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# Minding our business: the significance of self-funders to social work

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# Summary

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Older people who pay for care in their own home are almost invisible in policy and practice. Little is known about the ways in which older self-funders navigate the care market and negotiate buying care in a complex and fragmented care system; they have been described as effectively 'lost to the system' (Henwood and Hudson, 2008). There are growing numbers of self-funders in the context of austerity and tight eligibility criteria. Failure to achieve both eligibility based on risk and financial resources means that older people are left to turn to families for help if they have them, to purchase additional care and support services if they can afford it, or manage as best they can without help.

Councils have a number of responsibilities towards self-funders under the Care Act (2014), including: the provision of tailored advice and information; the offer of an assessment for anyone with an appearance of need and regardless of their financial status; shaping the market in order to develop care and support provision which meets the needs of the whole community and a method to record unmet need.

Our research showed that self-funders were not benefitting from Care Act provisions such as; tailored advice and information, assessments of need or an approach to market shaping which effectively included the needs of self-funders:

- Information was difficult to come by and older self-funders and family carers rarely knew where to go to get reliable and accessible advice and information.
- Participants who had contacted the Council were often given generic information, such as care brochures to search for care.
- Few participants had benefitted from an assessment of need, and those that had felt that support was often rapidly withdrawn when it became clear that they were self-funders.
- While there was acknowledgement amongst Local Authority stakeholders that they would benefit from knowing more about the experience of older self-funders, there was variable practice in terms of supporting self-funders to collaborate in market shaping and social care strategy.

## Introduction

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This briefing draws on research findings from the project *Ethical Issues in Self-funded Social Care: Co-producing knowledge with older people*. Conducted over 3 years and funded by the Wellcome Trust, this participatory research project explored how older people experience the process of finding and paying for personal care from their own resources in three local authority areas in England. For the full research report, further research briefings, booklets for older people and their families and more information about the project please visit: <http://www.olderpeopleselffundingcare.com/>

Traditionally, older people who pay for their care have been seen as outside the business of social work and adult care services. Self-funders have often only come to the attention of social workers and social care services when there is a safeguarding alert. However, provision within the Care Act (2014) makes it clear that Local Authorities have a number of duties such as, the provision of advice and information which should be accessible and offered to all people regardless of their funding status. Self-funders are – or should be – the business of social work and adult social care. Being able to access advice, support and assessment could make a big difference in the decision making of self-funders.

All names are anonymised.

# Advice and Information

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The Care Act (2014) highlights that Local Authorities *must* provide a range of information and advice for people who have care and support needs. This should include advice and information that is tailored to individual needs, accessible and presented in different formats. But older people and family carers in our project consistently told us how difficult it was to find reliable and up-to-date information about care options.

*'We don't even know how the system works, and when you're just given like 'right, go off and sort it', it's like, where do I even start? Where do you start? So ... there wasn't enough support for us to make the correct decisions in the first place. There wasn't enough understanding and help' (Andrea)*

When people did approach 'customer services' at the Council they said that they were often given a generic brochure or list of care agencies and care homes which they were expected to work through independently. Searching for possible care options involved a lot of additional work at a time when people were often facing a crisis or an emergency and the need for care was pressing.

*'...in the area that she lives there's a list produced once a week, I think, with, that lists those care homes that have got space, which basically isn't any of them. So it was a case of ringing round all of those and saying, can we come and have a look. An awful lot of them were sort of more nursing homes, which isn't really what she needed, she needed a residential home...you know, you'd phone up, well we haven't got any space, you're welcome to come and look, but we haven't got any space, or turning up to places and them being so dingy and, some of the rooms in the place she's in could do with a good lick of paint.' (Mary)*

Providing generic information, such as a brochure, also lost an opportunity to give more tailored information about care options, purchasing care, decision making and future support if or when a person reached the threshold for assessment for publicly funded care.

## Assessment

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Under the duties of the Care Act (2014), anyone with an appearance of care and support needs is entitled to an assessment of need, regardless of their financial circumstances. Our project found that most older people did not have contact with Local Authorities prior to purchasing care and very few had approached the Adult Social Care department for an assessment of need. A proportion of those that had contacted the Council customer services team were given generic information and did not recall being offered an assessment. Other participants were reluctant to approach the Council believing that they would not be offered any assistance and feeling reluctant to share personal financial information only to be told that they were not eligible for help:

*'I didn't want (to) go into that, because I knew we wouldn't qualify for anything, so I didn't want them to know all my financial details' (Arlene)*

Some participants felt that once it was known that they had more than £23,000 capital, social services were not interested in offering any further advice or assistance.

*'Everybody said, "Social Services will help you", and they were very good at first when [my husband] was in hospital. But once they discovered that we had more than £23,000 pounds in the bank ...they really didn't want to know.' (Marianne)*

A minority of people went through an assessment of need and were very disappointed at the outcome. They felt that involvement with social services ended abruptly when it was known that they would be self-funders and information and advice tended to revert to the provision of generic brochures and lists of care agencies and care home providers.

*'...(Social Services) never helped me in any capacity, if anything the social worker as soon as she knew mum had got a little bit of money was gone, I never saw her again. As soon as she knew that mum was self-funding and the fact that she had got me and my sister I suppose in the background, they obviously have other people that come up their priority list. But I have never seen the social worker since mum was in hospital.'* (Marylyn)

Interviews with social workers confirmed that they were often expected to have a 'hands off' approach to self-funders or, to provide only a limited service. Social workers' primary contacts with self-funders came about when the person's capital had reached the threshold limit or if there were safeguarding concerns about the person.

*'... if your manager sort of knows that you're working with a self-funder, the focus very much is, 'well keep your involvement as limited as possible and then close it as quickly as you can'. Whereas, I mean I have, on my caseload currently I have got somebody who's a self-funder and I am still working quite closely with her because we've got concerns about the way the Lasting Power of Attorney is acting.'* (Social Worker)

An assessment of need can be a service in itself and even if it results in a person being told that they must pay for their care, they should still have access to tailored advice and information, including, for example, about the implications of capital thresholds and the amount of money that the Local Authority will pay for care. Participants from Local Authorities certainly saw the benefits of being more closely involved with self-funders and were aware that the long-standing 'hands off' approach was not beneficial to self-funders or, ultimately, the Local Authority.

*'I think that Local Authorities are very, very aware of the potential for self-funders in terms of there is a need for us to get involved much earlier regardless of the Care Act kind of requirement that we should be supporting more people. Because it was always, when I was in practice the minute somebody said they'd got more than £23,250 it was thank you very much, see ya, off to the next one! And whilst I don't think that's gone away, I don't think it's resolved it, I think, I think that Local Authorities are starting to realise actually the earlier they start to have conversations with people the better they can help them inform their decisions later so that the impact is less'.* (Senior Manager, Local Authority)

## Reaching the financial threshold

Family carers told us that they often did not know or did not fully understand the implications of capital thresholds when looking for a care home and that Local Authorities generally only paid a contracted rate for a care home place.

*'She has my dad's Civil Service pension and her Civil Service pension, so she's got something like £19,000 a year,' ...she kept saying, "Can I afford this?", and we're going, "Yes, mum, of course you can, you know, it's the best place to be, you can't go home". It is just costing an awful lot of money, and I can see the money going down, and God alone knows what happens when the money goes. My mum is physically healthy, though obviously vascular dementia....'* (Liam)

Local Authority managers who took part in the study reflected concern that their lack of reliable data on the numbers of self-funders and their circumstances meant that they rarely had reliable information about who would be likely to approach social services for funding as a result of 'capital drop'. While there was some variation in practice between research sites, Local Authority participants understood the potential emotional trauma for older people and their families of having to move because their needs could be met in a cheaper care home but nevertheless had to try to make limited council financial resources stretch to meet growing needs for care.

Social workers reflected on the legal, but ethically difficult, practice of moving older people to an affordable care home which could meet assessed needs, if there was no one to pay the 'top up', that is, the difference between the cost of the care home and the Local Authority contracted rate. Some of the ethical concerns included: the notion of 'choice' meaning that people could purchase expensive care home beds without understanding the implications of capital depletion; older people may have spent huge sums of money before reaching the capital threshold, only to be told at that point that they will have to move to a cheaper care home; the potential

consequences of moving an older person with high levels of care and support needs from a care home where they are happy and settled into an unfamiliar environment.

*'...and that's heart-breaking because they've got relationships there, I've actually had 2 cases in the past and they've got friends there, that's their home and they've been there for years, the person that I've got to move has actually been there for years and the anxiety it's causing, it's not good'. (Social Worker)*

Our research also highlighted that the difficulties of finding suitable care mean that older people were often left with little choice but to take what they could get which may mean paying more than they could easily afford or wanted to pay. Older people like anyone else, make decisions about what they spend their money on and how much they spend. For example, we interviewed several people who were paying very high care costs for live-in care because they wanted to remain at home. In some cases, the older people had moved to a care home and returned home as they were very unhappy. But the reality of them reaching the capital threshold would be that they would be expected under current arrangements to have their needs met in a care home.

## Market shaping

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The Care Act places a duty on Local Authorities to shape the care market to ensure that it proves a flexible, relevant and effective range of care and support options which reflect the needs of the community. One of the prerequisites of effective market shaping is to understand the needs of the community. Our research, in common with other research findings, highlighted that Local Authorities did not have sufficient knowledge of self-funders, their experiences and circumstances or how many self-funders there were in their jurisdiction:

*'I think one of the difficulties is actually trying to get a really good understanding of the level of self-funders within our area. We know, because of being quite an affluent area, that we have probably got higher numbers than other areas. But actually ... some services are easier than others. So, care homes, if there is a care home and we know how many beds we're paying for then we know the rest of those beds are for self-funders. What we don't know find out is not just who are the self-funders within the area but who are the new self-funders who have actually moved into area.' (Senior Manager, Local Authority)*

Local authority managers and commissioners acknowledged that the lack of knowledge of, and engagement with self-funders, meant it was very difficult to develop an effective market shaping strategy which was responsive to self-funders:

*'the market shaping question is interesting ....it depends on what we actually know, because the more we know the better we can help shape the market. We don't know how many of the home care agencies have got self-funders, I mean I would probably assume that all of them have. We don't know how many, and we don't even know what they charge.' (Senior Manager, Local Authority)*

Combined with the ever-present challenges of social care funding, workforce retention and growing levels of demand for social care, it is easy to see how self-funders often struggled to find and purchase care that met their needs and aspirations. For example, our research highlighted the severe challenges that older people experience in finding care in rural areas and were often faced with paying a care premium, the cost of a minimum visit time and travel expenses to attract carers to work with them. Social work colleagues appeared to have little to do with informing commissioners and strategic planners about the needs of the community they work with, including self-funders.

# Policy and practice implications

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- The Care Act (2014) specifies a number of duties placed upon Local Authorities including, providing tailored advice and information and offering assessments of need. It is clear that self-funders are the business of Local Authorities and social care departments.
- Local Authorities must ensure that advice and information for self-funders goes beyond 'signposting' to make sure that people will get the right information, at the right time and in the right format.
- There is a need for Local Authorities to publicise the services they offer to the community including self-funders.
- Clear and accessible information should include the option for self-funders to request, for a fee, that the local authority arranges to meet their care and support needs and manage that care.
- Social workers are skilled in giving information, undertaking assessments of need, working with complexity and are often very knowledgeable about local services and resources. Utilising social work knowledge and expertise through assessments and information giving could provide vital knowledge for self-funders and their families and help them to think through care options as well as helping them to understand the implications of financial decisions and the possible implications or risks associated with choices they make.
- Local authorities and social workers can play an important part in ensuring that self-funders have access to independent financial advice.
- Our research has highlighted that finding, purchasing and managing care is hard work, involving practical and emotional labour. Older people with complex needs require support to negotiate and manage these challenges.
- Carer assessments should take account of the work involved in supporting an older person to manage self-funded care.
- Local Authorities should base their responses to self-funders on closer engagement with the lived experience of older people who pay for their care. This experience reveals that many of the assumptions made about self-funders are myths that prevent a more detailed understanding of the problems older people face.

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