – particularly residential care – is increasingly polarised, with providers targeting the higher paying self-funders rather than local authority funded residents. The cross-subsidisation by self-funders has been vital to provider sustainability and has enabled councils to continue paying below market rates (County Councils Network and Laing and Buisson, 2015).

Methods

Ethical approval was granted by the NHS Research Ethics Committee (17/LO/1729). The Association of Directors of Adult Social Services (ADASS) also gave approval for the research (RG17-05), and we received research governance approval in our local case sites. The first stage of the overall project considered the context of social care market-shaping and personalisation at a national level via interviews with twenty-eight senior leaders of key national organisations and opinion formers in the care sector and an online questionnaire administered to 152 local authorities in England with primary social care responsibilities (Needham *et al.*, 2018).

In the second stage of the project, eight case study sites were selected to provide diversity across relevant variables including care outcomes, the estimated proportion of self-funders in each site, type of council, geographical spread and political control. In total across the case study sites, the research team interviewed, via telephone or face-to-face, or ran focus groups with 438 people. These encompassed local authority commissioners and care managers, other local stakeholders (e.g., from health or the voluntary sector), providers, people using services and families. Participants were recruited through snowball sampling, using the local authority to recommend providers and providers to recommend users and carers. All interviews were digitally recorded, fully transcribed and analysed in QSR-NVivo 11, using a two-stage thematic coding process (Attride-Stirling, 2001).

A report of the full project findings is available elsewhere (Needham *et al.*, 2020); the current article draws on data from sixty-four interviews in which there was specific discussion around self-funders (involving fourteen self-funders or carers of people self-funding; thirty-three local authority employees and local stakeholders; fifteen representatives of provider organisations, and two other stakeholder interviewees). Our discussion guides included a question for local authority staff as to whether they provided specific information and advice for self-funders, along with whether estimates could be made of the proportion of self-funders. Providers were also asked whether their prices were different for self-funders, while service users were asked how they paid for their care. Whenever participants provided any information around self-funders in response to these or other questions, we applied an initial code of ‘self-funders’ and included this data in the current analysis. The number of interviews and sites on which the analysis is based is

relatively small and there may be limitations with the data. However, the findings build on, and are consistent with, the wider body of literature on self-funders; they revealed enormous similarity across the eight sites, and – at minimum – they raise significant questions about the approach to market-shaping in social care which require further investigation.

Findings and analysis

The Care Act signalled a substantial potential change in the status and engagement of self-funders. Rather than being left to find their way around the care system largely unaided, self-funders should in future have access to assessment and planning to meet their needs. In effect, self-funding would be just another form of self-directed support, comparable to a direct payment (whereby people eligible for publicly-funded care receive a cash payment with which to design their own care and support) (Miller *et al.*, 2013). The Care Act had the potential to create more of a ‘level playing field’ between people funding their own care and people receiving publicly-funded support; we explore below whether such changes have actually occurred in the fieldwork sites as reflected in approaches to market-shaping and people’s experience of personalisation.

Market-shaping

‘Market-shaping’ refers to the impact that Councils’ commissioning models have on service providers, and on local people needing care and support. The size and nature of the care market, and how it relates to self-funders, are critically mediated by local authorities’ actions and knowledge of local need and demand. We have developed a typology of market-shaping describing the interaction between commissioners and providers (Needham *et al.*, 2020). Approaches that are most likely to achieve the objectives of the Care Act, and benefit self-funders, stimulate provider innovation and diversity in order to maximise choice and control for people using services.

One of the reasons for the delay in full implementation of the Care Act was supposedly the lack of readiness of local authorities to manage care accounts for self-funders, or to have a clear sense of the scale of demand from self-funders (National Audit Office, 2015).

The delay in implementation does not appear to have been used by local authorities to engage more effectively with their self-funding population, or to address the implications of this group for market-shaping. If anything, it is probable that the hiatus and continuing uncertainty about the future arrangements for funding long term care have removed the incentives for councils to prioritise such issues. In our fieldwork sites it was commonplace for Councils to have minimal awareness of numbers of self-funders or the nature of the local self-funding population and how this might impact on the provider market, as these comments indicate:

We haven’t got a good idea about how many self-funders we’ve got. We can get it in terms of the care homes (. . .) But in the wider market, we haven’t really got a clue. (Site 4, Local Authority interviewee 1)

I don’t think we can provide details about exactly how many. We’ve got a hunch; but it’s just a hunch. (Site 6, Local Authority interviewee 1)

It's impossible; I couldn't really give you the statistics. (Site 7, Local Authority interviewee 7)

I have no idea, sorry! (Site 7, Local Authority interviewee 4)

Self-funders (...) they're the unknown unknown! (Site 3, Local Authority interviewee 2)

The invisibility of self-funders partly explains their low profile; it is difficult for local authorities to map this population if they are not in contact with people or are aware of them only through information from providers. However, although local authorities have poor awareness of the scale of the self-funding population, it appears they also continue to see self-funders as a separate group of little relevance to market-shaping. The following comments acknowledge that the Care Act responsibilities have not had the impact that might have been anticipated:

But locally, from a commissioning perspective, it's certainly not on my radar, self-funders. (Site 8, Local Authority interviewee 1)

It's just enough trying to provide for the needs of the people we are responsible for. (Site 7, Local Authority interviewee 1)

For the most part, self-funders were only seen as significant by local authorities to the extent that they impacted on the local care market, or if they ceased to be self-funding having spent down their capital and savings to the eligibility threshold and required public support. Some interviewees, for example, expressed concern that they did not know enough about the scale or whereabouts of the self-funding population and that this could become an issue further down the line:

All of those self-funders, particularly older people that we've got, that at some point are going to run out of assets, and what happens then? (Site 8, Local Authority interviewee 1)

At some point the local authority is going to have to pick up the bill if the money runs out. At that point there that becomes a shock because all of a sudden – that could be a person who's lived in a certain place for a number of years, who very much sees that as their home – they don't want to move but yet, it's in a very expensive place (...) they've run down all their money; it's a big fee for the local authority (...) So, all of a sudden, there's no forward plan in there. (Site 4, Local Stakeholder, interviewee 1)

The significance of self-funders is complex; while local authorities might see their own responsibilities principally concerned with people meeting both need and financial eligibility criteria, there is simultaneous recognition of the potential benefits that a self-funding population can have for the care market. For some commissioners there is an opportunistic recognition that self-funders create positive benefits for providers and for all users of a service: for example, in raising overall standards.

So, I think it's about trying to recognise what [the provider's] business model is reliant upon (...) If 30-40% of their income was from self-funders, they have an additional incentive to

maintain the quality of the whole home (. . .) what that does is bring an added benefit for the whole home really. (Site 6, Local Authority interviewee 1)

However, this is only part of the picture, and it is not just that attracting self-funders can enhance the quality of a service, but that the income derived from self-funders is vital both for providers *and* for local authorities. Diversifying the purchasers of care makes economic sense:

. . . so, for example, our domiciliary care providers, we would be very worried if their only form of income was from us. We want them to have a bit of us, a bit of CHC [NHS Continuing Health Care], a bit of self-funder, because that for me is about the sustainability and stability of their business going forward. (Site 8, Local Authority interviewee 1)

Self-funders are also vitally important to local authorities *and* care providers to the extent that the higher charges they pay creates a resource that subsidises publicly funded care. Private providers likewise understand the central importance of self-funders, and the scope to use higher fees to offset low public contract prices. As this interviewee described, the weekly fees for a care home might be well over £1,000 per week:

And if you were private funded you would be expecting to pay that. If it was [NHS] funded or local authority funded, or whatever like that, then you wouldn't necessarily get that, because they tend to tell us what they're going to pay. (Site 3, Provider interviewee 2)

The market-shaping relationship between local authorities and providers takes many forms – we found that in many circumstances it is a relationship that is contested rather than based on trust. Part of the lack of local authority knowledge or understanding of the local self-funding population reflects their inability to ascertain the scale of provider activity and provision for this market sector. Many providers regard such information as highly commercially sensitive and do not share it with commissioners, as these comments underline:

We just don't know what the self-funder market is. Providers won't give us that information; they don't have to give us the information. So, we can have our best guess estimates. Site 4 Local Stakeholder, Interviewee 1)

They are very keen to know what sort of level of self-funder work that you are doing; but I certainly don't tell them, and I don't know any provider that does! (Site 5, Provider interviewee 10)

We've not got that level of maturity to exchange information (. . .) If we could forward plan and understand and exchange information with self-funders better, it's a win-win situation. (Site 4, Local Stakeholder, interviewee 1)

The issue for service providers is to balance out the 'large volume, lower margin' work commissioned by councils with privately paid work:

If you're working purely with private work though it's a different story, because you can charge what you want really. (Site 1, Provider Interviewee 2)

The widespread nature of cross-subsidisation by private payers, particularly of residential care, has been increasingly recognised in the literature, including by the Competition and Markets Authority (Competition and Markets Authority, 2017). This practice – often done covertly and without the awareness of self-funders – raises questions about the ethics of fee rates and the extent to which self-funders are paying the price for a failing care system, but it also underlines the unsustainability of the model and the limited market opportunities in relatively deprived local authorities with small or non-existent self-funding populations.

Where self-funders make up a large proportion of people using services, local authorities benefit from higher quality service provision and opportunity for cross-subsidisation; conversely, where there are few self-funders, the market becomes highly polarised between public and private with no scope for investment or development and market-shaping being determined primarily by the purchasing preferences of self-funders, as this comment highlights:

That really does affect your ability to shape the market because it's being determined by those self-funders who are willing to pay astronomical figures (...) Some areas just haven't got the ability to shape that market, and therefore the existing residential care market ends up stagnating because they're solely reliant, very heavily reliant on local authority funded places. Therefore, their ability to invest and expand and do things is very limited. (Site 4, Local Stakeholder, interviewee 1)

In areas that are relatively poor, or which have pockets of affluence and areas of considerable poverty, the dynamics are more complex. In councils with low levels of owner occupation, and traditional working-class communities, the self-funder influence on care markets will be considerably reduced. Even where there are wealthier areas within a local authority, better off people needing support might choose to buy care elsewhere as this interviewee commented:

At the moment if you've got money, you move out to the suburbs to find a care home (...) We're looking at trying to improve the quality of homes so we're getting self-funders coming to those homes and not just local authority. (Site 6, Local Authority interviewee 1)

The risks to the sustainability of the care market overall of increasing reliance on self-funders, and the stagnation of the sector that results from having mainly local authority-funded residents, were also underlined by the Competition and Markets Authority (CMA) report on care homes (Competition and Markets Authority, 2017). Their analysis found 'on average a self-funding resident is paying over £12,000 a year more than an LA [local authority] to have a place in the same care home' (Competition and Markets Authority, 2017: 40). The inability of the sector mainly serving publicly funded residents to remain in business is increasingly stark:

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. (Competition and Markets Authority, 2017: 13).

If local councils' knowledge of the self-funding population is low, it is almost non-existent beyond residential and nursing care, and understanding of the home care market and its relationship with self-funders is poorly developed. Some interviewees outlined an understanding of market-shaping that was quite limited, or which was concerned with 'policing' the sector, as this comment suggests:

I'm aware that the local authority don't necessarily have that much power either around shaping the market. If I think about it from a home care perspective, I have the power to shape the providers that I am directly commissioning, but those providers that are providing for the self-funder market, where the only real power we have is through safeguarding (...) so we don't really have any power to stop them providing or taking on any more clients and stuff like that. (Site 7, Local Authority interviewee 2)

Although safeguarding is an important issue, market-shaping needs to engage much more with the nature and quality of the market that local councils wish to see develop, and to address the levers and opportunities to support such developments. In areas with larger self-funding populations there are likely to be a wider range of services available, as this interviewee commented:

We have a strong market, I think, in a number of places and I think the reason why we have a stronger market is because (...) we have a significant amount of self-funders locally. It's quite an affluent borough, so from an adult social care perspective (...) there really are a significant amount of services people are able to access. (Site 7, Local Authority interviewee 2)

Such a market may function well from a provider perspective, where self-funders are able to pay a premium for services; it may be less than ideal for people (and local authorities) seeking care and support at affordable rates.

Personalisation

'Personalisation' in social care can be defined in a number of ways (Henwood *et al.*, 2018). In particular, enabling people to exercise choice and control over the nature and type of support they receive, regardless of how that is funded, promotes more personalised care. For people funded by councils, 'personal budgets' and direct payments were envisaged by the Care Act as vital mechanisms for achieving personalisation and good care outcomes, with support tailored to individual needs and preferences. For people paying for their own care, it was assumed that better information, advice and advocacy would similarly equip them to make informed choices. The issues around choice also relate directly to market-shaping, as people need to be able to choose from the range and type of services that will best meet their needs, and this is likely to require a more diverse and innovative range of services than in the past.

Some provider organisations pointed out that they are better able to respond to the needs of people who are self-funding, and to tailor support to their requirements:

We very much make our care packages; they're tailor-made to people's needs because they're paying for them. The only money constraint is what their own budget is as opposed to what the local authority has allocated to them. (Site 8, Provider interviewee 1)

Certainly, it was the case that micro-providers (very small providers, often a sole trader or with only a handful of staff) were targeting their service on self-funders and people using direct payments, as this comment highlights:

We've identified because they're smaller, that's likely where they're more able to work and if somebody's looking for that choice and control, that they can be more flexible in terms of that anyway. Rather than knowing that actually in terms of the tender they may not have the capacity of what would be required (...) A lot of the micro-providers (...) they're looking to establish themselves, grow the business using the self-funders and the Direct Payments, and (...) they'll then look at contracting. (Site 3, Local Authority interviewee 2)

Where councils are focusing on prevention and developing wider community assets to support people's social inclusion and participation prior to them developing needs for social care services, signposting to micro-providers offering more flexible options can also be relevant:

[Self-funders] they're people that have got the means to pay, but there's another cohort of people and that's people that we're catching earlier because we're in the community. Providing the options around care and so on, giving them the micro-provider option, and these people are coming forward and saying 'actually I could do with two or three hours of that.' Site 5, Local Stakeholder, interviewee 2)

The shortcomings of the care system for people who are self-funding, particularly in terms of help with information and navigation, have been identified previously and are a recurrent theme in the research literature. Baxter *et al.* have pointed to the assumptions often made about the abilities of people with financial resources to exercise consumer choice in social care (Baxter *et al.*, 2020). However, there is considerable evidence that in practice self-funders struggle to find and make use of information and to exercise choice (Henwood and Hudson, 2008; Hudson and Henwood, 2009; Baxter and Glendinning, 2015; Baxter, 2016; Putting People First Social Care Consortium, 2011).

Few self-funders seeking care and support are so affluent (or of such high net worth) that money doesn't matter. As Baxter *et al.* also found, many self-funders have relatively modest means and are anxious about running down their savings (Baxter *et al.*, 2020). The self-funders and carers whom we interviewed were similarly concerned about the affordability of care, and how long their resources would last, as these comments demonstrate:

They did suggest that I paid someone; but I'm scared to pay now – all the money that I'm paying out now. So, I don't quite know what to do yet. (Site 8, Carer interviewee 4)

But it's costing so much! They're putting it up by £50 a week again, and you know that is over £4,000 a month now. Fortunately, he's a self-made man and he's got a pension and that's what's paying for that. (Site 3, Carer interviewee 16)

Some people also recognised that having money available meant 'we've had some choices in what we do.' Indeed, people recognised that choices could be significantly fewer for those without their own resources, as this self-funder remarked:

When [the care agency] pulled out, the carers came to see me and said could they work for me? And then the social worker turned up, and I said 'This is what I want to do'; 'You can't do that'.

And I said, 'Hang on, I'm paying for this, I can do what I want with my money!' She said, 'Oh, you pay! Oh, you can do what you want then.' So, I can have these really good carers because I'm paying them. (Site 1, Carer interviewee 2)

It is not only the financial assets available to self-funders that can mediate the degree of choice and control available to them; crucially, it is also their access to information, and the skills and ability to navigate the system, which will vary considerably between people, as this comment underlines:

But that's one of my major bugbears! I'm quite forceful, and quite articulate, but if you're not – what happens to you? (Site 1, Carer interviewee 2)

As in other earlier studies (Hudson and Henwood, 2009; Baxter *et al.*, 2020), the present research found self-funders getting little support or guidance on their journeys. People begin using care and support services under different circumstances and for a variety of reasons, but often in a crisis situation. This provider described how they experienced self-funders initially being funded by the local authority for a period of reablement (typically following a hospital admission), but then choosing to continue buying the services after the 'free' six-week support ended:

A lot of them now are through local authority referrals. Either we take them on reablement and they stay long term privately funded (...) and obviously we do have local word of mouth. (Site 1, Provider interviewee 2)

Such circumstances describe a route into services that is less characterised by active choice and deliberate planning than happenstance and opportunistic developments. These conditions *can* be successful for self-funders, but are not the result of informed seeking out of support that meets personal preferences.

It was acknowledged by local authority interviewees in some sites that the Care Act *should* have changed the landscape with more responsibilities for providing information, advice and advocacy, but in reality:

Once it comes to light that somebody's got funds above our threshold which means that we're not going to be funding those services, those people have got less support in terms of accessing services (...) The support is for people that we would fund. (Site 1, Local Authority interviewee 2)

It was exceptional for local authority fieldwork sites to take a more inclusive approach towards self-funders, and the view that everyone should have access to the same information and advice was extremely rare. Indeed, even when information and advice were being offered to self-funders, this was acknowledged to be inconsistent and reflected the particular approach of staff:

So, if someone goes out and does an assessment and that person is a self-funder, we do on an individual basis try and provide them with relevant information. But again, it's down to the individual practitioner, how much they know, how much they're aware of. They will give out the brochure that we have, the (...) Care Directory. (Site 7, Local Authority interviewee 4)

My view is very much that they are as much entitled as anyone else to that information (...) in terms of self-funders, if someone wants an assessment, they want an assessment. It doesn't matter if they're self-funding or not. They might just need the guidance and advice about actually where to go, what support might be necessary, what support might be available. For me, it's about actually you're doing an assessment of need; you're again providing advice, information – you're not expecting them to go and find out themselves. (Site 7, Local Authority interviewee 5)

In another site, an interviewee described an approach in which everyone seeking help is offered assessment of their needs, and financial eligibility is very much a secondary consideration:

But the Care Act tells us to assess everybody, regardless of resources. So, when they come [for assessment] (...) it gives you that rich insight into everybody's individual case, because they're all presented and discussed. You know, I would say that 30-40% now are self-funders, so we're providing a minimum, equal, equitable approach to people who are funding their own care. Because they're entitled to an assessment, to get quality advice and support around making a really life-changing decision, especially going into residential care. (Site 2, Local Authority interviewee 5)

Such a view was notable for its rarity.

It was also apparent that self-funders may still be 'below the radar' as far as councils are concerned; indeed if there is little knowledge about the local self-funder profile and an absence of a proactive approach to offering information and advice, it is highly likely that people will be unaware of what choices might be available to them. Some interviewees commented that they knew of people who would probably qualify for social care support but prefer not to engage with the council and continue to fund their own support:

People may be eligible but don't want the hassle of going through the state system. You've got an ageing population, people that don't talk about their issues openly because that's the era they've come from. And if you can provide them with a quick readily available solution, that's locality based, someone from their community, a trusted point of contact for them – it's a no-brainer and they don't want to be dragged through the eligibility. (Site 5, Provider interviewee 10)

This pragmatic approach may well be sufficient for relatively simple needs, but it raises questions about how appropriate it might be for someone with complex or increasing needs who requires more support over time, and who should have access – at minimum – to an assessment. It was also commonly assumed that self-funders are generally able to manage their own arrangements or they would usually have a family member able to help sort out arrangements on their behalf:

I think we've got some quite wealthy people whose parents become unwell or frail and so therefore they purchase care for them from the Home Care market. (Site 4, Local Authority interviewee 1)

[Self-funders] usually have quite active family members, or because they are managing, because they are funding it themselves, are more 'savvy' for want of a better word. (Site 5, Provider interviewee 10)

If self-funders get little information and guidance as they embark on their quest for care and support, they are even less likely to get help in ensuring that their support remains relevant to their needs and their best interests are being met; self-funders are unlikely to be reviewed other than in safeguarding situations:

We don't review self-funders normally. If it's safeguarding, if the person's in a care home – then we still have a duty to pick up and review and have involvement, but that's a handful of people. (Site 1, Local Authority interviewee 3)

Beyond such limited circumstances, the onus is on self-funders themselves (or their families) to seek help:

If their circumstances change, their funding drops to the lowest threshold, they're advised to contact the access team. They would then need reassessment if their funding changed, if you know what I mean. They're given the information to say 'If your situation changes you can still come back to social services if you need support advice and assistance with funding in the future.' (Site 1, Local Authority interviewee 3)

In just one of our sites it was remarked that self-funders can request the local authority to arrange care on their behalf and charge them accordingly, and that such arrangements carry an 'administrative fee' of £200 or £300, but this can have an ongoing benefit for the self-funder because:

So, they pay, and we oversee their care; and I think we do review in those cases. (Site 1, Local Authority interviewee 4)

Discussion and conclusions

The Care Act should have changed the status and engagement of self-funders within the social care market. Rather than being left to find their way around the care system largely unaided, self-funders – like anyone else in need of care and support – should have access to assessment and planning to meet their needs. In effect, self-funding would be just another form of self-directed support, comparable to a direct payment (whereby people eligible for publicly-funded care receive a cash payment with which to design their own care and support) (Miller *et al.*, 2013). In theory, the Act had the potential to create more of a 'level playing field' between people funding their own care and people receiving publicly-funded support. However, the partial implementation of the Act and the shelving of the introduction of a care cap and care accounts to monitor people's progress towards the cap meant that the context changed. The conditions that *could* have brought self-funders more into the mainstream of local authority awareness and ensured they were provided with information and advice, failed to emerge, and have left self-funders largely as by-standers to the parallel world of publicly funded adult social care.

The Care Act gave local authorities responsibilities for shaping the adult social care market and to promote choice and control for people using those services, regardless of how they were funded, in order to achieve personalised support. People who arrange and pay for their own care services have in the past travelled a parallel path, with minimal or

no contact with the local authority and little information about services other than lists or directories. The Act *could* have made a significant difference to this experience, but implementation has not happened as originally planned and the need to engage with self-funders has lost impetus.

Local authority interviewees in our sites acknowledged that the Act has not been ‘transformational’, particularly because of the permanent suspension of Part Two of implementation. In none of our fieldwork sites did we find market-shaping activity paying more than casual attention to the significance of self-funders. We have argued that is vital for local authorities to recognise self-funders as commissioners who also have a crucial impact on local care markets, and failure to do so limits councils’ ability to understand and influence those markets (Henwood *et al.*, 2018). At the same time, the presence or absence of self-funding populations should not be seen simply as a resource by local authorities. Councils with significant numbers of self-funders are able to benefit from cross-subsidies from the higher fee payments that allow councils to demand lower cost contracts from providers. This is an opportunistic strategy that is unsustainable in the long term and which institutionalises inequalities within and between local authorities and between privately and publicly funded care and support services. The size and shape of local care markets will have significant implications for people who commission their own care and support, and this needs to be understood and addressed by local authorities to ensure people are easily able to access and navigate diverse care markets. Failing to take full account of self-funders and their commissioning patterns also has wider implications for local authorities and their ability to understand and shape local care markets.

The expectations that the Care Act would provide self-funders with much improved access to information and advice, and would better enable them to make informed choices in care and support, have not – by and large – been realised. The reality reported across our eight fieldwork sites is a situation in which self-funders remain largely on the side lines. They are peripheral to the local authority view, which is often unaware of the number or characteristics of the scale of self-funding.

The adult social care system continues to operate as two polarised publicly and privately funded models. This results in a fragile and unpredictable market, ensures that people using it experience limited choice, have partial information and often make major decisions in situations of powerlessness. Local authorities, for their part, attempt to shape the market without fully understanding the role or wishes of individual self-funders, and assume little or no responsibility for helping them, while continuing to benefit from the considerable subsidy provided by private purchasers. This model does not offer a sustainable long-term approach and underlines the urgency of social care reform enabling a system that works for all users.

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References

- Adass (2019) *ADASS Budget Survey Report 2019*, London: ADASS.
- Attride-Stirling, J. (2001) 'Thematic networks: an analytic tool for qualitative research', *Qualitative Research*, 1, 385-405.
- Baxter, K. (2016) 'Self-funders and social care findings from a scoping review', *Research, Policy and Planning*, 31, 179-93.
- Baxter, K. and Glendinning, C. (2015) *People Who Fund Their Own Social Care: Scoping Review*, England, NIHR School for Social Care Research.
- Baxter, K., Heavey, E. and Birks, Y. (2020) 'Choice and control in social care: experiences of older self-funders in England', *Social Policy and Administration*, 54, 3, 460-74.
- Care Quality Commission (2019) *The State of Health Care and Adult Social Care in England 2018/19*, London: Care Quality Commission.
- Competition and Markets Authority (2017) *Care Homes Market Study, Final Report*, Competition and Markets Authority.
- County Councils Network and Laing and Buisson (2015) *County Care Markets: Market Sustainability and the Care Act*, London: County Councils Network.
- Department of Health (2014) *Care and Support Statutory Guidance*, London: Department of Health.
- Henwood, M. (2019) 'The prospects of the next government solving the social care crisis are poor', <https://blogs.lse.ac.uk/politicsandpolicy/social-care-ge2019/> [accessed 27.11.2019].
- Henwood, M. and Hudson, B. (2008) *Lost to the System? The Impact of Fair Access to Care*, London: Commission for Social Care Inspection.
- Henwood, M., McKay, S., Needham, C. and Glasby, J. (2018) *From Bystanders to Core Participants? A Literature and Data Review of Self-Funders in Social Care Markets*, Birmingham: University of Birmingham, Health Services Management Centre.
- Hudson, B. and Henwood, M. (2009) *A Parallel Universe? People Who Fund Their Own Care and Support: A Review of the Literature and Research into the Existing Provision of Information and Advice*, London: Association of Directors of Adult Social Services.
- Institute for Fiscal Studies (2019) *English Council Funding: What's Happened and What's Next?*, London: IFS.
- Miller, C., Bunnin, A. and Rayner, V. (2013) *Older People Who Self Fund Their Social Care: A Guide for Health and Wellbeing Boards and Commissioners*, England: Office for Public Management.
- National Audit Office (2015) *Care Act First-Phase Reforms*, London: National Audit Office.
- Needham, C., Allen, K., Burn, E., Hall, K., Mangan, C., Al-Janabi, H., Tahir, W., Carr, S., Glasby, J., Henwood, M., McKay, S. and Brant, I. (2020) *Shifting Shapes: How Can Local Care Markets Support Personalised Outcomes? Final Report*, Birmingham: University of Birmingham.
- Needham, C., Burn, E., Hall, K., McKay, S., Mangan, C., Allen, K., Henwood, M., Carr, S. and Glasby, J. (2018) *Shifting Shapes: Report of Work Package 1 - National Interviews, Local Authority Survey and Secondary Data Analysis*, Birmingham: University of Birmingham, Health Services Management Centre.
- Putting People First Social Care Consortium (2011) *People Who Pay For Care: Quantitative and Qualitative Analysis of Self-Funders in the Social Care Market*, England: Putting People First Social Care Consortium.