Self-Funders' Access to Information about Long-term Care in England:

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Abstract

The provision of long-term social care in England has changed dramatically over the previous two to three decades. One important change has been the increasing emphasis on user choice, control and personalisation, implemented through personal budgets (PBs). An integral assumption behind the development of PBs is that enabling people to manage the resources available to them will enhance their ability to access appropriate care and support, and tailor it to their needs. New roles to support people using PBs have developed, but these are not always available to self-funders (people who pay for their care from their own funds). This paper draws on data from a qualitative research project to consider the experiences of self-funders in the context of long-term social care policies promoting choice and control.

Introduction

The provision of long-term social care in England has changed dramatically over the previous two to three decades. One important change has been the increasing emphasis on user choice and control through personal budgets (PBs) (i.e. cash for care). An integral assumption behind the development of PBs is that enabling people to manage the resources available to them will enhance their ability to access appropriate care and support, and tailor it to their needs. As well as enhanced user choice and control, over recent years the thresholds for which people are eligible for local council funding have increased, resulting in greater proportions of the older population relying on their own financial means to purchase support. These people are known as self-funders.

This paper considers self-funders in the context of policies promoting choice and control in England by drawing on research about self-funders' experiences of seeking information about care. Self-funders pay for their long-term care from their own funds, either because they are not eligible for local council-funding or they opt not to approach the council for an assessment. They might be considered model consumers as they have the funds and freedom to purchase the type and amount of care they wish from any provider they choose. Indeed, a 2007 UK government paper suggested that the introduction of PBs for those in receipt of state funded social care support were being developed to mirror the opportunities available to self-funders:

> *Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders.* (HM Government, 2007: page 2)

New roles to support people using PBs have developed; these include help with planning and arranging support, and with managing budgets, from both local councils and voluntary/user-led organisations. Until very recently, SFs have had a low profile on the policy agenda. As a result, it appears that the help and support now available to people in receipt of state-funded care has opened a gap leaving those paying for care themselves relatively unsupported in their decision making.

The paper uses data from a qualitative research project which explored the experiences of self-funders in seeking information about long-term care in England. We interviewed people who had recently sought information about care at home or in a care home, for themselves or a relative; practitioners about their experiences of being asked by self-funders for information; and senior council managers about the place of self-funders in local priorities.

The analysis focuses on issues around choice and control in relation to accessing information about care, as well as topics raised in the introduction to the themed session – namely the influence of financial and social capital. Specifically, the analysis explores: the ability of practitioners to engage and offer the personalised information being sought; the extent to which experience and social capital generate knowledge about the social care system and so facilitate access to information; issues around the assumption that self-funders have sufficient finances to pay for care, but the reality that these funds are limited and people may be reluctant to spend their resources this way; and the challenges faced by self-funders in seeking information.

Policy and literature

Health and social care in England are funded differently. Health care is predominantly free at the point of access and funded through national taxation. Social care is means tested and funded via local councils. Long-term care in this paper refers to social care, not health care, and relates predominantly to older people.

Social care provision in England

Social care for older people typically covers activities of daily living, such as getting up and dressed, toileting, making meals and eating, getting out and shopping. This care is usually provided to people in their own homes (called home care) or in a residential/care home.

Local councils do not fund social care for everyone. To be entitled to state funding, people are assessed on (a) their need for care and (b) their ability to pay for it. Assessment of care needs is relatively straightforward – people discuss their needs with a trained assessor and if those needs are above a defined threshold then the person qualifies for council help, subject to a financial assessment. The financial assessment is based on a person's income and assets. If a person has assets (these include bank savings, other investments and in some circumstances the value of their house) of above £23,250 (about €26,680) then they are not entitled to any financial support from their local council. With assets below this level there is a sliding scale of contributions until a lower limit of £14,250 (€16,350) under which the council pays all the costs of care.

Local councils used to provide the majority of care via in-house services, but huge changes in the structure of the social care market following reforms to community care in the early 1990s (Department of Health, 1989; Lewis and Glennerster, 1996) led to the introduction of a quasi-market in social care (Le Grand and Bartlett, 1993). Local councils today provide very little care; their roles in relation to the provision of adult social care are focussed around needs assessment and support planning, commissioning and market shaping. The vast majority of social care is provided by independent organisations. Many are for-profit organisations but some are not-for-profit. In 1992, local councils purchased around 2% of home care from independent providers; in 2005 this had risen to 73% (Commission for Social Care Inspection, 2006b) and by 2011/12 it was 89% (Institute of Public Care, 2014). Around 61% of care home places were provided by the independent sector in 1991, rising to 91% in 2010 (Forder and Allan, 2011).

In parallel with changes in the provision of care there have been changes in the way in which care is purchased. Prior to 1997, people eligible for social care were provided with services over which they had little choice or control. However, the introduction of direct payments in 1997 following pressure from disabled people and organisations, resulted in more control for individuals who were then able to purchase care of their choice using direct cash payments (Riddell et al., 2005).

Direct payments were originally introduced for working age disabled people but are now available to a wide range of service users including older people, carers and parents of disabled children. The use of direct payments by older people has been low; 15% of eligible older people used DPs in 2014 compared with 37% of younger adults (ADASS, 2014). Other forms of individual level budgets have been introduced to enable people to benefit from the choice and control that DPs aim to offer, but without the responsibility for managing a cash budget. Currently, everyone eligible for council-funded social care is offered a PB. A PB is an allocation of funding offered after an assessment of care needs. A PB can be taken as a direct payment (cash held in a personal account), or as a 'managed PB' in which case the budget is retained by the council or placed in a third party's account to be managed on behalf of the person needing care. PBs can also be taken as a combination of a DP and managed PB.

In 2014, 80% of eligible people were using PBs (ADASS, 2014). New legislation in 2015 (Care Act, 2014) made it compulsory for councils to assign PBs to all people eligible for support.

Choice, consumerism and information

Two of the main concepts underpinning these policies are choice and consumerism (Glendinning, 2008). In basic economic theory, choice goes hand in hand with competition and is an important element of markets, driving up quality, efficiency and service responsiveness (Glendinning, 2008; Le

Grand and Bartlett, 1993). One of the mechanisms through which competition is achieved is 'perfect information'. With perfect information, buyers and sellers of goods and services are fully informed about their characteristics and the prices being charged by different suppliers, enabling fast and informed judgements about what to purchase and from whom (Le Grand and Bartlett, 1993; Baxter et al., 2011). The sociological concept of consumerism defines choice as an intrinsic good in itself, with the belief that choice should therefore be a key issue underpinning policy (Glendinning, 2008). Choice as viewed within the framework of consumerism is essential for achieving citizenship and independence.

An important concept underlying both choice and consumerism is information. In order to make informed choices, people need to gather relevant information to build a picture of available options along with their advantages and disadvantages (Baxter et al., 2008). Increasing people's opportunities to make choices without appropriate and accessible information is meaningless (Corrigan, 2005). Poor information and the high costs of obtaining it have been shown to limit the take up and effectiveness of choice policies (Propper et al., 2006; Thomson and Dixon, 2006).

Glendinning (2008) and Baxter et al. (2008) discuss a number of issues faced by users of social care in relation to choice and information. First, DP and PB users, who purchase services on an individual basis, may be affected by greater information asymmetries than local councils that purchase in bulk, meaning that they are in a weaker purchasing position (Barnes and Prior, 1995). Second is an assumption that people who have more financial resources from which to draw will find it easier to make choices by virtue of having a wider field of choice (Clarke et al., 2006). Third, non-financial resources are important determinants of ability to exercise choice; examples include knowledge of services and skills in dealing with professionals, or friends or relatives with appropriate skills to act as advocates or 'choice editors' (Glendinning, 2008: 457). Thus people with higher levels of cognitive or material resources can use those assets to find relevant information about care, make informed choices and further increase their inherent advantage (Rogers and Mead, 2004; Lent and Arend, 2004; Corrigan, 2005). However, even for people with existing high levels of knowledge and/or material or social capital, the costs of an exhaustive search for information can be prohibitive (Baxter et al., 2008). Formal information and support services can help to reduce differences in the level of non-financial resources people possess (Lent and Arend, 2004), but information needs to be accessible, of good quality and up to date (Baxter et al., 2008).

Support for personal budget users' in making choices

As the number of people using PBs in the UK has increased, new roles have developed to support them. Help with assessing needs has existed for a long time and has always been part of the process of assessing eligibility for council-funded services. In addition, new roles in support planning, brokerage (i.e. liaising with providers and arranging care) and management of budgets have developed. These roles are offered by local councils and in some cases by voluntary or user-led organisations. For people using managed PBs, these services are an integral part of the service from the local council; for people using cash direct payments, there is typically an option to use the council's services or those of an independent provider, with use of the services paid for from the DP budget. PBs (both managed PBs and DPs) are also audited, usually annually, to monitor their use, ensure people's needs are being met appropriately and check on the quality of services and any safeguarding issues.

None of these support services are generally available to self-funders, although self-funders can opt in some circumstances for the council to commission services for them, and then reimburse the council for the costs of care. This is usually offered only when the self-funder lacks the mental capacity to arrange their care themselves and has no family or other advocate to do so.

Rabiee et al. (2016), in a study of how support planning and brokerage assisted older people using PBs to exercise choice and control, found that choice was limited, not by the support planning role but by the low level of budgets offered and restrictions on what budgets could be spent on. Timeliness of choices was also perceived to be compromised by brokerage systems, with delays created by council support planners needing to explain people's care needs to brokers who in turn liaised with providers. Furthermore, once care was in place, there could be additional delays if PB users wanted to make any changes to their care – instead of being able to agree changes directly with the care provider, they also had to be approved by council support planners.

Despite these drawbacks, evidence from a national survey of PB users suggests that older people (who typically use managed PBs) value being involved in planning how to use their budget, and involvement is associated with better outcomes (Hatton and Waters, 2013). However, the level of involvement some people want in making choices is limited. Rabiee and Glendinning (2014) suggest that older people often do not want or get choice over what type or how much care they need or which organisation provides it. Choice and control for older people typically sits at the 'micro' level of the individual's daily routine. People want to make choices about what to eat for lunch or what to wear, which care worker visits and at what time, but not about which care agency delivers the care.

What is known about self-funders?

There is no definitive evidence on the number, or proportion, of self-funders in England, but estimates suggest up to 25% of home care hours are provided to self-funders and over 40% of care home paces are paid for by self-funders (Baxter and Glendinning, 2015). The growing importance of self-funders has been recognised in legislation (Care Act, 2014) which, among other things, made it mandatory for local councils to establish information and advice services for all people in their locality, whether they were council or self-funded.

A recent scoping review found the evidence about self-funders is limited but increasing (Baxter and Glendinning, 2015; Baxter, 2016). What is evident, however, is that self-funders struggle to find and understand information about social care and receive little support to do so.

Self-funders often do not think to approach their local council for advice (Wright, 2000) or can be deterred by a perception of stigma associated with asking the council for help (Putting People First et al., 2011). They have been shown to be the most disadvantaged and isolated people in the social care system, often ending up with their care arrangements by chance rather than active choice (Henwood and Hudson, 2008). Having sufficient financial resources to self-fund does not guarantee any greater control over care than people with fewer resources (Putting People First et al., 2011). People moving into care homes have reported feeling powerless and unsupported throughout the process (Commission for Social Care Inspection, 2007). What is particularly lacking is information and advice at the early stages of looking for care, and navigating systems.

According to the National Audit Office (2011), 69% of self-funders did not feel well informed about the financial implications of paying for long-term care. Almost a third of telephone calls to a national advice line were about the funding or quality of care, and the most common topic of information guides requested from the same organisation were about care home fees (Independent Age, 2012). However, key national organisations have been reported to be lacking in confidence in providing information and advice about finances (Hudson and Henwood, 2009).

Despite various recommendations that information, advocacy and advice services should be made available to self-funders as well as council-funded service users, only 23% of local councils in 2005/06 had identified a need to provide more advice and support to self-funders (Commission for Social Care Inspection, 2006a). Self-funders were often left to navigate the care system themselves (Care Quality Commission, 2009). Many felt invisible to local councils (Henwood and Hudson, 2008).

In addition to receiving limited help in choosing and arranging care, the appropriateness and quality of care self-funders receive is not monitored in the same way as for PB users. For example, Scourfield (2010) found that care home managers were concerned about inequities between council-funded and self-funded residents – only those funded by the council received annual reviews of the quality and appropriateness of care. Some care home managers undertook their own reviews, but were aware these were not independent.

Thus the limited evidence about self-funders suggests they are not well supported in making choices about social care and have received little recognition in local or national government policies. Our study aimed to add to this evidence base.

Methods and data

Study design and aims

The overall aim of the study was to explore self-funders' experiences of seeking information about social care using in-depth interviews with self-funders and their relatives. Complementary interviews with social and health care staff and third sector organisations examined their experiences of being asked for and providing information, and senior local council managers were asked about strategic perspectives.

Ethical approval was obtained from the Social Care Research Ethics Committee (reference: 15/IEC08/0026).

Data collection

Self-funders were purposively recruited in order to capture a diverse range of characteristics and experiences. The sampling framework addressed a number of characteristics identified from the literature which were considered possible factors which may affect experience. These included; urban and rural locations, to account for differences in the accessibility of information; age (working age, nearing retirement age and over 65s), to allow for different information needs and acceptability of different media; employment status, to account for differences in financial information needs and different social circumstances; and level of support needs, to include people ineligible for council funding due to low level needs (who may have high or low levels of finances) and people who have high level needs but self-fund because of their higher levels of finances. We also aimed to include relatives who were searching for information on behalf of self-funders.

To be eligible to take part people had to be living in England and to have looked for information or advice about paying for care in the previous 18 months, either for themselves or for someone else. Definitions of 'care' were broad and could include getting help at home (for example, help with washing or getting out and about) through to moving to alternative accommodation, such as a care home.

The research team worked with a wide variety of organisations to recruit participants. These included local councils, local and national voluntary organisations, individual and groups of care homes and home care agencies. Invitation letters were posted or given to potential participants by the recruiting organisations. In addition, posters, short adverts and a link to the recruiting page on the project website were displayed in relevant organisations, newsletters and social media. Recruitment took place between July 2015 and February 2016.

People who returned their details to the project team were contacted to confirm eligibility and arrange an interview. Most interviews were conducted face to face; some were by telephone, as preferred by the participant. The interviews were semi-structured, designed to last 60 to 90 minutes and covered: participants' circumstances and social care needs; their experiences of seeking information; and suggestions for a resource to help with the process of seeking information. The section of the interview about seeking information was designed to be the most comprehensive, covering all aspects of the process including knowledge of social care, starting points in seeking information, organisations contacted, help in seeking information, information found and usefulness of information.

Practitioners were defined as anyone who, as part of their job, was asked by self-funders for information about social care, for example, local council customer service officers, social workers based in the community or hospitals, information officers in voluntary organisations, GPs, and managers of care providers. These organisations covered a range of health and social care organisations, the voluntary sector and for profit companies.

Practitioners were recruited via direct contact through emails as well as via professional networks and social media. Recruitment took place between September 2015 and March 2016. Interviews lasted between 45 minutes and one hour and covered topics, such as the types of contacts from self-funders, typical questions asked, information provided, the process of offering information, training and impacts from the Care Act.

In addition, senior/strategic level managers from five councils were interviewed about local priorities regarding self-funders.

Analysis

The interviews were transcribed in full and analysed thematically. A sample of transcripts from the self-funder and relative interviews was read by two of the authors and a preliminary coding structure was developed using both *a priori* and emergent codes. This structure was further developed and refined through discussion by the study team as the remaining transcripts were coded and then charted, following the Framework approach (Ritchie et al., 2013). The main analysis of self-funders' data focussed on their journeys from initial triggers for considering care, through information seeking, to arranging care. Coding and analysis of interview data from practitioners and senior managers was closely aligned to interview topic guides and covered areas, such as the type and format of information and advice offered, its quality and current/future challenges.

Data for the analyses in this paper were taken from selected columns within the Framework charts and revisiting text coded at specific nodes within NVivo, focussing on issues relating to social or financial capital, personalisation, choice and control.

Participants

Tables 1 and 2 give the numbers of self-funder/relative and practitioner interviews respectively. Forty interviews were conducted with self-funders or their relatives. Three involved two participants (for example, a son and daughter-in-law searching for information for a parent), giving a total of 43 participants. Twenty-seven interviews were conducted with women, 10 with men and three jointly with husband and wife dyads. The majority of self-funders were aged over 65.

Table 1: Number of self-funder interviewees

	Age of interviewee	Self-funder	Relative	Total
Domiciliary care	<65 years	4	5	9
	65 and over	4	7	11
Care home	<65 years	0	10	10
	65 and over	8	5	13
Total		**16**	**27**	**43**

Table 2: Number of practitioner interviewees

Job title	**Number**
Community social worker	4
Hospital social worker	3
Local council customer service/first contact	3
Voluntary organisation	3
General practitioner	3
Care home manager	2
Home care agency manager	1
Total	**19**

Study findings

The policy and literature section has outlined some of the issues around information and support for older PB users and self-funders. This section provides detailed evidence from our recent study on the information and advice, and associated choice and control, available to self-funders.

Personalised information and advice

Both groups of participants, self-funders and practitioners, had views about personalised information and advice, but there was little evidence that self-funders were receiving a personalised service.

Self-funders wanted personalised guidance, tailored to their needs and communicated in an effective way. This was often articulated as being able to speak with a named individual, on more than one occasion if needed, to seek clarification without repeating their whole story, and to receive reassurance about their options and decisions. In reality, they found that they were provided with generic information and rarely spoke to the same person twice, even within a single organisation, such as a local council.

Self-funders felt particularly frustrated that practitioners were not allowed to recommend specific providers. For example, practitioners were able to advise people on what types of provider would best suit their care needs, and were able to offer lists of such providers, but could not suggest which on the list were best quality. This left people feeling uncertain about the choices they made.

> *There's a lot of information out there but it's not necessarily information you need; it's almost like you need advice and reassurance that the decisions you're making are good ones. (Relative of self-funder, SCH03)*

Occasionally people reported that practitioners had given them advice while making it clear this was something they should not be doing: *"one day this lady said "Look, I shouldn't tell you this, but…""* (Relative of self-funder, SCH39) and *"they are not allowed to recommend, although unofficially one of the ladies did…"* (Relative of self-funder, SCD04). Although frustrating, there appeared to be a degree of understanding about why professionals would not make recommendations:

> *… very often one person will manage absolutely beautifully in a home where somebody else just doesn't manage at all […] maybe that's another reason for not making recommendations, you can't actually say that because it's been all right for these people it's going to be all right for you. (Relative of self-funder, SCH06)*

Practitioners agreed that they did not, and were not allowed to, offer recommendations about specific providers. However, occasionally practitioners mentioned that, off the record, they might try to suggest to self-funders that they think twice before choosing some providers known to be poor quality. One interviewee from a voluntary organisation made this comment:

> *It would certainly not be something I'd want to put in an email [but] if the conversation went that way, if someone asked me, quite often people do ask "are they any good?" and all I can say is [that] we've had no negative feedback or we've had some bits of negative feedback; and that's not misrepresenting the fact, it's just, […] that's about as opinionated as we can be. (Practitioner, PVO15)*

Some practitioners based in local councils also explained that they did not make recommendations to people using PBs either – they were there to offer information on options and guidance on meeting care and support needs, but not to make choices for people.

Much of the information provided to self-funders was generic. For example, information about assessment processes, how to get help or where to look on council websites was in the form of leaflets or factsheets aimed at PB users as well as self-funders. However, practitioners suggested they offered "*tailored conversations"* (Practitioner, PAM14) that were intended to be as relevant to people's individual circumstances as possible. These conversations might be tailored around services on offer in specific localities or people's care needs (for example, care homes or care at home). Practitioners were also aware of the danger of overloading people with information and so made judgements about how much information people might find useful and how much help they needed in sifting through it:

> *So we have to play it by ear […] whether they want something there and then, or whether they just want to be told; if someone's happy to just go and look, […] do the research themselves, then we can just send them away with that, but if they want an actual list then we can make a bespoke list. […] [If someone needs] more intensive support than someone else then we'll tailor the information differently. (Practitioner, PVO01)*

The recent Care Act legislation made it mandatory for local councils to provide written information about care to anyone enquiring about it, including self-funders. This was mentioned by one council-based practitioner as helping her tailor information better; previously the council in question had sent people large amounts of generic information, but since the Care Act they had introduced a requirement to send people a form detailing what information they had been offered, and this acted as a catalyst for more concise and personalised information.

Although practitioners felt that the information they provided was tailored and of good quality, they expressed some disappointment and concern that they had few opportunities to check whether self-funders had acted on the information provided and managed to arrange suitable care. With PB users, a representative from the local council would check on the person's care and welfare a few months after a care package had been agreed. Checks were also made annually on people funded by councils and living in care homes. For self-funders, there were no such checks and this left practitioners concerned about the long-term welfare of those living in care homes, particularly if they had no family to support them. The inequity of offering a better service to people who were council-funded than those self-funding troubled some practitioners:

> *As a professional you want to be giving the same service to everybody regardless of their money, and sometimes it does feel that self-funders can get a lesser service, but I'm always conscious that I don't want that to be the case, but the frustration is obviously of workloads, sometimes it means that you have to focus on those that can't arrange [it themselves]. (Practitioner, PHS08)*

The role of experience and social capital in facilitating access to information

Self-funders often have to rely to some extent on their own experiences and social networks to aid their decisions.

A major determinant of self-funders' knowledge about social care came from their own or other people's work experience. Some worked in health or social care jobs; these roles were not usually related directly to finding information about care, but gave people insights into how the systems functioned and what they could (and could not) offer. Other people had friends or relatives with experience which gave them the confidence to know what to look for:

> *I knew it by reputation and I went to visit, looked round, spoke to the managers and made a decision. (Relative of self-funder, SCH31)*

Even without perceived knowledge of the system, self-funders drew on their own experiences of searching for information about care for other people in different contexts on previous occasions. People also developed a degree of knowledge and competence as they progressed in their current searches for information.

> *Now I know a lot of the problems, I'm becoming quite good at it, but it's a bit late in the day. (Relative of self-funder, SCH14)*

Advice and recommendations from people in their social networks were everyday occurrences:

> *It's just general conversations I think with people that I know and the friends that I have nowadays are […] mainly my age group and they have problems, usually with husbands, and things crop up in conversations. (Relative of self-funder, SCD18)*

People seemed to feel reassured about choosing a particular care provider if others within their networks had recommended it, although not all recommendations worked out well; some people found they had different experiences to their friends and changed choices quite quickly. This illustrates the potential problems faced by professionals with making recommendations as noted in the previous section.

Some people seeking information also made use of more formalised relationships, for example through membership of committees for disability-related groups or involvement in groups convened to advise councils on care issues to inform their information seeking and choices.

Many study participants searched the internet for information; some began with internet searches and others used the internet after being signposted to specific webpages by local councils and other organisations. Some undertook quite basic searches, just looking for contact details of care homes which they then rang or visited. Others accessed more sophisticated information including quality information and staff to resident ratios. However, to use the internet effectively, people needed a degree of knowledge and confidence that may or may not be present. Self-funders are typically older people, many in their 70s and over. While familiarity with web based searching is becoming increasingly common in ageing populations not all were comfortable beyond print media. These individuals sometimes received support from adult children with web based searching. However, some adult sons and daughters, although competent in using the internet, were confused or overwhelmed by the information on offer about long-term care. Regardless of whether people were comfortable in using the internet to find information, there was agreement that visiting a care provider rather than relying on internet advertising was essential: *"all the geese are swans, so you have to make your own judgements"* (Self-funder, SSH30).

Not all self-funders in this study had a network of family and friends to discuss their choices and plans with. Where they did, they drew on their knowledge, but some people felt quite isolated and found themselves feeling burdened with being in control of decisions about care for themselves or an elderly spouse, with little or no external support.

Financial capital and willingness to pay for long-term care

The people in this study felt comfortable but not rich. They talked of savings that were only marginally higher than the eligibility threshold and of modest pensions.

> *I don't consider we're rich, we're talking about £20,000 in the bank […] I wouldn't think that's a lot of money nowadays.* (*Relative of self-funder, SCD02)*

Some people were reluctant to use their resources to pay for care and looked for ways to avoid doing so. There was a lot of concern about money people wanted their children to inherit being eroded by paying for care. People approached solicitors for advice about protecting assets to leave as inheritance and clarification about the use of housing wealth to pay for care. Some learned that if they had planned in advance and set up trusts to protect their assets, they could have avoided paying for care, but once it becomes apparent that care is needed, this option is lost. People also spoke about signing their houses, or proportions of them, over to their adult children, and giving money away to children and grandchildren.

Many participants felt it was unfair that they were expected to use their hard earned savings to pay for care when other people who had been less frugal throughout their lives, and so had limited assets, had their care paid for by local councils. There was a perception that they were being cheated out of their money while people who were more aware of financial matters made plans in advance to move or give money away to ensure they were eligible for council funded care.

People were also concerned about the financial sustainability of paying for care in the long term and its effects on decisions. The cost of care home places can be over £35,000 (€40,200) a year so even substantial savings can be eroded quickly. This was a particular concern when adult children lived with a parent; people worried that houses would be sold to pay for care and relatives would be left with nowhere to live. Concerns over inheritance also affected judgements and caused family disputes. An older woman felt lonely living in her own home and was considering moving to a care home for companionship, but felt her children were reluctant for her to do so because it would mean spending their inheritance.

Of course there were also examples of people who did feel well off enough to pay for care and felt this afforded them more choice and control than people who relied on council funding for care. One man commented that he felt lucky to have enough money to pay for care as this allowed him to avoid "*becoming institutionalised*" (Self-funder, SSD37) in his own home – he was referring to people who receive basic levels of home care funded by local councils, that provide help with activities of daily living but little else. A couple in their late 70s who were content to pay for care noted that "*At our age, money's worth nothing*" (Self-funder, SSH09).

Challenges in seeking information, and impacts on choice and control

Overall, study participants felt confused about where to look for information and what to look for. They found it difficult to access meaningful information. This could lead people to feel uncertain about whether they had made fully informed choices or considered all options.

When approaching local councils for information, there were reports that councils were "*not terribly interested*" (Relative of self-funder, SCD26) once it became apparent that a person would be self-funding. Sometimes the lack of help was explicit but at others it was not:

> *She was quite nice, but the implication was, "why are you wasting my time?" (Relative of self-funder, SCH03)*

People in the main felt they received very little help from their councils with information gathering or decision-making. This made them aware that they might have made different choices if they had had more personalised support; they might also have felt more comfortable with their decisions:

> *I didn't make an informed choice when I put mum in the most expensive nursing home in the city, I just thought ooh it's local, we'll worry about the money later (laughs) and it was a worry. (Relative of self-funder, SCH29)*

> *Very difficult to make a decision, very difficult and you're not sure you're making the decision on the right grounds at all really, and I'm still not sure. (Relative of self-funder, SCH03)*

Despite these difficulties, for some people, paying for care for themselves or arranging self-funded care for a relative gave a sense of control and freedom. A common theme from participants was the speed with which they could arrange care, compared with the speed if had they relied on the council. People frequently mentioned long waits to receive council assessments and for care to be arranged. They reported being told the wait for an assessment of care needs was at least 48 hours (for quite urgent cases) but more usually a few weeks; waiting times for a financial assessment could be similar. People found that coming to terms with the need for care and then making the decision to find out about and arrange it, was hard. However, once they had made that decision, they wanted care as soon as possible, and for self-funders that could be arranged within a day or so:

> *We just rang up and somebody came out, because I think they're quite happy to have people who are self-funding, I think […] the private carers and homes like self-funders. (Relative of self-funder, SCD28)*

The same was true for equipment around the home; self-funders felt able to take control and purchase relevant equipment immediately instead of waiting weeks for the same equipment through local councils. There was also a sense that care providers were willing to make arrangements with self-funders very quickly – this is most likely because they are charged a higher rate than local councils and there are also fewer restrictions on the type of care provided.

Sometimes taking a long time to make a decision was desirable. This was particularly so in instances where need was not immediate but likely to become so in the near future. In these circumstances the time to explore choices was valued as was the ability to make an independent choice and settle into a new environment. This contrasts with the current view of councils and social workers that residential care is a place of last resort. Thus being self-funding helped these individuals make timely decisions and plan in advance for increasing care needs.

In contrast, relatives of self-funders ready for discharge from hospital reported feeling under enormous pressure to find out about and arrange care very quickly. Some reported choosing and moving into a care home within a day or two of being assessed as ready for discharge. For others, discharge from hospital to a temporary care home was followed by a move to a different care home within weeks or possibly months. Moving can be very disruptive and unsettling. Senior managers from local councils stressed the importance of enabling people to have the time to make informed choices about their place of residence on discharge; self-funders did not feel they had this time.

It was not just time pressure that made self-funders feel they lacked control. Often, difficulties in navigating the care system left people feeling overwhelmed. A woman in her 60s looking for information about home care for herself made this comment about her sense of control:

> *[I] quite often visualise myself as a beetle lying on its back with its legs flying everywhere in the air, flailing around, and sometimes somebody helpful picks me up and puts me the right way down and I can get on and do things, but at other times I have to work really hard to get in the right position so that I can then address issues myself. (Self-funder, SSD23)*

For others the issue was about losing control to the local council. Although people wanted hands on support from the council, or another third party, too much support could leave people feeling out of control. This could be due to the timing of arrangements and slow moving council processes, or to councils judging the amount (and thus cost) of care needed to be substantially more than people wanted or were willing to pay for.

Discussion

Social care policy in England has been driven by a desire to increase choice, control and personalisation for service users. An assumption when PBs were first introduced was that self-funders had more choices available to them than people in receipt of council-funded services (HM Government, 2007). At the time, this was probably true, as people in receipt of council-funded services had very little choice over their care or care provider. Exceptions were people using cash direct payments, but numbers were small. Since the roll out of PBs, systems to support choice and control have been developed specifically for PB users. Self-funders received very little policy attention until an inquiry into social care funding (Commission on Funding of Care and Support, 2011) considered solutions to the growing crisis and made a number of recommendations relevant to self-funders which were encompassed into legislation in the Care Act (2014).

Our qualitative study suggests self-funders and those looking for care on their behalf are not model consumers and are relatively unsupported in making choices. There is little evidence from this study that self-funders receive a personalised service from local councils with a particular frustration around the lack of specific provider recommendations highlighted. Personal experience and discussions with family and friends were very important in information seeking, and while skills in searching the internet were important this source was tempered by overwhelming amounts of information on care. The individuals in this sample did not consider themselves rich and were reluctant to spend what they perceived as large amounts of money on social care and worried over long-term costs and impacts on inheritance. Views about choice and control were mixed, with some people relishing the freedom to arrange their own care whilst others struggled to make sense of systems and timescales. Practitioners reported trying to judge how much help people need in arranging care and how much information they can digest. The absence of checks to ensure that self-funders acted upon information provided or were receiving appropriate care in the long term raised concerns about inequitable follow up of people who are self-funded compared to PB users.

The study focussed specifically on the experiences of self-funders and their relatives in seeking information about care, thus we are unable to make direct comparisons between the experiences of self-funders and people using PBs, or the social or financial capital and other support they received with making choices. However, the literature on PB users suggests a mixed picture, including a narrow range of choices available to older people using PBs, limited desires to be involved in choice other than at the micro/day-to-day level, but improved outcomes (Hatton and Waters, 2013; Rabiee and Glendinning, 2014; Baxter and Rabiee, 2015; Rabiee et al., 2016).

In considering some of the possible differences between self-funders and PB users, our evidence suggests that self-funders are frustrated that practitioners will not make recommendations about specific providers, with practitioners confirming this but also stating they are unable to give these types of recommendations to PB users either. It is not clear whether practitioners explained this to self-funders or whether self-funders felt they were receiving an inferior level of advice. However, other research evidence (Baxter and Rabiee, 2015; Rabiee et al., 2016) suggests that for older people using managed PBs to purchase care at home, despite the rhetoric that they choose their provider, there is little if any choice. This is because councils contract with limited numbers of providers for managed PB users and, of these, few have capacity to take on new clients at short notice. Thus managed PB users are in effect allocated a provider. In addition, older people using PBs do not wish to take responsibility for choosing providers as they are aware that they do not possess relevant information for making such choices (Rabiee et al., 2016). Moreover, the fact that councils have contracts and regular communication with providers delivering care to PB users means there is a degree of quality assurance and monitoring that may reassure PB users that care should be good quality; self-funders have the choice of provider but without this reassurance.

A further difference between self-funders and PB users is that PB users always receive an assessment of their care needs by the local council, followed by help with planning and arranging care and support. Not all self-funders will present for an assessment of needs and, even for those who do, there is generally little help with arranging care. Without help to understand which difficulties in daily living can be alleviated by care and in what ways, deciding what type and amount of care to choose is a challenge. Thus the fact that assessment of care needs and arranging care are not always formally linked for self-funders may be one of the reasons they feel they lack control and would like the option of help from a professional. However, despite wanting more hands on support, some people felt that this level of support reduced their control. These issues perhaps highlight the need for council (or other) practitioners to tailor the level of support they give to people, regardless of their means of paying for care.

It was suggested at the beginning of this paper that self-funders might be considered model consumers of care, as they have the funds and the freedom to choose the type, amount and provider of their care. The implicit expectation within systems seems to be that people with sufficient assets to be self-funders also have sufficient social and financial capital to navigate the social care system and make meaningful choices, without the support offered to PB holders. Indeed, the social care system has been shaped as a quasi-market founded on competition, choice and control and so the expectation is that service users will act as consumers, weighing up the most effective and cost-effective options. However, to be model consumers, people need to have relevant information. Many people in the UK (however funded) have a limited understanding of the social care system and only begin to learn about it when they need it, usually at a point of crisis. Self-funders, as our evidence shows, are no exception and struggle to access and make use of information, often making choices that they feel are compromised and not well informed.

The evidence also suggests an underlying assumption that financial assets and capacity to arrange care are related. Local councils have a duty of care for all their local residents, not just those whose care they fund. However, limited resources mean they have to focus on those most in need. This includes people not able to arrange care themselves because they do not have the mental capacity to do so, or they do not have family to help them, whether or not they are PB users or self-funders. Although there is a high correlation between people unable to arrange their own care and those funded by the council, that is, using PBs, it is not clear why people with greater assets should be any more or less able to arrange care than those with fewer assets. In fact it could be argued that people with fewer assets or lower incomes are more likely to have had contact with and so be familiar with welfare systems, putting them at an advantage.

Some have argued that policies aimed at encouraging choice (in health care) can, if properly designed, decrease inequities (Dixon and Le Grand, 2006), while others have suggested existing inequities might be exacerbated (Appleby et al., 2003). From the evidence presented, it is not possible to make concrete statements about if or how policies have affected equity of access to information about care or access to care for self-funders compared to PB users. Limited historical evidence about self-funders also means we cannot judge the extent of any changes in self-funders' access to information. However, there are areas where equity might be an issue.

For instance, many self-funders and their relatives expressed a desire to limit the amount of money they spent on care and to protect some assets. There were examples of lower levels of care being purchased than that recommended by councils. If this is a widespread issue, and it may be, as many self-funders have never had an assessment of their needs, then substantial numbers of older people may be receiving less than optimal levels of care. Over time, this might result in them becoming more vulnerable than PB users to falls or other events that could lead to hospitalisation or greater long-term use (and costs) of social care.

Another area of potential inequity is hospital discharge; self-funders and their relatives felt under extreme time pressure to make decisions when ready for discharge after an inpatient stay. An important issue for health and social care in England over recent years has been delayed transfers of care from acute hospitals to the patient's usual or a new place of residence. This situation arises when a patient is clinically ready for discharge from hospital but is waiting for a package of care at home, or a care home place, to be arranged before they can be safely discharged. Social workers arrange care packages for people using PBs, and although they may offer to do so for self-funders, this is not always taken up. Social workers therefore act as intermediaries for PB users, absorbing some of the pressure and potentially making arrangements more quickly. There is anecdotal evidence that self-funders and their relatives take longer to arrange care than PB users. If this is the case then self-funders' longer periods in hospital could potentially increase risks of infection, mortality or morbidity (Rosman et al., 2015).

Finally, our research did not make direct comparisons between PB users and self-funders, nor did it explore the impacts of choice and competition on the quality of life of self-funders, or their use of formal or informal care. These are evidence gaps where future research might help understand differences in access to and use of care services and so facilitate the design of better and more equitable support for people using long-term social care, however it is paid for.

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