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## article

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# Family matters: personal assistants' experiences of engaging and working with their employers' families

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Many people in England employ care workers using state funding or their own resources. This article explores working relationships, communications and experiences of personal assistants with their employers' family members. Data from interviews with 105 personal assistants (in 2016–17) were analysed to explore relationships and experiences. Three overarching themes related to personal assistants' engagement with family members arose: (1) possible complications over accountability and employment; (2) support for family; and (3) being part of care teams. This article provides new insights into personal assistants' relationships with employers' family members, highlights the relevance of the concept of immaterial labour and sets out a research agenda.

**Key words** personal assistants • direct payments • family • consumer-directed care

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## Background

As Fleming et al (2019) recently observed, there are many international examples of individualised funding being part of government social care support. In England and some other countries, encouraging people to employ their own care workers using such funds has become near symbolic of governments' promotion of choice in social care (Christensen and Pilling, 2014; Gill et al, 2018; FitzGerald Murphy and Kelly, 2019). In part, this ability to employ care workers directly by using a personal budget from a local authority mirrors consumer behaviour among those with the financial

resources to make such transactions independently of state funding. Under the Care Act 2014, adults eligible for publicly funded adult social care in England must be offered a personal budget to meet their needs. This personal budget can be managed by the local authority, held in an account by a third party or provided as a direct payment; for those lacking capacity to make such arrangements, a family member may assume the financial responsibilities. In 2017, around 240,000 people in need of care and support received direct payments, of whom 75,000 employed staff directly, with, on average, each person employing two people (Skills for Care, 2019: 18). These figures do not include self-funders and their family members who employ care workers using their own resources, including disability allowances (Baxter and Glendinning, 2015).

There has been substantial research on direct payments, some of which has explored the arrangements and relationships between the people in need of care and the individuals they employ as care workers. Shakespeare et al's (2018) interview (face-to-face, telephone and email) study of 35 personal assistant (PA) employers (care users) and 29 unmatched PAs found that some used the metaphor of a family-type relationship to suggest that PAs felt that this was appropriate for tasks that they performed either out of love and/or a sense of duty rather than simple instrumental economic transactions. More broadly, in a study of migrant care workers working directly for care users, Christensen and Manthorpe (2016: 141) suggested that such arrangements could be characterised as 'emotionalised relationships', adding: 'While these characterise much care work and may be very rewarding to both parties emotionally, they are heightened by the direct employment relationship that is not mediated by a manager or by colleagues, or a wider employment infrastructure of human resources personnel.' They suggested that the risks of such employment were unequally shared, often hidden from public view and 'personalised' by structural pressures to individualise care relationships.

Other studies have explored the views of the carers or relatives of people receiving direct payments or personal budgets, such as Moran et al (2012), who interviewed 129 carers (mostly face-to-face) and a control group as part of the IBSEN (individual budget evaluation) studies in a set of pilot sites hosting the individual budget initiative. Most carers interviewed in that study reported that their own lives had improved as a result of the greater flexibility enabled by an individual budget (a precursor to personal budgets) and data showed that they had better outcomes compared to the study's control group. Similarly, Larkin's (2015) interviews with 25 family carers of a person with a personal budget found that these had resulted in positive outcomes for over three quarters of her sample. Larger sample sizes confirm these findings, with a postal survey of 1,500 family carers and semi-structured interviews with 31 carers (Woolham et al, 2018) – all supporting an older relative – noting that while they retained direct involvement in their relatives' care, carers perceived that they had greater flexibility to juggle caring tasks with other activities. However, those carers supporting their relatives who had direct payment funding experienced higher levels of stress compared to those whose personal budget was administered by an agency that employed the care workers and made payment and other arrangements. The authors suggested that this was linked to the pressure of responsibilities for administration and the day-to-day management of care arrangements without support from the local authority, echoing some of the earlier predictions made by a carers' advocacy group that the new opportunities of direct payments were providing both choice and

chore (Carers UK, 2008). Findings from an interview study of 18 carers of people with severe and/or fluctuating mental health problems found that they also played a particularly influential role in initiating, pursuing and maximising the level of support available through personal budgets – the personal cost of which was generally accepted in light of the improved outcomes for their family members (Hamilton et al, 2017).

While this literature suggests some common themes among family members in supporting the implementation of personal budgets and direct payments, there is little evidence from those employed to provide care and support by this funding mechanism, or employed using an individual's or family's own resources, about their relationships with family members. This may be surprising considering the sizeable literature that has reported on the role of PAs as part of personalisation or consumer-directed care (Fleming et al, 2019), and the emerging interest in self-funders who pay directly (Baxter and Glendinning, 2015; Baxter et al, 2017). Considering this, our overarching research aims were to fill some of the evidence gaps about the PA role for workforce policymakers and the wider social care and healthcare sectors. We term directly employed care workers or self-employed care workers as 'personal assistants' and those employing or hiring them as their clients. The main research aims relevant to this present article were:

- to complement and update existing knowledge by identifying and describing any barriers to PA working, including difficulties with employers; and
- to identify any barriers to PA working and vulnerabilities of the PA role, including difficulties with employers and dispute resolution.

## Methods

### *Recruitment of participants*

This study interviewed a sample of 105 PAs in 2016–17 from different parts of England recruited using contacts within disability groups, employer-led organisations and centres for independent living. The networks and contacts helped advertise the study by contacting PAs on our behalf, sending them details about the study and requesting that PAs contact a member of the research team if they were interested in taking part. 'Snowballing' techniques were also used with PAs to identify other PA colleagues. Potential participants were then invited by letter or email to take part in a telephone interview and sent a study information sheet and consent form. Expressions of interest were followed up by telephone or email by the lead researcher (John Woolham), verbal or written consent was obtained, and all interviews were carried out by telephone (as with Shakespeare et al [2017]). Following the interview, participants were sent a letter of thanks and a high-street gift voucher to acknowledge their time. In addition, a set of interviews with policy experts and experts from disability groups and employment bodies was undertaken to provide contextual detail and different insights and perspectives. Findings from these latter interviews are reported elsewhere (Woolham et al, 2019a).

### *Data collection*

Telephone interviews enabled participants to schedule the interview at a convenient time. Interviews varied in length but took just over an hour on average. With consent, all interviews were digitally recorded and transcribed verbatim. Interview

transcriptions were pseudo-anonymised; participants were assured of confidentiality unless the interviewer felt that there were risks of harm, either to the direct employer of the PA or to the PA by the employer (in which case, there would be a referral to local safeguarding agencies or an appropriate agency).

### *Interview topic guide*

A semi-structured, conversational-style interview schedule was developed, informed by reviews of the literature covering self-funding employers (Manthorpe and Hindes, 2010) and by previous studies of direct payments or similar, of carers and personal budgets, or of individualised funding (for example, Woolham et al, 2018). Two advisory groups were consulted on the evolving interview topic guides and their comments were integrated into the final version. The interview schedule comprised open- and closed-format questions, with prompts to aid discussion where necessary.

### **Ethics and governance**

The study was an independent study funded by the National Institute for Health Research (NIHR) Policy Research Programme. Members of the User and Carer Advisory Group of the NIHR Policy Research Unit in Health and Social Care Workforce helped shape the study's initial research questions and methods. A favourable ethical opinion from the Health Research Authority was gained (IRAS ID 208501). A safeguarding protocol was developed should any concerns arise during the course of the interviews; on two occasions, we recommended that the PA seek advice from a relevant local agency about their circumstances. For the purposes of ease of reading, we refer to the PAs as 'employed' and the care user or family member as 'their employer', though a third of PAs were self-employed and the relationship was therefore contractual (Woolham et al, 2019b).

### **Analysis**

Data transcripts were first analysed using a statistical approach to collate details of participants' background, demographic characteristics, work history, current employment and terms and conditions (see Woolham et al, 2019a, 2009b). We initially undertook quantitative analysis on the closed-format questions using SPSS v22. Subsequently, qualitative data were analysed using framework analysis (Ritchie and Lewis, 2003). Data were entered into NVIVO qualitative research software to aid management. Transcripts were read and the arising themes were coded freely outside of the structure. These were discussed by the research team, all of whom were university-based researchers, including a gerontologist, former care worker employer, local authority and health service researchers. Two research team members (Caroline Norrie and Kritika Samsi) coded half the PA interviews each, and regular team meetings and cross-coding discussions of a small sample of interviews ensured that team members developed shared perspectives on coding decisions. Data covering relationships with family members are reported in this article and participant quotations are labelled according to their 'care work background', which encompasses those PAs with experience of care work and healthcare in sectors such as homecare, care homes, hospitals, housing support and children's social care, but not schools.

## Participant characteristics

Participants were mainly female ( $n = 91$  [87 per cent]), white ( $n = 90$  [86 per cent]) and British ( $n = 97$  [92 per cent]). A large minority ( $n = 41$  [39 per cent]) had previously worked in care or health-related work, most commonly homecare ( $n = 25$  [24 per cent]), with a further ten (10 per cent) referring to unspecified care work and six (6 per cent) holding nursing or healthcare assistant roles. This suggests that they may have been very likely to have experience of working with and alongside family members in previous jobs. Only four were relatives of the person for whom they were working. Their mean age was 45 years. Many ( $n = 61$  [58 per cent]) had previously been, or were currently, family carers, though not of the person currently employing them. The length of time that they had worked directly for care users or families varied, with 23 per cent employed by their current client for less than six months, while another 13 per cent had worked for the same client for over five years. The most common reason for leaving their previous PA work was the death of their client.

It was common for the PAs to be employed by more than one person, or to have several clients; indeed, only 41 (39 per cent) worked exclusively for one person, with the average number of clients being three per PA. Not surprisingly, this meant that very few worked full-time for one person. Few (four) of our sample were 'live-in' workers, whose commitments were generally full time but episodic; these were less likely to be working for more than one individual. While self-employed, these live-in workers had often been linked up with the individual or family through a care placement agency that undertook negotiations about the terms and conditions of the arrangements but was not the employer. Overall, participants with previous experience of care work reported that working as a PA provided far more job satisfaction than working for a care agency, partly as a result of reduced pressure to move rapidly from one client to another, giving more time to focus on the person and not just the tasks needed. Most perceived the PA role as providing the opportunity to be genuinely person-centred and relationship-based, often promoting a deeper relationship with their client and enabling more intuitive understanding of how best to offer support.

## Findings

Three overarching themes emerged from analysis of the interview data covering PAs' relationships with family members of the person for whom they were working (referred to as the client): (1) complexities of the relationship with family members; (2) support for the family as well as the individual client; and (3) being part of a team that included family members. [Table 1](#) shows sub-themes within the three overarching themes.

The employment contractual status of PAs varied, with many employed by their client (37 per cent) and a sizeable number (18 per cent) by family members. The near third (32 per cent) who said that they had self-employed status was difficult to classify in terms of whether the contract (formal or implicit) was with an individual or their representative. Overall, the complexities of these relationships indicate the value of our research approach in talking with individuals about their work, rather than setting out a range of options that they may have found hard to fit to individual circumstances. Additionally, although nearly a quarter (24 per cent) had no written contract, another fifth (20 per cent) had a contract with one of, but not all, their

**Table 1: Overarching and sub-themes of the data**

Overarching themes	Theme 1: Complexities of relationships with family	Theme 2: Support for family	Theme 3: Teamwork with family
Sub-themes	Family member explicitly the employer and exercising authority	Family member also in need of care and/or emotional support	Trust and mutual support
	Family member and care user taking employer role	Relationship-centred care for the whole family	PA teams and family
	Conflict and potential exploitation	Risk of over-involvement	

employers, and many who did have a contract said that it was vague or did not reflect the actual content of their role, accountability and responsibilities.

### Theme 1: complexities of relationships with family

#### *Family member explicitly the employer and exercising authority*

Most PAs had been recruited by a family member and several more said that they dealt with family members on a day-to-day basis. This seemed to be the case both when the care user was in receipt of local authority direct payments and when PA wages were paid from family funds. Some PAs with experience of local authority care work were familiar with direct payment arrangements but other PAs were uncertain about the source of their payment. Moreover, PAs often considered that regardless of the source of their pay, what was important was who had control of finances. In the following example, one PA recounts her experience that when relatives held the purse strings she was not often paid on time, which had led to problems with her own household budgeting (most PAs were paid just over the minimum wage):

‘Well, it’s more when you have to deal with family or people that have got authority over their relative’s money. When you invoice them, what I do is ask for it to be paid by a certain date that’s on the invoice that if, you know, people do make excuses quite a lot, so sometimes it takes a week or two, mostly two weeks you get that amount you’re supposed to be paid. It’s more ... I think that’s the worst aspect for me is juggling because everybody likes to pay different ways and people pay differently.’ (PA07, female, care work background)

Other instances of authority being exercised by family members related to their insistence about what was acceptable and safe care. At times, this differed from what some PAs knew to be good practice in the care sector and consistent with health and safety guidelines, such as using a hoist for safe moving and handling:

Interviewer: ‘What sort of things would be criteria for deciding not to take somebody on? Would there be things that would put you way outside your comfort zone?’

PA: ‘Yeah, there are some people that expect PAs to do things that perhaps wouldn’t happen in a care home. Like, “We don’t have a hoist, because ... we lift mother” ... you know what I mean? Where, because I’m a PA, I still

want the hoist, and I think there's people out there that are still being lifted and things like that.'

Interviewer: 'It's odd because things like hoists can be readily made available, so you'd think it would be easy.'

PA: 'I know, but you do hear things like, "Oh, mother wouldn't allow that", or "She doesn't want that."' (PA24, female, care work background)

Such experience may account for many PAs' impressions that some employers did not wish their PA to undertake training that might have alerted them to their right to safe working conditions.

### *Family member and care user taking employer role*

At times, some PAs experienced the whole of the immediate family of the person they cared for or supported acting as the employer. This led to potentially conflictual requests or instructions. Some thought that these tensions might be underpinned by dysfunctional family relationships, for example, long-standing family disputes about money or control. Illustrative of this, discussing her experience with one family where the client was a young disabled woman, a PA recounted:

PA: 'I think that, even though she's the employer, she's highly influenced by her parents, and because of the way the parents are, she just lets them decide, kind of thing. Rather than thinking, "No, I'm the employer. If I want to pay for my PA's food on this trip, then I'll pay." Do you know what I mean? It's like, "Oh, well it's a lot of money, etc", that kind of thing.'

Interviewer: 'Yeah. Okay. [Pause.]'

PA: 'It's like her parents are the employer, not her.' (PA43, female, non-care work background)

### *Conflict and potential exploitation*

A few PAs reported times when that they had felt exploited and, as a result, had left a previous job or been asked to leave (see [Woolham et al, 2019b](#)). However, most examples of conflict and exploitation were less overt and referred to pressure and 'tricky' negotiations. Whatever the extent or type of conflict or disagreement, all PAs quickly realised that they were on their own in such a situation. None reported having any support from the local authority or from a disabled people's organisation (even where the latter had helped in arranging their work). For many PAs, the security of having more than one job, or income from a pension, may have cushioned any loss of income from one source and so leaving a 'tricky' employer or family situation was possible. However, the situation seemed more distressing and financially precarious when PAs were 'living in' (perhaps unsurprisingly). Those who had considerable experience of care work or wider human services work seemed more sanguine about how to manage such situations, as illustrated by this PA:

'I guess I'm coolest about it from the point of view of dealing with the families; sometimes, that can be a bit tricky. I think I've found it quite difficult to say no sometimes, and I've felt a bit pressured to do things, or to work



when it's not really convenient for me. Yeah, so I think, pressure to do things and not really feel able to say "No" because you've got that personal tie. It's a bit of a double-edged sword: that's a really, really, lovely thing but it can also be quite tricky as well. Yeah, so the responsibility of that, I think ... and also, I think, sometimes, dealing with the family members' issues ... oh, I don't want to say issues – like, their worries and their concerns. You know, sometimes, dealing with that can be quite tricky, I think, as well.' (PA49, female, care work background)

This PA regarded the disabled person as her client but acknowledged that "the thing is as well, what you've got to remember or perhaps consider, is the daughter was the one who signed the cheque at the end of the day [laughs]".

## Theme 2: support for family

It was evident in their accounts that many PAs saw their role as providing practical and emotional support to members of their client's family. This could involve tasks that were agreed or simply general help with family arrangements and household chores. Some PAs considered themselves to be in the blurred position of a family friend who expected payment: "I'm there as a friend for mum and there to support the family and sometimes if [child] needed picking up from school and mum's stuck in traffic, I'd go for her, but I wouldn't expect to be paid for that" (PA25, female, care work background).

### *Relationship-centred care for the whole family*

As an element of their wider work, some made clear references to relationships with several family members to whom they also offered emotional support in the acknowledgement that these relatives were providing substantial care: "I feel as though I'm helping not just the person I'm caring for, but the whole family – taking some of the burden off them – and I feel ... it's nice to feel useful. I'm certainly not doing it for the money [laughing]" (PA18, female, non-care work background).

### *Risk of over-involvement*

Such assistance could be outside working hours and indicated the blurring of boundaries between some PAs and families. This was illustrated by one example recounted by a PA who was an experienced worker previously employed by a local authority to support people with Down's syndrome but was now working as a PA for clients with similar conditions:

'The lady that I support in her flat, you know, I've grown very close to her mum and dad and her dad has just lost his sister, so, you know, it was nice to be at the end of the phone if they wanted to chat. We went over and took some flowers and stuff. So, you know, it's not just about supporting the person; it's about being there. Sometimes, you know, for their families as well because a thing I find with a lot of families is there's a lot of guilt because their child



is born that way, so I'm supporting, so, you know, it's about supporting the families as well, not just that person.' (PA50, female, care work background)

However, at times, PAs thought that their support for the family appeared to be taken for granted, especially if extra support for family members took place outside working hours and was not remunerated. The following example emerged when the interviewer was asking about payment terms and conditions:

Interviewer: 'But do you ever find yourself doing any unpaid overtime? You know, you might be halfway through doing something with somebody, and time's up, but you'll carry on, obviously, because people do.'

PA: 'Yeah ... I think the main time that that would happen, that I've found as a PA, is when you finish the session, or whatever you're doing, and then the parent will need to talk, and quite often, it is a conversation – to me, I feel like I'm still working. So, it might be a conversation about their concerns about their son or daughter, it might be a conversation about how the session has gone, it might be a conversation about some frustrations they have, that's usually what it is.'

Interviewer: 'Do you think they see it as work or they just see it as having a –'  
PA: 'Yeah, I think they see it as, they need to offload because they are in such a stressful situation, quite often, and often they're in quite a desperate situation as well, and there might not be somebody for them to talk to, and they just need to ... talk.' (PA50, female, care work background)

### Theme 3: teamwork with family

#### *Trust and mutual support*

A feeling of trust and of mutual regard underpinned some comments about feeling part of a team that included the PA and family members, and potentially other PAs, in providing care:

'The three best things? Hmm.... The challenge, the respect between each other, the love. I could name a few, you know. Every day is never the same. The bond. I could go on, mate. I could go on. There's loads, there's loads of good things. Family, we're like a big family. I know all his family, his mum and dad, his girlfriend who just moved in with him, all his other PAs, just like a big team.' (PA42, male, non-care work background)

Becoming part of a team could take time and seemed fostered by the PAs' continuity with their employers, in contrast to what many saw as the disadvantages of working for a care agency, where time was short and several clients were on the rota of visits. In the following illustrative example a PA reports how her new client, who was living with dementia, had previously only accepted personal care from her daughter and trust had to be built up over time:

'Only to the extent that, when I first started working with this lady, her only carer was her daughter and she wouldn't actually accept any care from

anybody. So, when I initially started working for her, she wouldn't accept personal care, but because she liked me, and gradually she began to trust me, now she accepts any care that I administer, if you see what I mean. She trusts me entirely, so if I say "We should do this", such as check to see that the pad is comfortable and dry, and she trusts me, so she just goes along with it, in a sense.' (PA08, female, care work background)

### *PA teams and families*

Only a small proportion of PAs worked as part of a team with other PAs. Some discussed supportive relationships, though their contact with other PAs was generally limited to exchanging information at handovers. There were also clear variations of practice depending on their client, revealing that different boundaries were sometimes set that might involve some moral judgements about whether the family members were 'deserving' of assistance: "one lady, she had two PAs – a morning and an afternoon – and I was the afternoon and I did do her daughter's washing. The other PA refused" (PA52, female, care work background). Most had not known the other PAs working for their clients previously, but described being able to fit in with their way of doing things. As noted earlier, the sample contained a few live-in care workers. These had less contact with their shift replacements but did have some form of handover at the start or end of their stay (often for two-week blocks) and so formed a team in the sense that they could all report back to the family members who paid them. These live-in care workers had often found their job through a care placement agency but were not agency employees; for some, this made it difficult to raise concerns about the family or to work as a team to share ideas or new practices (a problem not exclusively found among live-in PAs).

However, for most PAs who were not living in, being part of a team with the family could mean that the PA felt obliged to assist the family, even at the cost of their own personal family time – a theme that touched on other themes, as noted earlier. In such cases, the PA might feel guilty about not sharing their client's family load or pressure, as the following example of a PA supporting a profoundly disabled young woman illustrates:

'It's hard. It's like ... I've got a family myself, so I suppose, if I needed time off with my children, or I'm unwell, with us being ... our lady having such a big care package, with her having 24-hour care, it does become quite hard sometimes to cover big shifts, so to get time off, it's not as easy as it would be in some jobs because it puts a lot of pressure onto other people.' (PA28, female, care work background)

## **Discussion**

### *Strengths and limitations of the study*

This was a large interview sample from across England and the semi-structured format enabled participants to give a reflective account of their experiences in the knowledge that what they said would not be reported to their employers, as well as to provide demographic and work-related data to contextualise their roles. The recruitment of PAs was mediated by contacts with disability groups, among others, which could

have produced a sampling bias. These limitations are perhaps inevitable as there is no national register of PAs and they are an occupationally isolated workforce. Participants were self-selecting and their accounts were not triangulated with the views of family members or their clients. While telephone interviews may have their disadvantages, this method seemed to provide the time for considerable conversation and probing where necessary, perhaps assisted by not requiring travel or hospitality.

### *Relationship to other studies*

While there were differences between our sample and those of a recent [Skills for Care \(2017\)](#) study, in that very few PAs in our sample were relatives of the person with care needs, our sample may be more representative of the directly employed care workforce. The Skills for Care study recruited through two large local brokerage organisations. In that study, over half (52 per cent) of PAs surveyed were working for a friend or family member. Family and friends in such roles were less likely to have experience of care work, access training and hold care-related qualifications than those working for clients with whom they had no previous connection as a family member or friend ([Skills for Care, 2017](#)). By contrast, most of our sample had substantial experience of care-related work. Our sample's employers were not generally known to them previously; therefore, when starting their new job, they needed to build relationships with the client and their family members. Several had family or friend connections with social care but, as other studies have observed, this is often the case with care workers and health and care professionals more broadly ([Manthorpe et al, 2012](#)). It appeared that those with such experiences were more able to draw on them to set some boundaries and to negotiate 'tricky' situations or personalities.

Few studies have highlighted that PAs often have more than one source of employment and may only provide a few hours of support to each employer a week. If there are substantial calls on their time by an employer's family, this may be difficult to sustain unless the PA chooses to take this as a demonstration of friendship rather than exploitative employment.

The data reported here suggest that [Christensen and Manthorpe's \(2016\)](#) theory of 'emotionalised relationships' is not only applicable to migrant care workers, but also relevant to PAs. Some participants in the present study, like some migrant workers, identified the risk of enmeshment through emotional ties to their employer and also, or perhaps instead of, to a family member for whom they have empathy or high regard. While such emotional ties may be rewarding, there are risks to both parties of exploitation, moral judgements about the 'deservingness' of support and 'performing' emotions.

[Gorz's \(2010\)](#) concept of 'immaterial labour' links PA work with other forms of human service work (for example, that of doctors or nurses) in that it is both 'hands on' (involving personal care, housework, transport and so on) and face to face (involving listening, mediating, comforting and so on). As with other professions, the concept of immaterial labour may be relevant to PA work, which appears to require judgement and discernment, openness of mind, and the ability to synthesise formal with experiential knowledge. Such immaterial work can be demanding and stressful, and made more so by its content – experiences of disability, illness, fear, pain and dying. As noted by others ([Iliffe and Manthorpe, 2019](#)), the stresses of immaterial labour are intrinsic to the work of nursing and medicine but our study suggests that

they are also part of PA work. PAs may become more skilled at the tasks of immaterial labour but the emotional relations remain hard and family members seem to assist or add to such pressures.

### *Implications for research and workforce development*

The article provides new insights into PA working relationships with family members. It would be helpful for future studies to consider a triadic method (Payne and Fisher, 2019a), whereby data could be collected from three parties: the client, the family member(s) and the PA. This would allow for a direct triangulated comparison of experiences and perspectives that may be fruitfully examined, as done by Payne and Fisher (2019b) in respect of power and subordination, as well as by Broady (2014) in respect of carers' confusion with the consumer model of care. Notable in our study was the lack of mention by PAs of any social work or local authority presence in reviewing and monitoring among those receiving local authority funding. Research could perhaps help with the development of approaches that might help support PAs in their work, including skills to sustain immaterial labour and reduce the risk of burnout. As our data show, much of the PA workforce may be very experienced, and sustaining them in the care sector may be one further way of addressing the problem of high turnover and substantial vacancy rates in social care. Similarly, contact with public services might assist PAs in developing their careers, either to take on more specialised PA roles – for example, working with people with major healthcare needs (see Norrie et al, 2019) – or to step up to new neo-professional roles in health and social care, such as nursing associates, where their experience would be valued, more financially rewarded and better recognised.

### *Implications for practice and policy*

For those working with family members, this study suggests the importance of alerting the families to the need to consider how they will relate to any PA that they employ, directly or indirectly. This may be best approached by bringing in insights from families themselves, who can draw on their own experiences and learning. Those advising potential PAs might also encourage them to consider that they might wish to maintain boundaries and establish proper terms and conditions from the outset, while also making the most of the opportunities that the work may give for fulfilling and meaningful relationships. If things begin to go wrong, then practitioners should be ready to signpost PAs to sources of help, while commissioners may wish to invest in third-sector groups that welcome enquiries from PAs, as well as employers, about the potential and realities of direct employment, which often includes relationships with their client's family.

## **Conclusion**

This study has provided the opportunity to consider PA and family relationships in the context of direct employment. It has noted the strengths of such relationships but also the blurred boundaries that may be hard to manage alone. It has also drawn attention to the relevance of the concept of immaterial labour to this work. It has also observed the heterogeneity of the PA workforce – some of whom were extremely

experienced – and the often-overlooked fact that many work for several employers simultaneously. For a PA, being person-centred seems to involve trying to negotiate several people's interests and wishes.

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### Conflict of interest

The authors declare that they have no conflict of interest.

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