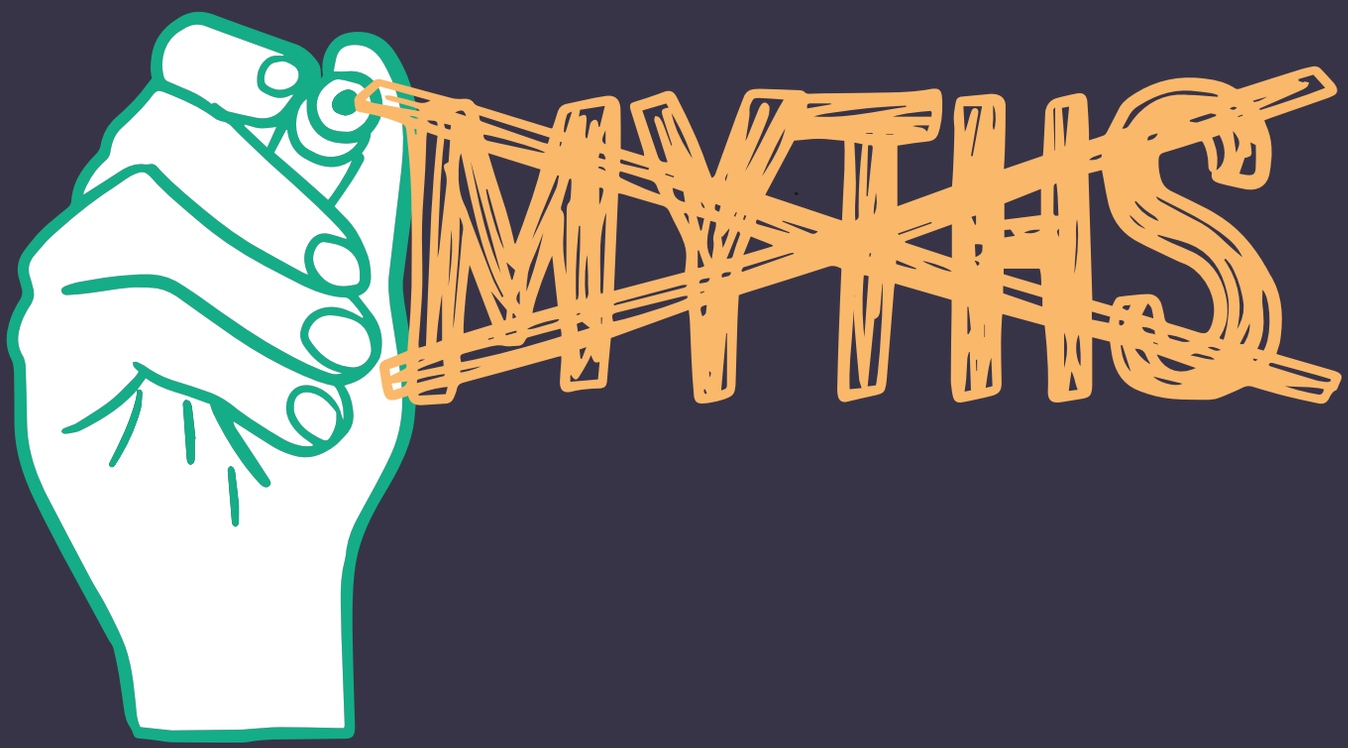

BRIEFING

Six myths about paying for care

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SUMMARY

Older people who pay for their own care remain almost invisible in policy and practice. Little is known about the ways in which they navigate and negotiate buying care in a complex and fragmented care system. In the absence of evidence, misplaced assumptions are often made about self-funders which mitigate against them getting the support they need. In this briefing, we highlight some of the 'myths' about self-funders identified in our research and the implications of engaging with evidence rooted in older people's experiences. Most significantly, engaging closely with the lived experience of older people reveals the chasm between stated adult social care policy objectives and the services received by older people purchasing care from the 'care market'.

INTRODUCTION

This briefing draws on research findings from the Ethical Issues in Self-funded Social Care: Co-producing knowledge with older people project. 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 and further information about the project please visit http://www.olderpeopleselffundingcare.com/

Despite little being known about older people who pay for their care, various assumptions are made about their experiences. Underpinning them is the commonly held view that self-funders have the choice and freedom that comes with being a 'consumer' with money to spend on their chosen care services. Based on the findings from our research, we challenge these assumptions,.

MYTH 1: Self funders have choice

There are several factors that seriously restrict choice for older people who self-fund their care.

Lack of information

For someone to have meaningful choice, they need to have enough knowledge about the options to make an informed decision. We found that older people and unpaid carers often did not know where to look for information and advice about care. At best, they may have been sent a list of care agencies but have no basis for distinguishing between those providers in terms of the types of service offered, their relative cost or quality.

> *I didn't have anybody to ask and I couldn't think of anybody who I could ask who could recommend somewhere.*
>
> Rosalind

Options

Choice depends on there being options from which to choose. Contact with care providers often led to disappointment as participants received no follow-up or were told that the agency did not have sufficient care workers in their area to take on new clients.

> *Well I just phoned a lot of places and we had a couple of people come and do assessments and then we never heard from them again. We had a lot of people say "no, we don't come out this far" or "we can't do those hours, we can't do what you want"*
>
> Piers

Sometimes the specific type of care or timing of care needed could not be accommodated by the provider. A lack of care services was particularly acute in some rural areas where people could be told that they must pay a premium to secure care or had to pay for more care than they needed to reflect travel time in hard to reach locations.

Circumstances

Choice requires the right circumstances, such as the time and ability to process information and weigh up options. Older people or their unpaid carers often had to look for care in a crisis which meant that they did not have time to contact several agencies, wait for them to call back or make exploratory visits. Instead, they had to make hasty decisions that involved compromises to secure care at short notice.

MYTH 2: Self funders have control

Our research showed that paying for care does not necessarily mean having control over care arrangements.

> *They'll promise you anything; "Oh yeah, there will be continuity," and as far as I was concerned with Jim having Alzheimer's I would have thought he needed continuity. He didn't want a different person coming in every day…And sometimes it would be 11 o'clock in the morning which was totally useless to me because he was only going to stay in bed for a certain time, and I don't want to encourage him to think that bed is the place where you lie because he needs to keep on doing things.*
>
> Jim's Consultee

Matters that were crucially important to the older person, such as the continuity of carers and timing of visits were in the hands of the care agencies, dependent on what they could provide, not determined by the self-funder. The ability to exercise control through 'voice' was difficult as some participants did not have the health, energy or abilities to complain. Others put up with less than satisfactory care because they were worried that making a fuss could make things worse.

Another way of exercising control as a consumer is through 'exit', that is, terminating the services of the unsatisfactory provider. Many older people were loath to do this as they doubted whether things would be any better if they changed provider. The biggest deterrent was the fear that they might be left with no care at all.

> *There's not enough carers so, so trying somebody else, it's probably the devil you know is better than the devil you don't.*
>
> Brenda

MYTH 3: Paying more means better quality

Paying more for care does not necessarily mean getting a better service. Older people could pay an extra £8 per hour for care that was not obviously different from a lower cost service. Some felt that the main motivating factor for care agencies was bringing in as much money as they could, not providing quality for the customer.

> *The care agency aren't interested in my concerns. They're running a business and that's the whole top and bottom of it, they're there for what money comes in.*
>
> **Norma**

Sometimes they had to pay more for care, not because it was any better in quality but simply because it was the only service available at the time. In some cases, self-funders may be receiving exactly the same service, from the same provider, as commissioned by the local authority for its service users but be paying a considerably higher charge. For care providers this helps off-set the low rates paid by the local authority. Many of our participants had to try and assess for themselves how much they felt they should pay and what counted as good value for money. This is a difficult assessment when the service is indispensable and bound up in feelings and relationships with people giving intimate personal care. No matter how satisfied participants were with the quality of care they received at the front-line, they were aware that the price they paid did not reward the carers providing the care. This was another gap between cost and quality.

> *I think it's about, oh it's £41 a week for 2 hours which is really quite extortionate, but equally I'm well aware that the carers don't get anywhere near that and that really upsets me.*
>
> **Winifred**

MYTH 4: Self-funders are nothing to do with local authorities

Our interviews with local authority stakeholders showed that they were aware of their legal duties and responsibilities towards self-funders.

> *We know following the Care Act that we have a duty of care to support people through the assessment process or to give advice and information I should say more broadly. And we also have a brokerage offer, so if somebody wants to be supported by the Council fully to procure services and to be provided with services that the Council quality monitor, there is an option for them to do that though there is a payment associated.*
>
> **Adult social care commissioner**

However, this sense of local authorities having responsibilities towards self-funders was not necessarily shared by other professionals or organisations.

> *There is definitely subtle discrimination against self-funders once a professional knows they're self-funding they're really told to go and sort it themselves.*
>
> **Independent social worker**

Moreover, it was not always reflected in the experience of our participants who felt that once it was known that they were self-funders, they were 'on their own' as far as the local authority were concerned:

> *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, Robert's Wife**

It was rare for our participants to have approached local authorities as most assumed that they would not receive help because of their circumstances. A few had received an assessment of need and a financial assessment but were subsequently told that they exceeded the financial threshold for funded care. This could come as a shock and an abrupt end to their involvement with the local authority:

> *… because I applied by phone and then … a lovely person came … she was very, very patient and understanding and on your side, I mean she was just such a lovely person and she was in charge of my case. So, she, you know, she questioned me and… it was about two hours, you know, she filled in all the forms and …. you know, I felt like I was sort of on a ship or something sailing towards calmer weather, had that feeling, you know, things are picking up at last sort of thing. … and then, the application went in and went to the funding panel they call it and then I just got a letter, no I wasn't going to be funded. And it was like hitting a brick wall and it was so shocking*
>
> **Penelope**

Local Authorities have the option of organising, for a fee, self-funders' care, although this is generally not well-known. Very few older people and family carers had explored this option. Most who had then rejected it because the care on offer was limited to the number of hours decided by the local authority, provided by their commissioned services, and subject to an additional charge imposed for managing the care.

MYTH 5: Self-funders are well-off

One of the reasons people self-fund their care is that they have assets above the financial threshold set by central government. Some people have financial resources only just above this limit and may not view themselves as by any means well off, especially when their assets are set against the high costs of personal care. Another reason for someone being a self-funder is that their assessed care and support needs fall below the eligibility threshold. Older people who pay for their own care because their needs do not meet the eligibility criteria may well have assets below the financial threshold and struggle to meet the costs of the care they need. Many of our participants had to budget carefully to pay for care, working out how much they could afford against how much care they needed. Some were trying to manage with insufficient care, jeopardising their wellbeing.

> *The evening is probably…when you could do with it, when you're tired but…I haven't got the money. I've only got pensions, you know I've got a small private pension, it's not that massive.*
>
> **Brenda**

Participants with more substantial personal finances still had to work out how long they could sustain paying for care. This was especially the case for people with the most complex needs who were paying for several care visits and/or overnight care or live-in care. This could easily cost around £1000 per week.

> *So, you know, it's a lot of money. So, it's completely knocked awry what we had anticipated.*
>
> **Isaac**

Some participants were only able to meet the costs of care because their families were 'topping up' the care fees, especially in care homes. Older people and their families had the impossible task of trying to work out how long their money would last when they did not know key facts such as possible increases in care needs or care charges or, crucially, how long the older person would live. Many participants felt a high level of anxiety about what would happen if or when their money ran out. Only a minority sought financial advice or were well-informed about when they would become eligible for local authority care or what would happen at this time.

Mum and Dad have got X amount of money, which we've worked out will do two years, eight months if they both still live. If there's one of them left, and we've talked about this openly, it's not a problem. It's the two of them [and if] the money runs out, what happens? …It's very difficult because it's such a delicate sensitive subject and I know from talking to other friends, that this is where we all seem to fall down. It becomes firefighting instead of actually facing something and making a plan. And at the very age where you don't really want to do it.

Bev and Walter's daughter

MYTH 6: Self-funders need 'a little bit of help'

It is not the case that people who pay for their own care necessarily have lower levels of need than people whose care and support needs are met by the local authority. As we noted in the myth that self-funders are well off, people may be paying for their care because their assets are above the financial threshold, not because they have low levels of need. Indeed, most of our participants lived with long term, coexisting conditions creating layers of complex care and support needs. The increased complexity of needs of older people living in the community and the challenges for them of finding and managing self-funded care were recognised by some care providers.

> *We get referred to us a lot of people who just don't have the support that they need, and in particular we've had some quite striking instances of people who did have money, or property, who … were left to their own devices. And if for example you're completely deaf and confined to your home, it's actually quite hard to source out the market in things, so I'm very concerned about those issues, about access for individuals and their vulnerability.*
>
> Manager of voluntary sector organisation

Our participants were not buying only 'a little bit of help' with tasks such as housework. All were paying for care to meet personal care needs (for example, bathing, dressing, support with medication, continence promotion and/or managing risks associated with cognitive impairment), sometimes involving several calls each day. Most had a range of additional needs, such as help getting ready for and travelling to health appointments as well as wider support services, such as gardening, shopping, transport and equipment.

Our research over an 18-month period showed that a significant number of our participants were paying for care in what turned out to be the last part of their lives. We heard about the need for significant increases in care, many hospital admissions, moves to care homes, and, sadly, several deaths amongst our participants.

POLICY & PRACTICE IMPLICATIONS

Social care policy needs to be founded 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 detailed understanding of the problems they face.

A fundamental review of the current market-based system of care is needed as this is not delivering choice, control or quality of care for many older people who pay for their care.

Much clearer and more accessible information is needed about the responsibilities that local authorities have towards self-funders. This includes their duties to provide information about care options; to assess care and support needs for anyone who appears to have these needs; the option for self-funders to request that the local authority arrange to meet their care and support needs; and the responsibilities and procedures that apply when people's financial assets dwindle.

Urgent review of the funding of social care is needed. It is not equitable that older people are subsiding local authorities by paying much higher costs for the same or similar services.

There needs to be a closer relationship between cost and quality, with clear information and standards published by care providers along with transparent charging structures.

The quality of care provided by care agencies should inspire older people's confidence and trust. They should not feel obliged to accept unsatisfactory care because they fear there is nothing better. This depends on adequate funding of social care to ensure a skilled, competent, reliable and suitably remunerated workforce.

Accessible and well-publicised avenues for finding out about and managing self-funded care are needed to support older people and unpaid carers. This includes support with future care planning for people with complex and changing health care needs.

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