



RESEARCH

Experience of Choice and Control for Service Users and Families of Direct Payments in Residential Care Trailblazers

Jacqueline Damant*, Lorraine Williams†, Raphael Wittenberg*, Stefanie Ettelt†, Margaret Perkins*, Daniel Lombard* and Nicholas Mays†

Context: Direct payments (DP) – cash for care – have been promoted in England as a mechanism to enhance the choice and control of service users living in community settings who are eligible for state-funded care. In 2011, the government decided to pilot DPs in residential care in a few areas and to commission an evaluation of the pilot programme.

Objective: To explore the experiences of care home residents and their families offered a DP, in terms of choice of and control over their care and of their consumer power in local care home markets.

Methods: We held 34 semi-structured interviews with care home residents and family members as part of the evaluation. Interviews were analysed using the “Antagonisms of Choice” framework to study the frictions caused by promoting self-directed care via private market mechanisms within publicly funded systems.

Findings: Findings suggest unequal access to DPs according to residents’ access to family networks, level of cognitive function and underlying physical health. Some participants expressed concern about the effects of DPs on quality of care home services. Several family members using DPs perceived enhanced power in relation to the care providers; others saw no benefit from DPs.

Limitations: Uptake of DPs was lower than expected, potentially limiting the generalisability of these findings.

Keywords: direct payments; residential care; choice and control; older people; personalisation

Background

A direct payment (DP) is a cash payment made by a local authority in England to a person with care needs so that the person can purchase their own care and support (NHS, 2018). Prior to the introduction of DPs, local authorities directly commissioned and managed care services for those eligible for support.

In 2006–2007, to widen user choice, the government piloted Individual Budgets (IBs) in England, designed to consolidate different cash benefits and service-related funding streams (Glendinning et al. 2008). Following the evaluation, a revised form of individual budget, ‘personal budgets’ (PBs), were implemented. These comprised monetary costs to the local authorities of meeting an adult’s social care needs. PBs can be self-managed by the service user (as a DP) or managed on the service user’s behalf by the local authority or a third party (Department of Health 2014). Subsequent governments encouraged the uptake of DPs as the main form of PBs (Netten et al. 2012).

The development of the DP policy became the foundation of the expanding “personalisation of care” agenda, aimed at enabling service users to “choose the exact service they want, when they want it, and who provides it” (Department of Health 2006, p. 15). The concepts of ‘personalisation’, ‘choice’ and ‘control’ in domiciliary (home) care began to merge and self-directed care, through DPs, PBs and IBs, was promoted as a key mechanism for attaining flexible, individualised community care services (Manthorpe et al. 2009; HM Government 2007). Central to the DP initiative was the empowerment of service users as active participants in their care as well as key actors in the care market, driving the demand for more individualised services. The economic reasoning was that personalisation through DPs would engender a ‘cultural shift’ in care delivery and result in greater competition in the market, improve quality of services, and achieve cost efficiencies (Kendall & Cameron 2014).

DPs were originally restricted to adults under 65 years with disabilities who were in receipt of domiciliary care. Later, eligibility for a DP was expanded to include domiciliary services for older people, parents of disabled children, carers and people with mental health problems (Jarrett 2015).

* London School of Economics and Political Science, GB

† London School of Hygiene and Tropical Medicine, GB

Corresponding author: Jacqueline Damant (j.damant@lse.ac.uk)

In 2011, the Law Commission raised concerns about the fairness of making DPs available exclusively to users of domiciliary care services and recommended that the Government consider broadening access to DPs to service users living in long-term residential care settings (The Law Commission 2011). In response to the Law Commission, the Department of Health (DH) launched a trailblazer programme to implement the option of a DP for service users living in residential care and commissioned an independent evaluation (from which this paper draws evidence) in twenty local authorities to test the feasibility and acceptability of the use of DPs in residential care between January 2014 and June 2016, with the aim of extending the offer of DPs to care home residents across England. DPs proved difficult to implement; uptake was far lower than had been expected at the outset (only 40 DPs were deployed during the trailblazers), with many residents and their family members declining the offer of a DP.

During the programme, local authorities mainly offered service users two types of DP. The first consisted of a 'full-DP,' representing the entire care home fee; the second was a 'part-DP,' a payment largely covering the activities portion of the care home fee, with the remainder of the care home fee payment managed by the local authority. By the end of the programme, 21 full-DPs had been set up, primarily for residents aged 65 years and older while 10 part-DPs were deployed, mostly by adults under the age of 65. Two other authorities set up an 'additional payment' scheme involving a monthly supplementary payment to users, over and above the care home fee. Nine of these 'additional' DPs were set up during the programme; all additional DPs were terminated when the programme ended (Ettelt et al. 2017).

Choice and control in the community using self-directed support

Studies of service users' experiences with self-directed care schemes in domiciliary settings in England demonstrate various uses of payments such as home care, transport, short breaks, home adaptations, personal assistance and, less frequently, leisure activities (Moran et al. 2013). Some of the benefits DP users experienced included a greater sense of control and personal power over their care and daily living (Netten et al. 2012; Hamilton et al. 2015), the development of management and administrative skills, and a general boost in self-confidence (Arksey & Baxter 2012). Specifically, some people with mental health problems who used IBs, reported significantly higher levels of quality of life compared to participants receiving care as usual (Glendinning et al. 2008). The benefits of DPs, PBs and IBs most often expressed by older people were a greater sense of control over – and satisfaction with – the type and timing of their daily routines and related care services, the opportunity to develop deeper relationships with carers, and the ability to compensate family carers financially for the help they provided (Rodrigues & Glendinning 2015; O'Rourke 2016; Arksey & Baxter 2012; Woolham et al. 2017; Rabiee et al. 2016; Moran et al. 2013).

However, studies also highlighted some negative aspects of self-directed schemes. Glendinning et al. (2008) found that people with learning disabilities who had accepted an IB had lower self-reported health compared with those who refused one. Some older people reported that IB and PB schemes reduced their quality of life, citing a lack of support and information from local authorities and heightened anxiety arising from the responsibilities of organising their own care (Netten et al. 2012; Moran et al. 2013; Rodrigues & Glendinning 2015; Arksey & Baxter 2012). Fernandez et al. (2007) notes that older people are reluctant to adopt DPs for domiciliary care, especially in less affluent regions of England where there may be fewer care services and independent living support agencies to help with recruitment of personal assistants and payroll management.

International evidence on choice and control in residential care

The international evidence on resident-led care models has also generated substantial debate about the advantages and disadvantages of promoting independence, choice, and personalisation in care home settings (Petrowskyj et al. 2016; Kim & Park 2017). Studies of the North American Culture Change Movement (Koren 2010), where services are largely driven by residents' choice and sense of individuality, demonstrate that residents in care homes dedicated to a personalised approach to care express higher levels of satisfaction with care services than residents of homes less focused on resident autonomy and self-determination (Poey et al. 2017; Bangerter et al. 2017); a decrease in depressive symptoms and an improvement in their quality of life compared to residents in care homes offering less personalised services (Doll et al. 2017). Similarly, person-centred care practices for dementia care in Europe, which include staff training and the promotion of resident-centred activities and social interaction, have the potential to create significant improvements in residents' quality of life and ability to perform activities of daily living as well as reductions in agitated behaviour and neuropsychiatric symptoms (Custers et al., 2013; Sjogren et al. 2013, Ballard et al. 2018).

However, studies also report challenges to promoting choice in residential settings. Hung et al. (2016) draw attention to the conflict between promoting independence and social interaction in care homes with self-service kitchens and the risks to health and safety. Roberts (2016) also refers to trade-offs caused by residents' choice, for example, if they wish to skip meals, which can have deleterious health effects and can be in direct conflict with care staff's duty of care. One study described the negative effects of choices exercised by some residents on other residents' quality of care (Doll 2003). Cooney et al. (2014) and Eritz et al. (2016) examine the challenges in offering choices to residents with advanced dementia and multiple co-morbidities who may be less able to relay their personal history and express their wishes. Finally, several studies suggest that some of the difficulties care staff face include building close relationships with residents and learning how to fulfil their wishes when working in care

homes affected by heavy workloads, high staff turnover and critical time constraints (Hunter et al. 2016; Quasdorf et al. 2017, Simmons et al. 2018).

Antagonisms of choice

Stevens et al. (2011) dissected the difficulties of incorporating 'choice' into a public care system, using Clarke et al.'s (2008) "antagonisms of choice" framework. This three-dimensional model explains the frictions caused by promoting individualistic self-care policies via private market mechanisms, within a publicly funded and resource constrained social care system.

It describes three dimensions: inequality, relationship between private and public care services, and power relationships between service users and paid carers.

The first dimension relates to the reinforcement of existing inequalities that arise from granting individual choice in a community where there is significant variation in social, cultural and financial resources. Clarke et al. (2008) argue that service users' access to social capital (e.g. family connections, ability to mobilise local community resources) predisposes their level of access to – and ability to benefit from – self-directed care schemes, thus generating further inequalities in terms of the range of choices available and individuals' ability to realise their choices.

The second dimension refers to the potential distortion of the organisation, delivery and quality of services within local care markets caused by dispersing the demand and the supply of services across a wide range of services which may be deemed neither professional care nor an appropriate use of public funds.

The third dimension considers the effect of choice on the power dynamics between service users and care providers. Self-directed care schemes are designed to empower service users by redressing the conventional power imbalances of the professional gatekeeping approach to care services (Hamilton et al. 2015), where care professionals bestow their knowledge and expertise on 'grateful' service recipients. Clarke et al. (2008) argue, however, that exercising choice through individual purchase of care services risks thwarting the legitimacy of professionals' appraisals and responsibilities and threatens their role in prioritising and allocating public funds in order to safeguard the health and wellbeing of the wider public (Stevens et al. 2011).

Using this framework in our analysis of interviews with service users and family members, this paper explores service users' experiences and perceptions of choice and control, their position as participants in local care markets and their buyer-supplier relationships with care providers and local authorities.

Methods

This analysis draws on interviews with service users and their family members who participated in the Direct Payments in Residential Care trailblazers. The methods and findings of the evaluation have been published in detail elsewhere (Ettelt et al. 2017). Ethical approval for the project was obtained from the national Social Care Research Ethics Committee (14/IEC08/0011).

Recruitment

As part of the evaluation, all service users and family members who had been offered a DP for their residential care in the trailblazer programme and had either accepted or declined the offer were provided with a questionnaire which included a question on whether they agreed to be contacted for an interview. Those who agreed were then contacted by a member of the evaluation team to organise a suitable date and time for interview. Information sheets were sent to participants providing details of the study, their right to withdraw from the study and their right to anonymity and confidentiality. All interviewees consented to being interviewed in writing.

The recruitment method was designed to preserve the neutrality of the evaluation team such that the analyses and findings would take account of the various ways in which councils interpreted and executed national policy according to their local needs and market structures. The evaluation team therefore did not attempt to influence the promotion – or offers – of DPs.

Data collection

Between January 2015 and February 2016, 34 semi-structured interviews were carried out with 26 care-givers and eight service users. The care-givers consisted of family members of care residents (FAM; n=21) and independent advocates (IA; n=2). All interviews with service users were held face-to-face, interviews with family members and advocates were carried out face-to-face or over the telephone. Two service users were interviewed on two separate occasions: before the DP was implemented and after the service users had started to use the DP. In four cases, the service users were interviewed together with a family member or a paid carer. All interviews were recorded with permission. The interviews explored interviewees' prior awareness and experience of DPs, reasons for accepting or declining a DP, the type and quality of information received when a DP was offered, and how the DP was used and managed.

Interviewees and local authority sites were anonymised by assigning each transcript an identification code. In total, the interviews related to 31 DPs (20 accepted; 11 declined).

Sample characteristics

Table 1 outlines the number of interviews by site according to interviewee type (service user (SU), family member (FAM), or independent advocate (IA)), decision on the offer of a DP (accepted or declined), type of DP (full, part or additional), and age group of the service user to whom the DP offer applied.

In most cases, we spoke to family members who took the decision about whether to use a DP and who also took on the responsibility of administering the DP on behalf of the service user. Of the eight service users we interviewed, six accepted and two declined the offer of a DP. All service users who accepted a DP discussed receiving help with administering and organising the DP from a family member or professional advocate. Two service users in site 7 and one family member in site 12 were interviewed

Table 1: Characteristics of interviewees.

	Interviewee			Direct payment decision		Type of direct payment ¹ (accepted only)			Age of service user (years)			Duration of stay in care home (years)		
	SU	FAM	IA	Accepted	Decl'd	Full	Part	Additional	<65	65–84	85+	<1	1–5	5+
Site 4	0	2		2	0	0	0	2	0	0	2	1	0	1
Site 6 ²	1	1	1	4	0	0	4	0	4	0	0	1	1	2
Site 7 ³	4	5	1	3	6	1	2	0	4	4	1	0	3	6
Site 8	0	2		1	1	1	0	0	1	0	1	2	0	0
Site 12 ⁴	1	10		9	1	9	0	0	1	2	7	5	4	1
Site 14	0	1		0	1	0	0	0	1	0	0	0	0	1
Site 15 ⁵	1	1		1	0	0	1	0	1	0	0	0	0	1
Site 17	0	1		0	1	0	0	0	0	0	1	1	0	0
Site 18	1	0		0	1	0	0	0	0	1	0	0	0	1
TOTAL	8	23	2	20	11	11/20	7/20	2/20	12	7	12	10	8	13

Number of people interviewed: 33

¹ Type of direct payment refers to accepted direct payments only (n = 20).

² One advocate from site 6 was interviewed twice about 2 different service users. The advocate is counted once in the table.

³ Two service users (SU) from site 7 were interviewed twice. Each SU is counted once in the table.

One service user was interviewed alongside a (paid) carer. This is counted as 1 user and 1 family member.

⁴ One interview in site 12 was held with a family member and service user at the same time. This is counted as 1 service user and 1 family member.

One family member was interviewed on two separate occasions. The family member is counted once in the table.

⁵ One interview in site 15 was held with a family member and a service user at the same time. This is counted as 1 service user and 1 family member.

a second time in a follow-up interview to gain insight in their experience of having of having a DP had an effect on their choices and control over their care. Of the 31 DPs discussed in the interviews, 19 were offered to people aged 65 years or older, of which twelve were offered to residents aged 85 years or older.

Data analysis and analytical framework

Interview transcripts were analysed by lead author, JD, according to the Framework Approach (Ritchie & Spencer 1994). To develop the themes, in addition to Clarke et al.'s (2008) "antagonisms of choice" framework described above, we also drew on Stevens et al.'s (2011) analysis of the IB pilot study (Glendinning et al. 2008), which considered various perspectives on choice and control in the context of self-directed care schemes in domiciliary settings. In addition to considering themes related to the potential frictions arising from facilitating individual choice in a communal setting, we identified themes around participants' expectations of choice from direct payments.

During the interviews, all service users and family members, regardless of their decision to accept or decline the offer of a DP, were asked to rate their satisfaction with the care services in their care homes in terms of the degree of choice and control they had over how their needs were being met; participants who had an active DP were asked to rate the services in the light of using their DPs. This prompted participants to describe how they thought DPs

could assist (or not) in promoting greater choice. A matrix was created to chart the relevant extracts from each interview according to the four themes.

Findings

Expectation of choice

Both the participants who accepted and those who declined the offer of a DP commented on their perceptions of the level of choice that adopting a DP could bring. Several participants who declined a DP (n=11) perceived that the funding scheme would not improve their range of choices. For instance, a few family members reported that they were highly satisfied with the choice and quality of services offered by the provider and did not believe that a DP would bring additional benefits:

"The care home already looks at what [my relative] wants to do or use money for a particular social benefit for himself. They would either provide it or make the family know that it's something which he would like to do."

(Fam3 (SU aged 70), Site 7)

Participants who had accepted the offer of a DP (n=20) had varying expectations of the level of choice the DP would enable. The timing of the interviews, resident's age group and type of DP offered (full or part) influenced participants' responses. For example, several par-

participants who had accepted a DP and were interviewed *before* their DP had been put in place, described their enthusiasm for the activities they would undertake with a (part) DP:

“I’m going to go to all the art galleries and National Trust properties.”

(SU2 (aged 62), Site 7)

The experience of choice amongst many participants who had accepted the offer of a DP and were interviewed *after* the DP had started were less positive. Many family members of older residents commented that they were discouraged by the lack of choice despite having a DP:

“If [my relative] needs a wheelchair, I can’t spend [the DP on it], because [the money] is for her care [home fees]. [The DP] makes no difference whatsoever, because it’s either me setting [the payment] up or [the local authority] setting it up. There’re not really more choices because there’re no choices to make.”

(Fam6 (SU aged 85), Site 12)

Differences in experiences were also noted between younger residents, who received a part DP covering the activities portion of the fee, and older residents, who received a full DP covering the care home fee. One family member described a (younger) resident’s positive experiences of having more options with a part DP:

“Her primary wish is to do something different and what she wanted to do. The direct payment allowed her that flexibility...”

(IA1a (SU aged 54), Site 6)

In contrast, family members of residents offered a full DP expressed disappointment at the lack of choices the full DP brought, as discussed by one family member:

“If the [direct] payment had been over and above the daily cost of the care home, I would definitely have used it for [different things]. But it’s the payment we get, there is no money anywhere for anything. I don’t even ask.”

(Fam 7 (SU estimated age mid 50s), Site 12)

Antagonisms of choice exposed by DPs

Equality

The first antagonism of choice described by Clarke et al (2008) relates to the inequalities that are created, or exacerbated, by the “choice” promoted by self-directed care schemes. Stevens et al. (2011) concludes that in order to make good choices one needs access to reliable information and that gaining such access requires a combination of skills, energy, and social and financial resources. It follows that service users who have the necessary skills, support and resources are better positioned to make and benefit from informed choices compared to those who do not.

Indeed, interviewees indicated that the health status of residents and their level of access to additional (unpaid) support strongly influenced their decision to accept or decline a DP, and which by extension, affected their access to an enhanced level of choice and control that DPs are designed to provide. For example, interviewees indicated that access to a DP in residential care was affected by the willingness of a family member or carer to champion and administer the DP on the service user’s behalf. One service user explained that he had declined a DP because the carer he approached refused to assume the administration, and consequently, he was denied the flexibility to engage in activities of his choice outside the care home:

“The [carer] said she would come with me [on outings], but she said ‘I don’t want [to do] it. It is too much paperwork’ and she’d get taxed and all that.”

(SU1 (aged 70), Site 18)

The service user also noted that he would not be able to do the kind of things that he would like to do with a DP because of the severity of his health needs that would prevent him from leaving the home for extended periods. He cited his health as a further reason for declining a DP and for his inability to improve his choice of leisure activities.

Other participants also discussed the lack of fulfilment of choice resulting from residents’ underlying capabilities and health status. For instance, one family member, who was unwilling to manage the DP on her relative’s behalf, emphasised her relative’s lack of motivation and ability to manage a DP herself due to her advanced age of 97 years, demonstrating the limitations of health – and age – related challenges:

“[My relative] just wouldn’t be able to manage it and she wouldn’t be interested in doing it; she wouldn’t want to have the stress. She doesn’t want any responsibility now; she’s very clear about that.”

(Fam5 (SU aged 97), Site7)

An independent advocate acknowledged that DPs could be useful, but believed the resident lacked the capacity to appreciate the flexibility that a DP could offer:

“If [the resident] had a bit more capacity, I think it may have been beneficial to give him more choices. But in [the resident’s] circumstances, introducing a change at his time of life would not be beneficial for him.”

(IA1 (SU aged 70), Site 7)

One family member mentioned the personal financial cost they incurred from administering the DP on behalf of their relative, suggesting that it was not planned for and was potentially problematic:

“I’m going to have to go out and either pay for copies or I’m going to have... I do need a new printer. I’ll probably get one that’s got a copier on it, but my hand is being a bit forced on that. That could

be a bit of a problem; there's an expenditure that I wouldn't have expected."

FAM1 (SU aged 90), site 12)

In summary, interviewees acknowledged that DPs in residential care could potentially improve residents' choices, but that they could not always compensate for the fact that some residents had limited social resources and substantial health care needs, which reduced their abilities to take on and manage a DP successfully and to improve their level of choice and control if they had a DP. Interviewees also discussed the personal costs of administering DP, suggesting that people's personal circumstances may preclude them from using a DP.

Public versus private provision of services

The second "antagonism of choice" underlines the conflict arising from creating a private market mechanism, such as DPs, set within a publicly funded social service (Clarke et al, 2008). The argument for DPs is that they empower service users to become valued stakeholders in local care markets by driving demand for better quality and more appropriate services, ultimately improving the overall cost-effectiveness of public care (Department of Health, 2005). However, Clarke et al. (2008) note that viewing care as a commercial transaction only diminishes the quality of the care relationship. Service users would be compelled to act as rational assessors of their needs and commissioners of their services, even if they experienced illness and distress, adding to the burden of people in need of care instead of supporting them.

In our study, a minority of interviewees explained that some service users gained a degree of market power by using a DP. One family member described a resident's empowered position, where the resident could choose both the type and the provider of her leisure activities. However, the resident's advocate also remarked on the time and effort needed to respond to this resident's requests:

"She originally wanted [the care home] staff that already worked with her [...] Now she would like a different provider to come and take her out with her direct payment. It's been a lot of work, it's taken a long time to get sorted."

(IA1a (SU aged 50), Site 6)

Other participants noted that, contrary to improving their market position, DPs often failed to empower residents and their families as service providers were often unwilling or unable to accommodate their requests. For instance, a family member who had accepted a full DP on behalf of their relative expressed disappointment about the restrictions imposed by the care service, such as not being able to use their DP to pay for lunches at a day-centre instead of the lunches in the care home:

"There is no negotiation in that sort of thing in care homes [...] I would have liked more flexibility."

(Fam 3 (SU aged 85), Site 12).

Similarly, a service user articulated her frustration with spending the (part) DP because of the objections of the local authority to her choice:

"The first meeting I had with [the local authority], it sounded as if I could spend it on anything. But later on [the local authority] started to say I couldn't spend it on everything I was thinking of spending it on."

(SU3 (aged 65), Site 7)

Similar to Clarke et al's (2008) views of the effects of choice on public services, some family members expressed misgivings about the effects of DPs on the distribution of care home resources and on the wellbeing of the wider resident community. For example, two family members who had declined the offer of a DP discussed the risks that DPs posed for the quality of the services provided collectively in the care home:

"The disadvantage to [the care home] is if a direct payment is made, the amount of money they receive from the [local authority] goes down and it makes it tougher for them to budget for the services they provide – particularly the extracurricular events [...] I know care homes are struggling for funds, and if [DPs] remove funds from care homes which they could use better to the benefit of the residents, then I think that's a problem [...] the [local authority] is also concerned about this."

(Fam3 (SU aged 70), Site 7)

Overall, only a small number of participants – mainly those with a part-DP covering the activities portion of the care home fee – described improvements in their market position as direct purchasers of care services. The majority of interviewees perceived DPs as an interference and distraction in the delivery of high-quality care in residential settings.

Power relationships

Clarke et al.'s (2008) third "antagonism of choice" relates to the power to take decisions on the eligibility of needs and the related allocation of resources. In traditional social care power structures, decision-making rests with care professionals and local authorities. Service users *receive* their judgements on the type and severity of their needs and the services deployed to meet those needs (Duffy 2014). Self-directed care policies advocate self-assessment and individual purchasing to redress the power imbalances of the professional gift by shifting care choices and responsibilities towards service users and their families. By contrast, Clarke et al. (2008) argue that the choices delivered by self-assessment of care needs cause disturbance to the legal duties of care providers and local authorities to manage risk, to prioritise the allocation of finite public funds and to safeguard the wider social benefits of social care, all of which rest on the judgement of the care professional (Stevens et al. 2011).

In the interviews, family members noted that they felt dependent on care providers who were able to determine whether they had access to a DP during the trailblazer programme and act as “gatekeepers.” Specifically, some family members commented that they were not offered a DP because the care home had declined to participate in the scheme:

“I found about this direct payment option [...] I followed it up and said I’d be interested [...] we never got to the point of actually talking directly with the provider about the DP option. They [provider] were less than keen to proceed.”

(Fam1 (SU aged 38), Site 14)

The reason for the provider’s decision to refrain from the programme is unclear in this example. However, interviews with care providers suggested that some of them feared the financial risk to care homes associated with (part) DPs and were sceptical of the suitability of DPs for their residents [Ettelt et al., 2017; Lombard et al., 2019].

Some family members expressed similar concerns about the effects of DPs on care practitioners’ authority to those described by Clarke et al. For instance, a family member explained that she had declined a DP because she expected that a DP would allow her relative to make inappropriate choices that could be harmful to her wellbeing:

“My [relative] would make the wrong choice. [For example] she’s put on a lot of weight because the new human rights allow her to eat what she likes, and I don’t think it does her any favours.”

(Fam2 (SU aged 32), Site 7)

Contrarily, some family members noted that access to the DP would help them redress the balance of power between the care homes and themselves. Several family members described their *perception* of enhanced control in their power relationship with the care homes and local authorities through managing a DP. For instance, in terms of their relationship with care homes, family members explained that DPs gave them financial leverage over the home should the family become dissatisfied with the quality of care that the home provides:

“I think [the DP] does give me more control with the care home because if certain things weren’t quite right, I’d just remind them that I’m paying the bill.”

(Fam10 (SU aged 86), Site 12)

Other family members suggested that DPs enabled a rebalancing of their relationship with the local authority. For example, a family member discussed his relative’s perceived vulnerability as a recipient of public support and said that the DP enabled them to gain a sense of control over their relative’s care:

“It’s almost giving me the control that using my own money would give me... [By] using [a DP], I am not

concerned that [the local authority will] decide that they can’t afford for [my relative] to go to this particular care home any longer because they’re putting fees up [for example] and [the local authority] are going to put [my relative] somewhere else and we’ve got to lump it. [With a DP], I have the choice of where [my relative] goes. Because I have the money, [I don’t] feel railroaded into something I don’t approve of simply because of financial constraints.”

(Fam2 (SU aged 52), Site 8)

However, the perceptions of increased power in their relationship with the care provider or local authority was not universal amongst participants. For instance, some participants perceived no change in their relationship with the care home or local authority because of using a DP. One family member discussed that the lack of choices resulting from a full DP reinforced their sense of powerlessness over local authority decisions regarding their placement:

“It’s just fees that have to be paid. I don’t really have any choice; I have to pay it [...] The choice is you pay it or your [relative] doesn’t stay in that home.”

(Fam9 (SU aged 80), Site 12)

To conclude, many family members discussed the effects of DPs on their relationships with care providers and local authorities, where several perceived a shift in the balance of power in their favour. It was unclear during the trailblazer programme whether this sense of control would translate into any changes in practice, as no example of family members challenging providers, for example, by moving their relative to a different home, were observed.

Discussion

Our analysis of the interviews undertaken as part of the trailblazer evaluation highlights the ambiguity of the choice and control agenda for service users living in residential care (Wilberforce et al. 2017; Lloyd 2010).

Our findings expose the tensions between policy objectives caused by existing inequalities between the care home population, indicating that residents who were younger, with higher levels of functioning and more family support, could use DPs to strengthen their market position, while older and more disadvantaged residents without family support were likely to be precluded from these benefits (Tanner et al. 2018). Existing inequalities were also observed by care staff interviewed for the trailblazer evaluation, suggesting that younger residents and those with fewer cognitive limitations, were more likely to benefit from choice and control, and thus more personalised services, associated with a DP than older people and those with cognitive impairments (Williams et al. 2017). There is therefore a tension between the objective of the Law Commission: to extend access to DPs to residential care as a matter of fairness and our finding that the DPs tended to exacerbate inequalities existing in publicly-funded residential care. While the DP in residential care can be seen as redressing the inequity identified by the Law Commission (i.e. between those in community settings and those in

residential care), its introduction simultaneously risks exacerbating inequalities amongst the care home population. These findings echo the difficulties of implementing self-directed care in the community reported in earlier studies and highlight the challenges posed by both the high level of need among the residential care population and the contemporary economics of care homes and residential care funding (Glasby 2014).

The findings also evoke concerns expressed by Ferguson (2007) that promoting personalisation in domiciliary care overstretch individuals' ability to exercise responsibility for their care, which ignores both the diversity and the social and financial inequalities of the people who make most use of publicly funded social services, and creates a care market that favours those who are better able or better supported to assume responsibility for their care, often disadvantaging those with the highest levels of need. Shifting responsibility from the service to the consumer also risks eroding public services and collective risk-sharing, with some arguing that it also deepens the stigma of dependency and vulnerability (Ferguson, 2007).

Applying Clarke et al's (2008) antagonisms of choice framework to the experiences of care home residents and family members who were offered a DP also exposes some of the practical challenges of introducing DPs in residential care settings.

Firstly, the analysis of the equality antagonism suggests that the varying effects of DPs on residents' choice and control in part resulted from the existing unequal access to social resources between younger and older (sixty-five and over) service users, and those with family advocacy and without such social capital. In particular, positive experiences were reported by both younger and older residents with vocal advocates and family members who often waded through the administrative complexities on their behalf. Families and advocates also noted the opportunity costs in terms of time, effort and expense related to coordinating a DP. Service users and family members explained the competing demands on their time and finances and participants alluded to the effort they made to manage a DP. For example, a family member (1, site 12) related they used personal funds to purchase a printer in order to comply with council auditing procedures. Families under more constraining personal circumstances may be unable to make similar concessions and consequently may find the DP scheme inaccessible. Glendinning et al. (2008) observed comparable dynamics in their evaluation of the IBs pilots for domiciliary services that service users who had access to third party support used IBs more successfully than others. In our study, data collected from family members who had accepted a DP showed that family members (or paid advocates) often supplied the motivation and skills needed for the DPs to be effective in increasing choice and control of the service user. Those without such support typically did not – or perhaps could not – accept the offer of a DP, suggesting that such support was seen as essential to facilitate the use of a DP. One implication of our findings could be that if DPs were to be introduced in residential care more widely, such differences in support should be explicitly addressed by

providing additional support for administrating the DP to those with less family resource (Daly 2012).

Secondly, the private versus public antagonism underlines economic inconsistencies inherent in DPs in residential care. In our study, DPs frequently failed as a conduit of buyer empowerment, as expectations of improved choice of services within care homes often went unfulfilled. This could be partially explained by the inevitable 'teething problems' associated with a new programme such as the inexperience of, and poor communication between, commissioners and care home staff (Ettelt et al. 2017). It could also be attributable to the lack of opportunities for service users and family members to spend the DP funds. Examples of a family member (6, site 12) willing, but not allowed, to purchase a wheelchair for their relative, and of a service user (3, site 7) who was denied access to the leisure activities they long to do, pointedly illustrate that improvements in choice can only occur when the DP funds are accompanied by credible alternatives to choose from (Rabiee and Glendinning, 2010). These examples echo Beresford's (2009) observation that self-directed care schemes are only genuinely practicable when there is adequate infrastructure, resources and support for service users and family members to take informed decisions on the choices and opportunities available to them.

However, and perhaps more plausibly, the reluctance of care providers, service users and families to participate in the scheme points to the inappropriateness of the DP as an instrument for improving care in the care home sector (Woolham et al. 2017; Hamilton et al. 2015; Baxter et al. 2011). The current fiscal environment places the public care sector under continued pressure to provide high quality personalised care with diminishing funds to an expanding older population with severe care needs (House of Commons 2018). Indeed, care home managers interviewed for this evaluation expressed concerns that, by shifting clients' funds away from the care home, DPs could further reduce the already precarious amount of state funding available to homes (Ettelt et al. 2018). To manage these challenges, some domiciliary service commissioners limit choices for DP users by reducing the number of providers available in order to achieve economies of scale and to stabilise local care markets (National Audit Office 2016), thereby constraining the choice mechanism that DPs are designed to deliver.

Perhaps DPs in the care home sector might meet more success if they were accompanied by a series of pre-organised, consolidated care alternatives, fashioned by effective co-production initiatives between local authority commissioners and care providers (Daly 2012). The hope will be that actors in care markets learn and adapt to changed local demands and that providers, through continued dialogue and cooperation with local authorities, could potentially develop a range of flexible services that help users to utilise their DP in the desired way without risking the collapse of the market. However, this would also require local authorities to revise the care home fee schedule, and subsequently offer corresponding DPs, at a value that is sufficient to enable care providers to afford to develop more flexible and responsive services.

Thirdly, while DPs disappointed in terms of the hope of more choice for many participants, they led, for some, to an emboldened sense of control. Analysis of the power antagonism highlighted the helplessness that many families experienced when navigating the care home sector, which for some was alleviated to a degree by the DP. For example, some family members of older residents using DPs stated that they had gained a stronger voice in shaping the quality of services vis-à-vis their care homes. With respect to their relationship with local authorities, family members spoke about their amplified sense of agency over their choice of care home. However, during the trailblazer programme, the existing power relationships between care providers, and local authorities and recipients mostly remained unchallenged. Fears of family members and local authority staff that certain uses of DPs could contradict professional expertise and safeguarding roles were speculative and family members' threats to challenge care providers remained hypothetical. Future research should examine whether and how the option to move care homes affects the behaviour of providers and the quality of their services, for example by comparing self-funders and those funded by local authorities.

Family members of younger service users primarily expressed a greater sense of control through using a DP. Family members of older service users never reported any perceived changes in power, which may be attributable to the cognitive and communication limitations of many of the older residents (most of whom were in the advanced stages of dementia) and which prevented families from appreciating DPs as a potential means of improving their relatives' market position. This result also mirrors previous studies of older people's experiences of DPs, PBs and IBs in domiciliary care (Glendinning et al. 2008), and the minimal effects these self-directed care schemes had on older users' sense of control and quality of life (Netten et al. 2012; Woolham et al. 2017). From this perspective, our findings lend support to the apprehensiveness about current cash-for-care models for older adults with high-level care needs (Woolham et al. 2017). They also raise new questions about the beneficiaries of DPs, and whether it is a legitimate aim for DPs to improve choice and control for families involved in organising the care of a relative in residential care, rather than to improve choice and control for residents directly.

Our findings also underline the discrepancies in power relationships between providers and publicly supported and self-funding residents, respectively. Family members likened having a DP to being a private care home client, suggesting they sensed potential differences in the quality of services and level of choice and control that were offered to those who paid for their own care either directly or via a DP. There is no evident disparity in the quality of services provision between state-funded and self-funded residents. Equally, given the narrow eligibility criteria for state funding many service users are faced with the high cost of residential care, leaving many self-funded residents with similar financial and social concerns to residents who are state funded. It seems that self-funding in itself is not a measure of individuals' social capital nor an indicator

of choice and control (Tanner, 2018). However, the perceptions shared by participants in this study suggest that there were tacit or assumed differences in the resident-care providers' relationships between self-funded and state-funded residents in respect of efforts to improve personalisation in residential care.

Our analysis has limitations. First, findings are based on a small sample of experiences. This was due to the low uptake of DPs during the trailblazer programme. In a preceding DHSC feasibility study, Local Authorities estimated that up to 400 people in residential care would adopt a DP. However, care homes reported difficulties in recruiting residents to adopt DPs, which limited the recruitment of participants to the evaluation, where at the end of the programme only 71 DPs had been accepted and of those, 40 were in operation. An in-depth analysis of the reasons for low uptake is provided in Ettelt et al. (2018), which identified the challenges council staff faced in promoting DPs to service users and families due to the lack of proven benefits. This led to a high attrition rate amongst participating councils: at the programme outset, there were 20 official council sites and by its end six sites had withdrawn, and an additional four sites reported not having issued a single DP.

Participant recruitment was also highly dependent on the willingness of individual providers and care home staff to promote the programme and to select suitable participants. However, care home managers explained their concerns about the complexities and costs incurred from organising alternative services in response to service users' new requests. Furthermore, providers expressed deep apprehensions about how DPs would impact on their, often fragile, funding model. As the level of enthusiasm for the scheme amongst providers varied, some councils were unable to collect comprehensive data on the recruitment process and therefore the precise number of DPs offered over the course of the programme was difficult to estimate.

A second limitation stems from the disproportionate representation of family members in our sample, resulting in a somewhat muted service user perspective. Several family members in the current sample confirmed their role as their relative's Power of Attorney, suggesting that without their involvement, it was unlikely respective service users would have been offered a DP. Our sample distribution also reflects the high proportion of people living in residential care who have advanced cognitive and communication impairments, and further emphasises the need for additional resources and support to help residents amplify their voice about their care preferences.

Conclusion

Our findings suggest that DPs for a highly dependent population living in a residential setting might have allowed some families to gain a sense of control, but also introduced new challenges around the equality of access to amplified levels of choice. Future iterations of residential self-directed care policies should consider redefining the beneficiary of a DP to include the wider circle of support that residents need to enable them to exercise their choice

and control over their services. Future policy should also consider preparatory measures for markets to develop a flexible range of responsive care home services that meet the needs of all residents, regardless of their funding status or payment plan, and achieve the necessary efficiencies to sustain reliable, high quality service provision.

Acknowledgements

We would like to thank the care home residents, family members and advocates who volunteered to be interviewed and to share their personal experiences and insights with us.

This analysis is based on independent research commissioned and funded by the National Institute for Health Research (NIHR) Policy Research Programme (Policy Innovation and Evaluation Research Unit; Project No: 102/0001). The views expressed are those of the authors and are not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, its arm's length bodies or other Government Departments.

Competing Interests

The authors have no competing interests to declare.

References

- Arksey, H** and **Baxter, K.** 2012. Exploring the temporal aspects of direct payments. *British Journal of Social Work*, 42(1): 147–164. DOI: <https://doi.org/10.1093/bjsw/bcr039>
- Ballard, C, Corbett, A, Orrell, M, Williams, G, Moniz-Cook, E, Romeo, R, Woods, B, Garrod, L, Testad, I, Carlton Woodward, B, Wenborn, J, Knapp, M** and **Fossey, J.** 2018. Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. *PLoS Medicine*, 15(2). DOI: <https://doi.org/10.1371/journal.pmed.1002500>
- Bangerter, LR, Heid, AR, Abbott, K** and **Van Haitsma, K.** 2017. Honoring the Everyday Preferences of Nursing Home Residents: Perceived Choice and Satisfaction with Care. *The Gerontologist*, 57(3): 479–486. DOI: <https://doi.org/10.1093/geront/gnv697>
- Baxter, K, Wilberforce, M** and **Glendinning, C.** 2011. Personal budgets and the workforce implications for social care providers: Expectations and early experiences. *Social Policy and Society*, 10(1): 55–65. DOI: <https://doi.org/10.1017/S1474746410000382>
- Beresford, P.** 2009. Personalisation, brokerage and service users: Time to take stock. *Journal of Care Services Management*, 4(1): 24–31. DOI: <https://doi.org/10.1179/csm.2009.4.1.24>
- Clarke, J, Newman, J** and **Westmarland, L.** 2008. The Antagonisms of Choice: New Labour and the reform of public services. *Social Policy and Society*, 7(02): 245–253. DOI: <https://doi.org/10.1017/S1474746407004198>
- Cooney, A, Hunter, A, Murphy, K, Casey, D, Devane, D, Smyth, S, Dempsey, L, Murphy, E, Jordan, F** and **O'Shea, E.** 2014. "Seeing me through my memories": A grounded theory study on using reminiscence with people with dementia living in long-term care. *Journal of Clinical Nursing*, 23(23–24): 3564–3574. DOI: <https://doi.org/10.1111/jocn.12645>
- Custers, AFJ, Westerhof, GJL, Kuin, Y, Gerritsen, D.L,** and **Riksen-Walraven, JM.** 2013. Need fulfillment in the nursing home: resident and observer perspectives in relation to resident well-being. *European Journal of Ageing*, 10: 201–209. DOI: <https://doi.org/10.1007/s10433-013-0263-y>
- Daly, G.** 2012. Citizenship, choice and care: An examination of the promotion of choice in the provision of adult social care. *Research, Policy and Planning*, 29(3): 179–189.
- Department of Health.** 2005. Independence, Well-being and Choice, United Kingdom: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272101/6499.pdf.
- Department of Health.** 2006. Our health, our care, our say: a new direction for community services, United Kingdom: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/272238/6737.pdf.
- Department of Health.** 2014. *Care and support statutory guidance: Issued under the Care Act 2014*, United Kingdom: Department of Health. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf.
- Doll, GA, Connelison, LJ, Rath, H** and **Syme, ML.** 2017. Actualizing culture change: The promoting excellent alternatives in Kansas nursing homes (PEAK 2.0) program. *Psychological Services*, 14(3): 307–315. DOI: <https://doi.org/10.1037/ser0000142>
- Doll, GM.** 2003. *An exploratory study of the process of culture change in three Kansas nursing homes (PhD)*. Kansas State University.
- Duffy, S.** 2014. After personalisation. In Needham, C and Glasby, J (eds.), *Debates in Personalisation*. Bristol, UK: The Policy Press: 167–184. DOI: <https://doi.org/10.2307/j.ctt1t892xn.22>
- Eritz, H, Hadjistavropoulos, T, Williams, J, Kroeker, K, Martin, RR, Lix, LM** and **Hunter, PV.** 2016. A life history intervention for individuals with dementia: A randomised controlled trial examining nursing staff empathy, perceived patient personhood and aggressive behaviours. *Ageing and Society*, 36(10): 2061–2089. DOI: <https://doi.org/10.1017/S0144686X15000902>
- Ettelt, S, Wittenberg, R, Williams, L, Damant, J, Lombard, D, Perkins, M** and **Mays, N.** 2017. Evaluation of Direct Payments in Residential Care Trailblazers. Final report. Available at: [http://www.piru.ac.uk/assets/files/DPs in Residential Care Trailblazers – Interim Report.pdf](http://www.piru.ac.uk/assets/files/DPs%20in%20Residential%20Care%20Trailblazers%20-%20Interim%20Report.pdf).
- Ettelt, S, Wittenberg, R, Williams, L, Perkins, M, Lombards, D, Mays, N** and **Damant, J.** 2018. Explaining Low Uptake of Direct Payments in Residential Care: Findings from the Evaluation of the Direct Payments in Residential Care Trailblazers.

- Journal of Social Policy*, 47(3): 505–522. DOI: <https://doi.org/10.1017/S0047279417000794>
- Ferguson, I.** 2007. Increasing user choice or privatising risk? The Antinomies of personalisation. *British Journal of Social Work*, 37: 387–403. DOI: <https://doi.org/10.1093/bjsw/bcm016>
- Fernandez, J-L, Kendall, J, Davey, V and Knapp, M.** 2007. Direct Payments in England: factors linked to variations in local provision. *Journal of Social Policy*, 36(1): 97–121. DOI: <https://doi.org/10.1017/S0047279406000390>
- Glasby, J.** 2014. The controversies of choice and control: Why some people might be hostile to English social care reforms. *British Journal of Social Work*, 44: 252–266. DOI: <https://doi.org/10.1093/bjsw/bcs125>
- Glendinning, C, Challis, D, Fernandez, J-L, Jacobs, S, Jones, K, Knapp, M, Manthorpe, J, Moran, N, Netten, A, Stevens, M and Wilberforce, M.** 2008. *Evaluation of the Individual Budgets Pilot Programme: Final Report*, Available at: <http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>.
- Hamilton, S, Tew, J, Szymczynska, P, Clewett, N, Manthorpe, J, Larsen, J and Pinfold, V.** 2015. Power, Choice and Control: How Do Personal Budgets Affect the Experiences of People with Mental Health Problems and Their Relationships with Social Workers and Other Practitioners? *British Journal of Social Work*, p.bcv023-. DOI: <https://doi.org/10.1093/bjsw/bcv023>
- HM Government.** 2007. Putting people first: a shared vision and commitment to the transformation of adult social care. Available at: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118.
- House of Commons.** 2018. *Long-term funding of adult social care*, London: Health and Social Care, Housing, Communities and Local Government Committees. Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/768/768.pdf>.
- Hung, L, Chaudhury, H and Rust, T.** 2016. The Effect of Dining Room Physical Environmental Renovations on Person-Centered Care Practice and Residents' Dining Experiences in Long-Term Care Facilities. *Journal of Applied Gerontology*, 35(12): 1279–1301. DOI: <https://doi.org/10.1177/0733464815574094>
- Hunter, PV, Hadjistavropoulos, T and Kaasalainen, S.** 2016. A qualitative study of nursing assistants' awareness of person-centred approaches to dementia care. *Ageing and Society*, 36(6): 1211–1237. DOI: <https://doi.org/10.1017/S0144686X15000276>
- Jarrett, T.** 2015. *Briefing Paper. Social care: Direct Payments from a local authority (England)*, London: House of Commons Library. Available at: <http://researchbriefings.files.parliament.uk/documents/SN03735/SN03735.pdf>.
- Kendall, S and Cameron, A.** 2014. Personalisation of adult social care: Self-directed support and the choice and control agenda. *British Journal of Learning Disabilities*, 42(4): 264–271. DOI: <https://doi.org/10.1111/bld.12069>
- Kim, S and Park, M.** 2017. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clinical Interventions in Aging*, 12: 381–397. DOI: <https://doi.org/10.2147/CIA.S117637>
- Koren, MJ.** 2010. Person-centered care for Nursing home residents: The Culture Change Movement. *Health Affairs (Millwood)*, 20: 312–317. DOI: <https://doi.org/10.1377/hlthaff.2009.0966>
- Lloyd, L.** 2010. The individual in social care: The ethics of care and the “personalisation agenda” in services for older people in England. *Ethics and Social Welfare*, 4(2): 188–200. DOI: <https://doi.org/10.1080/17496535.2010.484262>
- Lombard, D, Wittenberg, R, Ettelt, S, Williams, L, Perkins, M, Damant, J and Mays, N.** 2019. Evaluating direct payments in residential care: The perspective of care home providers. *International Journal of Care and Caring*. DOI: <https://doi.org/10.1332/239788219X15538555769480>
- Manthorpe, J, Stevens, M, Rapaport, J, Harris, J, Jacobs, S, Challis, D, Netten, A, Knapp, M, Wilberforce, M and Glendinning, C.** 2009. Safeguarding and system change: Early perceptions of the implications for adult protection services of the english individual budgets pilots – A qualitative study. *British Journal of Social Work*, 39(8): 1465–1480. DOI: <https://doi.org/10.1093/bjsw/bcn028>
- Moran, N, Glendinning, C, Wilberforce, M, Stevens, M, Netten, A, Jones, K, Manthorpe, J, Knapp, M, Fernandez, J-L, Challis, D and Jacobs, S.** 2013. Older people's experiences of cash-for-care schemes: Evidence from the English Individual Budget pilot projects. *Ageing and Society*, 33(5): 826–851. DOI: <https://doi.org/10.1017/S0144686X12000244>
- National Audit Office.** 2016. *Personalised commissioning in adult social care: report by the Comptroller and Auditor General*, London: National Audit Office. Available at: <https://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-update.pdf%0Ahttps://www.nao.org.uk/wp-content/uploads/2016/03/Personalised-commissioning-in-adult-social-care-summary-update.pdf>.
- Netten, A, Jones, K, Knapp, M, Fernandez, J-L, Challis, D, Glendinning, C, Jacobs, S, Manthorpe, J, Moran, N, Stevens, M and Wilberforce, M.** 2012. Personalisation through individual budgets: Does it work and for whom? *British Journal of Social Work*, 42(8): 1556–1573. DOI: <https://doi.org/10.1093/bjsw/bcr159>
- NHS.** 2018. Personal budgets. Available at: <https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/> [Accessed September 21, 2018].
- O'Rourke, G.** 2016. Older People, Personalisation and Self: An alternative to the consumerist paradigm in social care. *Ageing and Society*, 36(5): 1008–1030. DOI: <https://doi.org/10.1017/S0144686X15000124>

- Petriwskyj, A, Parker, D, Brown Wilson, C and Gibson, A.** 2016. What Health and Aged Care Culture Change Models Mean for Residents and Their Families: A Systematic Review. *The Gerontologist*, 56(2): e12–e20. DOI: <https://doi.org/10.1093/geront/gnv151>
- Poey, JL, Hermer, L, Cornelison, L, Kaup, ML, Drake, P, Stone, R and Doll, G.** 2017. Does Person-Centered Care Improve Residents' Satisfaction With Nursing Home Quality? *Journal of the American Medical Directors Association*, 18(11): 974–979. DOI: <https://doi.org/10.1016/j.jamda.2017.06.007>
- Quasdorf, T, Riesner, C, Dichter, MN, Dortmann, O, Bartholomeyczik, S and Halek, M.** 2017. Implementing Dementia Care Mapping to develop person-centred care: results of a process evaluation within the Leben-QD II trial. *Journal of Clinical Nursing*, 26(5–6): 751–765. DOI: <https://doi.org/10.1111/jocn.13522>
- Rabiee, P and Glendinning** 2010. Choice: What, when and why? Exploring the importance of choice to disabled people. *Disability and Society*, 25(7): 827–839. DOI: <https://doi.org/10.1080/09687599.2010.520896>
- Rabiee, P, Baxter, K and Glendinning, C.** 2016. Supporting choice: Support planning, older people and managed personal budgets. *Journal of Social Work*, 16(4): 453–469. DOI: <https://doi.org/10.1177/1468017315581529>
- Ritchie, J and Spencer, L.** 1994. Qualitative data analysis for applied policy research. In Bryman, A and Burgess, RG (eds.), *Analysing qualitative data*. London: Routledge: 173–194. DOI: https://doi.org/10.4324/9780203413081_chapter_9
- Roberts, E.** 2016. Negotiated risk and resident autonomy: Frontline care staff perspectives on culture change in long term care in Nova Scotia, Canada. *Work*, 54(4): 837–851. DOI: <https://doi.org/10.3233/WOR-162373>
- 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. DOI: <https://doi.org/10.1111/spol.12099>
- Simmons, SF, Durkin, DW, Rahman, AN, Schnelle, JF and Beuscher, L.** 2018. Managing Person-Centered Dementia Care in an Assisted Living Facility: Staffing and Time Considerations. *The Gerontologist*, 58(4): e251–e259. DOI: <https://doi.org/10.1093/geront/gnx089>
- Sjogren, K, Lindkvist, M, Sandman, PO, Zingmark, K and Ecvardsson, D.** 2013. Person-centeredness and its association with resident well-being in dementia care units. *Journal of Advanced Nursing*, 69(10): 2196–2206. DOI: <https://doi.org/10.1111/jan.12085>
- Stevens, M, Glendinning, C, Jacobs, S, Moran, N, Challis, D, Manthorpe, J, Fernandez, J-L, Jones, K, Knapp, M, Netten, A and Wilberforce, M.** 2011. Assessing the role of increasing choice in english social care services. *Journal of Social Policy*, 40(2): 257–274. DOI: <https://doi.org/10.1017/S004727941000111X>
- Tanner, D, Ward, L and Ray, M.** (2018) 'Paying our own way': Application of the capability approach to explore older people's experiences of self-funding social care. *Critical Social Policy*, 38(2): 262–282. DOI: <https://doi.org/10.1177/0261018317724344>
- The Law Commission.** 2011. *The Law Commission*, London: The Stationary Office.
- Wilberforce, M, Challis, D, Davies, L, Kelly, MP, Roberts, C and Clarkson, P.** 2017. Person-centredness in the community care of older people: A literature-based concept synthesis. *International Journal of Social Welfare*, 26(1): 86–98. DOI: <https://doi.org/10.1111/ijsw.12221>
- Williams, L, Ettelt, S, Perkins, M, Wittenberg, R, Lombard, D, Damant, J and Mays, N.** 2017. Will direct payments make adult residential care more personalised? Views and experiences of social care staff in Direct Payments in Residential Care Trailblazers. *Social Policy and Administration*, 51(7): 1060–1078. DOI: <https://doi.org/10.1111/spol.12276>
- Woolham, J, Daly, G, Sparks, T, Ritters, K and Steils, N.** 2017. Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment. *Ageing and Society*, 37(5): 961–984. DOI: <https://doi.org/10.1017/S0144686X15001531>

How to cite this article: Damant, J, Williams, L, Wittenberg, R, Ettelt, S, Perkins, M, Lombard, D, and Mays, N. 2020. Experience of Choice and Control for Service Users and Families of Direct Payments in Residential Care Trailblazers. *Journal of Long-Term Care*, (2020), pp. 42–53.

Submitted: 23 September 2019

Accepted: 02 March 2020

Published: 17 April 2020

Copyright: © 2020 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Unported International License (CC BY-NC-ND 3.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by-nc-nd/3.0/>.



Journal of Long-Term Care is a peer-reviewed open access journal published by International Long-Term Care Policy Network based at the London School of Economics and Political Science.

OPEN ACCESS