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'Paying our own way': application of the capability approach to explore older people's experiences of self-funding social care

DENISE TANNER University of Birmingham, England LIZZIE WARD University of Brighton, England MO RAY University of Lincoln, England

Abstract

Adult social care policy in England is premised on the concept of personalisation that purports to place individuals in control of the services they receive through market-based mechanisms of support, such as direct payments and personal budgets. However, the demographic context of an ageing population and the economic and political context of austerity have endorsed further rationing of resources. Increasing numbers of people now pay for their own social care because either they do not meet tight eligibility criteria for access to services and/or their financial means place them above the threshold for local authority-funded care. The majority of self-funders are older people. Older people with complex and changing needs are particularly likely to experience difficulties in fulfilling the role of informed, proactive and skilled navigators of the care market. Based on individual interviews with older people funding their own care, this paper uses a relational-political interpretation (Deneulin, 2011) of the capability approach (CA) to analyse shortfalls between the policy rhetoric of choice and control and the lived experience of self-funding. Whilst CA, like personalisation, is seen as reflecting neo-liberal values, we argue that in its relational-political form, it has the potential to expose the fallacious assumptions on which self-funding policies are founded and to offer a more nuanced understanding of older people's experiences.

Key words: capability approach; eligibility; older people; self-funding; wellbeing.

Introduction

In the UK, whereas the majority of health care is free at the point of use, funded through taxes paid to central government, social care is funded by local authorities, restricted by eligibility criteria and means-tested. An increasing number of older people are funding all or some of their social care from their own resources, either because their needs fall outside of tight eligibility criteria for care and support services and/or because their financial assets are above the prescribed capital limit for state funding.¹ Despite the growth of self-funders, there is a dearth of information about their numbers, characteristics, needs, spending and outcomes (Baxter and Glendinning, 2014; National Audit Office, 2014). Accurate information is hampered by the sheer complexity of the self-funding landscape, encompassing geographical variations, different types of funding arrangements, multiple care sectors and providers, and changing individual arrangements over time. Whereas outcomes are monitored for adults receiving publicly funded care, the needs and experiences of self-funders are largely invisible (Ismail et al, 2014).

A significant gap in knowledge is how self-funders experience their navigation of care services (Baxter and Glendinning, 2014: 26). This knowledge is necessary to: support local authorities (LAs) in meeting their statutory responsibilities; avoid the creation of unnecessary health and social care costs as a result of older people making uninformed decisions; and establish greater parity between self-funders and people who manage their

¹ This is currently £23,250. The contribution of those who meet eligibility criteria and have assets below £23,250 but above £14,250 is determined by a financial assessment. Local authorities must meet the full costs of care of those with eligible needs who have capital below £14,250. An exception is intermediate services, including reablement, which must be provided free of charge for six weeks to all those eligible, regardless of financial means.

own care via local authority-funded budgets (Miller et al, 2013). Older people are the largest group of self-funders of social care (Baxter and Glendinning, 2014) and amongst those most likely to experience difficulties in accessing and managing their own care (Moran et al, 2013). This paper aims to advance understanding of the experiences of older people living in the community who are self-funding their own social care by applying the capability approach (CA) to these experiences. We first explain and justify our use of CA, then review the literature pertinent to older people's experiences of self-funding. We outline our study methods before applying a relational-political interpretation of CA to the situations and experiences of two of our study participants, selected to illustrate different dimensions. The wider implications for understanding self-funding are discussed in the final section.

The capability approach as an analytic tool

CA is a useful framework for evaluating the impact of self-funding in that both the tool (CA) and the focus of analysis (older people's experiences of self-funding) can be seen as supportive of individual self-determination (Veal et al, 2016) through neo-liberal mechanisms. Here it is important to distinguish person-centred care, concerned with supporting people to take control of their own lives, from 'personalisation', which also professes the promotion of service user choice and control as its central aim, but seeks to achieve this through market-based solutions (Ferguson, 2007). Self-funded care falls under the umbrella of personalisation which operationalises the concepts of choice and control by rendering individuals responsible for selecting and managing care and defining their preferred outcomes. Similarly, CA's concern with individual freedom incorporates the *process* of freedom, 'the ability to *act* to do what matters' and freedom of *opportunity*, 'the

actual opportunity to achieve the functionings that are valued and preferred' (Braber, 2013: 68). Thus both CA and personalisation view the individual as an 'autonomous, rational and self-serving individual motivated towards maximising the benefits that accrue to them' (O'Rourke, 2016: 1010).

The capability approach (CA), originating in the work of Amartya Sen (2005), has been developed and applied in a variety of disciplines. CA is described as a family of theories, which if viewed as a cartwheel, have a shared inner circle but, outside of this, have a number of optional 'wedges' (Robeyns, 2016). Deneulin (2011) suggests that in view of the many different interpretations of CA, it is more appropriate to refer to the capability 'tradition', rather than 'approach. She sees this as characterised by concerns to increase individual wellbeing, defined by capabilities, and respect individual agency. Key concepts within the 'tradition' of CA are: commodities; conversion factors; capabilities; agency or choice; and functionings.

Commodities refer to the resources, goods and services available to individuals to meet their needs. In relation to self-funding, the main relevant commodity is money to pay for social care services. This may originate from older people's own savings or income, including from welfare benefits, or from financial support given by family or others.

Conversion factors recognise that it is insufficient to look only at the means at an individual's disposal; it is also necessary to consider the factors that enable or prevent those means from being utilised to achieve outcomes. Conversion factors include: personal circumstances, such as health, ability and experience; social and cultural environment, such

as policies and cultural norms; and physical environment (Robeyns, 2005). For example, an older person might be relatively affluent but severely disabled, confined to the home and have no knowledge of care services or how to purchase them.

Capabilities are defined by Sen (1993: 30) as 'a person's ability to do valuable acts or reach valuable states of being'. They are 'freedoms of particular kinds' (Sen, 2005: 151), that is, *opportunities* to achieve what individuals value, whether or not they make use of these opportunities. For example, an older person might have the commodities and favourable conversion factors to purchase care services, but prefer to prioritise other needs and spend money in different ways. Whereas capabilities represent potential achievements, *functionings* are the actual performance of ways of doing and being (Sen, 2005).

Whereas Sen (2005) argued that capabilities are context-specific and should not be predefined, Nussbaum (2011) outlines ten essential capabilities that she sees as constituting 'a life worthy of human dignity'. These are 'basic' capabilities, including life, health, and bodily integrity and use of the five senses. Goerne (2010) argues that those applying CA must define their own normative reference points in terms of the capabilities and functionings by which to evaluate policies as these are not intrinsic to CA itself. A normative reference point for UK social care policy is the Care Act Statutory Guidance (Department of Health (DH), 2016), which sets out eligibility criteria for care and support (para. 6.109). Eligibility is based on determination of three conditions: that the needs for care and support arise from or are related to a physical or mental impairment or illness; that as a result of the needs, the adult is unable to achieve two or more of a specified list of ten outcomes; and that failure to

achieve these outcomes has a significant impact on the person's wellbeing (DH, 2016: para 6.101-9).

The outcomes, defined in the guidance as the things an individual is *able to achieve*, can be seen as capability factors whilst the wellbeing measures, referred to in the guidance as *the impacts* of the outcomes being achieved or not achieved, can be viewed as functionings. For example, a disabled older person might be *able* to access facilities and services in the local community independently (an outcome/capability) but *choose* not to do this due to a lifelong preference for a solitary lifestyle (impact/functioning).

CA is criticised for its assumption of self-interested individuals detached from others: 'the priority is individual liberty, not social solidarity; the freedom to choose, not the need to belong' (Dean, 2009:5). Both the selection of functionings by individuals in CA and the implementation of personalisation construct choice narrowly in terms of informed individual subjects having the capacity to identify their wants and needs and select their preferred options for meeting them. The structural factors that create social inequalities and hardships and the social and economic constraints and personal impairments that constrain choice and agency are side-lined (Ferguson, 2007). Mladenov et al (2015) argue that the marketisation of care that has accompanied and infused personalisation has obscured structural dimensions, eclipsed values of trust and co-operation and bestowed service users with responsibility and, therefore, blame. In similar vein, CA has been criticised for failing to allow sufficiently for the influence of social structure on the construction of capabilities (Carpenter, 2009; Dean, 2009).

There is a counter-critique to these arguments in respect of both personalisation and CA. Personalisation developed from a democratic model, rooted in the social model of disability and the philosophy of independent living advocated by disabled people themselves. It has the potential to promote social justice by enabling service users to live their lives on the basis of equality with non-disabled people (Beresford, 2014). However, personalisation as a policy has been implemented in the wake of new managerialism and, furthermore, at a time of austerity, obliterating its democratic potential. Simon Duffy, who led the development of self-directed support in England, acknowledges that personalisation has become one of the routes to spending cuts and, at its worst, morphed into 'zombie' personalisation: 'The language and structures of self-directed support are used, but the underlying spirit is hostile to citizenship and hostile to community' (Duffy, 2014: 178). As far as CA is concerned, Robeyns (2005) argues that it does address the influence of structural factors; first in its acknowledgement of the role of social and environmental factors in permitting or obstructing the conversion of commodities into capabilities, and second, in facilitating or constraining choice at the juncture between capabilities and functionings.

As applied in practice, both personalisation and CA are individualised, rather than collective, approaches to conceiving of needs and outcomes (or functionings and wellbeing). However, whilst individualised approaches to meeting needs through personal budgets obscure the possibility of collective forms of support (Roulstone and Morgan, 2009), the *potential* for collective interventions remains. Similarly, CA can also be applied more democratically. Deneulin (2011) distinguishes between a 'liberal-evaluative' interpretation, focusing on individual freedom and ethical individualism, and a 'relational-political' interpretation, concerned with the political, economic and social conditions that give or deprive people of

capabilities and with relational, rather than individual, reasoning. Deneulin sees a relationalpolitical interpretation as 'bringing issues of politics and power to the heart of the capability approach' (p.3) since the concern is not just to evaluate policy, but to explain and counter capability deprivation. It also embraces what Deneulin (2011: 7) refers to as 'structures of living together', that is, the structures and relationships that influence how people reason.

Here we argue that a relational-political interpretation of CA is a useful analytic tool to expose the realities of experiences of self-funding as it extends the focus from the primary goods, income or resources available to individuals to their capabilities to attain a life of value. More specifically, CA sheds light on: whether and how older people can convert commodities into care and support; how their capabilities in respect of meeting care needs relate to functionings; and whether their engagement with care services enables them to attain wellbeing outcomes. A relational-political lens embraces structural factors that prevent, restrict or facilitate capabilities and relationships that impact on wellbeing.

Legal context of self-funding

Current Care Act 2014 guidance (Department of Health (DH) 2016) emphasises that financial assessment is a separate process from the determination of needs. If individuals referred to the local authority (LA) have eligible needs, their financial means determine the charge levied for care services, not whether they receive assessment and support. However, implementation of the previous community care policy showed that concern about rising demand for social care services and resource shortfalls fuelled the practice of screening people out of assessment and 'signposting' them to third sector services if initial contact

suggested that they were likely to be ineligible for services (Ellis et al, 1999). This included people whose financial means indicated liability for the full costs of care (Commission for Social Care Inspection (CSCI), 2008). The CSCI report found that for some people these signposts led to 'a dead end where they remain with no further assistance' (p.28), while others were propelled into residential care without other options being explored.

LA responsibilities towards self-funders are more clearly defined since the advent of the Care Act and there should, at least in legal terms, be less scope for LAs to take the 'they are nothing to do with us' approach that prevailed previously (Henwood and Hudson, 2008). The Care Act's 'wellbeing principle' (section 1) gives LAs a duty to promote the wellbeing of all adults with care and support needs, including older people who are arranging and funding their own care and support. Those below the eligibility threshold still come within the remit of the LA through the duty to prevent, reduce or delay deterioration (section 2) which applies to all adults. The provision of information and advice to the whole population of an area (section 4) is seen as fundamental to promoting wellbeing and facilitating prevention. The new LA duty to engage in market-shaping and commissioning to ensure the supply of quality services (section 5) also has the potential to benefit selffunders. However, although, as under the previous legislation, the Care Act requires LAs to undertake assessments when there appears to be a need for care and support, irrespective of whether the individual has eligible needs (DH, guidance, 6.6), severe cuts in adult social care mean that LAs increasingly lack the resources to meet core functions (Ismail et al, 2014; Hastings et al, 2015). This context saps optimism about the likelihood of the Care Act having a positive impact on self-funders.

Older people who self-fund their social care

Self-funders comprise a sizeable proportion of those who use care services and their number is increasing (Baxter and Glendinning, 2014). Accurate data is hampered by difficulties in accessing information from providers and differing definitions of what constitutes self-funding (Putting People First Social Care Consortium (PPFSCC) 2011). PPFSCC (2011) estimated that around 44.9% of places in registered care homes in England were self-funded while a follow-up report estimated that about 30% of people receiving home care were self-funders, with another 6% paying for extra services in addition to those funded by the LA. Unsurprisingly, there seemed to be a link with eligibility criteria in that more people were self-funding care in areas where eligibility criteria were stringent.

A study on the impact of tight eligibility criteria for social care services concluded that selffunders 'constitute a significant and often highly vulnerable population, but are often effectively invisible to politicians, service managers and practitioners' (Henwood and Hudson, 2008: 7). It went on to describe them as 'lost to the system', echoing the message of the CSCI (2008) report. Whilst the tactic of diverting people elsewhere via 'signposting' was common, the impact and effectiveness of this was not monitored or reviewed. A stark conclusion of the study was:

People who fund their own care and support might be thought to have the greatest choice and control of all – they can use their money as they please. In practice, the study found that self-funding people on the contrary were often the most disadvantaged and isolated in the whole system.

A second report on qualitative data, 'Journeys without maps', highlighted that crucial decisions about care often have to be made in a crisis, in the absence of information, advice and support (PPFSCC, 2011). Baxter and Glendinning's (2014) scoping review also noted the inadequacy of information and advice for self-funders. Difficulties lie not only in the limited response given to self-funders by local authorities and the tendency to rely on 'signposting' - often a euphemism for 'no help available here' (Henwood, 2014: 83) - but also in people's reluctance to approach them because of the stigma associated with state help (PPFSCC, 2011).

Self-directed support is distinct from self-funded care in that it involves publicly funded, rather than privately funded care; however, some of the findings about how older people access and manage self-directed support are relevant to experiences of self-funding. Indeed, self-funding can be viewed as a different type of self-directed support as both selffunders and individual budget holders are purchasers of their care (Miller et al, 2013).

A key finding from research on older people's experiences of managing their own care via individual or personal budgets is that the responsibility for organising care and managing budgets can generate anxiety (Moran et al., 2013), leading to a reluctance to assume the burden of arranging care (Baxter et al., 2013; Rodrigues and Glendinning, 2015). This seems to be reflected in the low take-up of direct payments by older people. Woolham et al (2016) concluded that the policy aim of independence through personalisation is unrealistic for

older people with complex needs who require support from others in order to exercise choice and control. Moreover, it may not align with their personal priorities and aspirations.

Evidence of older people's experiences of self-directed care corresponds with that on selffunding in that entry to services is often at times of crisis and change, when they feel unable to make decisions and assume new responsibilities (Routledge and Carr, 2013; Zamfir, 2013). This seems to be one reason why less positive outcomes are reported for older people receiving personal budgets than for younger people. For the potential benefits of personal budgets for older people to be realised, all of the following need to be in place: support and guidance at times of crisis and change; strong networks of information and advice; sufficient funding to meet needs holistically; and a well-developed care market giving access to appropriate services (Routledge and Carr, 2013; Zamfir, 2013; Woolham et al, 2016).

Other literature that helps to contextualise the experiences of older self-funders concerns how older people with increasing and often complex needs negotiate losses, manage change and make decisions. Older people invariably need care at the very time when they are facing: multiple losses, such as of abilities, activities, identity and self-worth; fears about the future and concerns about dependency; and conflicting feelings about recognising the need for help but not wanting to be a burden on others (Janlöv et al., 2005; De São José et al. 2016).

Methods: Exploring older people's experiences of self-funding

Our pilot study explored older people's experiences of self-funding and their pathways through finding and using care services. The study arose from discussions with older people, social care practitioners and commissioners that highlighted the complexities of selffunding, the difficulties faced by older people and the challenges of conducting research in this area. The objectives were to identify key areas to explore in a larger multi-site study and to test out methodological processes, including the use of a co-production approach based on research partnerships with older people.

Pilot work was undertaken in two sites in different parts of England between March to November 2015. Ethical approval was given by the relevant University Research Ethics Committees. The study used a participatory methodology, working with a voluntary sector older people's organisation and their established co-researcher group. The academics and older co-researchers collaborated in the design of topic guides for semi-structured interviews and focus groups that would encourage participants to share their views and experiences of self-funded care.

Eight people, recruited via the local voluntary organisation for older people and other local networks, took part in semi-structured interviews. These included seven people who were self-funding and one who was supporting a family member with self-funded care. Two people who were self-funding lived in extra care housing; the remainder lived on their own in the community. All were either widowed or divorced. Their ages ranged from 70 to 92; five were female and three were male. All were of White UK ethnicity. In addition, nine members of a Black and Minority Ethnic (BME) elders group who were supporting family and/or community members in managing self-funded care took part in a focus group,

though this data does not form part of the analysis here.

The interviews were digitally recorded and transcribed verbatim. The transcripts were first analysed thematically (Ritchie et al, 2003) using NVivo software. This identified recurring themes, but lost a sense of participants' individual journeys through the process of negotiating self-funding. The transcripts were therefore subsequently re-read as coherent narratives and presented as case studies, reflecting the previously identified themes. The purpose here is not to give a comprehensive account of the study findings, but to illustrate some of the complexities involved in self-funded care by applying a relational-political CA framework.

Applying a CA lens to experiences of self-funding

The interview transcripts were first analysed thematically. The themes were grouped into two broad categories that related to different stages of the process of finding and using care services. These categories in turn relate to different components of CA: the conversion of commodities into capabilities and the translation of capabilities into functionings (*see Figure 1*).

Figure 1: Summary of categories and themes

Seeking and engaging care:

Factors affecting the conversion of commodities into capabilities

- Poor access to information
- Own needs not prioritised
- Costs of care not justified/prioritised
- Lack of access to available, affordable and appropriate care
- Absence of confidence and trust in services
- Lack of physical and mental ability to source and engage care/ no support from others to do this

Managing care:

Factors intervening between capabilities and functionings

- Stress and anxiety related to care arrangements
- Needs remaining unmet/new needs generated
- Poor quality care outcomes not achieved
- Inability to renegotiate or end care relationships
- Concerns about wellbeing of carers
- Infringement of personal boundaries
- Damaging/devaluing care relationships
- Loss of self-esteem, identity and/or dignity

Reflecting our approach of combining a focus on the coherence of lived experiences via study of the 'case' with identification of themes based on comparison across 'cases', the analysis here is based on illustrations from two participants' transcripts, selected to highlight themes from each of the above categories.

Helen²

Helen is aged 85 and lives with her son. She has multiple health needs, including severe arthritis and glaucoma, and received a local authority funded reablement service for six weeks after her discharge from hospital. Helen explains what happened when the free reablement service ended:

When at six weeks the agency stopped doing it under this scheme and I got horrendous bills from them ... I was taken by surprise by having to pay for it ... eventually I had bills that I almost couldn't pay from that agency. So I stopped it ...I just sort of cut off my communication with them as soon as I could 'cos I got scared about the money.

Helen's experience shows that the costs of care can be a shock, especially for people needing lengthy or multiple visits or who are unfamiliar with the level of fees charged. Eligibility criteria represent the threshold below which needs are not seen as legitimating state funding and which must therefore either be funded privately, met through other sources (such as family) or remain unmet. However, the high threshold means that even people with ineligible needs may face significant difficulties with personal care and everyday living and perceive the costs of care as beyond their means. Their perception of the affordability of care and willingness to prioritise this expenditure are key factors affecting the conversion of commodities into capabilities. Assuming an ability and willingness to pay solely on the basis of a certain level of financial resources ignores individual feelings and perceptions about paying for care, the costs involved and the nature and level of needs.

² The service user names are pseudonyms.

The LA had already identified Helen as a 'self-funder' and she received no assessment at the end of the reablement period. There was no opportunity for her to discuss her concerns, even though they are significant conversion factors that influence the deployment of financial commodities to the purchase of self-funded care. Consequently, Helen ended the service abruptly, with potential adverse implications for her longer-term health and wellbeing.

Other conversion factors are access to information about sources of help and the ability to access these. For Helen, this was facilitated by support she was already receiving from a volunteer from a home library service:

She ... said she had stumbled across somebody who was doing cleaning for other people that she visited and ... she had noticed that this person seemed very caring, so maybe she would help me, and sure enough ... I got in touch directly with (*carer*) ... otherwise I would not have known anybody.

However, even having arranged care does not give Helen the reassurance of knowing that help will be available when she needs it. Without regular administration of eye drops, her glaucoma will deteriorate. This is a particular concern when her son is away at weekends. Even though Helen pays for help, she trades her own needs against her concerns for the carer:

It's hard for me sometimes to winkle out whether I'm inconveniencing the person more than they ought to be. (Carer) is very very sweet, but I have to ask her for things that I'm sorry to ask, you

know, sometimes very early in the morning ... or I feel so self-conscious about the weekends and that's when she's needed the most, because the surgery isn't open.

This illustrates relational factors that intervene between capabilities and functionings. Helen is not acting as a self-interested consumer, but basing her decisions on the perceived impact on the paid carer and moral judgement about what it is reasonable to ask or expect.

It is not just a matter of securing appropriate help, but how receiving care makes Helen feel, which in turn is affected by carer motivation, attitude and behaviour. Helen explains:

(It's) important ... for me to get the feeling that they actually want to do it, and I wouldn't care if the only reason they wanted to do it was the money because at least that would be a genuine motivation on their part.

Helen's account highlights a fundamental difference between the purchase of care and the purchase of commodities; namely that the purchaser, who is assumed to wield power and control in the exchange, is often in a position of vulnerability and insecurity. Helen describes the first time she received help with showering:

You knew that if you didn't hold your nose and jump in it simply wouldn't happen so it was a choice between never having a shower ever again, or getting over the fact that you were going to get undressed in front of someone who wasn't intimate.

A key factor in rendering this care acceptable, and therefore in determining whether receipt of care resulted in improved wellbeing, was the quality of the relationship established with the carer:

One of the two helpers became such a close friend that I can't picture anything that I would genuinely need that she wouldn't genuinely want to do. I mean that sounds very extreme but I got lucky, we're still in touch, we became intimates, very little in common but except for the fact that there was this sympathy on both sides, and she's very good at her job ...

However, even securing good quality care from someone who is liked and valued does not mean that wellbeing is achieved. Helen added,

It's a very hard one because in fact the way I feel way down, way down deep is I don't want you to be here ... the whole procedure ... it's something I don't choose.

Sally

Sally is aged 70, divorced and lives alone. She has had rheumatoid arthritis for over 50 years but has become more disabled with age. She receives a mix of privately funded care and state funded care, provided by different agencies. Sally lives some distance from the town, making it more difficult to find care, especially for short visits:

It's tricky because it's a long way for anyone ... people aren't going to want to drive all the way here for one hour's work are they?

The extra charge to cover carers' travel costs reduces the amount Sally has available to pay for the care itself. The supply of care by private providers is subject to the limitations of the market (Scourfield, 2012) and in rural areas that are difficult to access or have low demand, care costs are likely to be inflated.

Sally accepts the need to purchase private care over and above her state-funded care:

I don't want to be the sort of person who's grabbing every bit of money that they have a right to, do you know what I mean? I don't think that everything is just a right. I want to live with myself so I don't want to get every penny I can get.

Sally's experience demonstrates the significant role of attitudes and values as conversion factors between commodities and functionings. Moreover, it refutes any construction of Sally as a detached and rational consumer acting in her own interests. Rather, she is invoking personal and cultural values to make complex judgement about what help it is morally acceptable to ask for and accept.

Sally's views about exercising control over care via a direct payment resonate with the findings reviewed earlier. Recruiting and managing carers and dealing with the financial management were seen as burdensome tasks that added to the stress and anxiety she was already feeling:

And then you ring somebody and then you interview them and I just thought, oh I can't cope with that, I would find that really difficult interviewing someone. What if you don't like them, it's really difficult isn't it to say, well no I don't think you'll be suitable, you know.

Despite being a self-funder, Sally is obliged to receive a service she does not want and her physical vulnerability and dependence detract from any sense of being 'in control' of her care. She comments: 'It's sometimes really difficult to feel like an equal if you're not equal physically'. Even though she is paying for the service, Sally finds it difficult to voice her wishes and requirements about personal care, partly because she is concerned about the impact on her carers:

I mean, even with my legs, can you put extra (cream) here, and then they're just sort of doing, you know, they're chatting and not necessarily doing quite what you wanted. ... I just think a lot of it's adapting yourself to something that you'd rather not have had, if you know what I mean and I'm a bit shy. ... I know that (carer) has a problem with deformities and so again, I wouldn't like to ask her to put cream on my legs because they're ... not how they should be!'

This reveals the intensely personal and interpersonal nature of the 'service' that is being purchased and the extensive ramifications this has for identity and emotional wellbeing. Wellbeing depends on relational processes through which care is transacted, rather than the 'product' (such as being bathed) itself. Sally reveals some of the subtleties involved in this process as she describes one of her former carers:

She's just like a whirlwind and the minute you opened the door she started talking and she never stopped for an hour!... And she did everything at such a pace ... I do feel uncomfortable when

someone's practically running round ... it makes me feel more disabled, you know, it makes me feel more different if someone's practically running around.

Familiarity and trust in the carer's competence are needed for the functioning of having access to personal care to convert to an outcome of wellbeing:

Someone who doesn't know me coming and doing the bath bit ... I'm lying in the bath when you should be relaxing, getting really anxious about getting out because that is very difficult, getting my legs over the side, getting me onto a stool and down, so I think because I know she's there behind me and she's pretty big and strong ... So if you just had a stranger doing that I'm just not sure. ... she's pretty strong, you know, and I think well, she'll catch me if my leg gives way or something.

Discussion

Applying a relational-political CA lens to participants' experiences of self-funding exposes the fallacy of presumptions that their commodities enable them to exercise choice and control and that their processes of seeking, arranging and managing care are rooted in rational self-interested decision-making.

Starting with the relational dimension of CA, relationships are intrinsic to understanding processes through which commodities are converted to capabilities and functionings to wellbeing. Older people's relationships with others act as commodities in their initial efforts to find care, and the amount and type of care received from informal sources is itself a commodity that generates capabilities and potentially diminishes the need for paid care. At

the level of capabilities, older people's potential to achieve outcomes is enhanced by their formal and informal care relationships when these allow negotiation and choice. As well as influencing decision-making processes, relationship factors are also central in older people's evaluation of functioning or wellbeing. There is abundant evidence that older people view the nature of their relationship with carers as 'a core determinant of the quality of care' (Walsh and Shutes, 2013: 402; see also de São José et al. 2016). O'Rourke (2016) found that the *experience* of personalisation was not about individualised support, but relationships of mutual empathy and understanding, in which both older person and care worker accommodate to each other's needs and preferences.

Like Sally and Helen, older people frequently make decisions about care based on relationship considerations (Sutton and Coast, 2012; Rabiee, 2013; Rodrigues and Glendinning, 2015; Ward and Barnes, 2015). However, this can prevent capabilities from becoming functionings; for example, an older person might refrain from asking a carer to provide weekend care because of concern about inconveniencing the carer. The centrality of relationships means that their decision-making is entwined in considerations about others. Equally, many older people are embedded in networks of relationships and their care arrangements have direct implications for others. For example, Woolham et al (2016) found that the ability of people to manage direct payments and personal budgets was closely linked to the availability of help from others, especially with paperwork.

Outcomes or well-being depend not just on functioning, in the sense of having access to and being able to manage care, but on a range of psychological and emotional factors that influence participants' attitudes and experiences in respect of self-funding. For example, permitting strangers to engage in intimate care of their bodies requires older people to realign their personal boundaries. Relational factors between the care recipient and provider determine whether this is accomplished in a way that enhances wellbeing or, conversely, detracts from it, trust being a key factor (Woolham et al, 2016). The dislocation of identity associated with acceptance of personal care may delay and restrict the *functioning* of 'physical and mental health and emotional wellbeing', even when the *capability* is present in terms of access to purchasing power and appropriate services. This is relevant not only to functioning, in terms of personal dignity and emotional wellbeing, but also to feelings of vulnerability and powerlessness that restrict the ability to operate as an employer.

Moving on to the political dimensions of a relational-political interpretation, the wider structural context that gives or deprives people of capabilities in relation to self-funding has to be recognised if CA is to be a useful tool for understanding experiences of self-funding. There is no straightforward relationship between commodity and capability. Being a selffunder does not in itself indicate affluence. Older people who are self-funding may have fairly high levels of need, just below the eligibility threshold, yet very limited financial resources, restricting their ability and willingness to purchase care. Being a self-funder also does not indicate choice; as O'Rourke (2016) found, 'choice' is not a relevant concept when referring to older people's use of social care. Genuine choice depends on a number of significant conversion factors, including: access to information about services; availability of appropriate service options; the skills and confidence to engage with carers/care providers; the time and capacity to weigh up information and make carefully considered decisions; and a situation that renders the purchase of care a preference, not a necessity. These conversion factors are less likely to be available to older people who are socially disadvantaged.

A combination of structural and relational factors influenced the processes for converting commodities to functionings. Links to sources of help were often a matter of chance (or 'stumbled across', as Helen expressed it); recommendations made by someone known to them helped to establish trust in the service from the outset. However, older people who lack social capital - often those with the highest level of needs – may be the least likely to have access to trusted sources of information. Robeyns (2005) distinguishes between personal, social and environmental conversion factors and here they are intertwined; individual abilities and lifestyles, social networks, community facilities and geographical considerations, such as rural/urban living, all affect connections with potential sources of information and support. Whilst most LAs provide 'signposting' services to direct individuals to relevant sources of help, such as assistance with claiming welfare benefits, this does not address the conversion factors that may deter people from acting on this advice, such as sensory or mobility impairments, lack of confidence, depression, or cultural attitudes that render them resistant to claiming benefits or seeking help.

Conclusion

When evaluating policy from a CA perspective, the central question is whether it is 'conducive to expanding the opportunities for people to live a life they value' (Deneulin, 2011: 3). Many older people who are self-funding their care face numerous obstacles to leading the life they have reason to value. Our application of CA to experiences of selffunding is original and significant in highlighting the differences between purchasing

commodities and purchasing care and facilitates analysis of the complexities involved in finding, arranging and managing care, particularly for older people with multiple needs.

While policy and practice tend to focus on commodities – whether someone's financial means is above the prescribed threshold – our research highlights the significance of conversion factors that intervene between commodities and capabilities and the subtle processes that intervene between capabilities, functionings and experiences of wellbeing. Rather than a straightforward sum in which a certain level of financial assets equals the purchase of care (and thereby assumed wellbeing), CA reveals a far more complex equation involving multiple variables and interactions between personal characteristics (such as age, gender, ethnicity and impairment), available resources, and environment (incorporating physical, social, economic and, political factors (Mitra, 2006). In particular, our findings refute the notion that older people's wellbeing can be viewed as a product of individual purchasing power and consumer choice; rather, it has to be understood as generated through relationships with others (Barnes et al, 2013). This requires the application of a relational-political interpretation of CA (Deneulin, 2011), widening the lens to incorporate networks of care, including those providing care, and viewing capabilities and functionings in collective and relational terms.

To facilitate a thorough analysis and critique of the impact of self-funding policy on older people's wellbeing, CA needs to engage with broader concerns beyond that of 'the life that the older person has reason to value', encompassing mechanisms through which social and economic inequality is created and sustained – causes as well as symptoms (Sayer, 2012). A relational-political interpretation of CA allows examination of the broader context of

capability deprivation; for example, the impact of the lifecourse and structural factors earlier in life that impinge on current capabilities (Lloyd-Sherlock, 2002). It also takes account of the significance of relational factors that influence individual reasoning and decision-making. Further work is needed to develop the potential of a relational-political CA as a critical tool for exposing the social inequalities that underpin the experiences of many older self-funders and, more importantly, for formulating more socially just policy responses to the funding of social care.

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References

- Barnes M, Taylor D and Ward L (2013) 'Being well enough in old age', *Critical Social Policy* 33(3): 473-493.
- Baxter K and Glendinning C (2014) *People who fund their own social care*. Scoping Review, NIHR, School for Social Care Research.

- Baxter K, Rabiee P, and Glendinning C (2013) 'Managed personal budgets for older people: what are English Local Authorities doing to facilitate personalized and flexible care?' *Public Money & Management* 33(6): 399– 406.
- Beresford P (2014) 'Advancing the positives of personalisation/person-centred support: a multi-perspective view'. In: Needham C and Glasby J (eds) *Debates in Personalisation*. Bristol: Policy Press, pp.153-166.
- Braber C den (2013) 'The introduction of the Capability Approach in social work across a neoliberal Europe', *Journal of Social Intervention: Theory and Practice* 22(4): 61–77.
- Carpenter M (2009) 'The capabilities approach and critical social policy: lessons from the majority world?', *Critical Social Policy* 29(3): 351–73.
- Commission for Social Care Inspection (2008) *The State of Social care in England 2006-7*. London: Commission for Social Care Inspection.
- Commission on Funding of Care and Support (2011). Fairer Care Funding: The Report of the Commission on Funding of Care and Support. (The Dilnot Report). London: The Stationery Office.
- Dean, H. (2009) 'Critiquing capabilities: The distractions of a beguiling concept', *Critical Social Policy* 29(2): 261-278.
- Deneulin S (2011) *The Capability tradition: a note on two interpretations*. In seminar on Martha Nussbaum and the Capability Approach. University of Bielefeld, June (Vol. 26).
- De São José J, Barros R, Samitca S and Teixeira A (2016) 'Older persons' experiences and perspectives of receiving social care: a systematic review of the qualitative literature', *Health and Social Care in the Community* 24(1): 1–11.

Duffy, S (2014) After personalisation. In: Needham C and Glasby J (eds) *Debates in Personalisation*. Bristol: Policy Press, pp.167-184.

- Ellis K, Davis, A and Rummery K (1999) 'Needs assessment, street-level bureaucracy and the new community care', *Social Policy and Administration* 33(3): 262-80.
- Ferguson I (2007) 'Increasing Choice or Privatizing Risk? The Antinomies of Personalization', British Journal of Social Work 37 (3): 387-403.
- Goerne, A (2010) The Capability Approach in social policy analysis: Yet another concept? Working Papers on the Reconciliation of Work and Welfare in Europe. Edinburgh: Dissemination and Dialogue Centre. Available at:

http://www.sociology.ed.ac.uk/ data/assets/pdf file/0006/43809/REC-

WP 0301 Goerne.pdf (accessed 14 October 2016)

- Hastings A, Bailey B, Bramley G and Gannon M (2015) *The Cost of the Cuts: The impact on local government and poorer communities.* York: Joseph Rowntree Foundation.
- Henwood M (2014) Self-funders: the road from perdition? In: Needham C and Glasby J (eds) Debates in Personalisation. Bristol: Policy Press, pp. 75-83.
- Henwood M and Hudson B (2008) *Lost to the System? The Impact of Fair Access to Care.* London: Commission for Social Care Inspection.
- Ismail S, Thorlby R and Holder H (2014) Focus On social care for older people:Reductions in adult social services for older people in England. London: The Health Foundation/Nuffield Trust.
- Janlöv A, Rahm Hallberg I and Petersson K (2005) 'The experience of older people of entering into the phase of asking for public home help: a qualitative study', *International Journal of Social Welfare* 14: 326–336.

- Lloyd-Sherlock P (2002) Nussbaum, capabilities and older people. *Journal of International* Development 14: 1163–1173.
- 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. London: OPM.
- Mitra S (2006) 'The capability approach and disability', *Journal of Disability Policy Studies* 16(4): 236–247.
- Mladenov T, Owens J and Cribb A (2015) 'Personalisation in disability services and healthcare: A critical comparative analysis', *Critical Social Policy* 35(3): 307–326.
- Moran N, Glendinning C, Wilberforce M, Stevens M, Netten A, Jones K, Manthorpe J, Knapp M, Fernández F, Challis D and Jacobs S (2013) Older people's experiences of cash-forcare schemes: evidence from the English Individual Budget pilot projects. *Ageing and Society* 33(5): 826-851.
- National Audit Office (2014) *Adult Social Care in England: on overview.* London: National Audit Office.
- Needham C (2011) Personalising Public Services: Understanding the Personalisation Narrative. Bristol: Policy Press.
- Nussbaum M (2011) 'Capabilities, entitlements, rights: supplementation and critique', Journal of Human Development and Capabilities 12(1): 23-37.
- O'Rourke G (2016) 'Older people, personalisation and self: an alternative to the consumerist paradigm in social care', *Ageing & Society* 36(5): 1008-1030.
- Putting People First Social Care Consortium (2011) *People who Pay for Care: Quantitative and Qualitative Analysis of Self-funders in the Social Care Market.* Putting People First Social Care Consortium. Available at:

http://ipc.brookes.ac.uk/publications/pdf/People who pay for care -

report 12 1 11 final.pdf (accessed 30 March 2016)

- Rabiee P (2013) 'Exploring the relationships between choice and independence: experiences of disabled and older people', *British Journal of Social Work* 43, 872–888.
- Ritchie J, Spencer L and O'Connor W (2003) 'Carrying out qualitative analysis'. In: Ritchie J and Lewis J (eds) *Qualitative Research Practice*. London: Sage, pp. 219-262.
- Robeyns I (2005) 'The Capability Approach: a theoretical survey', *Journal of Human* Development 6(1) 93-117.
- Robeyns I (2016) 'Capabilitarianism. Journal of Human Development and Capabilities'. Epub ahead of print 18 February 2016. DOI: 10.1080/19452829.2016.1145631.
- Rodrigues R and Glendinning C (2015) 'Choice, competition and care: developments in English social care and the impacts on providers and older users of home care services', *Social Policy and Administration* 49(5): 649-664.
- Roulstone, A and Morgan, A (2009) 'Neo-liberal individualism or self-directed support: are we all speaking the same language on modernising adult social care?', *Social Policy and Society* 8(3): 333-345.

Routledge M and Carr S (2013) Improving Personal Budgets for Older People: A Review, Phase One Report. London: Think Local Act Personal. Available at: <u>http://www.thinklocalactpersonal.org.uk/ library/PersonalBudgets/TLAPImprovingP</u> <u>ersonal_BudgetsforOlder_PeoplePhaseOne_D4.pdf</u> (accessed 2 April 2016)

- Sayer A (2012) 'Capabilities, Contributive Injustice and Unequal Divisions of Labour', *Journal* of Human Development and Capabilities 13(4): 580-596.
- Scourfield (2012) 'Caretelization revisited and the lessons of Southern Cross', *Critical Social Policy* 32(1): 137-148.

Sen A (1993) Capability and wellbeing. In: Nussbaum M and Sen A (eds), *Quality of Life.* Oxford: Clarendon Press, pp.30-53.

Sen A (2005) 'Human rights and capabilities', Journal of Human Development 6(2): 151–66.

Sutton E and Coast J (2012) "Choice is a small word with a huge meaning": autonomy and decision making at the end of life', *Policy and Politics* 40(2): 211–226.

Veal D, King J and Marston G (2016) 'Enhancing the social dimension of development: Interconnecting the Capability Approach and applied knowledge of social workers', International Social Work 1–13. DOI: 10.1177/0020872816651703.

Walsh K and Shutes I (2013) 'Care relationships, quality of care and migrant workers caring for older people', Ageing and Society 33(3): 393–420.

Ward E and Barnes M (2015) 'Transforming practice with older people through an ethic of care', *British Journal of Social Work*. Epub ahead of print 7 April 2015. DOI:10.1093/bjsw/bcv029.

- Woolham J, Daly G, Sparks T, Ritters K and Steils N (2016) 'Do direct payments improve outcomes for older people who receive social care?', *Ageing and Society*. Epub ahead of print 22 January 2016. DOI: 10.1017/S0144686X15001531.
- Zamfir M (2013) 'Personalisation through personal budgets: its effectiveness for older adults in social care services. Findings from an English-based literature review', *Research, Policy and Planning* 30(2): 77-89.

Author biographies

(Corresponding author) **Denise Tanner** is a Senior Lecturer in Social Work at the University of Birmingham. Her teaching and research interests centre on social work with adults, especially older people. She has a particular interest in participatory approaches in research

and practice. Prior to commencing an academic post, she worked for fifteen years as a social worker in the voluntary and statutory sectors and is still a registered social worker. Recent publications include: Tanner, D. (2016) 'Sustaining the self in the "fourth age": a case study', *Quality in Ageing and Older Adults*, **17**(3): 157-167.

Lizzie Ward is a Senior Research Fellow in the School of Applied Social Science at the University of Brighton. Her research interests centre on ageing and care ethics and she is the Principal Investigator of a Wellcome Trust Collaborative Award investigating ethical issues in self-funded social care. Her recent publications include the edited collection: Barnes, M., Brannelly, T. Ward, L. and Ward, N. (2015) *Ethics of Care: Critical Advances in international perspective,* Policy Press.

Mo Ray is Research Director in the School of Health and Social Care at the University of Lincoln. Her teaching and research interests centre on social work with older people, social gerontology and care and older age. She has a long-standing interest in practice development and in participatory approaches to research and practice. Prior to commencing an academic post, she worked for many years as a social worker and social work manager in the statutory sector. Recent publications include: Phillips, C., and Ray, M. (2016) Ageing in urban environments: Challenges and Opportunities for a critical social work practice. In C. Williams (ed) **Social Work and the City,** Basingstoke, Palgrave MacMillan.