



King's Research Portal

DOI:

[10.18742/pub01-005](https://doi.org/10.18742/pub01-005)

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Woolham, J. G., Norrie, C. M., Samsi, K., & Manthorpe, J. (2019). Roles, responsibilities, and relationships: hearing the voices of Personal Assistants and Directly Employed Care Workers. London: NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London.
<https://doi.org/10.18742/pub01-005>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Roles, responsibilities, and relationships: hearing the voices of Personal Assistants and Directly Employed Care Workers

John Woolham, Caroline Norrie, Kritika Samsi and Jill Manthorpe

NIHR Policy Research Unit in Health and Social Care Workforce
The Policy Institute, King's College London



September 2019

Table of Contents

Roles, responsibilities, and relationships: hearing the voices of Personal Assistants and Directly Employed Care Workers	1
Acknowledgements and disclaimer	5
Introduction.....	18
Methods.....	21
Objectives.....	21
Design and methods	21
Findings.....	25
1. Who are PAs?	25
2. Why did PAs choose this work?.....	29
3. Who do PAs work with, what is their employment relationship, and what do they do?	32
a. <i>Who do PAs work with?.....</i>	<i>32</i>
b. <i>Employment situations.....</i>	<i>33</i>
c. <i>What do PAs do?.....</i>	<i>34</i>
4. Recruitment	44
a. <i>Finding the right employer: the perspective of PAs</i>	<i>44</i>
b. <i>Finding the right PA: key informant perspectives</i>	<i>45</i>
c. <i>What makes recruitment easier/harder? PA perspectives</i>	<i>47</i>
d. <i>What makes recruitment easier or harder? Key informant perspectives</i>	<i>51</i>
<i>PA registers: PA perceptions of advantages and disadvantages.....</i>	<i>53</i>
e. <i>PA registers: key informant perceptions of advantages and disadvantages</i>	<i>54</i>
f. <i>Matching skills or experience of PAs with requirements of employers: PA perspectives</i>	<i>57</i>
g. <i>Matching skills or experience of PAs with requirements of employers: key informant perspectives</i>	<i>58</i>
5. The distinctive nature of the PA role.....	62
a. <i>PA perspectives about differences between working as a PA and working in other care settings</i>	<i>62</i>
b. <i>Key informant perspectives about the distinctiveness of the Personal Assistant role</i>	<i>65</i>
6. What makes an effective Personal Assistant?	67
a. <i>Views of Personal Assistants</i>	<i>67</i>
b. <i>Key informant perspectives.....</i>	<i>69</i>
<i>Strengths.....</i>	<i>70</i>
<i>Weaknesses.....</i>	<i>71</i>
7. Employment status and working conditions.....	74
a. Findings from PA interviews.....	74
b. <i>Key informant perspectives.....</i>	<i>83</i>
8. Safeguarding	87

a. <i>PA experiences of abuse or unreasonable behaviour by employers</i>	87
b. <i>Key informant perspectives on safeguarding and protecting PAs</i>	91
c. <i>Key informant perspectives on safeguarding of employers</i>	96
9. Training and support for PAs	99
a. <i>Findings from PA interviews</i>	99
b. <i>Key informant views on the training and support needs of PAs</i>	100
c. <i>Key informant views about initiatives planned or underway to support or develop the PA role</i>	103
10. Training and support for employers	107
11. Interest in expanding the PA role to take on more health-related tasks	112
a. <i>PA perspectives</i>	112
b. <i>Key informant perspectives on scope for the PA workforce to be employed by people with Personal Health Budgets</i>	112
12. Personal Assistants and other community health and care professionals ...	117
a. <i>The experiences of PAs</i>	117
b. <i>Key informant views on the co-ordination of the PA workforce with other community professionals</i>	118
13. Barriers and facilitators to the development of Personal Assistants in the social care workforce.....	122
a. <i>PA perspectives</i>	122
b. <i>Key informant perspectives</i>	122
Discussion	126
Limitations and strengths of the study	126
Underlying issues	137
Conclusions	143
References	146

List of tables

Table 1. Participating organisations and individuals, key informant interviews.

Table 2. Employment relationships of PAs

Table 3. PA views about average weekly income.

List of figures

Figure 1. Were any of the following reasons for you starting work as a Personal Assistant?

Figure 2. Does your job involve providing care and support for...?

Figure 3. How long have you been working as a paid Personal Assistant – for the person you started working for most recently?

Figure 4. During your work as a Personal Assistant, do you perform any of the following duties for your employer?

Figure 5. Tasks PAs did not do but would be willing to if asked

Figure 6. Tasks PAs said they would not want to carry out, even if asked to do so.

Figure 7. Tasks PAs said they would not carry out because they had not received training.

Figure 8. Tasks PAs said they should not be asked to do.

Figure 9. PA Perceptions about what might make an effective Personal Assistant.

Figure 10. Have you had any training about any of the following since becoming a Personal Assistant?

Figure 11. Do you have any contact with other Personal Assistants – in your area or on-line?

Acknowledgements and disclaimer

The authors thank several groups of people for their contribution to this study. We are grateful to members of the then NIHR Social Care Workforce Research Unit's Service User and Carer Advisory Group for their advice about questionnaires and research design; to policy officers at the Department of Health and Social Care, to members of Skills for Care's Personal Assistant (PA) Framework Steering Group for their early support and contacts; and to the many people working in Centres for Independent Living, Disability Rights and user-led organisations who helped put us in touch with PAs. We thank our key informants, who shared their knowledge and insights. Last, but certainly not least, we thank the PAs themselves who talked to us about their experiences of working as PAs.

This study was funded by the National Institute for Health Research (NIHR) Policy Research Programme (Policy Research Unit in Health and Social Care Workforce: Ref. PR-PRU-1217-21002). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Roles responsibilities and relationships: hearing the voices of Personal Assistants and directly employed care workers: Summary

Key findings

Who are Personal Assistants (PAs), what they do, and are they interested in extending and developing their role?

The 105 PAs who took part in this study were overwhelmingly female (87%), White (86%) and British (92%). Their average age was just under 45 years. Over a third had dependent children and a similar proportion cared for someone else in their own family. Most had previous experience of working in a care setting before becoming a PA. On average, people had been working as PAs for 4.5 years. Half had other jobs. Most were directly employed or employed by a relative of the person needing support or care, but a third were self-employed. Just under half had a qualification relevant to their PA job. Most were working for someone with physical disabilities, but a wider range of other 'care-groups' were also mentioned. A third were working for the same employer since starting work as a PA. Where changes of employment had occurred, this was most frequently due to the death of an employer (31%) but unreasonable or abusive behaviour was mentioned (12%) as well as a move into residential care (10%).

PAs were asked questions about the tasks they carried out, about any other tasks they would be willing to do if asked, and whether there were any tasks they would not do – either because they had not been trained or because they felt it was not something a PA should do. The responses revealed that PAs were highly flexible about the kinds of things they would do, but some drew the line at any involvement in the financial affairs of their employer, holidaying with them, and looking after their children. Some were reluctant to help with health-related tasks such as medication or dressings because they had not had the necessary training.

PAs were asked if they might be interested in expanding their role to take on health-related tasks because of the current roll-out of Personal Health Budgets (PHBs). Only 17% said they did not already carry out tasks that could be described as health-related. The majority expressed interest in expanding their role but wanted to be properly paid for the extra responsibility and be given higher pay in recognition of having acquired new skills. There was no consensual view among key informants (other people interviewed who are familiar with PA work). There was awareness that funding arrangements for PHBs differed from Direct Payments (DPs); amongst them the challenge that choice and control might present to clinically led, evidence based health care. Questions about matters such

as role demarcation, access to training, budget 'topping up' and insurance were also raised.

Finding a PA or an employer

Both PAs and a small number of employers, or people working in Centres for Independent Living or User-Led Organisations who were key informants, agreed that finding the right person was vital if the relationship was to work. They felt that 'personal chemistry' and 'matching' of PA and employer were vital to successful recruitment. Key informants emphasised the need for clarity from the outset about the PA role and tasks, and for both PA and employer to be clear about the kind of person they were looking for. This was generally much more about shared values and outlooks and not about specific kinds of skill or experience.

Key informants were asked what kinds of things made recruitment easy or difficult, what methods they used and how successful these were. Informal recruitment channels and local advertising were generally favoured. Commercial websites (for example Gumtree) were seen as expensive. PA registers – usually set up by user led organisations or Centres for Independent Living and funded (at least in part) by a Local Authority (LA) were thought useful too, but only if they were properly maintained, updated and monitored. One organisation that ran a register insisted on compulsory basic training, undertaking of Disclosure and Barring Service (DBS) checks, and ensuring that people were registered for tax and had adequate insurance before they could register (this scheme required PAs to be self-employed). Student placements had been used with some success by a very few informants. There was general agreement that Job Centres were poor places to recruit PAs since the PA role was not well-understood, and many applicants were simply fulfilling benefit requirements by applying. Things that made recruitment easier were prior relationships and 'word-of-mouth'. Local labour market conditions could also make it hard to recruit in affluent parts of England where unemployment was very low. Both PAs and informants mentioned the importance for both employer and PA of being clear about the role and having a proper contract.

What's distinctive about PAs, and what are their strengths and weaknesses and what makes them effective?

Most PAs had previous experience of working in social care and were able to compare their current role with previous jobs. Most said they had found working as a PA far more fulfilling and rewarding. Key ingredients to this were that there was time to build a caring and respectful relationship with their employer, which meant greater consistency in care or support. Many key informants felt that direct control over employment meant that people needing support or care were much more likely to get what they required, and that the PA role was more flexible, adaptable and responsive to changes in the employer's health.

PAs felt that to be effective as a PA, respectfulness, having appropriate background checks, willingness to learn, and to adapt to the employer's individual needs, family, social and cultural backgrounds were most important. A less tangible skill that was regarded as highly important was an awareness of, and ability to negotiate and maintain 'boundaries' to their relationship with their employer. Some PAs gave examples of how a failure to set or maintain boundaries had created problems in their relationship with their employer. Key informants added that lack of previous experience was something some employers often actively sought so the PA could be trained by the employer rather than working from experience. Informants also drew attention to what some saw as obstacles to effectiveness. These included PAs who had a 'carer mentality', who found it difficult to set and manage 'boundaries', the comparative absence of skills when working with people who had complex needs, and where the employed PA was a family member. It was recognised that in some situations, a family member might be the right person to employ as a PA, but concerns were also expressed about the employment role creating fundamental changes in relationship between family members which could be damaging.

What are PAs' employment status and working conditions?

Just over half of PAs said they had a written contract and job description: the rest either had no contract (24%) a contract for only some of those for whom they worked (20%) (PAs generally worked more than one employer) or did not know (2%). Half described having fixed hours with occasional variation and over a quarter (29%) that their hours were always variable. Most were on 'flat rate' contracts and so received no overtime payment for anti-social hours, bank holiday work or weekends. A large proportion (43%) said they did unpaid overtime. This amounted to about 3 hours per week, on average. Most PAs did not receive travel expenses and over a quarter (28%) said they were not provided with relevant disposable items such as gloves or aprons. For this group of PAs, if such things were needed, they had to buy them themselves.

Only a minority (17%) overall were contributing to a pension scheme: although multiple employments meant that while the hours worked exceeded entitlement thresholds, they were not exceeded for individual employments. Almost a quarter (22%) were not paying national insurance but for some this may have been because their wages were too low. A fifth (20%) said sick pay was available should they be unwell, but for most (66%) it was not and 13% were either unsure or felt the question did not apply. Just over a quarter said they could take time off *in lieu* but 64% said they could not. The absence of support for PAs in the event of a dispute with their employer was striking. Centres for Independent Living and other user led organisations were usually not funded to provide support to PAs (being funded to support employers). Occupational isolation was also common.

PAs were usually lone workers (a few worked in teams for employers requiring 24 hour support) and there were few opportunities for them to meet with other PAs for support. Indeed, some reported that employers were reluctant for them to meet other PAs because they feared both that their privacy would be breached, and that PAs might be exposed to ideas from other PAs that might challenge the '*status quo*'.

Some key informants felt that the 'casualised' employment conditions experienced by many PAs might have consequences for the PA's family or social life. Some reported that PAs lacked access to information about their rights as employees and maintained that PAs needed more support. There were views that a national association to represent PAs might be helpful and some similarly felt that more could be done to unionise the PA workforce. The absence of support for PAs was also noted by key informants who were PA employers, some of whom supported unionisation, providing the first loyalty of the PA remained with their employer.

Safeguarding

Unreasonable behaviour by an employer was cited by some PAs as a reason for job 'turnover' or leaving a job. Some PAs were prepared to tolerate aspects of unreasonableness, describing it as a manifestation of pain or ill-health. Reports of abusive behaviour by employers to PAs were rare, but when it occurred, it could have a devastating impact on the PA. In part, this was because of an absence of organisations to which PAs could report abusive behaviour and get support.

Key informants felt that where poor behaviour by an employer toward a PA occurred, this was often because of a 'blurring' of boundaries allowing employers to develop unreasonable expectations. Absent or vaguely worded contracts were said to be an important contributory element. Some key informants said that as lone workers, PAs could also be subject to false allegations, which might make it impossible for them to continue to work. Key informants felt that poor employment practice was more often due to an employer's inexperience rather than deliberate, and that providing PAs with access to information and advice about their employment rights would be protective. Some key informants considered that the prevalence of unreasonable or abusive behaviour by employers might be higher than supposed because of the almost complete absence of regulatory oversight. However, key informants who were PA employers felt strongly that external scrutiny removed an element of direct control: for example, there was a strongly held view by a minority that Disclosure and Barring Service (DBS) checks (of PAs) should be at the employer's discretion (in other care settings DBS checks are mandatory).

Training and support for PAs and employers

Most (61%) PAs said they had undergone training after starting work as a PA to help them with their job. For nearly a third (30%) this included Care Certificate enrolment. Training in manual handling, safeguarding, and health and safety were the most frequently mentioned forms of training received. Availability of training seemed much better in some parts of the country than others. Not all employers were reported to be keen on formal training because they felt it reinforced a 'task focused' and 'medical model' mind-set and did not deliver the skills employers felt they needed. Some key informant employers felt strongly that training should be left to the discretion of the employer, while others felt that employers could be a barrier to PAs receiving training, in part because of concerns about the nature of the training, but also because of local authority Direct Payment funding arrangements, where this sum was supposed to include funding for training. This might dis-incentivise employers from obtaining training for PAs because the consequence would be less funding to pay for care or support. (Skills for Care's training grants for PA employers were generally not mentioned by the PAs interviewed.) This was not the case with PHBs, where funding for training was ring-fenced.

Much more support was available for PA employers than PAs, though key informants noted this was only available in some parts of England. It included access to advice about drawing up job descriptions and contracts, organising payment and payroll, how to calculate hours of work and overtime, holidays, sick pay, national insurance and pensions. Key informants who worked in Centres for Independent Living and user led organisations referred to a range of training opportunities and information sharing, including 'good employer' courses. Some referred to the need to avoid major pitfalls if hiring a self-employed PA. (As well as checking DBS status, ensuring self-employed PAs were registered with HMRC and had appropriate employment insurance were mentioned). One informant suggested a need for a national 'hub' that would be a source of advice for both employers and PAs¹. Others felt that there was also a need to recognise that some people might not be able to manage a PA even with significant levels of support.

The absence of support for PAs was widely acknowledged. Though some Centres for Independent Living and user led organisations offered some support to PAs, they were – with one exception – not funded to do so.

¹ Skills for Care has an information hub for individual employers and PAs, but its existence was not widely known amongst participants (www.skillsforcare.org.uk/iepahub). The information hub provides wide ranging guidance and signposting to specific resources.

PAs and other community health professionals

The PA role, though not new, has until recently been uncommon, and PAs thought they were not well understood by community health professionals. Though PAs were often likely to know their employer better than other community health professionals, the need to maintain the privacy of their employer was seen as essential and meant that many PAs felt unable to take part in information sharing. Key informants who were employers felt that disclosure of information about them without their consent amounted to a gross breach of trust and that it was essential for disabled people to be in the 'driving seat' and the ones to decide what information should be shared.

Barriers and facilitators to the development of PAs

Many PAs with previous experience in the care sector considered that the PA role was much more rewarding and satisfying than working for a care agency and that this offered a huge impetus toward their personal growth. However, many felt that the administrative and emotional responsibilities that were sometimes associated with the role could be significant obstacles to further developments.

Key informants saw PA growth as a consequence of rising demand and a policy environment that supported more self-care and control as well as response to demands for rights-based service delivery. Barriers included lack of demand for PAs because of low public awareness in some areas and the limited support available to people with the employment role. There was also a recognition that PAs might not be the right way to deliver care or support for some people.

Recommendations and policy implications

1. For increases in the number of PAs to continue in a context in which there is evidence of considerable slow-down in care sector growth (Skills for Care 2018, p.4) more may need to be done to support this process. This could include improving awareness of the PA role as an employment or self-employment option, for the development of accredited training for specialist PAs working for people with PHBs (and for pay differentials to incentivise people to undertake training) as well as improvements to employment terms and conditions – at a minimum, ensuring these are legal (p. 128).
2. It could be argued that self-employment, rather than direct employment of PAs reduces choice and control for the employer; that tax, insurance, and other employment conditions, such as holiday entitlements sick pay will produce poorer working conditions. There are also risks associated with the hiring of PAs who are not HMRC registered or insured. However, the findings in this report suggest that employment conditions of directly employed PAs are often poor anyway, and a self-employment option may offer more choice and control to PAs themselves. Our study found no evidence to suggest that self-employed

PAs were less satisfied with their working conditions. Local Authority funded registration schemes to verify that prospective PAs are HMRC registered and insured would reduce potential risks to employers. This can be done, for example, the agency Support with Confidence in East Sussex requires verification of these as a condition of registration. It carries out DBS checks and offers basic training for prospective PAs who wish to work with it, who are all required to be self-employed. (p.128-9)

3. The role was also said to be poorly understood by professionals working in community teams: some respondents felt that there was an assumption that PAs were effectively unskilled care workers. This was something PAs felt significantly downplayed their skills and experience. Improving the 'visibility' of the role will require co-ordinated national, regional and local activity. Nationally, government sponsored or led advertising campaigns to support local recruitment, including use of newspaper, online, and 'trade' media advertisements could help foster professional-type identity (p.129).
4. If national campaigns require local organisations to provide the operational support for people who may respond to advertising that is promoting the PA role, then they will need reliable funding. Other social care employers are far easier to identify, with many having local or regional bodies, often running recruitment processes online (p.129).
5. Local support for employers who wish to recruit a PA is likely to be essential for most prospective employers who lack experience of hiring staff or whose family members are not able to assist. In Wales this is highlighted as available to both people receiving local authority funding but also for self-funders (p.130).
6. It is important that recruitment practices are fair, non-discriminatory, and legal so that PA work gains a good reputation and credibility. Local support for employers could be audited or inspected by the Care Quality Commission as we suggest as a policy option elsewhere (p.130).
7. Mandatory checks on, for example, Disclosure and Barring status, HMRC registration (for tax purposes) and employment insurance were not favoured by some informants who were employers, who strongly felt that disabled people should be left to make their own decisions and without oversight. Such a permissive regime runs the risk of colluding with poor or precarious working conditions and undermining government efforts to ensure employment law is respected (p.131).
8. Local authorities seem to be best placed to pay for the set-up and running costs of registers, but those that are not already doing so may be unlikely to pay for a register unless mandated to do so. Our evidence suggests registers are an important resource when properly set up and managed, and should be encouraged, alongside other approaches to recruitment (p.131).
9. There is no national 'template' as to what information should be collected and made available on a register, or who should have access to what is collected,

though Skills for Care has produced guidance for organisations that wish to set up a register², Centres for Independent Living and user led organisations may help those considering whether to set up a register about content. Skills for Care would be well positioned to review and co-ordinate guidance, bringing in support from its existing PA Framework Group, and drawing in others as needed (p.131).

10. Guidance should also include advice about compliance with the General Data Protection Act and other relevant legislation to ensure registers are non-discriminatory and not open to abuse by either employer or PA. (p.131).
11. There is a strong case for mandatory Disclosure and Barring Service (DBS) checks of PAs in our view, particularly those paid for by public funds. Such a check should not remove the ability of the employer to choose whether to employ a PA, even if the check reveals that the PA has a criminal record. People paying for their own care are able to ask an applicant to obtain their own DBS check but we lack information of the uptake of this option. Where LAs or local NHS organisations (or others who have been commissioned to do this) are carrying out checks on behalf of individual employers then control over the suitability and responsibility for acting on the information rests with the organisation requesting the check. Furthermore, these bodies have a duty to act on the information revealed (to consider the details and context of the case) and cannot pass the information on to an individual employer in order for them to decide on suitability. Nor can PA employers organise their own checks: they can only request a check be made by the LA or the NHS or other registered bodies or ask their PA to get a basic check. (p. 132).
12. At the present time (mid 2019), the decision as to whether checks should be *mandatory* rests with individual LA or the NHS services and of course only applies to people using public funds to pay for a PA. The employer does not know or make a judgement about the contents of the check. There is a policy option to reform this system and to support LAs and NHS organisations to ensure that people seeking to work as PAs are checked and set up systems to do so (p.131) in the context of risk management. The non-registration of social care workers in England is a wider debate but registration would likely include DBS checks (as in Wales where a current DBS check is required as part of registration application). Another policy option is to consider the situation

² See <https://www.skillsforcare/Employing-your-own-care-and-support/Resources/Information-for-local-authorities-NHS-and-support/Other-useful-resources/Developing-a-local-network/Developing-a-PA-register.pdf>. This contains useful guidance, though no provision for self-employment as an employment option. Our study also found that in relation to 'key points' within this document, that in relation to key point 1, not all LAs or Centres for Independent Living were able to keep their registers up-to-date, largely because of insufficient resources. In respect of key point 2, in practice, existing registers did *not* seem to be funded to support PAs. In relation to key point 3, PA recruitment interviews are being conducted at the employer's home.

applicable to child minders who are entitled to get a check through Ofsted and assess if this is transferable. (p.132-3)

12. Checks to ensure HMRC registration and employment insurance cover would help avoid the situation that if an employer chooses to hire a self-employed PA; at the moment public funds may be being used to pay people, mainly women, who may not be paying tax, contributing to their own pension, or lack insurance cover (p.132).
13. Both employers and PAs need access to clear information about safe practice, and what both parties may need to do to comply with relevant regulations and guidance, although information is not of course always taken up or regarded as personally relevant. In our view it would not be appropriate to recommend the extension of Care Quality Commission (CQC) inspections to PAs and employers: quite apart from the lack of evidence to justify this, it would likely be impracticable. However, the quality of local authority support for the arrangements of publicly funded PAs could be explored by the CQC or local auditing. An alternative policy option may involve encouragement of local authorities to offer more light touch oversight: through the funding of proactive guidance and support from staff working in Centres for Independent Living and user led organisations that might also be taken up by self-funders. The insularity of the PA - employer relationship also means that neither are exposed to others with whom ideas and experiences can be shared. Local third sector organisations could play an important role in creating opportunities for employers and PAs to form separate networks: protected spaces for discussion, operating as communities of practice. These would need to be moderated to ensure ground rules – for example, for PAs to respect the privacy of their employer - but they could create opportunities for informal learning, also uncovering and challenging poor practices, exploitation and safeguarding concerns (p.133-4).
14. Though only a few examples of direct exploitation and abuse were reported, where it did occur it had serious consequences for the PAs concerned. Poor employment practices, lack of employment protection and the absence of support for PAs seemed contributory factors. The report has already noted resistance to oversight or regulation by some employers; there may be room to debate this further with care using representatives to inform policy makers if such views are being moderated over time (p.135).
15. Unionisation of the PA workforce would be one way of establishing more equitable arrangements; another option for policy makers is the registration of care workers as being undertaken in Wales (building on the Social Services and Wellbeing (Wales) Act 2014 which is professionalising the homecare workforce by registration, enhanced employment security and intervening in working time arrangements). Another option might be the creation of a

national professional association to represent PAs, though this might only be an option taken up by few and would not necessarily have any bargaining rights (p.135).

16. Employer training was reportedly not well attended. It is possible that some employers may have found it difficult to attend due to illness or disability, but also possible that some employers may not have seen training as their priority. The outcomes of training do not appear to have been evaluated and we suggest that more work on what makes for effective training might be appropriate rather than to repeat the trope that 'more training is needed', especially since this often seems to refer to the imparting of information and advice (p.136).
17. Improving access to training would involve planning it carefully to ensure it is enjoyable to attend as well as informative: perhaps combining it with a social activity of some kind; advertising and marketing the event extensively; choosing venues that are disability friendly and arranging programmes so PAs can attend (to provide support if this is needed), and arranging (and possibly paying for) specialist transport to and from the venue. One policy option is that consideration might be given to making 'one off' training compulsory for new employers whose funding comes from the public purse: such requirements are present in other jurisdictions to help ensure that employers of potentially vulnerable home care workers are fully informed of their employer responsibilities (e.g. Singapore's mandatory Employers' Orientation Programme (EOP) for people employing a foreign domestic worker for the first time or who have changed workers frequently) (p.136).
18. Ring-fenced training for PAs whose employers were funded by NHS Personal Health Budgets (PHBs) removed any disincentives for employers to pay for training but may have been more overtly necessary because of well-defined clinical skills sometimes required for PAs to safely work with employers with health-related needs. However, the absence of control over funding for training challenges the view of some disabled employers who felt strongly that the PA should do things 'their' way rather than the 'prescribed' way. Solutions to these concerns may involve initiatives to encourage employer 'buy in' by supporting the co-production of the design and possibly delivery of training offered to PAs to ensure it reflects employer values (presuming these are shared) and there is shared control over content. Extending the use of ring-fenced funding for training used for PHBs to DP users would clarify funding arrangements but would remove control over some of the budget from employers. A ring-fenced training budget would have to cover travel costs and the cost of back-filling the PA post to enable the PA to attend the training. (p.136). Peer-to-peer training is another option that might improve knowledge and skill-sets of PAs, both those paid for by DPs and also PHBs. This could be informal, or competency based, but there may be a need to address concerns

of employers about breaches in confidentiality and of course to consider its effectiveness. (p.137).

19. Changes to the way in which contracts are set up may also be needed to address possible problems with boundaries. First, policy makers could consider making sight of contracts mandatory if the PA's time is paid for through public funding, even if they are employed on a part-time basis and over a small number of hours. One way of doing this would be to amend the Care Act 2014 guidance. Second, these contracts may need to specify as far as possible the full range of task and duties of the PA which could be done by the local authority representative agreeing the care plan that is being funded by a Direct Payment (a social worker or care co-ordinator). Third, it may be necessary to review them more regularly than in other employment arrangements to allow for changes to care needs and the need for the PA to take on different tasks from time to time (this again could be part of local authority monitoring and review). The aim would be for the contract to accurately reflect the purpose of the role and its content. This oversight could be carried out by the local authority, but employers may find it more acceptable if this was a delegated responsibility of a Centre for Independent Living or user led organisations; providing of course that PAs see such bodies as effective and impartial. Funding would be needed to enable them to do this. Training and support needs of employers and PAs, mentioned above, are also relevant here (p.139).

20. PAs are at a considerable disadvantage compared to their employers in the event of a dispute, and need access to similar levels of support, and protections. Control by employers therefore could be mitigated by PAs having:

- (a) Access to legal and employment advice from trades union, or professional association or, providing the potential conflict of interest can be effectively managed, third sector organisations that support PA employers.
- (b) Access to training or skills development, possibly extending current funding and training arrangements used within the NHS for Personal Health Budgets for Direct Payments (DPs) and encouraging those organisations approving DPs (local authorities) to work with PA employers to develop plans to support their PAs.
- (c) The ability to form local networks and associations to provide greater transparency to their work and the opportunity to discuss elements of their role in a moderated, but protected environment. Such developments could be part of local employment or economic initiatives rather than a local authority adult social care obligation and shared with NHS bodies in the development of integrated working (p.141).

Methods note

This study used an opportunistic, prospective, qualitative design, using semi-structured telephone interviews with 105 social care Personal Assistants (PAs) and 26 'key informants'. Questionnaires, information sheets, consent forms and the research protocol were designed by one team member but with advice from the wider team and the Social Care Workforce Research Unit's User and Carer Advisory Group.

To be eligible to take part, PAs had either to be directly employed (by the person in need of support or care), or self-employed. Key informants were people with an interest in promoting the development of social care PAs or people from national organisations with a non-pecuniary interest in this workforce. Interviews with both groups lasted around one hour, with one exception were recorded (with consent) and fully transcribed.

Quantitative data from the PA interviews was analysed using SPSS computer software, and for qualitative data NVIVO software was used. One member of the research team conducted the interviews but three team members analysed the qualitative data, meeting regularly to cross check emerging themes. All members of the research team contributed to writing the report.

The study received a favourable ethical opinion from the Health Research Authority Social Care Research Ethics Committee before data were collected.

Introduction

Personal Assistants (PAs) or directly employed care workers are significant and growing members of the social care workforce in England. There are an estimated 145,000 PAs working for 70,000 people with needs for support in activities of daily living or social care³ (Skills for Care, 2019). Following the introduction of Direct Payments, Individual Budgets, and then Personal Budgets by the Department of Health (DH, 1997), a development from the permissive Community Care (Direct Payments) Act 1996, these jobs have moved from being a small proportion of the social care workforce, to be one that is growing rapidly. Indeed, with the proposed expansion of Personal Health Budgets (NHS England 2019)⁴ more people may take on this work.

Personal Assistants (PAs), as discussed in this report, are directly employed or self-employed. They may be paid by an individual or their proxy (such as family member) from the individual's Local Authority (LA) Personal Budget (PB) or their own resources (including disability benefits and their own savings or income). In a small number of LAs the terms Self-Directed Support or self-managed funding are also used. While the legislation is different in Wales (Apteligen 2014) and in Scotland (Pearson et al., 2014), this form of employment and its funding base are common to other parts of the UK.

Some English LAs fund brokerage services to assist people with peer support, support planning (Baxter and Glendinning, 2015), staff recruitment or payment arrangements (see Currie, Kinn, Thompson and Hamilton 2016; Baxter and Rabiee, 2013). National Health Service (NHS) funded Personal Health Budgets (PHBs) can also be approved to pay directly employed care workers using national advice.

Many people in need of care or support and their families say that employing someone directly provides them with much needed continuity of care and flexibility (SCIE 2012; Disability Rights UK 2018). However, one report summarising international developments summarises the progress with self-managed funding thus:

'The evidence on the outcomes with self-managed funding is overwhelmingly positive for consumers but more mixed for workers and while arrangements can work well for both parties, there is also scope for things to go wrong with consequences for quality and safety of support'

Independent Advisory Committee for the NDIS (2017)

³ The report from which these figures are taken does not contain details of the methodology used to obtain them.

⁴ The NHS Long Term Plan (NHS England 2019) sets out a target of 200,000 people to be supported by a PHB. At the present time (mid 2019), 55,000 people have a PHB.

The indirectly publicly and privately funded PA workforce, referred to in the above quotation, is a largely unknown quantity, reflecting the lack of knowledge about care workers who are employed by individuals using their own resources or register with them or with voluntary sector organisations to find work (Manthorpe et al., 2015). This is partly because, as for most of the social care workforce in England, there is no professional register or database of employees. Indeed, many people who carry out the tasks associated with a PA role do not use the term PA or self-identify as PAs, using terms such as home carers (see D’Astous et al., 2019, for discussion of the wide variety of terms used in home care) or directly employed care workers. Until recently, little has been known about their perspectives on their work, their role, their pay and conditions, their training and their feelings about taking on tasks that are more typically health-related than care. It is that deficiency that this research was designed to address.

This present study sits alongside three earlier exploratory English studies of PAs: the first commissioned by Skills for Care, and carried out by IFF Research (2008), a later study conducted by Skills for Care (Skills for Care 2017) and a study by Shakespeare et al., (2017). A further report from Skills for Care (2019) was published in 2019 and a study is presently underway on relationships between PAs and community health professionals at the Policy Research Unit on Health and Care Workforce.

Both Skills for Care studies report on findings from large scale surveys. Its 2008 survey interviewed 525 employers and received 486 completed returns from questionnaires left with employers for their PAs and conducted a further 100 follow-up interviews with these workers (IFF Research 2018). Though now a decade old, the report offers the first substantial set of information about the characteristics of employers and their PAs from England. Some of these findings, for example, relating to what employers most valued about the backgrounds of PAs, their ability and willingness to pay for training, are consistent with those of this present study. The 2008 study used a quantitative design, and almost all questions were in ‘closed’ format which created limitations in understanding the dimensions of the working relationship between employers and PAs, and the self-completion survey of PAs was very short. Our own study adopted some of the follow-up interview questions for PAs but we found that, in practice, there was a lack of fit between some of these questions and the ‘story’ the PA had to tell, and so some questions were quickly dropped from our interviews because they seemed irrelevant to our own participants.

The second Skills for Care (2017) study is based on a larger survey, of over 1000 PAs and their employers recruited from two national agencies who provide a brokerage service. Most recently, Skills for Care (2019) published combined

findings from this and a further open online survey which had collected responses from 1,882 individual employers and 2,269 PAs. Like the 2008 survey, the design was quantitative: a major aim of the study was to compare the characteristics of the PA workforce with Skills for Care's NMDS-SC (National Minimum Dataset – Social Care, as from August 2019 the Adult Social Care Workforce Data Set). Some of the findings of this later survey are also mirrored in the findings of the present study, though others are not. Further discussion is provided in the discussion of the strengths and limitations of our own work, below.

The third study, by Shakespeare et al., (2017) is in some respects closer to our own, since this team undertook semi-structured, exploratory interviews with 27 PAs and 35 employers. Though our own study did collect data from some employers, our dataset of PA interviews is much larger, covers in detail their employment terms and conditions, and we did not rely on help from employers to engage with their PAs.

Methods

Objectives

This study was designed to gain a better understanding of the PA role for workforce policy makers and the wider social care and health care sector. The main research aims were:

- To complement and update existing knowledge by describing and documenting this emergent workforce, exploring the backgrounds and motivations of PAs, job content, terms and conditions, and their perception and experiences of their job, and its relationship with the wider social care and health workforce.
- To explore what mechanisms are used by local authorities (LAs) to create and match PA supply with demand and examine any evidence available about the effectiveness of initiatives and interventions from which other local authorities LAs and funders might learn.
- To investigate the potential of the PA workforce to support people with personal health budgets (PHBs), as well as social care personal budgets (PBs), and what implications this might have for training and workforce development.
- To identify any barriers to PA working, including training and certification requirements, immigration requirements, vulnerability of the PA role including lone working, difficulties with employers and dispute resolution, access to peer support and mentoring, and any alternative models to direct employment (if this is a barrier).

Design and methods

The study collected data prospectively from two opportunistically selected samples of PAs and key informants, both of which used a qualitative design from which quantifiable data were extracted. Semi-structured telephone interviews were undertaken, though a small number of interviews were conducted face-to-face. The research proposal, participant information sheets, consent forms and interview questionnaires received a favourable ethical opinion from the Health Research Authority Social Care Research Ethics Committee on 23rd September 2016 (Ref 16/IC08/0028). An application for support was made to the Association

of Directors of Adult Social Services (ADASS) research sub-committee over the same time period but the application was not approved. This was because the reviewer requested substantial changes to design and methodology and not all of these could be agreed.

The study was supported throughout by members of the NIHR Social Care Workforce Research Unit's Service User and Carer Advisory Group. Members commented on and suggested changes to questionnaires and other documents intended to be shared with PAs and key informants, and these were revised in accordance with this guidance. Several of the group use social care services or are family carers, and some possess direct experience of employing PAs on their own or others' behalf which was particularly beneficial in this study by bringing direct experience from different local authority areas.

Personal Assistants or directly employed care workers

The first and largest sample was of social care Personal Assistants (PAs). Between October 2016 and August 2017, 115 telephone interviews were completed. To be eligible to take part, PAs had either to be directly employed by the person they cared for or supported or to be self-employed. A small number of interviews (10) were completed with people who described themselves as PAs but in the event turned out to be employed by a care agency. These were excluded. However, one PA, employed by an organisation that existed to support people recovering from serious or enduring mental health problems, insisted that her clients had the power to 'hire and fire' her. Following much discussion, it was decided to include this PA's interview because the role, and relationship, offered a valid and different perspective.

Recruitment was challenging; self, or directly employed status meant that PAs were difficult to identify and contact. Most LAs seemed to collect little information about PAs, so contact was made with commissioned or independent sector organisations such as Centres for Independent Living and User-led organisations, many of whom agreed to pass on written information about our study to PAs – sometimes via their employers – to invite them to make contact if they were interested in participating. Subsequent telephone conversations with those who made contact enabled the lead researcher to explain the purpose of the study and what would be entailed in taking part. Though no participants declined to take part at this stage, a small number (12) did not keep the scheduled interview appointment and did not respond to subsequent emailed requests or telephone messages inviting them to suggest another time for interview. Participant information sheets and consent forms were sent to each person prior to interview, and immediately before each interview, checks were made to ensure the information sheet had been read. They were also reminded that they could terminate the interview at any point without offering a reason and could choose

not to answer any questions. None chose to do this. Interviewed PAs were widely spread geographically throughout England.

The interview comprised 67 open and closed format questions. The duration of interviews varied but, on average, each took just over one hour to complete. Quantitative analysis was carried out initially on the closed format questions using SPSS v22. Subsequently, qualitative data was analysed using Framework Analysis (Ritchie and Spencer 1994). With consent, all interviews were digitally recorded and fully transcribed. Data were entered into NVIVO qualitative research software. Two research team members focused on the PA qualitative data analysis and coded half the interviews each, using a coding system devised to follow the initial interview questions but also to allow the addition of emerging themes. Regular team meetings and cross coding discussions of a small sample of interviews ensured team members developed shared perspectives on coding decisions.

Key informants

The second sample comprised people we identified as 'key informants' (KIs). These were directly involved in some way in supporting the development of the PA workforce locally or nationally; or PA employers, or representatives of national organisations that had a non-pecuniary interest in this workforce (see Table 1).

A total of 26 telephone interviews was completed between October 24th and 7th December 2017 (see Table 1). Participants were identified via direct prior knowledge, internet search, or 'snowball' techniques building on other participant ideas for helpful perspectives.

	Local Authorities	3
NHS staff working for Trusts or Clinical Commissioning Groups		2
	Centres for Independent Living	6
	National Voluntary Organisations	3
	Trade Union	1
	Arbitration and Conciliation Service (ACAS)	1
	Non-Governmental organisations	2
	Disability advice organisations	4
	Academics and activists	3
	Other kinds of support organisation	1
	Total	26

Table 1. Participating organisations and individuals, key informant interviews

Key informants were also widely spread geographically throughout England. They were first contacted by telephone where the study was explained, and their participation invited. Information sheets and participant consent forms were provided. None withdrew after agreeing to take part, but some asked not to answer a small number of questions because they felt unable to offer an informed response. We used a semi-structured design and 'open', not closed, format questions in the interviews. Of most people we asked 20 questions which took about 40 minutes to about 2 hours. With consent, all but one interview was digitally recorded (notes were taken in the unrecorded interview and the participant supplemented this by subsequently providing further written responses to questions). Each interview was fully transcribed and analysed by another member of the research team using Microsoft Excel software and using 'Framework' analysis (Ritchie and Spencer 1994). Individual participants were given assurances of confidentiality subject to duties to report safeguarding concerns, but the kinds of organisations that employed them are described where this was unavoidable: the risks of this were explained and accepted.

Findings

1. Who are PAs?

Demography

Participants were overwhelmingly female (n=91/87%), White (n=90/86%) and British (n=97/92%). The gender of PAs working in the Skills for Care (2017) survey was similar overall, although male PAs were more common among PAs who were family or friends of their employer. In contrast the proportions of White PA respondents and of non-UK nationals to the Skills for Care survey were lower. Five of the eight non-UK PAs in our study were from EU countries.

Over a third (n=40/38%) of our sample had dependent children living at home or as students, and just over a third (n=39/37%) cared for someone else in their own family.

Participants' average age was 44.8 years: the youngest PA interviewed was 20 and the oldest 70 (very similar to the ages of those participating in the Skills for Care (2017) survey).

Small numbers (n=8/8%), (n=7/7%) and (n=13/12%) claimed family or universal credit, housing benefit, or a pension respectively, indicative of other sources of income to households that were low income overall.

Previous occupations

Most PAs had previous experience of working in a care setting before becoming a PA: in response to the question '*Before working as a Personal Assistant have you ever worked for/in...*' one-fifth (n=21/20%) had previously worked for a LA Social Services/Adult Services Department, just over a third (n=37/35%) in care homes, just over a quarter (n=27/26%) in either a hospital or as a care worker for a home care agency (n=27/35%). Many (n=61/58%) had previously been unpaid or family carers; however, a fifth (n=22/21%) said they had not worked in a care setting previously.

Responses to the question '*Before you started working as a Personal Assistant, what was your last paid job?*' revealed great diversity of occupational background. The largest single previous occupation was home care work (n=25/24%), while a further 10/10% referred to unspecified care work and 6/6% said their last paid job was as a nursing, or health care, assistant: in total 41 people (39%). A very wide range of non-care related but 'person focused' occupations were also mentioned, including teaching or teaching assistant (n=12/11%); retail assistant

or retail manager n=9/9%; general office work (n=8/8%); work in the service or hospitality industry (n=4/4%); housing support (n=4/4%). For a small number (n=5/6%) the PA role had been their only occupation since they had started working as a PA after leaving school, college or university. A range of other previous employment was mentioned, including work in the leisure industry, childminding, school lunchtime supervisor, Revenue and Customs officer, self-employed editorial work, legal executive, senior local government management, mortgage broker, debt collector and musician/composer.

Time working as a PA

On average, PAs had worked in this role for 4.5 years. Just under a quarter (n=24/23%) had been working in the role for less than 6 months, whilst 14 (13%) had worked as a PA for more than 5 years.

PA work as first or secondary employment

Half (n=52/50%) were also in secondary employment. PAs reported other jobs, such as foster parent, art therapist, golf club worker, actor, security worker, taxi driving, pub landlady, badminton coach and TEFL (Teaching English as a Foreign Language) teacher. Some PAs said they enjoyed the variety this offered:

'... basically, I want to do two jobs; one is teaching language, and the other is PA, and I want them to run alongside each other, along with other interests, really'.

DM550149

Other PAs found the role fitted around their existing zero-hours type contract jobs:

'[I] did the security (work) for nine years. The care (work) was just to pick up some extra money, and because I know the people that I've done the care for. A carer might have let them down and I'll just step in, sort of thing. I suppose now, because of all the experience, it would always be a back-up, but I don't think it would ever be a primary job, it'll always be a secondary job'.

DM550142

Some PAs mentioned being involved in voluntary work related to social care, for example, via church or other community groups:

'I volunteer interpret as well in different towns, at deaf churches...with a deaf vicar or a hearing vicar and I will interpret either. And I freelance as well, freelancing interpreting, because I'm training to become a qualified interpreter'.

DM550249

Employment relationships

Though the definition of PA used to define eligibility for this study may have seemed straightforward, the actual employment relationships of PAs varied as Table 2 shows.

Employment relationships	
Employed by the person needing care or support	39 (37%)
Employed by a relative of the person needing care or support	19 (18%)
Service provider organisation	1 (1%)
Self-employed	34 (32%)
Some other arrangement (relative paid to provide care who did not describe this as employment)	8 (8%)
Self-employed, but also employed by some people needing care or support	1 (1%)
By a person needing care or support and also by a relative of another care recipient	3 (3%)
TOTAL	105 (100%)

Table 2. Employment relationships of PAs (n=105)

Though most PAs were directly employed or employed by a relative of someone requiring care or support, almost a third were self-employed. Eight described 'other arrangements', including, for example, where the nominal budget holder was the person requiring support or a family member but where the PA was a relative acting as a proxy.

One person was employed by a service provider organisation. Since this kind of employment relationship does not, at face value, meet the definitional criteria used for recruitment, it deserves explanation. The provider organisation was not a care agency but a commissioned service to support people recovering from serious, long term mental health problems. The employee in question functioned *as if* a PA and perceived themselves in this role: providing personalised support on a long-term basis, with the supported person apparently retaining the right to dismiss their PA. However, we accept that this case may not be strictly one of direct employment and suggest that it is indicative of the 'grey area' between direct employment and feelings of being subject to the control of the care user.

In the report, we refer to 'employer' or 'employee' regardless of the actual legal relationship between employer and PA, unless there is a specific reason for a narrower focus.

Qualifications and training

Just under a half of PAs had either a qualification or training certificate relevant to their role. (Some participants had more than one qualification, so the total number of qualifications do not match the total number of PAs with qualifications.) These included National Vocational Qualification (NVQ) level 2 in Health and Social Care (25) NVQ level 3 (n=15) and NVQ level 4 (n=3). A few PA participants had social work, nursing, counselling and psychotherapy qualifications: small numbers had worked as PAs during student placements (e.g. whilst training as a social worker or teacher) and had remained working as PAs after qualifying. However, 31/30% had no relevant qualifications or training.

2. Why did PAs choose this work?

Interviews with PAs included a multiple-choice question about motivations for working as a PA (see Figure 1).

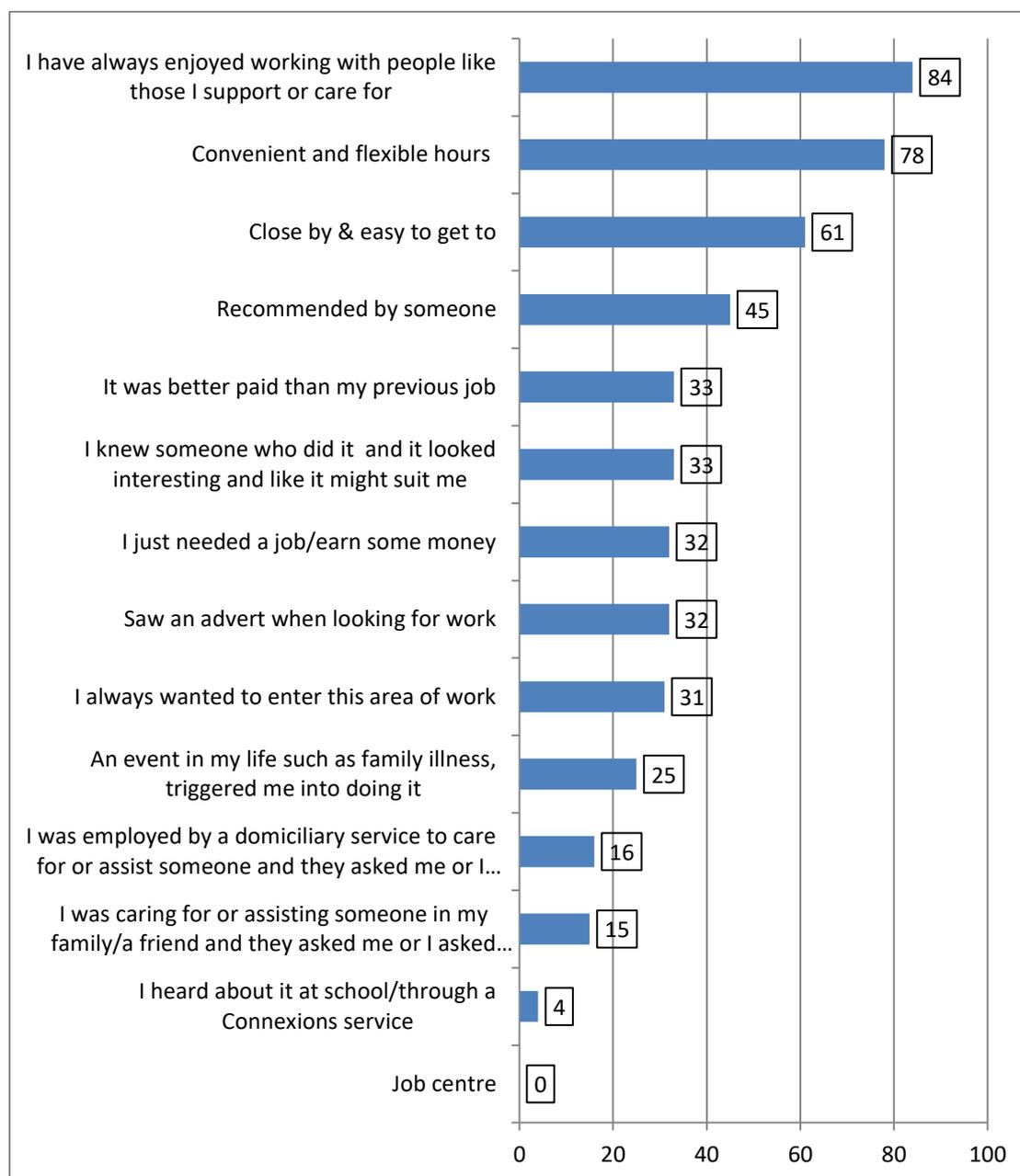


Figure 1. Reasons for starting work as a Personal Assistant

Figure 1 shows that the great majority of PAs chose this work because they thought they would enjoy working for those who employed them. Matters of convenience or pragmatic considerations, such as the need for an income, hours to fit in with the needs of family or lifestyle, were also important. Recommendation by someone, or knowing someone who worked as a PA, were

also common reasons for choosing this work: having friends or relatives who worked as PAs, for example. None of those interviewed found out about PA work via a Job Centre, and only 4% through a Connexions service⁵.

Most PAs seemed settled in this choice of job with 81 (70%) saying they would be 'very likely' to want to continue to work as PAs in the future and a further 13 (11%) saying they would be 'quite likely' to do so:

'I would most definitely love to...because that's the only job I've ever known and then to start from this job and go into another carer [organization], it would just be... I couldn't go through all the training and stuff again, so I'd rather stick to what I know, hopefully, and something will come up and it'll click on from there, really'.

DM550180

Amongst the smaller numbers of those who were unsure or not likely to want to continue, some were students intending to go or return to college, and even smaller numbers were either 'between' jobs or needed to return to better paid work.

A few PAs felt that job insecurity and the absence of a career structure would mean that at some point they would likely choose to do something else:

'I really enjoy the work, and if there was enough of it, and if it was steady enough, and the pay was good enough, and all of that kind of thing, I would; but it's just with mortgages and all that stuff, you know, I'm tied to teaching in that way – but if I could do it on a more permanent basis, I think I would'.

DM550245

Other PAs mentioned taking retirement or ceasing work due to their own health problems or other caring commitments:

⁵ Connexions was a national service that evolved from local authority Careers Services. It provided advice and support to young people entering the job market to enable them to find and keep employment. Though local Connexions services still operate, wider changes to the way Careers guidance was offered implemented by the 2010-2015 Coalition Government mean it is no longer nationally co-ordinated.

'I guess if someone else came up, it doesn't have to be someone I know, but this, I think, is a long-term role, so I'm, kind of not thinking about it as such and, also, I have to bear in mind my husband's needs... So, it might be that even I have to, you know, leave this role, depending on how my husband progresses. So, yeah, it's just one of those things, isn't it, and a bit of an unknown'

DM550218

'Whether they think I'm able to help or not, because I've got fibromyalgia... some days I struggle, so it would depend on their health needs whether I can assist or not.'

DM550191

Just one PA was thinking about changing jobs in the future due to the demanding nature (physical and emotional labour) of the role:

'You do [a lot] for your client and it depends on their moods, so I think maybe, four five years. I might want to change because it is a demanding job and there's a lot that goes with it, so you do a lot of things. And you can be their confidante; counselling. If your client's upset and is crying, you have to listen, even though you've got things to be doing'.

DM550217

Another PA specifically criticised the 'high reward but low pay' nature of social care sector and cited it as the reason for moving from their current job:

'Yes, to be honest with you, I am looking at alternative employment because the pay is very poor and the prospects for progression are quite limited as well; two very important things that (laughs) – in anyone's career, so it sounds quite cold, I do like the job, I enjoy it very much but I've got to earn a certain amount of money to pay my mortgage and pay my bills and as it stands, it's not really a job that can fulfil those criteria'.

DM550220

This report will discuss employment conditions of PAs more fully below.

3. Who do PAs work with, what is their employment relationship, and what do they do?

a. Who do PAs work with?

PAs were asked about the age groups and 'care-group' categories of those who employed them or (if self-employed) they worked with. Most (n=84/80%) said they worked with a person or people aged between 18 and 64; 41/39% older people aged 65 years and over, and 19/18% with children/young people under the age of 18.

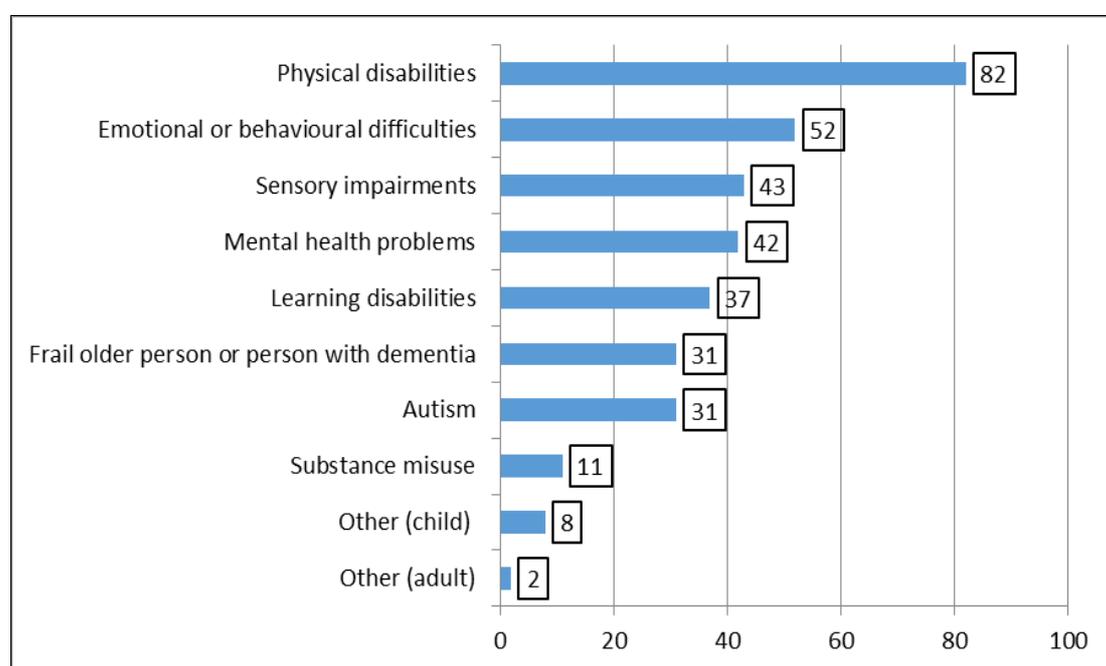


Figure 2. Does your job involve providing care or support for a person with...?

The information presented in Figure 2 should be treated with mild caution because it is based not on formal diagnostic categories but the opinion of the PA. Moreover, some conditions were overlapping. PAs were most frequently providing care or support for people with physical disabilities (n=86/82%); behavioural or emotional difficulties (n=55/52%); mental health problems (n=44/42%); sensory impairments (n=46/44%); people with learning disabilities (n=39/37%) and frail older people (n=33/31%). Smaller numbers worked for people with a diagnosis of autism, or people who misused drugs or alcohol. Just four participants were related to those they worked for. (This is in substantial contrast to the Skills for Care (2017) survey where just over half (52%) of its respondent were related to or knew their employer.)

It was common for the PAs in our study to be employed by more than one person or to have several clients. In our sample, only 41 (39%) worked exclusively for one person: the average number was 3.1. Not surprisingly this meant that very few worked full-time for one person. This was far more than those responding to the Skills for Care (2017) survey whose respondents held an average of 1.27 PA jobs each.

b. Employment situations

Interviews with PAs found a relatively high degree of employment stability⁶. About a third (n=34/32%) had not changed jobs but were working with the same employer they had started with when they started working as a PA. As Figure 3 shows, for most PAs, their relationship with their employer/client had been quite longstanding. Almost half had been working for their most recent employer/client for over a year.

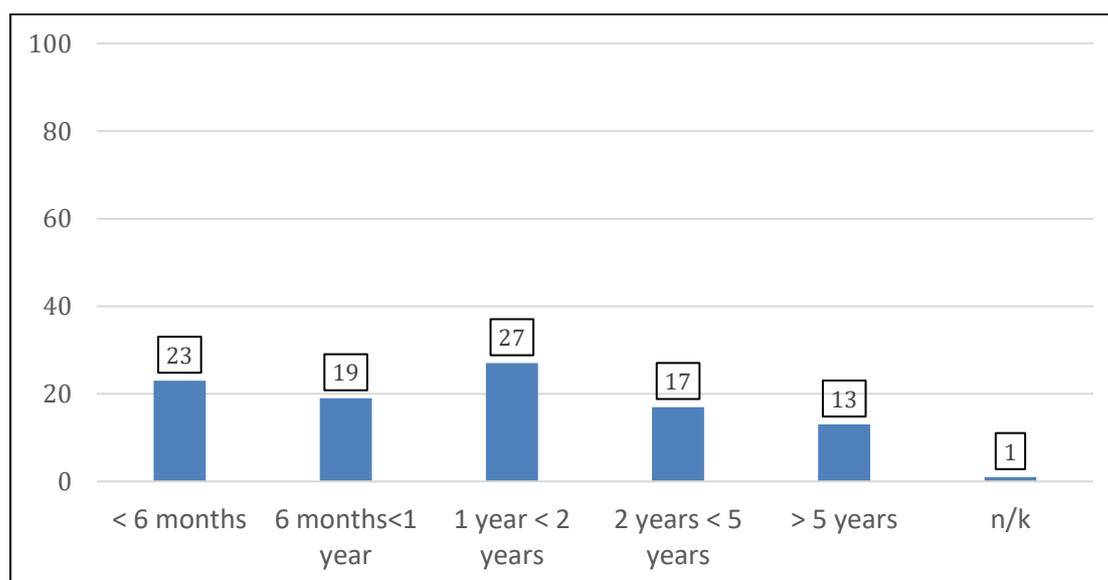


Figure 3. How long have you been working as a paid Personal Assistant - for the person you started working for most recently?

PAs were also asked if they were working for different employers currently from when they started, to explain the reasons for the change or employer ‘turnover’⁷. The most frequently mentioned reason (by n=33/31%) was the death of the employer. This is an observation that has not previously been highlighted in other studies. Other reasons cited included unreasonable demands and expectations or abusive behaviour by the employer (n=13/12%), a move by the employer into

⁶ Skills for Care (2018) also suggested that there was less turnover among PAs than other care workers.

⁷ In Skills for Care’s survey (2018) PAs had been working an average of 3.5 years in this role.

residential care (n=10/10%), and situations in which the support had always been intended to be short term (n=6/6%).

Other reasons for 'turnover' involved changes affecting both employer and PA. Changes to the circumstances of the employer included, for example, relatives being able to take on a greater caring role, changes in need which meant that the PA could no longer provide enough support, and reductions in the employer's/client's Direct Payment (or other benefits). For the PA, changes in circumstance could involve situations in which their employer moved to a different location, that the PA had been unable to work through ill-health, or that they had acquired other caring responsibilities (typically involving members of their own family) which meant they had to reduce the number of hours they worked for others.

c. What do PAs do?

A multiple-choice question asked about the kinds of tasks that PAs carried out. The question had five elements:

- What kinds of task they carried out;
- if they would be prepared to carry out any of the tasks they did not do, if asked;
- if they would refuse to do any of the tasks they did not do if asked;
- if they would decline any tasks they did not do because they *had not received training*; and
- if there were any tasks they felt an employer should *just not ask them to do* because they were not something a PA should be required to do.

Responses to each are presented in the Figures (4-8) below.

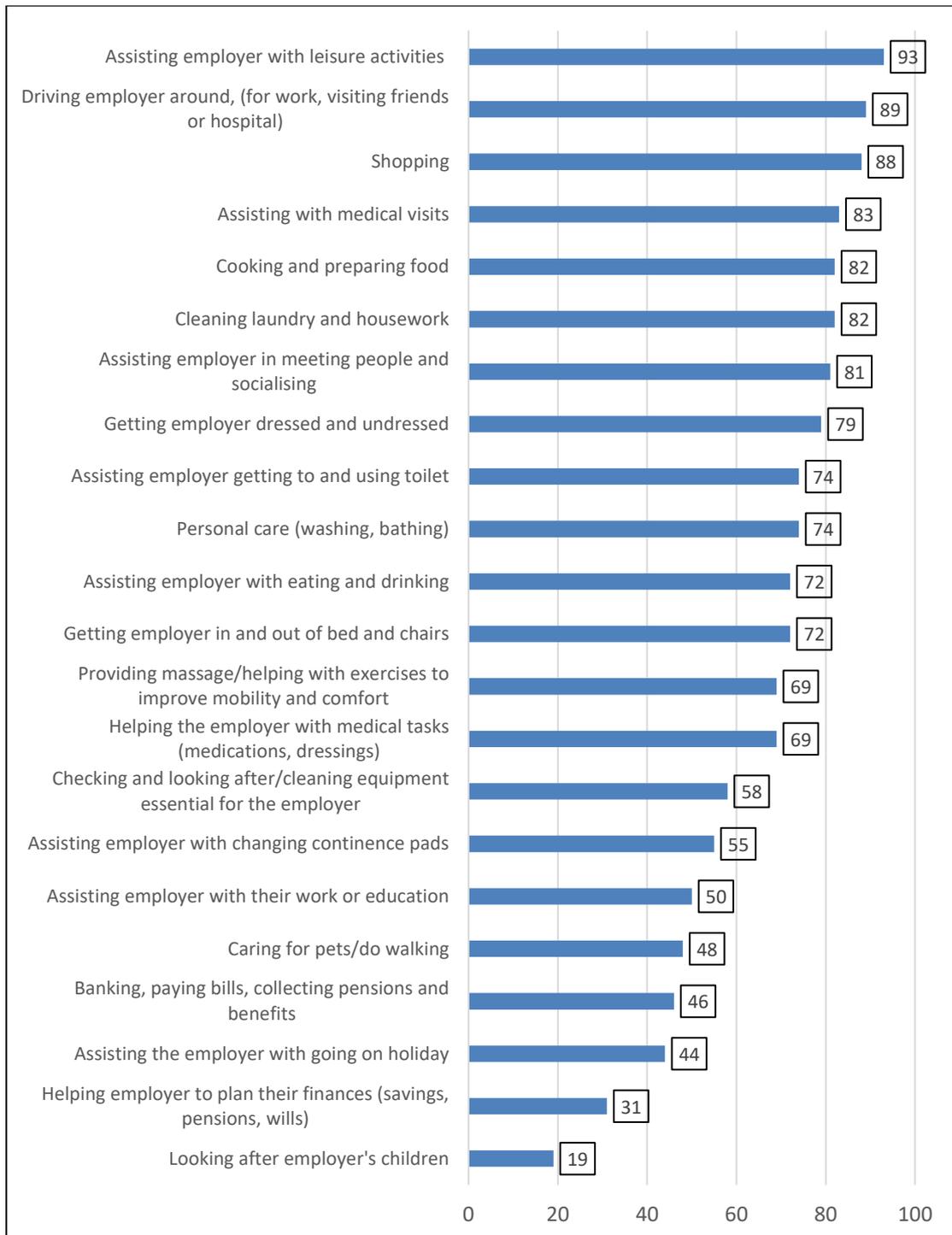


Figure 4. During your work as a Personal Assistant, do you perform any of the following duties for your employer?

The most frequently mentioned tasks performed included helping and supporting the person with leisure activities (n=98/93%); driving their client/employer around for work, to visit friends or for other reasons (n=89/85%); shopping (n=92/88%); cleaning, laundry and housework (n=86/82%) and assisting people in meeting others and socialising (n=85/81%). These appeared to be the tasks

most requested by their employer; personal care (dressing, washing and help with the toilet) was requested by around three-quarters.

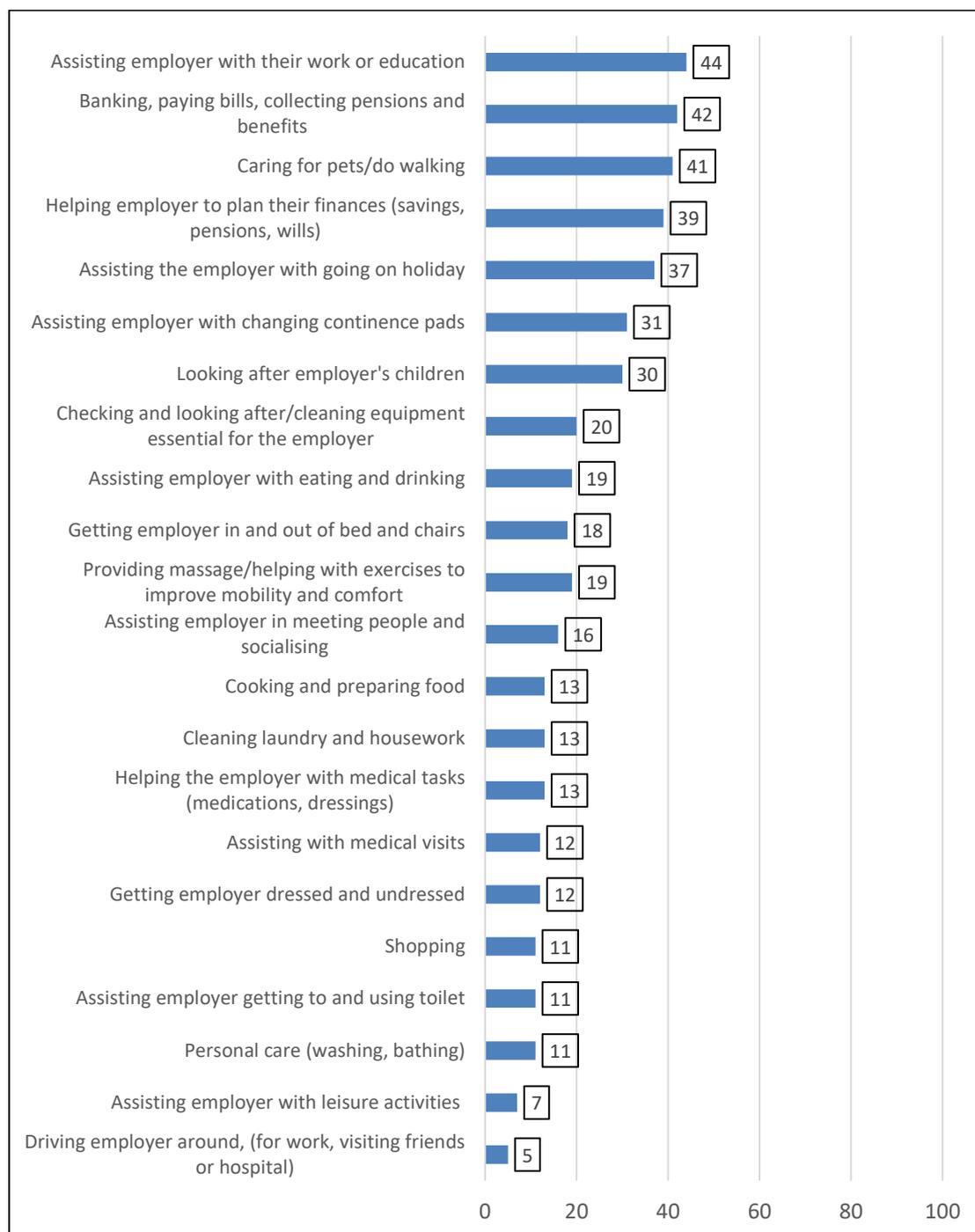


Figure 5. Tasks PAs did not do but would be willing to if asked

Most PAs seemed to be prepared to be willing to carry out a wide range of tasks that were not part of their current responsibilities. Many saw the need for a flexible approach to their work as a very important element of the PA role, and something they said they would welcome because of their desire to offer a very person-centred approach to their work; these included help with personal care.

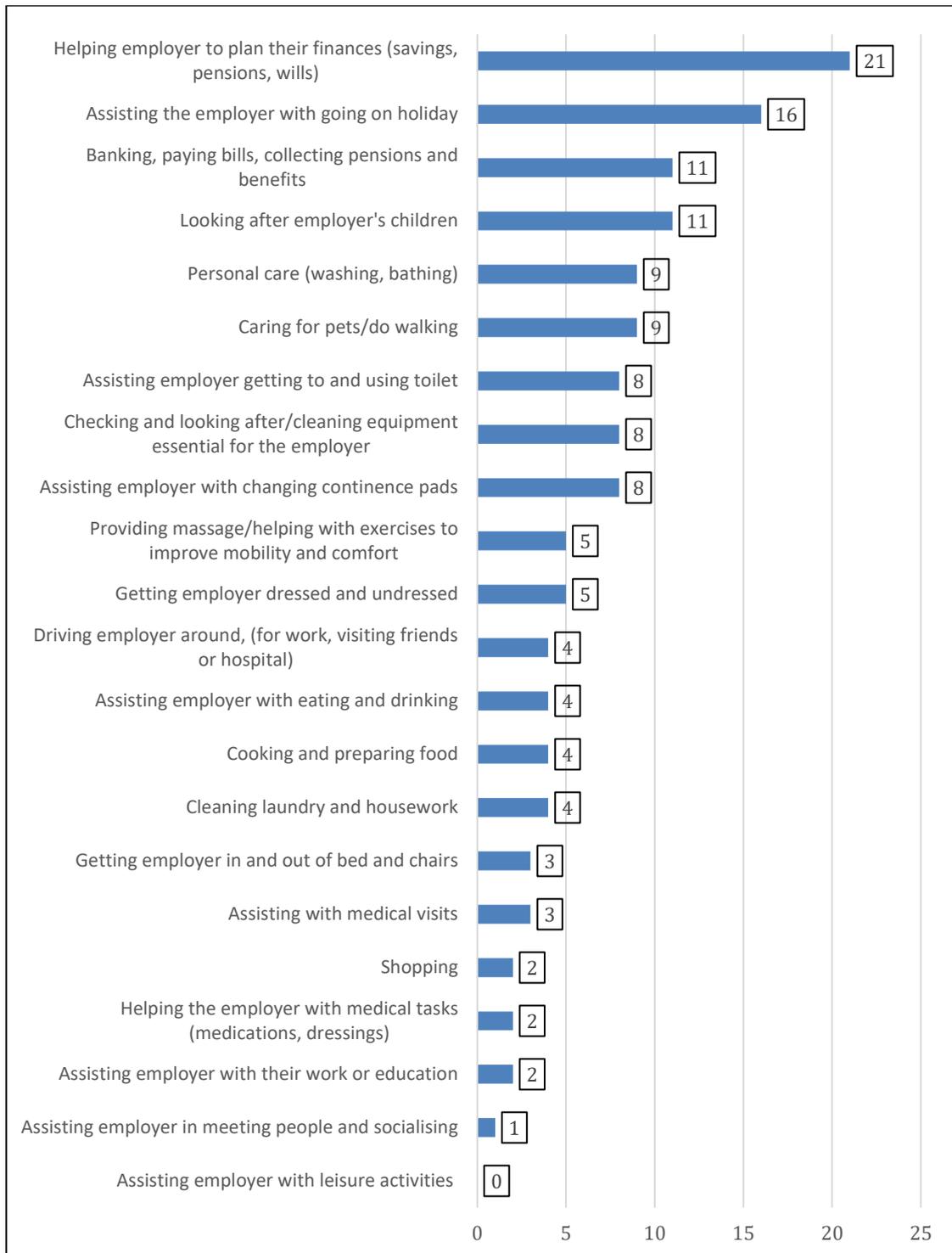


Figure 6. Tasks PAs said they would not want to carry out, even if asked to do so

Though there was considerable willingness to be flexible, some PAs also said that there were things that they would not wish to do, if asked. This was largely to do with personal preference: for example, some PAs had consciously chosen to work for employers who did not have personal care needs.

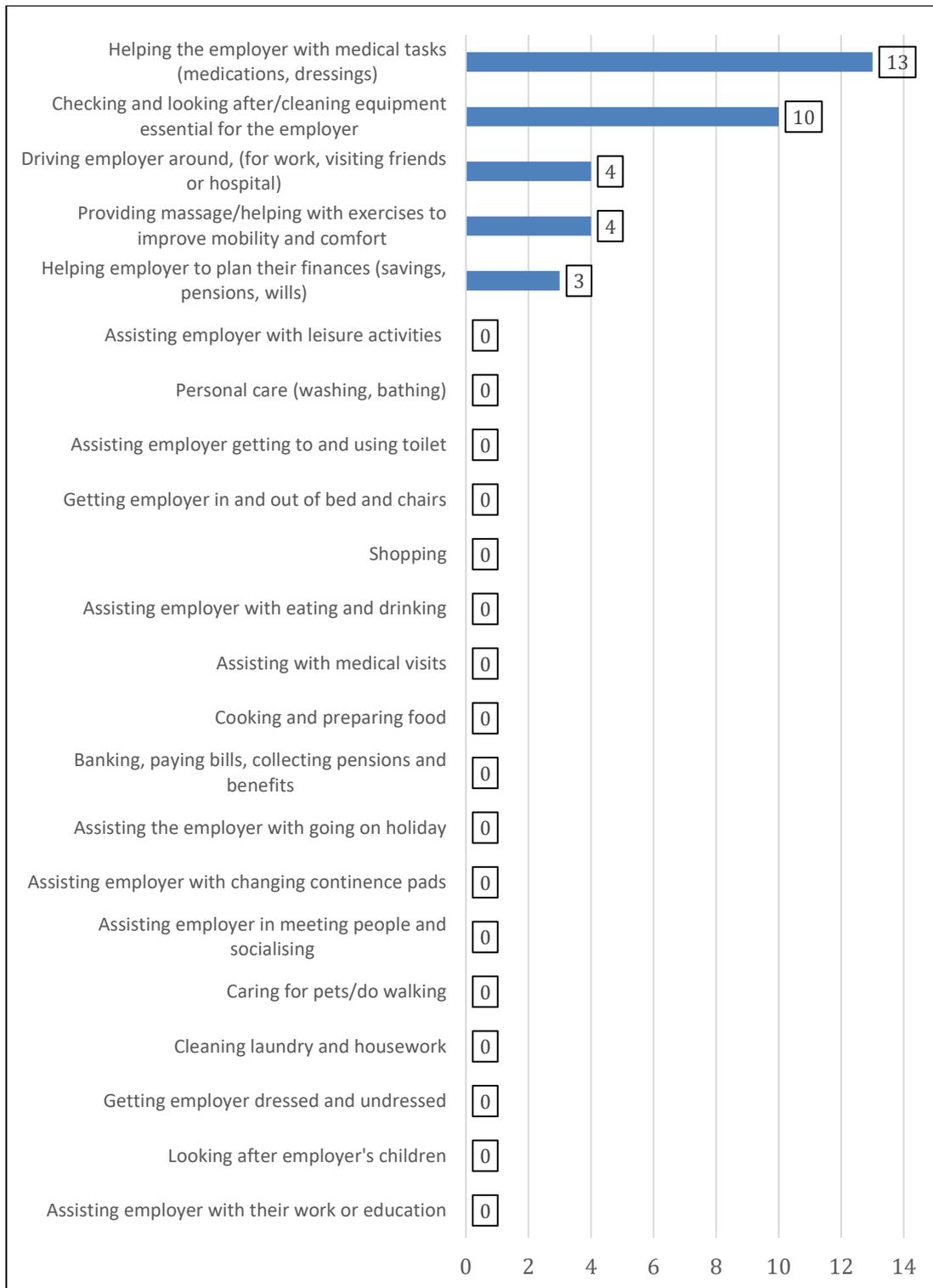


Figure 7. Tasks PAs said they would not carry out because they had not received training

Many PAs also felt that they would need additional training to take on more complex or technical tasks:

'We have a basic medical training as part of the (name of Centre for Independent

Living), but I would definitely want more training if I was doing anything more personal than I'm doing now'.

DM550145

One PA discussed 'sorting out' an employer's 'needle' who had epilepsy and another mentioned using an Epi-Pen. Another PA had given injections:

'I very occasionally have... I have given injections... Like, maybe sort of twice, I think in the time that I've worked as a PA'.

DM550228

Several PAs expressed reservations about helping employers plan their finances (savings, pensions, wills) without proper safeguards being in place because of the risk of false allegations:

'Well, particularly with a will, you could be accused of being... if there was anything in the will for you, well, you couldn't do it, could you? Vested interest and all that. I think it's just a bit tricky that you have to be quite careful with handling people's finances. Depending on what state they're in perhaps. I mean if they know what they're doing and they're quite compos mentis, that's a different thing from somebody who doesn't really know what they're doing. I think you just have to be a bit careful... It doesn't seem quite ethical'.

DM550250

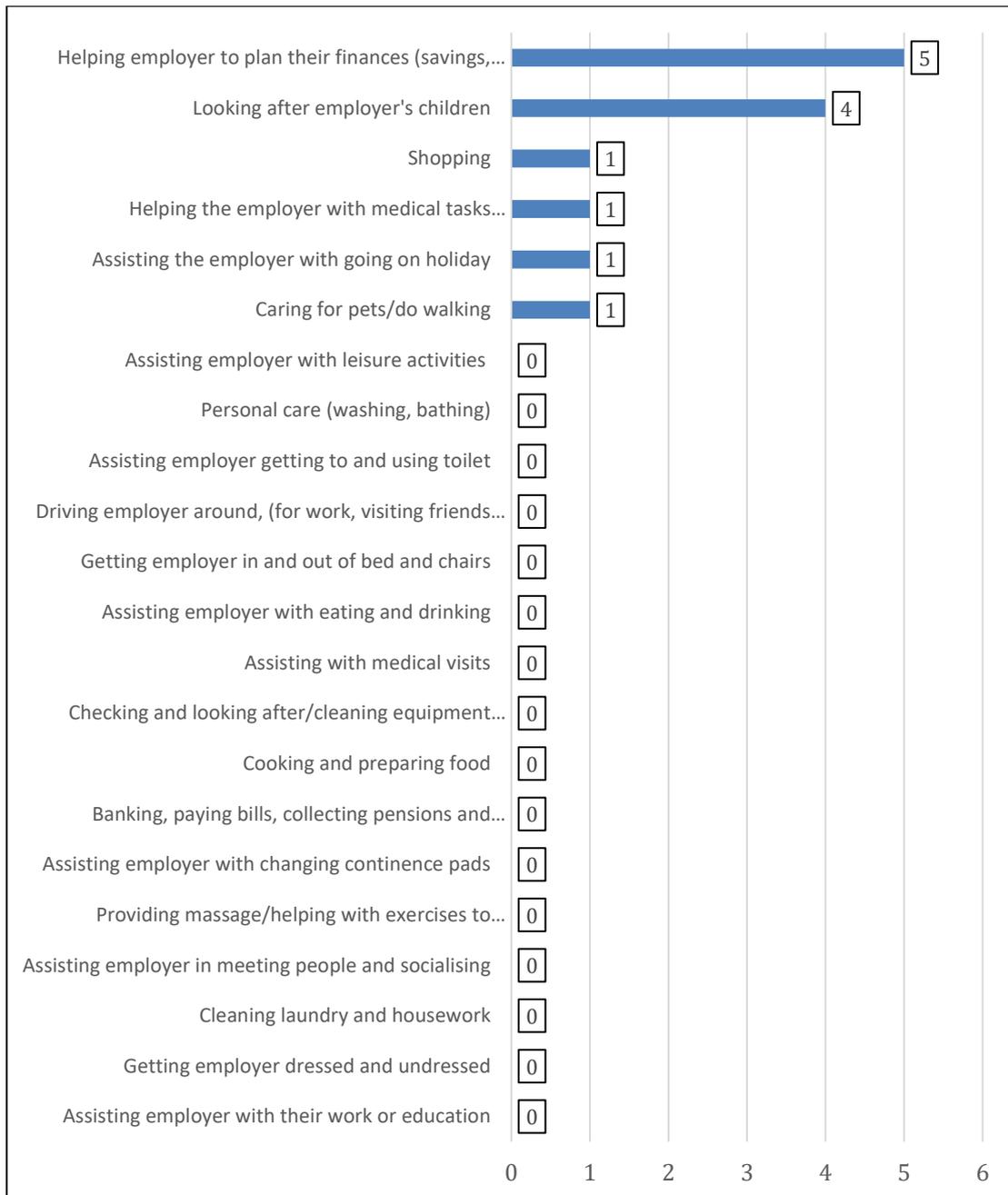


Figure 8. Tasks PAs said they should not be asked to do

A very small number of PAs said that they did not feel some of the tasks listed should be regarded as part of a PA's role.

The wide range of financial tasks with which PAs could be involved demonstrates why some individuals may not have wished to take on such duties:

'Well, interestingly enough, I went and bought this car with this lady and she was asking me to do all sorts of financial – she wanted insurance because she was going on holiday and that was very hard for her to get, so I did that. I would give

her the information, I would research information, but there's a line there that I wouldn't go over, that I'm not a financial advisor.'

DM5502505

Three PAs expressed strong views about not looking after children. For one it brought back unhappy childhood memories. One had had a negative previous experience:

'Well, with that family in particular, I sort of... I think they more wanted a housekeeper that would look after the child, and I didn't end up working for them for very long. Yeah, I think they were expecting quite a lot... yeah. Their son had quite demanding needs, actually, and then I think she was wanting me to do quite – oh, the other thing as well is siblings. So, I used to have a couple of families where there was a sibling that I would be expected to look after as well, so that could be quite difficult...When I used to do that, I was quite young, and sometimes I look back on it now, and I think, "God, I can't believe I did all that!" (laughing). It's kind of one of those things you do as a 23, 24-year old!'

DM550245

A small number of PAs did not want to take on personal care:

'I don't do it. I'm quite reluctant to take on people that need personal care. Similarly, when I am with somebody if we're out and about, if they need help and support, I will give it to them, but I don't generally do personal care'

DM550147

Some described personal care as non-negotiable and one responded that this was a reason they had been reluctant to be a PA before a friend told them they could negotiate the terms of their work role:

'Yeah, I suppose I ... when we had... I suppose you could call it an interview, I made it clear that personal care was non-negotiable; I basically just couldn't deal with that, but pretty much anything else, social activities, or anything else would be considered'.

DM550167

While some PAs were happy to go on holidays with employers, others were not. One PA recalled being given a lump sum payment by the family of a disabled person to enable this person to go on holiday. The level of payment was far below the actual number of hours the PA worked, and this left the PA feeling that she had been exploited:

'I think when it comes to going away, and things like that, that's where, pardon

my language, but I feel like the family take the piss and, don't get me wrong, that three weeks away was amazing. It was an experience that I wouldn't have had if I hadn't have done that trip, but it was extremely tiring, it was extremely hard work and, when wages were brought up, I felt very under-valued and I felt quite disappointed in that the parents were happy to pay us the wage they said when we were looking after their daughter, and I just thought if that was me, I'd be mortified that my parents were willing to pay peanuts for my care. Do you know what I mean? And then the fact that, because I had to feed myself, food wasn't catered for, for a three-week trip, I came back worse off and I actually lost half a stone'.

DM550210

A very small number of PAs also described requests by their employer that made them feel uncomfortable because they seemed inappropriate:

'With one of my employers, it was personal care. They basically wanted trimming in their personal areas, which made me feel really uncomfortable. I felt like it was my job to help them, so I felt like I had to try. I just kind of... I said, look, it makes me feel uncomfortable, and they was like, I'd really appreciate it you do it. So I kind of felt guilty, but you just don't feel you've got a choice. You don't want to cause issues with the job. Don't want to cause any kind of ... don't want to make them feel bad when you've done that'.

DM550133

'There's also an element where you are, even as a Personal Assistant, you are just made to feel uncomfortable and I did have one chap I went to, I agreed to go and help, and I went once and that was it... I said to my husband, "I'm not going back", I just didn't like the way he talked to me... And another woman I used to work for... partly because she was incredibly frustrated being wheel chair bound... but it's not acceptable to take it out on your PA and even the disabled woman I used to look after, a couple of times she threw a wobbly because she wanted something or other which was totally unreasonable and I said, "No you can't, you don't have the money" or, "It's not safe" or whatever it was and she would fly into a temper with me and I had to say to her, "Look, you can't speak to me like this, you have got to make up your mind. I will come back if, and only if, you promise that you're not going to behave like this again." So, it is really just establishing, well not just, but it's a matter of establishing boundaries. And you do have to be tolerant of people, but you can't be tolerant of intolerance'.

DM550232

One PA referred to having to mediate between the client and her client's family. This was problematic because it compromised her ability to support her client as intended to and made her feel uncomfortable:

'I suppose bridging between the client and the family. You're the middle person for what can be quite difficult... it depends; if the family are also there, then that can be a daily thing, where you're trying to mediate because the carer's exhausted and really fed up with Mum or Dad or whoever it is, and they're bossing them about and telling them what they should or shouldn't do and they haven't done it fast enough and it's not quick enough or whatever, and then of course the person's saying, can you tell them that I did try, or can you tell them... whatever. So you can be the middle person that way'.

DM550170

This PA went on to describe a problem with one family where the employer, the daughter of the cared for person, lived some distance from her mother, and was unaware of her day-to-day needs:

'Mum is actually really, really, really rich, but Mum doesn't know that; Mum thinks she's really, really living on the breadline, and that's hard because the daughter pays me, but I have a good relationship with the mother and I'm always looking after the mother's interest and I'm always making recommendations of what I think will help Mum, where Mum won't ask herself because she doesn't think she's got any money and she doesn't want to be a burden on the family....She [daughter] just doesn't have time. She's got two kids, she's got a husband, she's got his elderly parents are also ill. So I say to her, your Mum needs a new kettle, she might burn or catch her hand on this one, or it doesn't work, or she needs new slippers because they're misshapen and they're actually pushing on a bunion, and I can say it, and I can say it, and I can say it and, with all the will in the world, the daughter, because she wants to be a good daughter, puts it on her own to-do list. You know, get Mum's slippers, get a new kettle; and she lives in (distant rural English county), it's going to sit on that list for six months, and it does, because she won't... she can't in herself say, I can't do this, let the PA do it, because she thinks she's not a good daughter but, equally, she's not being a helpful daughter by not doing it. So then I get frustrated and Mum gets upset because she thinks she can't afford these things. So, yes, mediator, middle person, whatever; that is a big part of it, I think'.

DM550171

4. Recruitment

a. Finding the right employer: the perspective of PAs

Being able to choose whom to work for was important for some PAs and a major contributor to their enjoyment of the role. PAs described jobs where there was a 'good fit':

'Okay, so the trick to why I can appear so flexible and helpful and lovely is because I'm really careful with who I choose in the first place. I will... the whole purpose of personal budgets is that the client only employs somebody they like and are happy with in their home but, in doing that, of course I only work for people I like, and they like me. So, I therefore have a wonderful relationship with the very few people I do choose to work with, and it tends to be a long-term relationship. So when you're having four or five hour sessions, which can be three or four times a week, no, there isn't really anything I wouldn't do because I really, really know them, we really trust each other, we've got a really good relationship, we can laugh together, cry together, scream together. We've built it up; it doesn't come out of nowhere.'

DM550171

Some PAs described fulfilling relationships which had lasted over many years and could be described as friendships. In one instance a PA employee had eventually come to live with a couple in their family home. The following comments demonstrate how PAs' good relationships made their role enjoyable:

'You get to do some really fun things that you wouldn't necessarily do and certainly wouldn't do if it was an office job.... To see that person's face light up at this exciting activity that you've planned for them is lovely, or they've planned for you, depending on who it is. And the people, I guess, as well. The families of these people are just some of the nicest people I've ever met.'

DM550168

In contrast, other PAs felt that if their relationship with their employer did not 'work', for some reason, this could have negative implications for both PA and employer:

'If you choose a role and it's not working, it can feel so laboured, and you feel bad within yourself because you want to be able to help someone, you want to be able to offer quality care that's compassionate and everything else and you can just tell that it's not clicking and that you're not really getting on, and that's the worst part, is knowing that you feel like you're letting them down, but you have to have

that inability to know that you're letting them down, only that they'll find someone better, not that you're letting them down'.

DM550175

Personal 'chemistry' was seen as vital for the PA role to be a success because of the extensive face-to-face contact between employer and PA:

'If your personalities just don't mix, then the likelihood is that you would say, I'm sorry, but it's not working for me. You'd know within the relationship and you're saying it's obviously not working for you, and they wouldn't want to put up with someone that they don't like working with. And when I say like, it's just the awkwardness of when you're with somebody for eight hours, if you're not getting on, it's just so apparent'.

DM550175

Several PAs described cases where they were initially not welcomed by an employer who might not want to face up to their need for care, but, over time, good relationships became established:

'When I first went in, for this lady, having anyone help her with removing her false teeth or anything like that was completely alien, and it took her a long time before she could relax into that... okay, I need all this personal care, I trust this person, therefore I'll just accept that and go... if you see what I mean...and she had no experience, except of her daughter looking after her, so it was completely alien. Initially I walked in and I was a stranger. Thankfully, apparently, she liked me straightaway, so that helped matters. If she hadn't have liked someone, I think it would have been more difficult; she would have had to have like the person'.

DM550149

b. Finding the right PA: key informant perspectives

Key informants were asked about the best ways for employers to find PAs and for PAs to find work, and what made recruitment easier or more difficult. Most of those whose role included the recruitment of PAs said that the recruitment process was not easy, but that it was of great importance to both parties, not least because of the very close working relationships between the PA and employer.

A wide variety of approaches to recruitment was reported with opinions expressed about the methods that were most and least successful.

Informal recruitment channels

Informal approaches were highly regarded by some participants. They included:

- (i) *Word of mouth.* Because the potential PA was known it was possible to assess more easily if they would be 'compatible' with an employer. It was also seen as less time-consuming than more formal recruitment methods, less 'risky' (because the prospective PA was someone either 'known' or came with a personal recommendation), and less expensive (in respect of advertising).
- (ii) *Family member PAs* were also favoured by some participants because they were easier to recruit and may already have been carrying out at least some elements of the PA role already, but without pay. However, the employment of family members could also be problematic because the introduction of payment for care could negatively affect family relationships.
- (iii) *Local community.* A third informal recruitment channel used by some were contacts with local community organisations in which the prospective employees participated, including clubs, societies, churches or other religious institutions:

'...we've found the person has to go far and wide. So, we would recommend tapping in...to newspapers, tap into local shops, we ask about hobbies, for example, we had somebody that found their PA through a church magazine, so we talk about hobbies. We talk about where people go...'

KI Interviewee 22

Local advertising

Several key informant 'recruiters' said that simply putting a postcard advertisement in a shop window produced very positive results. A key advantage of the approach was claimed to be the very local nature of applicants, which reduced travel time and costs and offered more opportunities for flexible working hours. However, others counselled against shop window advertisements in rural areas because of the greater likelihood of the prospective employer being known to people who might read the advertisement, thereby compromising their privacy. Local newspapers had been used by some participants with good results, and local radio stations were also mentioned.

Commercial websites

These were also used by individuals, but not without difficulty in some cases where intermediaries were involved. This was because some of the national websites such as 'Gumtree', where adverts were said to be placed, regarded Centres for Independent Living, user led organisations or other small voluntary organisations as commercial recruitment agencies and insisted that commercial – and expensive – rates for advertising were applied.

PA registers

These are essentially on-line platforms on which people seeking work can register. Though details of the PA were usually made available to prospective employers, most registers are constructed so PAs are unable to contact prospective employers. The amount and relevance of information contained on registers also vary. Some allow PAs seeking work to provide detailed CVs, interests and values, and a passport-type photograph. Information about the interests of the prospective PA was valued because it helped employers to match people against their own interests and possibly also their values and beliefs. One participant worked for an organisation that had set up a social media platform with open and closed groups. Information about PAs was made available on the closed site, and the open site was one way in which this local organisation raised awareness about PAs amongst the general public.

Student placements

Some participants had contacted local universities or colleges and offered PA employment to students on vocational courses in health or social care as work experience placements or as part-time work. These were generally regarded as successful, with some students continuing to work as PAs even after they had graduated.

Job Centres

Those who had tried to recruit PAs via Job Centres were generally agreed that it was not a good approach. First, the term 'Personal Assistant' was misleading, and even though an advertisement might make clear the true nature of the work, applications would still be received from people seeking administrative, office-based work. Second, recruiters found that they also received many applications from people they regarded as manifestly unsuitable. This was because there is a requirement in the UK benefits system that claimants able to work should provide evidence of job-searching to receive their benefits. Most of these applicants appeared to have applied simply to satisfy benefit claim requirements. This was thought to waste everyone's time, including that of the claimant.

c. What makes recruitment easier/harder? PA perspectives

Prior relationships

These were also mentioned by many PAs as an easy way of gaining employment in potentially well-matched situations where the employer and employee may be already 'known'. This was easier for PAs currently or previously employed in roles where they encountered potential clients, such as care agencies. Other PAs were well networked locally and/or had relatives working as PAs as this daughter of a care worker described:

'...when I've been taken [by] my Mum to visit them, and then that's generally when they're like, would you mind covering and start offering a few hours a week, because I weren't really looking for a job because I already had my retail, and then it just kind of snowballed from there and I ended up going full time for two of them.'

DM550142

Other routes to employment

Other channels were discussed by PAs. These included the use of LA affiliated organisations, general internet jobsites, specific Facebook groups and other brokerage services:

'The first one put an advert in our local newsagent's window. And then I saw the [Name of organisation] advert, followed that up, put my details on that with references and I had one lady reply to that who was a little bit out of my area, but by going to her, I then put an advert in the local shop and in the local magazine and I got two more people off that. And then I had another one from the [name of organisation], who's on Direct Payments, and the other ones have been word of mouth. And the one that didn't work out was through [name or organisation] and my most recent one was through [name of organisation] as well.'

DM550178

The local labour market context

Local employment rates greatly influenced the ability of PAs to find work. Some PAs discussed having to turn work away, while others were more concerned about finding work:

'...once I started working with one family, then the parents all talk, and then... Yeah, I got quite busy, actually, to the point where I was having to turn work away.'

DM550245

'...being paid by social care, social services, cut-backs, there is a shortage of staff and expectation from you is more and more, and very isolated, people just fight. I am lucky that I have other jobs, but people fight to earn their living, maintain some standards and maintain some professionalism.... you need to have money, certain amount of money when there is pressure, certain environment can be very difficult to work with. It's quite isolating and you really... it's very hard to remain in the job, basically'

DM5501841

Clear negotiation about the role

Role clarity was mentioned by many PAs as an important part of making recruitment easier. The quotation below was typical of how an experienced PA assessed a potential role, whether they were suitable, and what they could offer:

'So, there's always an initial, you know, meeting and conversation where I discuss with the son or the wife or whoever it might be what exactly they need and whether they think I'll be suitable and whether I think that I'll get on with whoever it is. That's usually a fairly detailed conversation and then it's a matter of starting work I think and seeing what areas, what other areas might need covering or making suggestions, you know, based on your observations or, I think it is quite tricky, you have to be careful because you obviously want to be pro-active but you don't want to be pro-active to the point where you're infringing on somebody's autonomy.'

DM550232

However, not all PAs found this approach useful because an employer's health could fluctuate. To address this, some PAs referred to more informal conversations during recruitment:

'So there was a lot of going back and forth and if there was something I felt perhaps I couldn't, just wasn't in my, you know, just didn't want to do it, then I would be quite truthful or I might say, "Well I'll try it and we'll see how we go and if it doesn't work out" so yeah, I think there has to be give and take and also like I'd always go in quite open and say, "Look, let's see how we get on in the next couple of weeks, you might not like me or it might not work and that's fine but at least we'll be honest and say so".'

DM550222

One PA felt the initial discussion and contract, although useful, had not been reviewed and revised when circumstances and needs changed:

'Yeah, it's been ongoing as his needs have changed as well. Yes, and I know one thing his Mum said when it came doing more domestic tasks – it used to be he was completely immobile in bed and it was very much to do with... very much focused on him and just his care and she was not working at that time and looking after all the household things, but he is not so dependent now and she's working again, so she was very kind of ... would it be alright if I asked you to do some of the household tasks, because that's what he needs in the way of support now as a family, that's what they needed, so yeah, it's been ongoing discussion.'

DM550177

Another PA recalled not being provided with all the information needed at the time the initial contract was drawn up, and she felt this hindered appropriate care being provided for her employer, who was described as having mental health problems:

PA: *'... there were things that I feel that I should have been told about prior to that by the mental health team, because I have actually never met the mental health team until yesterday. Now, I've been working with him since last October and I actually met one of the mental health workers that he deals with yesterday for the first time. And I did say to him that, in hindsight, I think from the minute I started with him they should have had a meeting with me so I was aware of – I had no phone numbers for them until I actually asked for one, and that was only because my guy was having a complete meltdown and was thinking irrational thoughts and wanting to top himself. And that part of it, I feel I should have been given numbers, I should have had contact with them. When I explained all this to the guy yesterday, I said, "Actually, I think I was let down", in the sense that they had put all these things into place, but I wasn't aware of what they had put into place. I was only given what my guy told me.'*

Interviewer: *'So, communication isn't very good?'*

PA: *'I didn't think was very good at all, no. And, obviously, my guy could obviously basically say what he wanted to say, and I just went along with it because I assumed that's what everyone had agreed on, not knowing any different. But yesterday, I think there was a long chat, let's put it that way, between me, my guy and the mental health visitor. And I said, "Basically, it was unfair that you put me in that position where I should have known from day one, from when I first started working with him, what you had in place for him, his boundaries and everything else.'*

DM550230

By contrast, other PAs were given information but preferred to rely on 'instinct' when deciding with whom to work:

'I remember [in previous job] one of the social workers came to... and they threw a support plan at me to give me an outline of the child, and I threw it back at them because I said I'm not interested in reading about people on paper; I like to meet them, because you can read about someone's individual experiences on paper, but when you actually meet ...'

DM550160

Difficult recruitment decisions

Not all PAs were able to choose their employers, which could lead to hard choices about working for someone where the relationship was unhappy or uncomfortable:

'There has to be mutual respect and without that you can't because, you know, there's nothing more galling, frankly, than working for somebody... and being treated like dirt, which has happened... and just this is completely wrong, you know, you're paying me £10 an hour but you think because I'm working as a carer I'm a sort of glorified skivvy.'

DM550232

d. What makes recruitment easier or harder? Key informant perspectives

From experience of recruiting, either for themselves or on behalf of someone else, key informants also felt that some things that could make recruitment easier or more difficult. Things that made recruitment *easier* included the following.

Prior relationships

Previous relationships between PA and employer were also seen as helpful by key informants who felt if both parties knew one another, many preliminary kinds of question that would otherwise be necessary could be set to one side. However, though efficient and cost saving, some felt this approach may not necessarily represent good equal opportunities recruitment practice.

Clear job descriptions, person specifications and information about pay rates

These were also seen by some as a way of ensuring both parties had an idea of what to expect, and to 'manage' expectations. Others emphasised the importance of making the job sound interesting and attractive to solicit applications. Though some key informants also felt that lack of clarity of job descriptions and contracts was a recipe for 'boundary' issues and conflict, others felt that though clarity was important, this was not incompatible with emphasising the positive elements of the job:

'When we're advertising positions...we talk about, you know, the positives about what the role's going to involve. You know, if it's going to the cinema, it's - go and do this, it's very much we hope people reading it, from all walks of life, thinking, "Yeah, I could do that". You know, we don't want it to be, you know, "Can you support this severely disabled person who needs help to use the toilet?" and things like that. Some of that may be involved, but that's not the be all and end all of the nature of the support; it's more about kind of, you know, enriching somebody's life and the opportunities that you can have....'

(KI) Interviewee 17

One key informant felt that spelling out some of the more 'menial' elements of the role in an advertisement might deter some people from applying. This was in

contrast to general care work for an agency where, *even if* personal care was part of the role, the opportunity to develop deeper relationships with their employers - and potentially make much more of a difference to them - was not so easy although it might mean that the work could be much more attractive, fulfilling and rewarding.

Clear information about other aspects of the job

Participants felt that clear information about rates of pay, hours, days and location of work was helpful, but could make it harder to recruit, depending on employer requirements: for example, if the employer wanted someone for very limited hours or 'anti-social' hours: typically, early morning or late evening. Information about the location was also important because of the potential costs of travelling to and from work.

Local labour market conditions and low pay

Key informants living in the south of England generally said that it was very hard to recruit because PA pay was comparatively low, and the cost of living was high. One consequence of this was concern that desperation might lead employers to hire 'the first person to come along' rather than the 'right' person. By contrast, in north-east England, participants said that local wages were low and unemployment levels were higher, which meant that the PA wage was more 'meaningful' and recruitment was easier.

More *difficulties* were mentioned about recruitment than things that made it easier. Some of these 'difficulties' have been mentioned above and included things like out-of-date PA registers, and time lost to inappropriate applications because the nature of the job had been misunderstood.

Expertise of recruiter and their support needs

Key informants said that many prospective PA employers had no previous experience of recruiting an employee (or managing one) and some needed a great deal of help with the recruitment process. Some felt the amount of time needed to do this was sometimes disproportionate to the funding that was available for this purpose.

Awareness of prospective employees

Several key informants felt that a significant problem with recruitment was that members of the public had no awareness that the role existed and that little information about the role was getting through to the general public.

Misuse of the register or misunderstandings about its purpose

A handful of key informants referred to misuse or misunderstandings. One participant mentioned that sometimes the PA register in their area was mistaken

for an agency register, which meant that there was an expectation on the part of the employer that they could phone in to recruit someone to work in an emergency or to cover sickness or holiday shifts if private care arrangements had been made. This person also referred to misunderstanding and misuse:

'...our initial plan was to have a list of PAs and then to allow disabled people to possibly look at those and think 'oh, I would like to employ Fred, or Sally, or whatever'. However, what we found in those early days, as soon as we tried to do that some disabled people would ring the person up, saying 'Right, you, I want you tomorrow morning' – and they saw it as agency work. And the other thing we had; sometimes people would look through and say 'Oh, well, I like the look of her, she is 19' and so we quickly decided that wasn't a suitable way of doing it'.

KI interviewee 23

The solution to both complications was to step in to act as a 'broker' between PAs who were signed up to the register and prospective employers. As a result, information contained on the site was made visible only to those responsible for maintaining it who 'matched' employer and PA. Another participant also referred to discriminatory or racist behaviour by some prospective employers and the necessity to challenge this when necessary.

Other recruitment difficulties were mentioned infrequently. Unrealistic expectations of employers were one such. These could create delays in the recruitment process if the employer was waiting for *exactly* the right applicant. Online advertising, mentioned above, was seen by some as a 'scattergun' approach that could lead to many inappropriate applications. One person said that HMRC employment status categories (for tax purposes) were not helpful: this person felt that these categories had originally been developed for self-employed workers in the building industry and the requirements were largely not applicable to PAs. One person also expressed concern that in some parts of the country, BREXIT might lead to an exodus of PAs who were EU nationals. (8% of the PAs interviewed were non-British.) Finally, one participant described the existence of 'dodgy introduction agencies' in which people from other EU countries had been recruited to work as PAs by 'pop-up' organisations without any form of checks or consideration for their suitability: for example, people with limited knowledge of English language. The existence or prevalence of such arrangements could not be verified or substantiated by this participant.

PA registers: PA perceptions of advantages and disadvantages

The variation in the purpose and functions of PA registers locally, and their differing roles explained the variety of experiences of them among PAs from different localities:

PA: *'Yeah, it's not like an agency. They basically match carers up with people who need the care, you know, and then [the client is] in control.... They just kind of recommend people... So, like the person I'm with now, x, I work for x but [name of organisation] put us together and (they) do x's wages, you know. He'll send them the wages and they'll sort it out all from that end.'*

Interviewer: *'So they act as a kind of brokerage service?'*

PA: *'Yeah, I think that's what it is. I get confused as to what it exactly is sometimes, but I think that's pretty much it, yeah.'*

DM550238

Many PAs referred to being 'on a register' and being vetted (having completed a Disclosure and Barring Service (DBS) check) before they could be accepted for work and saw this as good practice. Where training was offered as part of this process, it was hugely appreciated. However, one PA drew attention to some operating procedures that were part of one register:

'...another thing that annoys me is if a complaint goes in about a PA, straight away you're pretty much guilty until you can prove you're innocent and you're removed from the approved register...a colleague of mine actually left being a PA because of this situation. She was going on a contract, obviously, all the support was agreed... went in, provided the service, the client went into hospital, but this colleague of mine, she was owed about three weeks' money, so she followed the processes of sending in the invoice, then there was a reminder and a complaint got put in. (She) followed all the procedures exactly as they should have done, complaint got put in and she was actually removed from [name of organisation]. I actually tried to help her with the procedures of appeal and stuff, but it was all very much in favour of the actual client. And, to be honest with you, if I wasn't such an advocate of people being approved in order to give clients the security that you've PAs going in that are DBS checked; if I wasn't such an advocate of that, I would have actually left the team, I didn't agree, because I thought I could be in that boat myself... No, it was really bad. So, I've never really had much respect for the scheme, but I have respect for some of the people that are associated with it, so I carry on.'

DM550160

e. PA registers: key informant perceptions of advantages and disadvantages

Many key informants also referred to the lack of public knowledge of the PA role, which contributed to difficulties PAs and their employers might have in recruitment. Some of them worked for local organisations that had established registers to overcome these barriers, and all of them supported the development

of registers. There were, though, mixed opinions about their real value, the relative advantages for employers and PAs, who should set up, manage and pay for them, and what information they should contain.

Registration as accreditation

Several participants drew attention to the risks that employers ran by employing people who were not 'registered':

'I've had a case where the tax man has come after someone because the PA – self-employed PA, been their PA for 20 odd years, client dies, PA claims redundancy, "No, you can't do that, you're self-employed". Talk to the insurers, "Oh yes, they can, they actually can". So, he claims redundancy and the widow is distraught because that's a lot of money. Then, when the redundancy is paid, lo and behold HMRC go, "Hang on a minute, where's the NI (National Insurance) contributions for the last 20 years?" and it's been cash in hand, self-employed, they haven't kept records, so HMRC thinks, "Okay, he's been doing 30 hours a week for the last 20 years". Even though he might not, they take the last snapshot and they come after the client for unpaid National Insurance, any – if the PA hasn't been paying their tax and the employer has no way of knowing that they are doing, they'll come after them for that as well'.

KI Interviewee 16

These participants felt that registration could be used as a form of PA 'accreditation' system, in which there were conditions attached to registration. One worked for an organisation that required compulsory basic training, checks on HMRC registration and insurance (because all those who registered were regarded as self-employed) and DBS checks. Not all those who applied to join this register as a PA were successful. This participant argued that this kind of approach offered both safeguards and quality standards and observed that registration was an effective way for PAs to secure employment. Some other key informants felt that using a register in this way might be desirable, even though it was not possible for them to establish one in their organisation within existing budgets. Another participant made the point that any kind of register would be *seen* by many people using it as offering reassurance - that those registered had met a required standard or had been 'approved' in some way; regardless of whether this was the case. This participant argued that because it would be 'seen' in this way, if there were no standards, and exploitation or abuse occurred, reputational damage to the organisation would be inevitable.

'Non-accreditation' registers

By contrast, some participants worked in organisations that managed PA registers where the PA was invited to effectively 'self-register' by describing themselves, their experience and expertise, things they were willing and not willing to do as a

PA, and upload these to the site. Information was not verified, and no background checks were made, for example, on DBS status:

'We have a PA noticeboard which is an online website. It's a free website for our clients and PAs which they can use without our assistance. They register online, ...so PAs would then write their own profile of their skills and the kind of work they're looking for and that would be uploaded; and the clients will upload a job description of a PA that they're searching for, and really, then it's up to them to look for each other...It's not vetted. The people who are advertising as PAs and their profiles are not checked and we actually make that very, very clear to clients.'

KI Interviewee 19

Clear advice was given to prospective employers to consider background checks, and this participant felt that prospective employers were perfectly capable of assessing someone's suitability for themselves.

Who manages the register and what information should it contain?

Key informants had different views about what 'registration' meant, and some, though recognising the benefits of register of PAs, also felt registers could be inflexible if compulsory which could lead to control being taken away from employers. Several participants felt that it was important that registers were either managed by user-led organisations or co-produced by them. As well as conferring greater legitimacy on the register, it was argued that user ownership or participation would lead to improvements in the relevance of information collected. Some suggested that the question of 'ownership' raised more fundamental questions about the purpose of a register and how it should operate: should it, as one participant put it, operate as a kind of recruitment agency, or a support service for employers or prospective employers?

Other 'register' issues

Irrespective of the purpose and contents of a register, some participants referred to operational and other matters that would need to be considered for any register to be useful.

One such was the need to continually refresh and update the information contained on it. Some key informants who themselves employed PAs said that prospective employers could waste a great deal of time contacting PAs on some registers who, though still registered as looking for employment, were not seeking more work. One said that in the organisation in which they worked, PAs were required to update their details monthly and, should they fail to do so, their details would be removed from the register.

Geographical coverage was another concern. One participant noted that in London, several different Borough (local authority) registers were kept, and 'at scale' efficiencies could be realised if these collaborated or combined. At present, it was noted that each collected different information, operated in different ways and had different levels of resourcing. A prospective employer living close to a boundary between neighbouring Boroughs might find it easier to attract and retain a PA from a different Borough simply because of geographical proximity.

Some key informants reported that attempts by their organisations to establish registers had not been very successful as they had not had many enquiries from prospective PAs or employers. The reasons for this were not pursued but may be related to the amount of time and resources available to establish and maintain a register, the ease with which the registration site can be navigated by other PAs and employers, the reliability of the information on the site and its relevance to prospective employers.

Other wider regional differences, including employment levels, proportions of people in local populations likely to need the services of a PA, and local costs of living may each have affected the relative success of different registers. Some participants also suggested that to maintain registers in the medium term, it might become necessary to ask prospective employers and PAs to pay to join or use.

f. Matching skills or experience of PAs with requirements of employers: PA perspectives

It seemed clear from comments that most PAs 'self-selected' people to work with according to their prior experience and knowledge. For example, a PA with a background in teaching (as a SENCO - a Special Educational Needs Co-Ordinator) described working with the same young person with physical disabilities for the last eight years, encouraging their employer to fulfil her potential and gain independence.

Another PA had taken voluntary redundancy from a school specialising in autism. Subsequently most of her PA 'clients' were referred to her through the school because of her acknowledged skills in working with this group.

One of the few PAs who had previously undertaken professional training (midwifery) discussed working for a person who was severely disabled (paraplegic), her confidence in carrying out nursing related tasks for him, and her enjoyment of learning and developing new skills:

'We change dressings, he is fed through a pump, so we have to set that up and

make sure that's all in working order, do the bolus feeds and administer certain things through the tube and we give medications, apply both tablets and some medications go through the tube and he has patches as well for certain pain relief, like certain analgesia through patches which we have to change either daily or weekly, depending on the type, so ... It's a lot more nursing-based.... obviously, with my training as a midwife I've already done certain things'.

DM550163

g. Matching skills or experience of PAs with requirements of employers: key informant perspectives

Though there was broad agreement from key informants that matching of PA and employer was important, there were different views about the criteria that should be used for matching, who should do the matching, and how. Though assistance in finding PAs for employers could be there, all said this fell short of recommending specific people, or trying to influence the decision of the employer. However, where background checks (covering criminal records) were not carried out, it was strongly recommended to the employer that these be done, though whether they were done remained unknown.

Clarity about role and tasks

A small proportion of key informants referred to the need for clarity about the precise nature of duties a PA might be expected to undertake. (The report has already drawn attention to this, as raised by PAs.) Key informants saw role clarity as important to avoid 'boundary' problems and conflict. The matter of 'boundaries' between employer and PA, how they were established, where the boundaries were drawn and how they were negotiated and maintained were important and recurring themes for both key informants and PAs and the report will return to these questions below. Others said that it was also important that PAs were also clear about the kinds of tasks they were prepared (and not prepared) to do, so there was no mismatch in the expectations each might have of the other. It was also considered important by some that a job description should include any essential requirements. Apart from, for example, common requirements such as possession of a clean driving licence, there might also be a need for more specialised elements: liking pets (including dogs), and not being allergic to cat hair were two examples mentioned.

Clarity about kind of PA and the 'kind of employer'

Some participants felt that it was important for the employer not only to be clear about the tasks, but also the kind of PA they were looking for. This was seen by some key informants as also being contingent on the employer being clear, too,

about the kind of person *they* were. Most key informants did not feel the most important criterion for recruiting a PA to be skill or experience.

The criteria used by employers to find compatible PAs.

For some key informant employers who wanted to find out if they would be able to 'get on' with a PA on a day-to-day basis, following an orthodox recruitment process was problematic. One participant described formal recruitment interviews as unhelpful, because the interview format meant that an applicant could not relax. To overcome this, a series of meetings might be arranged, and conversations begun, to enable the employer to put the job applicant more at ease, find out what the applicant was 'really' like and how they might respond in different employment situations.

Shared values were regarded as very important by most key informant participants:

'I think ultimately, for me, it's not about having a standardised list of criteria. So, you know, when PAs come to interview with me I am solely basing my decision on their values and their behaviours and their ethos around disability issues and disabling barriers'.

KI Interviewee 18

Some key informants who worked in support organisations were clear that it was not their role to match PA and employer, and purposely did not collect detailed information on a register. For example, one participant had abandoned attempts to collect detailed information on a register in favour of a small range of factual 'core questions':

'...we tend to look at...quite practical things at that point because then everything else is a bit of a value judgement and that's not our, it's obviously not our – values that are reported, it's the PA's and the employer's; so that's why we would encourage people to meet one another so that it's not a decision that you're making based on what's on a piece of paper or what we've said...'

KI Interviewee 24

By contrast, other participants *did* work in organisations that attempted to 'match' PA and employer. In some cases, this was for very specific reasons:

'One of our PAs said the other day that the stigma of mental health (sic) is so great for one particular client of hers, and she was amazed when this client suggested they go out for coffee; and that's never happened. And then the client said to her 'Well, we could just be two girls out having coffee together, no-one would notice

us': so it was important to her that she was physically similar and that they would attract no attention'.

KI Interviewee 27

Being able to 'get along'.

The close personal relationship between the PA and their employer meant that 'being able to get on with one another' was seen as essential. The report has already referred to the ability of some PAs to choose their employers. Key informant PA employers drew attention to this too:

'I think the first requirement is relationship. So, it's not necessarily – I mean, there's obviously some core skills that a PA has to have. They have to be able to deliver the task. But I think the overriding issue is the relationship between the employer and the employee, given the particular role. So, in terms of the matching, the primary focus has got to be on the initial interview, contact, exchanges, and whether there's some kind of probationary period. However, it works, it will succeed or fail on the quality of the relationship, and what the service user is looking for and what the PA is able to offer. I think relationship is – I know it's not really a skill. It's just, you know, being able to establish the relationship of trust and confidence'.

KI Interviewee 30

Some participants felt that 'getting along' was more likely if they had things in common. Training and equipping PAs with core skills were also regarded less highly by some participants than the 'life experiences' of the PA.

Other criteria often mentioned by many were values and attitudes – particularly towards disability, shared likes and dislikes, as well as interests and hobbies:

'We've had some fantastic stories of people who've you know, just ended up with brilliant PAs. We had one guy; his main criteria for a PA was that you just had to like motorbikes basically, and ideally own their own motorbike. And we did him a job advert and we advertised it around. He put this fantastic picture of a motorbike, a particular model, like I don't know what it was, but we advertised in (name of local motorcycle shop/dealer) and he got himself three PAs who are all petrol heads, who've never done it before in their life...'

KI Interviewee 17

In some localities, a possible need for PA applicants to be able to speak the same language as their employer was also mentioned because impaired communication would affect the ability of both employer and PA to 'get on' with one another.

Matching by geographical area

Finding PAs who lived reasonably close to an employer meant reduced travel costs for the PA and greater potential for flexibility over time. This arose particularly in rural areas, though this was weighed against the need to maintain privacy in small, close-knit communities.

5. The distinctive nature of the PA role

PAs and key informants were both highly aware of the distinctive nature of the PA role compared to other social care experiences.

a. PA perspectives about differences between working as a PA and working in other care settings

Many PAs with experience of working in care settings described the PA role as 'very different' to any previous jobs they had held in that setting. Most reported that the PA role was more personally fulfilling and rewarding:

'The thought of having to go back to home care would fill me with dread now that I've had a taste of this... And once I'd discovered it it's, wow, there's a whole world out there that gives you everything that a good carer needs, it's that time element again, it's all there'.

DM550208

Opportunities to build caring and respectful relationships

PA descriptions of home care work often referred to rushed encounters rather than caring relationships:

'It's as simple as that; you're basically going in to check they're still alive, feed and water them, make sure they're clean and off you go, there's no leeway for anything extra like the bins or changing a ... – obviously you wouldn't leave them sitting in the dark but you spend another five or ten minutes doing something extra for them that you could easily do as a PA because you have the time, but as a Dom (domiciliary) Care Worker, you don't have the time so that means then you're running late and you get stuck in traffic to the next one and you can be half an hour late and it just spirals ... I know one agency I worked for, we were only supposed to use a microwave. One lady I'd go in and she'd say, "Oh, you'll boil me an egg, won't you?" because she liked a boiled egg, she didn't want a rubbery... out of a microwave egg and yes, I'd put it on and boil an egg for her, [but] I'd get told off if I was caught'.

DM550251

PAs also greatly appreciated having the time to care for people in the way they wanted to:

'You can help someone when they want you to help them, not when you're in this time-frame. If they need you a bit longer then they need you a bit longer; you can

actually say – you don't feel that you've got to leave and get to someone else really quick, you can sort your times out and fit everyone in to a certain – fit them all in because that's what they want and not what you want, if you see what I mean? It's just so much nicer to be personal to them and you're not being told by a company that, "Oh you're going in there for 15 minutes, you come out and you're going somewhere else"; you're actually spending time with someone that actually is asking you what they need. Because that's what it's about really, isn't it, it's what they want?'

DM550238

One major contributor to greater work fulfilment of PAs seemed to be the time available to develop more meaningful relationships with their employers:

'I have [employer] on a Tuesday and his mum and dad are both out at work so quite often, we'll come back to my flat and have lunch with my husband here sometimes.... They get on really well and it's more like a friendship with him so obviously, my husband isn't the paid one, I am. I'm always around, [but] the chap... will ask if he can see my husband. And I check with my husband and if he says yeah so, we come back, and we have, you know, some lunch and stuff. Yeah, and then off to our next activity.'

DM550247

Greater consistency of care

Consistency was also seen as a benefit of the role:

'Care is more personal and plus [the employer] can trust you more because they're not having five or six different people going in every day... Yes, and plus they have consistency; when you have five or six different people going in, something might not be done...'

DM550238

Many PAs who had worked in other care settings compared their current employment situation favourably because it was less task and more relationship focused:

'In the duties I sort of do today, a carer, for me, suggests someone needs looking after and that doesn't sit well with me when it comes to being a Personal Assistant. I believe that being a Personal Assistant is about facilitating, about enabling somebody to live the life that we all live, that we take for granted, to enable people to become part of their communities, create some, you know, a social life for them and it's not about sort of making sure they're toileted, making sure they're fed and then sort of left till the next time they need a task performing... PAs - we like to see what's strong in people, not wrong with people.'

DM550219

Some PAs also felt that the role afforded the employer much more control:

'... it's perfect for [employer] in the fact that he has a Personal Assistant because, again, he makes all the decisions. He decides when he wants to go out, when he wants to come back, who he goes out with. He makes all those decisions, absolutely every decision, he makes.'

DM550219

Others felt that it could also enable more effective liaison with family members and multi-professional health and social care teams:

'Involvement - you're more involved with families whereas generally when you're a home care worker you're going in because the families can't go in for whatever... Responsibility; I've got a much bigger responsibility now with this client that I am with at the moment. Contacts; I liaise with so many professionals it's unbelievable.'

DM550238

Several PAs noted that the role enabled them to advocate for their employer: for example, in relation to applying for benefits, or obtaining medical treatment:

'I found that working for local authority, I was wearing a set of handcuffs. So, you can't actually be as creative and as flexible, and I believe that if it's someone's best interest to break the rules slightly for them on their behalf in order to fight their corner for them, then it's a lot easier being an independent adviser, rather than having to cut through the red tape, really.... you tend to be able to get a lot more done for them than you can working for the corporate world.'

DM550158

b. Key informant perspectives about the distinctiveness of the Personal Assistant role

Most key informants used the same kind of words as those used by PAs to describe the difference in outcomes between a PA and more 'traditional' forms of care and support provided by care workers.

Control

This referred variously to the ability of employers to recruit the person, or people of their choosing – being in control of who comes in and out of their home - the kinds of tasks it was possible to ask PAs to do, and over the times of day in which support was provided. Rather than having to fit in with rotas arranged by a care provider organisation, this could be arranged to fit in more closely with the lifestyle and needs of the employer.

Flexibility and adaptability

These referred to the ability to rearrange timing of the working day between the PA and their employer (within limits and acknowledging their other jobs), their duration, and the tasks that they could ask to be carried out, freeing employers from the obligation to adhere to support plans agreed with social workers or care managers.

Continuity

Continuity meant that the employer had the same worker, or workers, providing higher quality care and support, rather than potentially continually different workers from a care agency with varying skills.

Responsiveness

This referred to the ability of the PA to respond to changes in their employer's physical or mental health, picking up and responding to changes much more quickly because they knew their employer better than a general or new care worker.

Relationship building

This was seen as possible because of the continuity of support which enabled employer and PA to establish a much deeper more mutually satisfying relationship. For PAs, it offered the potential for more fulfilling and rewarding employment, and the chance to achieve much deeper levels of insight and understanding of the needs of their employer, which some felt could lead to a point where care and support could be anticipated, facilitative, innovative, empathetic and intuitive. It also meant employers could 'train' PAs so tasks were carried out in the way they wanted, rather than, if care was provided by an agency, having to

repetitively explain how tasks should be carried out to people they did not know, and did not know them.

Companionship

Companionship was something on which key informants held different views. Some valued the opportunity to form relationships and bonds based on shared interests and values. Others saw the PA as an extension of their own body, or a 'tool for independence' and wanted the PA they employed to work unobtrusively to enable them to achieve their own objectives, goals and lifestyle.

Several key informants suggested that when these qualities combined very special things could happen: three quotations, although not directly from care users which therefore must be read in that context, below illustrate some of the facets of this relationship:

It's not someone coming in and doing a,b,c, and then bugging off; it is something where they have more of a... you're not just purchasing a service and some transactional items: there's an added personal touch with that that I would define as, you know, 'connection', inverted commas'.

KI Interviewee 7

'What we find is that Personal Assistants sort of support people who they've got a common bond with and a shared interest to develop that and quite naturally, because they also share those interests, it becomes part of their social network. So people, by consequence, by happy coincidence, end up with greater social networks, more friends and people they probably wouldn't be able to meet had they been receiving support from a more traditional service by people who are predominantly paid to be there by an organisation and are not really there by choice, if that makes sense'.

KI Interviewee 17

'they work really positively to support people to meet their health and social care outcomes and keep people well and maintain their health and social-health condition more proactively, because they understand and know the signs. So, if someone suffers from pressure sores, they will pick this up because they know the person so well if their health is deteriorating, they pick up the signs much quicker than agency staff that are in and out'.

KI Interviewee 41

6. What makes an effective Personal Assistant?

a. Views of Personal Assistants

PAs were asked a series of questions about qualities or experiences that might make a PA particularly effective (see Figure 9).

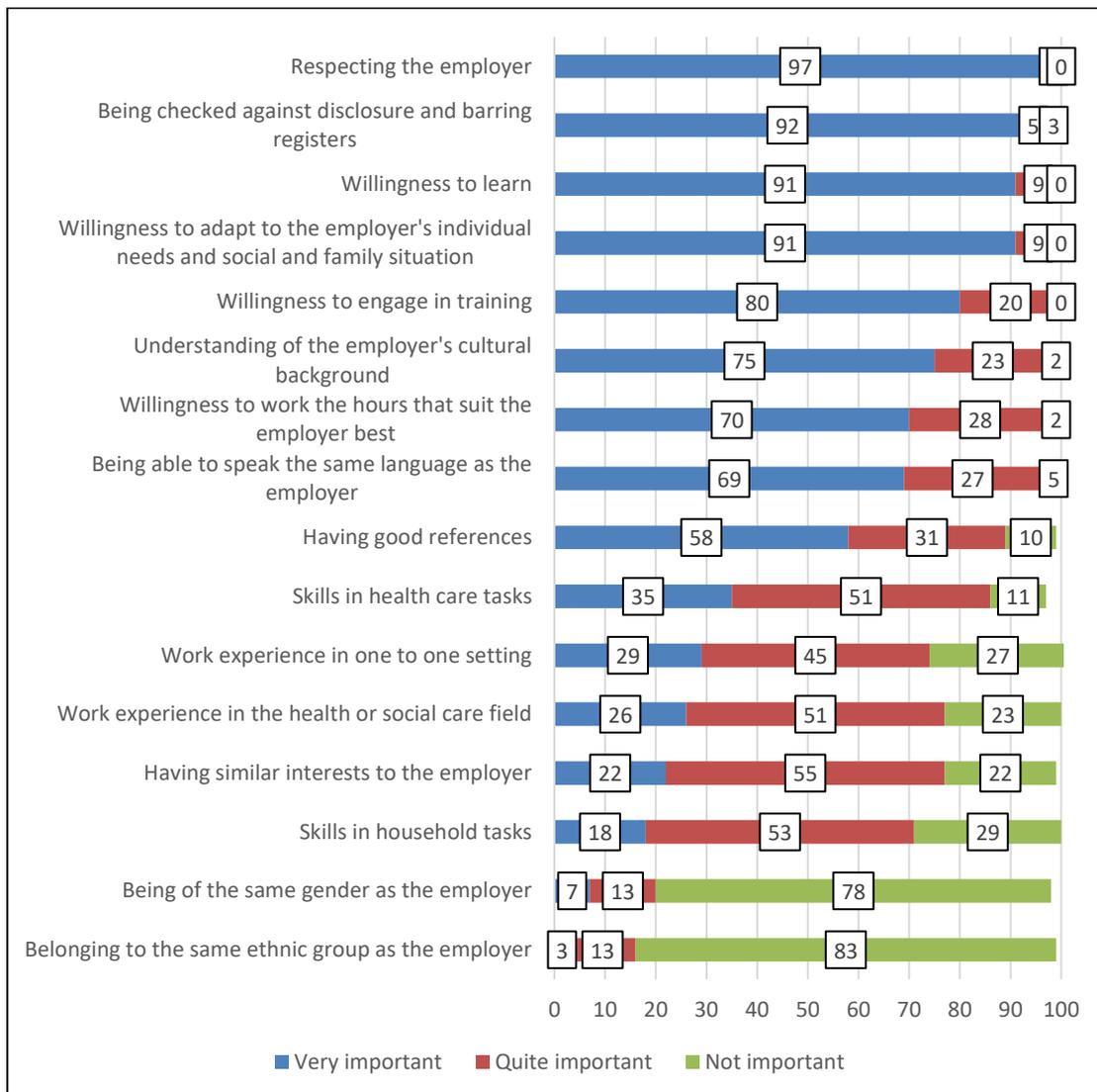


Figure 9. PA perceptions about what might make an effective Personal Assistant

'Respect for the employer' was most frequently mentioned as being 'very important' by almost all PAs (n=92/97%), followed by 'being checked against DBS records' (n=89/95%). 'Willingness to learn' and 'willingness to adapt to the employer's individual needs and family situation' were seen as very important by large numbers (n=87/93% and n=85/90%) of PAs respectively. By contrast, only 6/6% felt that being of the same gender as the employer, and 3/3% that belonging

to the same ethnic group, were very important. Just a fifth (n=19/20%) of PAs felt that previous work experience in a health or social care field was very important.

PAs were also invited to respond to the question: *'thinking of the skills and experiences that enable you to work effectively as Personal Assistant, which has been the most valuable skill or experience?'* Many referred to the importance of having an awareness of 'boundaries' in the relationship with their employer:

'I think one of the most important things is having an awareness of...boundaries, an awareness of what's appropriate and what's not, and what your role is, and what it isn't. It's difficult to explain, but, yeah. Does that make sense?'

DM550228

'Like it's very hard to describe really because it's not like your everyday job in any way. I wouldn't say there's any boundaries between us. I'd never not do something because I thought – because he's the boss, you know what I mean. But at the same time, it's just like – like I said, you're in his house and I am there to help him live his life in whatever way he wants to live, do whatever he wants, but I wouldn't say there's a boundary there because he is the boss. I think it's more just an understanding that you're going in, you want to have a certain level of professionalism, make sure things are right before you get too relaxed, you know what I mean? I think that's a good way to say it actually, it's just making sure you keep the professionalism when you're in. As close as we are, if things need mentioning, he will mention it.'

DM550208

Some PAs had found that neglecting these boundaries could cause difficulties. For example, PAs could find themselves being asked to do chores that did not necessarily relate directly to their client's care. This could be quite finely calibrated. A PA might be comfortable with helping their employer with chores that the employer might otherwise be expected to do as a family member – for example, washing and ironing children's clothing. On the other hand, one PA described her chagrin at an expectation that she should do these same tasks for other adult family members who seemed perfectly capable of doing this for themselves:

PA: *'Some days you can't even get in to the sitting room for the washing; that's not just hers, that's her partner's as well and it's in the sitting room, it's upstairs, it's in the bathroom, it's in the bedroom, it's in the spare room.'*

Interviewer: *'So, do you do the partner's washing as well as hers?'*

PA: *'I do, yes, because I think if I'm putting a wash on, then I'm not going to distinguish between – it's a dark wash and therefore anything that's dark goes in, whether it's his or not and that has become the norm and to be honest with you,*

to start with it was very much, "If you'd wanted a cleaner and somebody to do all this, then you should have..." –because what she said she wanted at the beginning was to get out in to society, help with appointments, leisure activities etc. and that's not how the role has become at all, but she's physically or emotionally – anxiety stops her from going out, so she still needs that support but I'm there in a different role, if you see what I mean and for a while, it rankled because I just thought – to be honest with you, £7.35 and I would go in and the washing up would be all around the kitchen, even though she has a partner, and I was very much, "This is not what I came in to".'

DM550227

The ability to mediate between family members has already been mentioned, but other PAs also saw the implication for occupational boundaries. For one PA, the role of mediating between family members and the client was a skill often needed at the start of the contract because each family member might have different perspectives about the PA role:

Interviewer: *'Was there any give and take, or negation over, you know, for example, what you do, or when you do it; or was it a case of, "This is what we need, can you do it?".'*

PA: *' "This is what we need, can you do it?" from the family, yes. But then, we had strict instructions from the lads. I mean, silly things like, "We don't do gardening, we don't do anything arty," so they were telling me what they don't do. When I was suggesting things – because I had to suggest things, what we could do, and take them out, and things – so, yes, the parents and their family was asking me to do what I can do; but then, the young men were telling me, when their parents weren't there, what they don't do, and what they wouldn't want to do. So, I have to work round both of them.'*

DM550257

PAs also focused on attitudes and behaviours. They mentioned life experience, empathy, sense of humour, patience and kindness, caring, having good communication skills, drawing on personal wisdom, being a good listener, having patience and seeing past people's disability as all part of being effective as a PA.

b. Key informant perspectives

Key informants were also asked what kinds of qualities made a good PA from an employer's perspective. They tended to use the question to describe their views about differences between PA and care worker roles whilst offering additional insights. There was a consistent emphasis on personal qualities of the PA rather than specific skills or expertise. These desired personal qualities were diverse,

and included *kindness, compassion, respectfulness, trustworthiness, respect for confidentiality and privacy, dedication and commitment, open-mindedness and being non-judgemental*. The importance of shared interests and values has been highlighted elsewhere in this report. One employer also referred to the importance of a PA being able to both use their initiative *and* take direction.

Less abstract desirable qualities that were mentioned included *reliability and punctuality*, and a smaller number of key informants referred to the importance of specific skills such as the *ability to drive, to speak English to a good standard, and knowledge of household tasks and 'how to run a household'*.

Key informants were asked about PA strengths and weaknesses when working for their employers. Some drew on their own personal experiences as employers when responding to the question, whereas others drew on perceptions gained through working with or alongside employers.

Strengths

Responses to what PAs were 'good at' were widely interpreted: some referred to the particular combination of skills values and experiences that a 'good' PA might have to offer, others referred to more general opportunities a PA might confer on an employer, and some combined these perspectives in their answer. Some responses also referred to 'ideal' strengths – things they felt were potential qualities rather than necessarily things that all PAs possessed.

An overriding perceived 'strength' was that a PA could offer personalised support. This offered direct accountability by the PA to the employer but was also often an 'umbrella' term that embodied several different qualities, summarised below.

Flexibility and responsiveness

Flexible employment arrangements - principally over the times a PA could be asked to work, and about the kinds of tasks the employer could expect them to do - were frequently mentioned as strengths. One key informant took a rather different perspective, and though acknowledging that the PA role required a new and different skill set to care work, they argued that if properly funded, the same levels of responsiveness and flexibility could be achieved through regulated care and support services.

Role 'plasticity'

Some participants also referred to flexibility in 'role' – so that a PA could 'blend into the background' when this was required (for example, if the PA accompanied the employer to their workplace) or offer active encouragement or support: for example, discouraging retail workers from speaking to them rather than their employer, by providing motivational support to people recovering from mental

health problems, or facilitating greater contact between isolated employers within their local community.

Another manifestation of the 'plasticity' of the PA role was in the relationship they might have with their employer. Some employers, as we have seen, were clear that they primarily wanted their PA to be an 'extension' of themselves – a tool to enable them to overcome physical and societal barriers. However, others emphasised the opportunities offered for the PA and their employer to develop deeper relationships than would be possible with agency employed care workers and act as companions to their employer.

Previous experience

A few participants emphasised that a particular 'strength' was often that PAs were more responsive to the requirements of their employer if they had *no* previous experience of care work. Many felt that the PA role was so different from that of agency care work that care workers often had preconceived ideas about how things should be done, which were not always ones that employers appreciated. Manual handling and lifting were two examples of this.

Self-organisation

A final 'strength' suggested by some key informants was the ability of PAs to be 'self-organised'. This referred particularly to a view among some that PAs were good at taking responsibility for sourcing and attending any training that might have been needed. The topic of training is one to which this report will return below, and it will suggest that 'self-organised' training probably applies only to PAs who are self-employed. For directly employed PAs, access to training was more problematic.

Weaknesses

Some participants identified the absence of some of the qualities referred to above as weaknesses because these qualities were not always available within the PA workforce. Examples of these included PAs who were ex-care workers and had a 'carer mentality', leading to a tendency for some PAs to 'take over', particularly in public settings, and difficulties finding PAs with the skills needed to support employers to become more integrated within their local communities. Some responses to the question also referred less to the qualities of a PA (or lack of them), than problems relating to the infrastructure of support available for both PAs and employers. These are discussed below.

Boundary maintenance

The importance of maintaining a 'boundary' between employer and PA employee roles was again frequently mentioned. This was often seen to be a consequence of some of the strengths of the PA role. Some key informants described the

evolution of supportive relationships into companionship and friendship, and how this could easily lead to shifts in the dynamics of the relationship, and the distribution of power. It was suggested that this could lead to one side taking advantage of the other and potentially lead to a situation in which each could put themselves in 'risky' situations. Contributory factors to a failure to manage boundaries were said to be *poor communication* and *lack of clarity about the nature of the relationship* from the outset.

The flexibility of the role, some felt, might be sanctioned in 'fluid' contracts of employment for the PA. Contracts which did not clearly specify the role and responsibilities of a PA were seen by some to make 'boundary maintenance' more difficult. As we shall report shortly, many did not even have a contract.

Skills of PAs in working with people with complex needs.

Some key informants, particularly those working in clinical settings, and as managers rather than PA employers, felt that though PAs were usually good at working with people whose needs and requirements were straightforward, there was a 'skills gap' among those who might be employed by people with a personal health budget (PHB):

'I wouldn't say everyone but often they are under-skilled at treating people – not treating in the medical sense of the term but working with people with complex needs or maybe multiple issues and problems, especially when it comes to people who face a number of social inequalities or people with a number of mental health problems as well. So to me, there's something about upskilling them in that...'

KI Interviewee 10

'...very generalist support PAs do really well, because it is that values based, that relationship based, but sometimes it can be difficult if people need to have experience of clinical...with Personal Health Budgets, more clinical based tasks or very specific experience, expertise, training and knowledge'

KI Interviewee 24

The subject of PHBs will be discussed later in this report.

The employment of family members

Key informants saw both very significant advantages and disadvantages to the employment of family members as PAs. It was advantageous in situations where, for example, a family member was already caring for a relative, and non-family PAs might experience difficulties in communicating with the family member needing support. However, several participants expressed concern about the potential for this to create difficult situations because of fundamental changes in relationships: for example, difficulties in being able to 'discipline' a family

member. Others were concerned about the potential for abuse: where, for example, the family PA might not fulfil their responsibilities as an employer: by not working the required hours, for example:

'Sometimes the family member is the best person to be employed; especially with someone with very specialist communication needs that only a family member can deal with. But it is always a concern with families because there is that 'oh, everything will be fine' and then in the past we have seen where PAs have, well, frankly, abused the system; so where they're working three hours a week instead of 30 and 'well, it is my mummy so nobody minds.'

KI Interviewee 23

7. Employment status and working conditions

a. Findings from PA interviews.

PAs were asked several questions about their conditions of employment, distinguishing this study from others covering PA employment.

Contracts

Just over half of PAs (n=57/54%) said they had a written contract including a job description, a fifth (n=21/20%) said they had a written contract but only with/for some but not all of those they worked for; a quarter (n=25/24%) said they had no contract, while 2/2% said they did not know. However, those with contracts sometimes said these needed updating to more accurately reflect the kinds of role and tasks they undertook. These changes sometimes seemed to reflect changing dynamics in the relationship between the PA and their employer. The report has already drawn attention to how, as each got to know the other better, some PAs were able to anticipate how to best provide support and care without being asked, as relationships of mutual trust developed. Many PAs also 'willingly' (or voluntarily) worked beyond their contracted hours or performed extra tasks because their relationship with their employer/cared for person was seen in terms of a friendship or one in which the PA felt there was genuine reciprocation in their relationship, from which each benefited. However, for a smaller number of other PAs, misplaced trust or a failure to maintain clear 'boundaries' led to relationships with the cared-for person or their family members that could justifiably be described as exploitative. There appeared to be little support available to PAs who found themselves in this situation:

'[I would like to have] a support service. I know there's the carer's network, but there's nothing just for PAs to say, 'is it okay for me to do this?' Just like a support service where you could... like ACAS,⁸ for instance; you can ring them and say, is it okay to be expected to do it, or can I ... am I allowed to do this, so not really knowing.... [name of organisation] only provide support for the employers. The older people, because that's what it's centred around... Like, when I've had problems with being paid, they've said we can't help you because it's a conflict of interest. If personal assistants have their own organisations to go to and say, I'm having these issues. I think that would be beneficial'.

DM550133

⁸ The Advisory, Conciliation and Arbitration Service (ACAS) is a non-departmental and independent Government body that exists to improve organisations and working life by promoting and facilitating good industrial relations practice.

The report will return to the subject of exploitation below.

Pay and overtime

Average take-home pay over the previous 7 days prior to the interview was £221.83. The lowest weekly income from working as a PA was £21.75 for a part-time PA and the highest was £960. Only 20% of PAs had earned more than £300 in the previous week (median income was £186.50). Three-quarters (n=78/74%) said the income they had received that week was their usual wage (see Table 3).

This is the usual amount	78 (74%)
Usually I get paid more	12 (11%)
Usually I get paid less	11 (11%)
The amount varies from week to week	4 (4%)
TOTAL	105 (100%)

Table 3. PA views about average weekly income

On average, PAs worked for 22.3 hours per week (p.w.), though this mean figure concealed considerable variation: the hours worked ranged from 3 to 100p.w. A fifth (n=21/20%) said their employment had fixed hours (i.e. that the same number of hours were worked each week): for the remainder, hours varied. Just over half (n=54/51%) described their hours as mainly fixed but with occasional variation, and over a quarter (n=30/29%) said their hours were always variable. Some PAs reported feeling undervalued and stressed due to poor pay:

'You know, I'm in a stable marriage. I have my husband and if I had two weeks off, he would be able to cover the bills with his pay but one of the ladies that supports – you know, one of my fellow colleagues, she lives on her own in a flat and she's never been able to afford to have a holiday... It really helps to have good money because I'm really sorry but money does make the world go around and you feel that because you're getting a decent wage, you feel appreciated... You know, at [name of previous employer organisation], they dropped a lot of our wages... I know people who lost their houses. You know, my friends lost their houses. They couldn't afford to keep them, so they got their houses repossessed.'

DM550247

For some, poor pay made it difficult to balance work with a social or family life. A small minority of our sample (n=4/4%) lived in with their employer on a shift basis, providing round-the-clock care and support as needed: two of these lived in full-time. However, a quarter (n=26/26%) did overnight stays at least 'sometimes'.

Most (n=77/73%) did not receive paid overtime and described being on a 'flat rate' contract. A minority (n=16/15%) said they 'sometimes' or 'often' did paid overtime.

Unpaid overtime

Nearly half of PAs (n=45/43%) said they often or sometimes did unpaid overtime. Most of this group (41/45%) provided an estimate of the weekly overtime completed. This averaged out at 10.1 hours per week. These figures were skewed because two participants gave a figure of 100 hours per week, because the employer lived in the PA's home. In these circumstances, care and support were provided *potentially* on a round-the-clock basis if needed. Furthermore, 30% of PAs said they provided about three hours unpaid overtime per week.

Paying for travel and disposable items

Only 12 PAs (11%) said they received travel expenses, or, as self-employed people, made arrangements to cover their travel costs as tax deductible expenses to get to and from their work. Just over a quarter (n=29/28%) said they were not provided with disposable items such as aprons or gloves; if these were needed, they had to buy them themselves.

Transport to and from place of work

Most PAs (n=86/82%) travelled to and from work by car; smaller numbers walked (n=16-15%) or used public transport (n=16/15%).

The distance PAs lived from their employer varied, but geographical distance was not the only factor that increased the length of their working day. Some PAs who lived in the same city as their employer spoke of time-consuming journeys through congested roads. Public transport was not always an option. PAs discussed how transport costs were met by themselves or by employers, or not, as noted in the previous paragraph. For some, asking for petrol mileage or a flat fee was part of the initial negotiation over terms and conditions, as this self-employed PA illustrated:

'If I have a client that's outside of a certain radius, say it's going to take me more than 25 minutes to get there, say, and 25 minutes coming back, that's pretty much an hour of my time, in my opinion of unpaid work, so how I do it is, it's charged by per mile. So, it's 45p per mile and the first ten miles there's no charge, and then also any time if a client (is) in my vehicle, because they've chosen to go somewhere or there's a specific errand shopping, blah, blah, blah, then it's 45p per mile.'

DM550160

Use of own vehicle for the employer's benefit

Some PAs used their own car to drive their employer to various destinations for purposes such as work or education, social visits, health care appointments, or outings:

'...also, I do a lot of ferrying around, so that's one of... for some of them that's the main reason they employ me, because they know that I can always take them anywhere they need to go'.

DM550131

'The lady asked me in one day to drive her all the way to (the seaside), there and back, in the one day.... And, it was very extreme. It was a lot of driving. I think I must have driven like seven hours in the one day, pushed her around the town. I was exhausted! I think we got home at like four in the morning, but I done it because it was an exceptional circumstance and, you know, I didn't mind, because it wasn't every week'.

DM550237

One PA mentioned having vehicle business insurance specifically for the purpose of driving clients. The extent to which PAs used their own vehicles to transport their employers/clients was not explored in detail, but it seemed that in some instances, there were risks involved but these applied to PAs and others providing support with mobility:

'I drive one [client] to a farm and he has epilepsy and I drive him on my own; that would have never been allowed at college and I think that's a risk every time I do it. And, his taxi driver that takes him on the other days does the same – it's a big risk and I think you are put in that situation quite a lot. So, [in previous job] we would never take them off college campus... there's no support of a second person'.

DM550207

Choosing to wear gloves and aprons

Though in most employment situations, where disposable items were needed, they were provided, some PAs chose not to wear gloves or aprons because wearing protective clothing made them feel awkward and uncomfortable. To them it signified a degree of formality and 'professionalism' about their role that distanced them from their employer, was at odds with the friendly and informal nature of their relationship and felt vaguely stigmatising. To do so would therefore create a subtle but unwelcome shift in the balance of the relationship between PA and employer:

'Me, personally, I don't use gloves. When I'm, like, toileting, I don't use gloves because I'm not actually touching her. I'm wiping and then washing my hands,

like I would do myself. I don't wipe myself with gloves on, do I? Do you know what I mean?... Whether she goes for a number one or number two, wiping her nose. When I worked with the boy that was padded (used incontinence pads), that was a bit different, because it is a bit more medical. You know, you are cleaning rather than just wiping, but I think, as well, because her disability is physical, not mental, she hasn't got a learning disability or anything like that, I think it's quite belittling... disgusting or something like that'.

DM550210

Pensions, National Insurance, sick pay, payment if work was interrupted and 'back-up' for the employer

Only a minority of PAs (n=18/17%) were contributing to a pension scheme and for four of them this had only started very recently.

Nearly a quarter (n=23/22%) were not paying National Insurance (or this was not being paid if they were directly employed) but this may have been because their earnings were too low. A few (n=5/5%) did not know if National Insurance was paid.

A fifth (n=21/20%) said sick pay was available if they became unwell, but for many (n=69/66%) it was not, while another small group (n=14/13%) said either that they did not know or felt that the question did not apply to them.

Just over a quarter (n=27/26%) said they could take time off in lieu if they worked late one day. However, two-thirds (n=67/64%) said they could not, while a further small group (n=10/10%) said either that the question did not apply, or that they were unsure.

Over a third of PAs (n=39/37%) said they would not be paid if a pre-arranged visit was cancelled by the employer. Just over half (n=56/53%) said they would, while a small number (n=8/8%) did not know, or that the question did not apply.

Over a fifth (n=22/21%) felt that if their work was interrupted for some reason (e.g. hospitalisation or death) that they would continue to be paid, at least for a while. Just over a half (n=55/52%) said they would not be paid while another 22/21% said they did not know, or the question did not apply. Only 8 (8%) of the PAs were able to provide an estimate of how long they would be paid, if work was interrupted. There seemed a similar lack of provision for the employer should the PA be unable to work due to illness or for some other reason. Just over a third of PAs (n=38/36%) felt that there was no 'back-up plan' to ensure that care and support would be provided and a further 6 (6%) said that they did not know if one existed. Such findings should be considered in the light of claims made about

continuity of care noted above. Occasionally PAs described the situation as them being a 'one-man band' with no guarantee of back-up.

Other PAs gave a range of responses to what would happen if they were unwell and could not support their employer, as the majority had a plan in place. Some PAs had formalised back-up plans to ensure that care and support would be provided and worked in small teams for this reason and also to enable each other to take holidays. Other PAs stated that back-up could be found through their brokerage services or agencies they had links had previously worked with, or by friends or former colleagues. In some circumstances care would be the responsibility of family members who get help through an agency or PA website if they needed.

The lack of back-up was more acute if the PA worked as a live-in care worker, where the client had no-one else to turn to and the PA felt the full weight of responsibility for supporting them:

'At the beginning was just, well, just like you're living at the house, you need to do that, that, that; there wasn't a specific list. The needs were coming naturally, according to her age, to her deterioration of her health. In the beginning she was mobile, I didn't need to deal with incontinence and so on, but by the time I had to, it came to the point that I had to change her, to wash her, provide personal care and so on, by time, but when the man came from [Adult Social Care Department], as I mentioned, there was in the contract you have to do that, that, that, but that was the formal [element of the contract], you know. Because we are live-in carers, it's radically different from other care because you're living there, you have to... not because you have to do it, but you are living in her house and like someone who is yours, you have to provide, to do something; you can't just... you're providing, and that was for years and years. Year after year, 24/7. We didn't have time to go out, we didn't have time... when on holiday, once a year, we were arranging, we were calling the social services because we need some rest at the end of the day. Only for two weeks for holiday we went abroad somewhere and for those two weeks the social services were arranging for this lady to be in a care home somewhere nearby. That's it. And then after, when we are coming back, we are taking her back home again for another year.'

DM550190

PAs also discussed what might happen if their services were no longer needed; for example, if their employer died. Many felt that this would lead to an instant cessation of employment since they were on a zero-hours contract, if any, and accepted this as a part of the PA role. One described saving money for these situations. Some PAs had been paid retainers to maintain their relationship with

an employer at least for a while (about a month): for example, if an older person wanted to try living in a care home.

Many PAs stated they would visit their employer if they were admitted to hospital to help ensure their wellbeing and would be paid for this. However, some had experienced problems with Direct Payments being continued to enable a retainer provision for an employer when in hospital:

'Say, for example, I had a client, he went into hospital...his daughter lived away and she wanted the security of knowing that when he came out of hospital I would still have that availability for her father, so she wanted to continue paying for the service, basically....[but] I battle with the local authority, who cannot keep them slots open for people on the possibility that they might be coming out, so I believe you should be able to put within your contracts that a service can be retained for a duration of time with payment, because there is no way that I would keep an hour slot open in the morning and not fill it with anybody else, you know what I mean? So that's another grey area that I battle with them about'.

DM550160

Sources of help for PA in disputes

PAs were asked if there was any source of advice and support if they became involved in a serious dispute with the person they supported or their family which could not be resolved. Many PAs could not envisage such a situation arising with their employer (quite the contrary) but dispute resolution procedures were very unclear, with most PAs suggesting that they would seek help from the organisation that put them in touch with their employer – even though they might therefore not be considered independent. However, key informants working in these organisations said that they would be unable to offer the support envisaged by the PA because of a conflict of interest, lack of funding, or lack of expertise. Only a small minority of PAs referred to having either professional insurance or union membership: resources that could be used for legal advice.

PAs mentioned a range of other general potential sources of legal advice or support including ACAS, Citizens' Advice, Trading Standards, the small claims court, indemnity insurance companies, an LA supplied contact list, safeguarding services (local authority), or an employer's social worker or team leader (if there was one).

Some PAs stated they avoided disputes, or managed any that arose, through clear and professional communication with their employer and their family. However, some conceded that if a dispute occurred, they would probably just resign:

'I don't know what I'd do. I suppose I'd go to Citizens' Advice or something like

that. Although I wouldn't. To be absolutely honest with you, I'd just say, right, I won't do the job. I happen to be in a position where it doesn't matter to me... I would just walk away, if it was as bad as that. Yeah. I sound horrible, don't I?'

DM 550158

This PA's response seemed a realistic assessment of the fact that should a serious dispute occur, the relationship they had with their employer would likely be irretrievably damaged.

PA experiences of disputes

PAs described experiences of disputes on a range of subjects. First among these was not being paid:

'It's happened on a few occasions, where they don't put paying you as a priority. And if that's your only source of income... not all of them, because the last guy was great, but two or three of them, if they were going away, say on the Wednesday and I was due to be paid on the Saturday, I'd have to wait until they got back to be paid. They wouldn't pay anything in between... And there's been twice when I've handed in my notice and they've refused to pay me. I eventually got paid, but it took a lot of negotiation to be paid for it. [One employer] I had to send them a letter. Not a nasty letter, but I went to Citizens' Advice and they helped me write a letter and then I wrote it. Obviously, it wasn't a nice letter.'

DM550133

Conflict about working hours and managing an employer's expectations around them was another source of dispute:

'Well, with the lady that I worked for, for seven years, there were meant to be three of us, and one of the three workers left, leaving the two of us that she knew very well. And we ended up working way more hours than we wanted to, both of us. And even though both of us were saying to her, you know, "Please can you get a third carer?" She would get a third carer, interview them, employ them and then be so unpleasant to them that they left. And we knew she was doing it because she liked the two of us. She didn't want a new person and so she was deliberately pushing them away, knowing that we would carry on, really... Yes, it was, yes. And we did, both of us... we had families, we both did, you know, more hours than we wanted to for quite a long time... We were kind of locked into it really because we wouldn't forsake her, as it were...I was getting to a bit the end of my tether, and I think the other carer was too.'

DM550222

A few PAs mentioned differences of opinions over what was safe for an employer to be doing:

Interviewer: *'The first person you started working for, there was a disagreement between you and the family about how safe it was for this person to climb some steps to a snooker club....'*

PA: *'I mean, he went with his brother, and they walked up the stairs and he didn't play snooker with him, and they walked him down the stairs and he says, 'Well, my brother would let me fall on him if I'd have fell down the stairs'. And I said, 'Well, that's not happening to me.'*

DM550186

Some PAs, working for challenging employers meant being accustomed to resolving disagreements. For a few, it was a key skill:

'It happened a lot, because the people I was dealing with had challenging behaviour and stuff, so there would often be disputes. The majority of the time, I'd walk away and let them calm down and come back, because the dispute would normally be inside of their head, rather than a real dispute.'

DM550172

A small number felt that their occupational isolation and lack of independent sources of support could put them at risk of physical harm:

'I think when you're a Personal Assistant, you're very on your own; there's much more risk management involved than working for an organisation because, when I'm working for the organisation, I've always got other staff with me, in case of crisis; I've always got risk assessments and I've always got a manager to go to ... and have support – yeah, to go for back-up. Whereas a Personal Assistant, you are very on your own, and sometimes you're in situations where you're a little bit worried about what's going to happen, because it could go one way or the other and it could be particularly dangerous, especially working with people who I'd say have got learning disabilities and autism, because obviously people with autism see the world very differently and a lot of people do have challenging behaviour because of communication difficulties. I have been in situations where I've thought... I've had people in the middle of town, in Boots (shop), basically hitting me, pulling everything off the shelves in the store, and actually, if I was working for an organisation, I wouldn't be with that person on my own because of them reasons and them risks'.

DM550198

PAs and occupational isolation

PAs were also asked about the amount of contact they had with other PAs, locally or on-line (see Figure 10). Though it appeared that the majority had some level of

contact with other PAs, this was usually for the purposes of supporting the employer – for example where the employer had a team of PAs to meet their care or support needs – rather than as support for the PA. Only a minority of PAs from one or two local areas had access to closed online forums or periodic opportunities to meet because these had been set up by a local Council for Independent Living or support organisation.

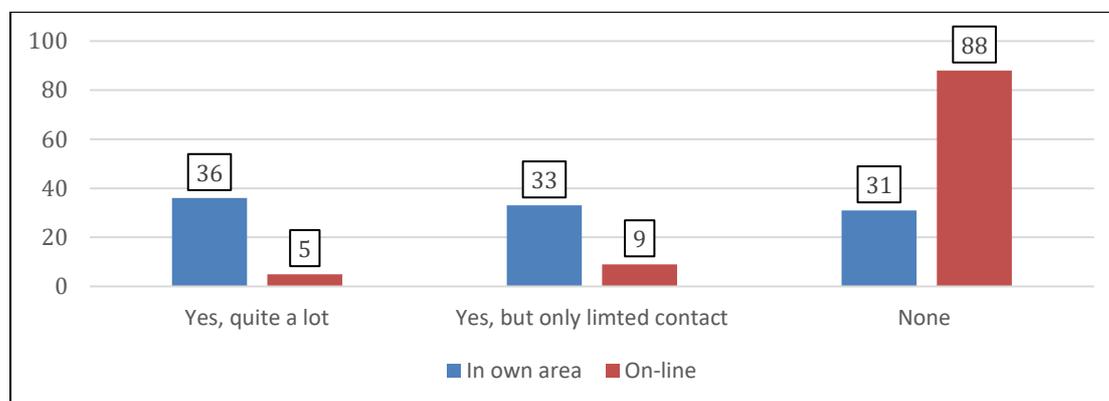


Figure 10. Contact with other Personal Assistants – in own area or on-line

Self-employed PAs and additional requirements.

Some of the few registration schemes checked not only DBS status, but that PAs had professional indemnity insurance and were registered with HMRC for tax purposes. For self-employed PA participants, awareness of the need for insurance and HMRC registration was, unsurprisingly, higher than other PAs'. This may in part also have been because many self-employed PAs we interviewed had registered with an organisation that insisted on checking these things as a condition of registration. It seems likely that despite the risk to employer and PA alike, there will be 'invisible' PAs working in the hidden, underground, shadow or 'black' economy (Doyle et al., 2017). One limitation of our data is that seemingly perhaps only participants working formally participated, although we found that some did not pay tax, or National Insurance, had no pension or sick pay arrangements, and thus may be unknown to authorities.

b. Key informant perspectives

Key informants were also asked about working conditions of PAs and employer practices. Several broader issues were raised.

Labour market flexibility

A smaller number of key informants drew attention to casualised employment conditions (in the sense that to achieve the flexibility of hours of work so valued by employers, though weekly hours might be the same, the times of visits might

vary), which might be expected to have consequences for other aspects of a PA's life outside of employment.

Absence of career structure

The absence of career structure for PAs was also mentioned by some participants. Some noted that even if training was made available for PAs, although this might raise their skill levels and enrich the content of the job, it would not usually be rewarded with higher pay. The need for training to provide 'portable' skills for a PA has already been mentioned and was raised by key informants too. However, it was also pointed out that not all PAs would necessarily want to follow a career path. Family PAs and PAs who were already training for one of the caring professions were cited as different examples. One participant commented that the recruitment of students as part of a placement experience had been very successful in meeting the needs of the employer and the student, albeit usually for a relatively short period, and a few examples were also provided of other students who had acquired a professional qualification but chose to remain working as PAs.

Lack of awareness of rights as an employee

Several key informants felt that many PAs lacked an understanding of their employment rights. Some felt this was a problem because of the extremely isolated nature of the PA role. They felt that PAs did not know where to go if they encountered problems with their employer. There was widespread agreement that for PAs employed through informal channels their access to support was likely to be even more difficult.

Workforce fragmentation and isolation

Some key informants also referred to the isolation of PAs, noting that even PAs working as part of a team to support an employer might have little contact with each other than at 'handovers' or via their employer.

Moving from the reasons for support with PA work, to the *kinds* of support that were seen to be needed, key informants thought there was a need for a national body to 'represent' PAs. Some key informants felt that the absence of such a body was a huge omission, and that there should be equivalent levels of support offered to PAs as to their employers:

'...when we think about the number of resources that go in to support our NHS and Adult Social Care colleagues who work in registered providers, it's probably pretty scandalous that there is no formal designated support to Personal Assistants, because actually, if anything they're more vulnerable than anybody else'.

KI Interviewee 21

However, there were some differences of opinion between participants about how to most effectively arrange this support. As one disabled employer participant noted, some kind of national support organisation would be welcomed providing the first loyalty of the PA remained with the employer and not the support organisation.

Trades unions and ACAS

These organisations were mentioned by several participants as potential sources of support. Some key informants felt the trades union Unison had been slow to 'reach out' to PAs in the social care workforce, allegedly because of suspicions that PAs were being used to drive down pay and impose poorer working conditions. Some key informants considered that Unison's position had changed; but it remained difficult for the union to recruit PAs as members since they were employed by individual employers rather than local authorities or care agencies. Both Unison and ACAS were also widely seen as a resource of 'last resort'. There was a strongly held view by some participants that if a PA reached a point in their relationship with their employer that necessitated seeking advice or support from one of these organisations, relationships between employer and employee would be extremely strained, if not irretrievably broken, and it would be much better 'practice' to establish working relationships from the outset that might minimise or prevent disputes that might ultimately lead to time-consuming and stressful employment tribunal hearings.

Preventing employment problems

Some key informants noted that, though the close working relationships between PA and employer meant that should conflict arise it might be more intense than in more orthodox forms of employment, some preventive measures could be taken.

The first was the need for contracts that *clearly specified the role of the PA* and the tasks that they could be expected to carry out. Contracts containing phrases like 'and other duties as required' created opportunities for unreasonable requests to be made by an employer and created difficulties should the employee challenge a request they considered unreasonable. Another reason for clear job descriptions was mentioned by a minority of key informants. These had come across PAs who had expressed unhappiness to find, shortly after taking up a post, that amongst the job requirements were particular kinds of personal care tasks which they found distasteful. These had apparently not been mentioned in job applications or interviews.

Second, several participants referred to *the importance of establishing and maintaining clear employment relationship boundaries*. This has been noted earlier and has also been observed in other studies of PAs (Shakespeare et al. 2017) and of agency-employed care workers (Abrams et al. 2019). However, though this

might serve the interests of both employer and PA in some respects, it could also be seen as introducing an unwelcome 'rigidity' to the PA role. Several key informants and PAs emphasised the value they attached to the flexibility of the role and the opportunity it afforded to each to develop deeper, more mutually fulfilling relationships than possible if support or care were provided by an agency care worker rather than a PA.

Third, several participants from Centres for Independent Living agencies or similar referred to the work they did to offer *informal advice and mediation*. Some felt there were strict limits to this, however, because they did not have specialist expertise in employment law, and were funded only to support employers, not PAs.

The need for national support for social care PAs

Funding for a new or an existing workforce support organisation was mentioned in some key informant interviews. Though detailed description of such a possible arrangement was not provided, some felt that there might be a need for a new professional association for PAs, although they also questioned how this would be funded and how it might recruit such a fragmented workforce. Others felt that an overarching national body that could offer support to both employers and PAs would be desirable, while others still felt that an existing organisation such as Skills for Care could be funded to offer dedicated support to PAs as well as employers.

Local sources of support

The provision of informal support by local organisations such as Centres for Independent Living has already been mentioned. One had established a regular series of workshops for PAs which the participant felt provided an opportunity for PAs to report exploitation or abuse, and some of these, and other key informants, said that they were personally always available to talk to PAs who might be having difficulties. There was, however, little financial incentive for such organisations to offer more extensive local support to PAs and take up by local PAs was not reported.

Networking and peer support

Though the isolated nature of PA employment was widely acknowledged, there was less agreement about possible remedies. One such was peer support and networking. However, though these are widely used in other professional settings to share best practice, discuss and resolve problems, and to mitigate isolation and stress, some key informants were not in favour of such initiatives. This was because of some employers' concerns that they could become 'gossip shops' and lead to the sharing of personal and confidential information that would undermine the privacy of the employer, and betray mutual trust between employer and PA.

8. Safeguarding

Working as a PA could often involve extended periods of time when employer and employee were alone together in the employer's home. Questions were put to both PA and key informant participants about how both could stay safe and avoid being abused or exploited.

a. PA experiences of abuse or unreasonable behaviour by employers

An earlier section of this report observed that unreasonable behaviour by the employer was mentioned as a reason for PA 'turnover'. A small number of PA participants referred to past or current experiences of abuse by their employer which might be cast as such unreasonable behaviour. Though the number of PAs who said they had experienced abusive behaviour was very small, its impact could be devastating and long lasting. Two detailed case examples are presented to illustrate this.

Case one was a male PA from a non-EU country who had been working with a young man with autism. His employer was the young man's father. At the time of the interview, the PA was not working due to stress. Over the 12 years of working as a PA he had worked for two employers: the first period of employment had been a very positive, rewarding and satisfying experience but his employer had died. The interviewer asked if he had a contract with the second employer:

PA: *'My employer refused to give me a contract.'*

Interviewer: *'They actually refused to give you a contract? What did they say?'*

PA: *'... Financially...his Dad, this chap's Dad, he has a huge budget. There is a room for abuse, for financial abuse, for abuse of the employment law... My employer refuse me to give a contract. Can you imagine working for four years for a person, for someone, and their employer tells you that you are not getting a contract, and the reason was... you wouldn't believe now. He said, look, if I give you contact, I'll be... what he said, he said, it's not my interest to give you contract because as employee, because I'm not giving you contract, I can do with you whatever I want; I can sack you overnight. That's his words.'*

Interviewer: *'Mmm'.*

PA: *'Can you imagine? I mean, we are living in a developed country, and someone tells you, no, I don't give you a contract because otherwise I'll not be able to sack you overnight.'*

Interviewer: *'That's outrageous'.*

PA: *'Yes. There is room for abuse, and I was abused, actually'.*

Interviewer: *'So why did you decide to work for him?'*

Participant: *'Yes, that's exactly... well, because I was thinking, well, at the beginning it wasn't like that and I was... again, I attach myself to this chap, in a sense. He's disabled, and gradually I have attached myself, it was mistake to attach myself, which led to depression; that's why I'm off work now, actually. The internal situation with this chap was dreadful, was very bad... For instance, I'm providing services for this chap, but the working environment, he lives with his Mum who is separated from his Dad, they are divorced, and she lives there, and part of the day I have to work in her house to provide care for him, instead of him. But his Dad is divorced, as I said, and he doesn't live there, but he's my employer. Now, his Dad and his Mum, they are in such bad relationship, there is revenge between them there; they are trying to revenge each other, they are trying to fight each other, and the carer (Mum) to this situation, in her house, she is requesting for me to do separate set of tasks, his Dad is saying, is manipulating and saying no. In order to take revenge over his ex-wife, he's using the carer and he said no, I'm your employer and you are staff, and he said something contrary to his ex-wife, and he argued that employer, if you not do that, I will sack you. So, it's outrageous; it's unbelievable.'*

Interviewer: *'I'm speechless that you should have to put up with such bad behaviour'*

PA: *'No, I took some stress, but believe me, because of this situation I just couldn't cope anymore and I went to the doctor and said to me, look, you have to leave this job, otherwise you'll... anyway... they advised me, but I thought what next step to take because... well, you are employer, you have to be accountable to someone in this country. I can't believe that there is no-one you are accountable to. As an employee I'm accountable to you, but as employer, you have to be accountable to someone. I found out that maybe it is good idea to address these questions to [Organization that helped to secure his employment]. I don't know.'*

Interviewer: *'I was going to ask you about that. Did you contact them, and did they help?'*

PA: *'No, they didn't help. You wouldn't believe. They said, look, because he is our... they employers are their clients. Because he is our client we are not dealing with your complaints. We've got to protect his rights, basically.'*

Interviewer: *'You'd think they'd have a moral obligation to consider your rights as well.'*

PA: *'They said maybe you have to contact social services.'*

Interviewer: *'Yes.'*

PA: *'I have contacted social services and they didn't do nothing. It's a rotten system, come on'*

Interviewer: *'Mmm'*

PA: *'I couldn't find any sound help in this area. I couldn't tell to anyone, say, look, it's outrageous, but look at what happens. I wrote in mail with complete dates of abuse, the psychological abuse, the verbal abuse from my employer, and they replied me, they said, well, I'll tell to my manager.'*

Interviewer: *'And you didn't hear anything back?'*

PA: *'No'.*

DM550190.

This lengthy extract from the interview highlights the vulnerability of this PA when facing an apparently unscrupulous and abusive employer. The absence of a contract seemingly meant the employer felt they could behave unreasonably, and the PA, torn between trying to provide care and support for the employer's son and maintaining his own mental health, found that the places he had assumed would support and advise him did not: he felt failed by these organisations and was unable to secure support from any source.

Case study two was a female PA, also originally from a non-EU country, working for a female employer who appeared to have mental health problems and mis-used alcohol:

PA: *'Well, to tell you the truth, I am supposed to cover two hours per day and sometimes I'm doing more than I'm supposed to do because if the (other) carer comes and if because of her behaviour they don't stay. So, because I'm a bit more lenient and understanding, I don't really look into what she's saying, because she had behavioural problems because she's very insulting at times. Yes. So that's... because one carer actually complained to me, she's supposed to start after I leave at 12, she starts at 12.30, so the carer was saying she was very rude to her and she was going to leave at the end of the month, but she came and heard the carer saying it to me and she said to her she can leave straight away. So that left me with a bit of stress because what the other carer was doing, I have to be doing it in two hours. Yeah.'*

Interviewer: *'This person you're working for, do they have dementia, or anything like that?'*

PA: *'Well, I would think that something is slowly developing there because she will tell you one thing this minute and next minute she says she didn't say it. And the thing is I've been working there since 2015 and I haven't been given any holiday because of the behaviour that she has. No carer stays, so I am the only one there and I can't just get up and leave her and say I'm taking my holiday because she doesn't have anybody to look after her.'*

Interviewer: *'Okay...does she have any problems with alcohol or drugs or anything like that?'*

PA: *'Well, because you said this is confidential, yes, she does drink a lot on the quiet, yeah. She drinks until she sometime fell out of the chair and hurt herself.'*

Interviewer: *'Just as a matter of interest, have you spoken to (organisation that helped to secure her employment) about the problems her behaviour causes you?'*

PA: *'I have been ringing them because what happened is, because she hasn't phoned me since her grandmother is there because it's a bit unfair for her'*

grandmother to be there and for somebody to be going in there to look after her and her grandmother for the same money. She [the other care worker] fell ill so she got somebody else to cover, so I've been ringing the Direct Payment team for two days now and nobody's answered it'.

Interviewer: *'Okay. I was just thinking, from what you've said, it sounds like you're carrying quite a burden of responsibility because of this person's behaviour to the carers.'*

PA: *'Yeah'.*

Interviewer: *'And maybe you need a bit of support'.*

PA: *'Yes. But the problem is, from what I learned from her, there's a lady at the disability team, whenever anybody said anything to her, it is fed back to her, so I'm a bit... conscious about it, so ... because I hear her talking that so-and-so said this and so-and-so said that and so ...'*

Interviewer: *'So you're concerned about confidentiality being breached?'*

PA: *'Yes'.*

Interviewer: *'The hours that you work: from what you've said, they do seem to vary quite a bit?'*

PA: *'Yes. And she's very indecisive because I will get out of my bed at six o'clock for her to have appointment for eight o'clock or seven o'clock and then when I get there she change her mind about the appointment...During the week, and it's a whole lot of work, because I'm there for two hours. And I'm supposed to give her personal care, breakfast and get her out of bed and make her bed make her place tidy, but when I go and I wake her up, she will say, give me an hour; go and do some ironing, go and... then when it's time for me to leave, that's the time she want me to do things, and I have another job....I get to her sometimes at six in the morning. My contracted hours is 10 to 12, but when I get there for ten o'clock sometimes, she doesn't want to get up, so then when I'm ready to leave, when she finally gets up and she has her bath and I help her get dressed and stuff like that, when I'm ready to leave she's telling me, can I change her before I go, which cause me to be late for my other job....She'll text me early in the morning to go to the shop before I come, the next morning she does the same thing, just for one item or two items, so it's like... for me, I'm not really used to that because I do my shopping once per week, and it's so stressful because, in the morning when you wake up and look, instead of going at ten o'clock, you have to leave at eight o'clock to go and get the shopping for her and go back to her... yeah.'*

Interviewer: *'Does she have any children that you have to look after?'*

PA: *'Well, as of late, the son has moved in... and what I was worried about was that she wanted me to go and change the son's bed and put on new sheets and stuff like that, which was not a part of the contract'.*

Interviewer: *'So how old is the son?'*

PA: *'He's about 48'.*

Interviewer: *'So he's probably old enough to change his own bed and things like that, isn't he?'*

PA: 'Yes'.

Interviewer: 'So you're not doing that for him, are you?'

PA: 'That what she makes us do. We change and we have to wash them and press them and put them on back, yeah'.

DM 550193

Although this PA had a contract, the nature of her role had changed: originally, this PA had been working with another PA who appeared to have left her post because of this employer's unreasonable behaviour, and she had not been replaced. This PA's apparent kindly disposition and willingness to work flexibly seemed to have been taken for granted by the employer, and any boundaries there may have been had not been maintained, so she was now providing support not only for her employer but (with another worker) for her grandmother and her (able-bodied) son too. She could not afford to walk out on her employer, and also felt responsible for her well-being. Her attempts to raise these issues with the organisation that had arranged her employment had been compromised because she believed that anything she said would not be kept confidential (though the ability of this organisation to resolve these problems might seemingly have been compromised in any event because they were funded only to support the employer).

Both cases suggest how PAs can be caught between a desire to care and support and the risk of exploitation and abuse. Training to reinforce the importance of boundaries and strategies for maintaining them might have helped, but the need for employment income (and possibly difficulties claiming welfare benefits) meant that the option of resignation was not one that either had been willing to consider at the time of the interview. Though these were 'outliers' (interviews with some other PAs revealed other problematic aspects to the employment relationship but to nothing like the same extent) they have been presented in full to demonstrate the potential vulnerability of the PA because of the absence of support and advice. Being non-UK citizens may have also exacerbated these PAs' vulnerabilities. Though membership of a Trade Union may have been able to provide some protection, neither appeared to have considered joining a union, and the fragmented and 'hidden' nature of the PA workforce creates a clear obstacle to a Trade Union trying to reach out to this group.

b. Key informant perspectives on safeguarding and protecting PAs

Most key informants felt that the *status quo* left PAs unprotected. Some felt that the one-to-one nature of the role removed some of the protections someone working for an organisation might enjoy, and several provided examples of situations in which PAs had been abused or exploited by their employer.

Job insecurity

Job insecurity was seen as a serious problem by a small number of key informants who worked in organisations that aimed to support employees and resolve disputes:

'...we've had it with the zero-hours contract debate about, you know, people value very highly, and business and government offer to do flexibility in the labour market because it allows businesses to respond quickly... It makes them value customer needs more greatly and in theory it offers employees the chance for work-life balance the chance to do other things and all those sorts of things: the flexibility is there. But on the other hand, there's the issue of exploitation. You know, zero hours contracts ... job insecurity, lack of clarity about when your next shift or whatever is coming.'

KI Interviewee 40

'We obviously ally to the need to ensure that all workers are treated fairly, and we think more generally that the regulation of the care workforce in England, particularly, will allow it to become a more professionalised sector; it will hopefully encourage more people to want to work in the sector'

KI Interviewee 13

Changes to 'boundaries' or blurring of boundaries between formal and informal care

Typically, some key informants described a situation in which a PA might offer to do something out of kindness that might subsequently become expected by the employer. In these kinds of situation, some participants felt it was very difficult for a PA to subsequently say that they would not do such a task routinely in future:

'...if there is room for ambiguity, around...the tasks that they could do, you know, there are potential traps for the Personal Assistant. For example, if it's not clear whether you should handle money and they suddenly ask you to.... you feel, well, I'm doing them a favour, but I think issues like that can be potential areas where you're getting yourself into trouble if it's not made absolutely clear from the beginning how this is to be done. So, I think – and it must be very, very easy for a Personal Assistant to want to help, to want to please because it's part of their role as carer and, you know, to overstep the line and maybe do things which potentially could be misinterpreted, and they could be accused of becoming too familiar and overstepping the line. I suppose we're coming back to boundaries, being clear about things.'

KI Interviewee 40

False accusations

One participant referred to the vulnerability of PAs to false accusations; which this person felt that within the present regulatory environment meant that the PA had to prove their innocence, or an employer could give a PA a 'bad name' and by posting inaccurate information on social media or other communications. Recalling previous employment involving direct supervision of care workers – not PAs, this key informant said:

'I've had to deal with staff who were accused of taking money and we sort of had to, you know, open up disciplinary proceedings (only) for the older person to phone up and say 'Oh no, I've found the 200 quid I'd put it somewhere else', you know, Oh, okay, well it's been found, that's clever; but I was employing these people directly. If they're self-employed and they're on a local authority list or a Clinical Commissioning Group list, to be accused of something by someone who is probably not in a great place anyway would be very frustrating, and, you know, who's to say who's right...? The other thing is the way these things tend to come out. It won't come out through official channels: it might be hearsay, you know...you could have a Personal Assistant being accused and really having no recourse and no way of stopping maybe rumours going round quite an informal economy'.

KI Interviewee 7

Short term contracts

One participant, though accepting the desirability for PA employers to insist on a probationary period, felt that PAs like other care workers were employed on casual worker contracts that did not encourage them to regard the job as a permanent one. The current 2 year period before many basic employment protections are conferred on employees was felt to be too long for people working as PAs: a 12 month period was felt to be more appropriate.⁹

Vague, poorly written or out of date contracts were also mentioned as the cause of some difficulties. Though not all PAs who took part in the study had a contract, as noted above, a further problem was that sometimes the kinds of requirements of the employer changed because of changes to their own health, though contracts remained unchanged, or were written very imprecisely and without reference to the actual content of the PA role:

⁹ Legal claims for unfair dismissal, redundancy and period of notice of redundancy, are determined by length of service. Some protections depend on when the period employment commenced. www.gov.uk/dismissal/what-to-do-if-youre-dismissed; [https://uk.practicallaw.thomsonreuters.com/7-503-4973?transitionType=Default&contextData=\(sc.Default\)&firstPage=true&comp=pluk](https://uk.practicallaw.thomsonreuters.com/7-503-4973?transitionType=Default&contextData=(sc.Default)&firstPage=true&comp=pluk)

'...it can be a very fluid relationship. In (our organisation) obviously one of the first things we say when we get calls to our helpline is 'What does your contract say? Check your contract'. And if that contract is based upon a kind of fluid nature, of 'well, the tasks may change, things may change', that does become difficult...so that lack of clarity...it is open to potential abuse...We do have lots of calls about that. But I think on the other side, lots of people who employ Personal Assistants are often well aware that they've suddenly become employers.'

KI Interviewee 40

Inexperienced or poor employers

Some key informants described individuals with a lack of interest in the needs of their PA and a lack of experience of how to be a good employer:

'... time and time again PAs are saying 'I feel so isolated: who's there to support me, because my client doesn't want to supervise me because it's their support time. They want to be looked after and get out and about or have their personal care. They don't want to be wasting their time supervising me'. So there is a desperate need. Like Mumsnet, we need a 'PA net' really, to get out there and be a forum where people can discuss issues because obviously, with employment issues, when they come to us time and time again, we have to send them to ACAS because unless they have their own insurance, they're not covered through their employer's liability insurance ... so the only recourse they have is to ACAS. (Interviewer: And you've actually had occasion to do that on a number of occasions?) Oh, loads and loads of times. (Interviewer: Really?) Yes, because it's about boundaries, it's about safeguarding, it's about clients firing their PAs in a text message. No matter how much you tell people how to be good employers and what they should and shouldn't be doing, people...they forget, and they're very vulnerable and they get all het up in the heat of the moment...'

KI Interviewee 19

The need for information

Several key informants felt that one of the best protections against exploitation or abuse was the provision of accessible information to both employer and PA about the duties of the employer and the rights of the employee. Though the provision of the former was felt to be patchy, for the latter it was seen as virtually non-existent.

The absence of places to report abuse and exploitation

Though some PAs felt (wrongly) that organisations with which they may have registered would support them, those who had encountered problems noted that there were few specialist places for them to go. Though organisations such as Citizens Advice were mentioned by key informants, it was thought that these organisations might not understand the nature of the PA role.

The need for public funding

Extra funding from public sources such as local government was also mentioned quite frequently by key informants as needed in the care system to support PAs. Lack of support for PAs was universally acknowledged but lack of funding prevented this from being addressed. Though there was a widely held view that PAs were unsupported, most local organisations said they were not funded to offer this: the available funding had been allocated to support employers:

'Ours is more a resource issue really because we're only paid to directly support the individual to run their payroll. Everything else we do is, like, pro-bono. ...We'd love to do more, but there isn't the funding to do it, unfortunately.'

KI Interviewee 17

Some also felt that this, and poor information, were contributory factors in PAs sometimes not being properly paid. A recent court judgement clarifying minimum wage payment rates for overnight (sleep over) work¹⁰ was cited as an example of this in the care sector.

Consequence of bad experiences

Though mandatory employer training might reduce poor employment practices arising from inexperience or lack of knowledge, some key informants felt that there would still always be a minority of bad employers. One consequence of bad experiences was that rather than trying to resolve problems and conflict (because there were so few places to go for support) PAs tended to drop out of PA work and find other employment even though PA turnover may not be as high as other parts of the social care sector.¹¹ A small number of key informants felt that the concerns amongst some disabled people that a more regulated workforce would create unwelcome bureaucracy had to be balanced against the need to ensure care workers – including PAs – were treated fairly, and that this had been currently overlooked.

One participant queried where the boundaries between a 'demanding' employer and an exploitative one lay. This participant felt that any one-to-one relationship built on the basis of trust could be exploited, but that if an employer led an

¹⁰ Schwehr, B., *What the Mencap sleep-in payments judgment means for the sector*, Community Care, Accessed 9th July 2018 <https://www.communitycare.co.uk/2018/07/13/mencap-sleep-payments-judgment-means-sector/>

¹¹ Skills for Care (2019) reports that retention rates for PAs, though high, are lower than those for care workers: at 18.4% compared to the rate for care workers in the independent sector (38.5%). It should be noted however that over half the PAs in the Skills for Care survey personally knew those employing them which may make changing jobs more complicated or undesired.

extremely busy life, knowing what it might be reasonable or unreasonable to expect was not always clear.

c. Key informant perspectives on safeguarding of employers

Key informant views around some elements of this issue strongly diverged.

Prevalence

Some concern was expressed that the prevalence of abuse of employers by PAs might be greater than supposed. Several reasons for this were put forward. First, some felt it was because of a lack of regulatory oversight (one participant pointed out that other UK countries were moving towards formal registration arrangements for care workers). Second was an inability of local authorities to monitor employment relations or offer adequate support to employers because of funding cuts. Safeguards against hate crime were seen as particularly inadequate. Third, some participants felt that the stoicism and gratitude of employers, their sense of vulnerability if care was withdrawn, or through fear of retribution, created a reluctance to speak out:

'Well, actually, if you rely on support from somebody and that person is actually exploiting you or causing you pain and suffering and so forth, then how do you articulate that when you actually may have to go through the PA in order to be in this environment where you can then raise that issue and concern?'

KI Interviewee 18

Others felt that abuse was sometimes not recognised for what it was by the employer:

'We had one lady who came on training and this is a lady who is quiet as a mouse ...and after the first day, we were talking about various issues; she came for the second session and during the second session she actually sat there and she said "I think I'm being abused"; so we all said 'Okay....' and she told us about the situation which was not physical abuse at all, it was financial abuse, it was abuse of trust, it was certainly emotional abuse by her PA.... How could she speak to this PA about this situation? Because the PA was a very strong person and had started off as a friend. Once again, blurred boundaries...'

KI interviewee 15

By contrast, other participants pointed out that they knew of no evidence to suggest that PA employers were any more or less at risk of abuse than other people who needed support or care, though there was widespread agreement that

self-funding employers had less protection. Some felt this was an area in which further research is needed.

Disclosure and Barring (DBS) checks

This was a particularly contentious subject for key informants. Most participants felt that a DBS check was a minimum standard, and that it should be carried out by the organisation funding the budget used to pay the PA and not left for the employer to do (thus not including self-funders). Several people felt that DBS checks should be mandatory though some also said that it was also important to apply 'common sense' in relation to DBS checks for family members. Other participants felt that DBS checks should remain discretionary but said they strongly urge people who were interested in becoming employers to take them up. One of these said that though their organisation provided information and advice about staying safe and strongly recommended DBS checks, they felt that only a minority of employers with whom they were in contact *actually* requested one. A third group of participants felt very strongly that DBS checks should be at the discretion of the employer. There were several reasons for this. First, some participants felt that a DBS check could lull employers into a false sense of security. It was pointed out that someone might have carried out offending behaviour such as abuse but evaded detection - so it would not show up on a DBS check. It was also argued that a DBS check was also no guarantor that future offending or abuse would not occur. These participants felt strongly that DBS checks should be at the discretion of the employer and that to make it compulsory was patronising and retrograde because it removed choice and control from the employer. They thought that clear and balanced information should be given about the strengths and limitations of DBS checks as one element of advice about how to stay safe, but that it should then be left to the employer. One PA referred to a well-known disability campaigner who had decided to employ as one of their PAs an individual who had previously been employed as a driver by the notorious Kray twins, even though this had been disclosed. The example was used to make the point hypothetically that if PA applicants had a criminal record - regardless of whether the offence was historic or 'spent' (under the Rehabilitation of Offenders Act) - local authorities or NHS organisations might put the prospective employer under great pressure not to employ them even though these applicants might potentially be excellent employees. A small number of participants also emphasised the importance of getting to know applicants before employing them. This involved using a recruitment process that did not depend on a single interview but several meetings, on monitoring their reaction to certain situations to assess their suitability, and on their 'gut reactions' rather than placing faith in DBS checks. By contrast, one key informant argued that far from taking choice and control from someone, a DBS check enabled more informed choice:

'...we've talked about the disability lobbies that are really happy just to make their own choice and their own mind up; but surely there would have to be some clarity about transparency about exactly what experience or skills somebody has because that allows you to make an informed choice about employing them...I would have thought the logical thing would be to have more standards or at least checks so that someone can make an informed choice...'

KI Interviewee 40

Assessed capacity to manage employment responsibilities

A small number of participants who worked for local authority commissioned services to support people in employing and managing their PA felt that adult social care departments' assessments of people's capacity to manage a PA were not fit for purpose. This was because a proportion of those people referred to their service were not able to take on responsibilities as an employer even with the support that was provided by that organisation:

'I think the main problem we have is with, actually when social services decide on the capacity of the person, that is probably the biggest problem, because obviously they can go and see somebody and say 'would you like a cup of tea?' and (if) they say 'yes' it doesn't mean they have got the capacity to be an employer....you have got to make sure that person is suitable to be an employer, and they don't seem to be able to grasp that point very easily. I will tell them, 'no, no, don't do that, you have got to do this, this and this'. And we have certainly got a number of long-standing clients who as far as we are concerned shouldn't be on a Direct Payment at all, because they clearly can't manage: they go through PAs like no tomorrow, but again, it is not our decision. All we can do is, if social services have made that decision, we have just got to support people the best we can.'

KI Interviewee 23

Speculating that these inappropriate referrals might have been the result of Department of Health and Social Care (DHSC) performance indicators imposed on local authorities to get service users to take Direct Payments, another participant said that lack of suitability was not just because of impaired mental capacity (though this was apparently also a problem) but also because of the inability of the referred person to 'stand up for themselves'. They felt that safeguarding problems and abuse were more likely to occur if the employer was unable to manage. This participant also thought that in her area the local authority tried to 'off-load' – transferring risk and responsibility – and were reluctant to re-engage if the person was unable to cope with a PA arrangement.

9. Training and support for PAs

Both PA and key informant interviews included questions about the kind of training PAs might have received and kinds of training they felt would be most valuable.

a. Findings from PA interviews

Training

Most PAs (n=65/61%) said they had received training after they had started work as a PA to help them with their role. For almost a third (n=31/30%) this had included Care Certificate enrolment.

PAs were asked if they had received any training relating to a range of basic care or support skills since starting work as a PA, and if they had not had training in any of these areas whether they would like to receive some training (see Figure 11).

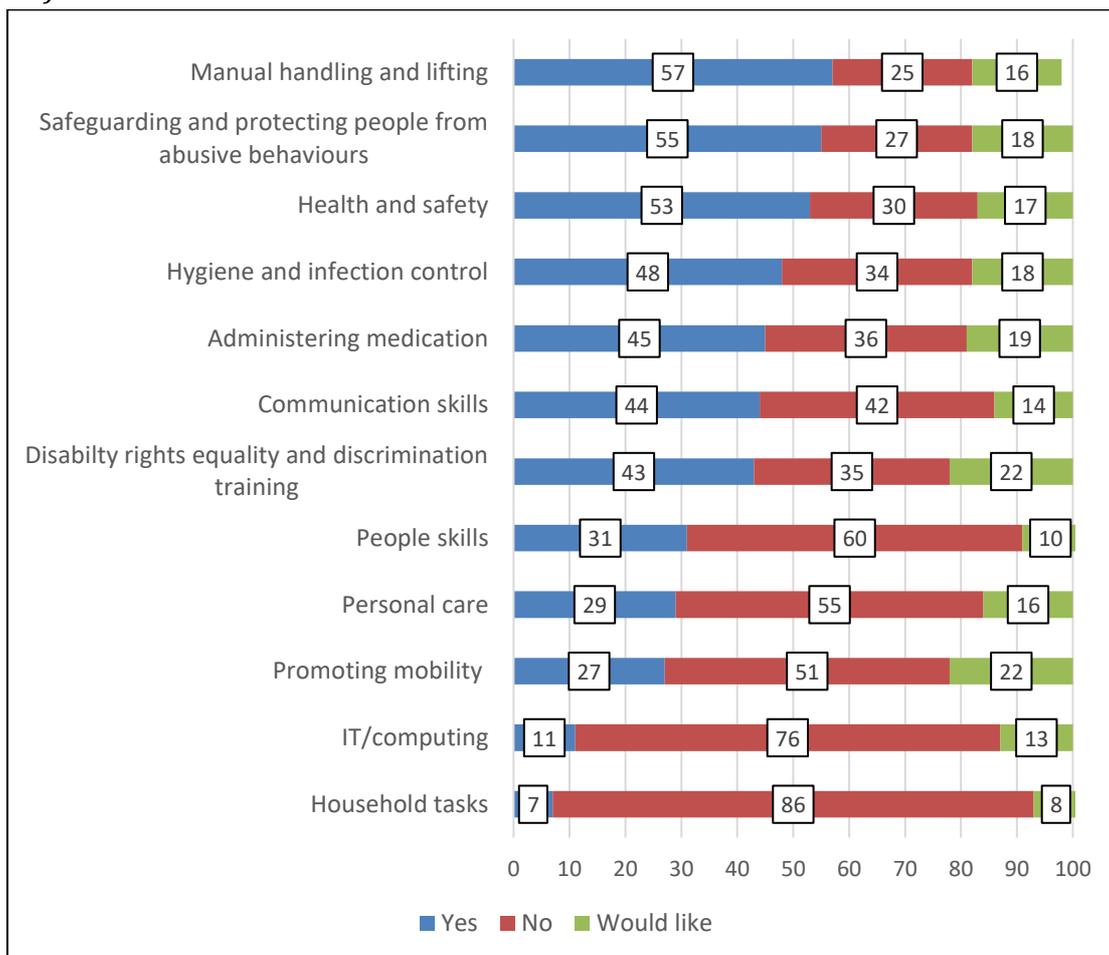


Figure 11. Receipt of training on specific topics since becoming a Personal Assistant

PAs most frequently cited receiving training in manual handling and lifting (n=60/57%), safeguarding and protecting people from abusive behaviours (n=58/55%) and health and safety (n=56/53%). Provision of training seemed to be much better in some parts of the country than others: most of the training referred to by PAs had been organised by local authorities, or voluntary sector organisations such as Centres for Independent Living or other User-led organisations (n=37/36%) with whom PAs were linked: just under a fifth (n=20/19%) was provided by the employer, and 10/10% of PAs said they organised their own training. A couple of organisations provided mandatory basic training for PAs before they could register on their lists.

Not all PA employers were reported to be keen on formal training. This was thought to be because the training available encouraged a 'task focused' or 'medical model' mind-set which did not provide the employer with the skills they felt were needed. Instead, some employers were reported to prefer to recruit PAs with no previous experience in care or health settings, which made it easier for them to train the PA to meet their own requirements rather than have the PA carry out tasks or duties in the way they may have been taught. PAs also emphasised the importance of any training being tailored to their current employer/s' needs, rather than being too general.

b. Key informant views on the training and support needs of PAs

Almost all key informants felt that PAs were insufficiently supported. There was a widespread understanding of their needs, but the organisations employing many of these informants were only funded to provide support to employers:

'...we would see our role here to support the employer and there's an inherent conflict of interest occasionally around giving PAs advice and support and giving employers advice and support'.

KI Interviewee 24

The exceptions were participants from a very small number of Centres for Independent Living and one local authority funded 'arms-length' organisation which offered support to both employers and PAs. These were not always funded to support PAs but some did so anyway, as far as possible, at no charge.

Several reasons for the need for support were raised, some of which have already been mentioned previously, but specifically in relation to training, it was widely felt that the skill requirements and level of commitment required of PAs were greater than for other kinds of care worker. Some took the view that PAs paid from

PHBs needed to have even higher skill levels, and that it was sometimes difficult to recruit people with these skills leading to some risk for the employer:

'I think they are, to an extent, under-skilled in terms of managing people with some complex needs.'

KI Interviewee 10

Though this might suggest a need for skills training, some were opposed to the introduction of *mandatory* training requirements for PAs (as for PHB PAs). This was rooted in a belief that training needed to be left to the discretion of the employer:

'I don't think it should be mandatory, so for example, the Care Certificate, then if PAs do that and pass that then all well and good, that is good for their future, but I don't think it should be mandatory that an employer has to do that, has to ensure their PA does that.'

KI Interviewee 9

By contrast, others argued that, in their experience, employers could also sometimes be a barrier to PA training. This was because the marketing and advertising of training opportunities for PAs were often mediated by the employer (because it was the employer with whom the support organisation - and training organiser - had contact). Since any costs or time taken for training would need to be met by the (DP funded or privately funded) employer, there was little overt incentive for the employer to allow their PA to attend training.

Previous experience

The value to an employer of having a PA with no previous experience of care work and who could be 'moulded' to the specific requirements of the employer has previously been mentioned: subsequent training might also encourage PAs to carry out tasks in different ways to those desired by employers.

Employer insecurity

Some also felt that barriers to training arose from the insecurity of some employers:

'...a lot of employers are reluctant to release staff, because they think they'll start talking to other PAs and then they may find out that there are other jobs out there which might be nicer than the job they're doing. So they're quite concerned that they may lose staff or if staff come on training, that they may then expect to have an increase in wages, (and) obviously there's no funding for that.'

KI Interviewee 15

Training arrangements for PAs employed by Personal Health Budgets

Some key informants were able to compare funding arrangements for learning and development for PAs funded by Direct Payments or PHBs:

'With the NHS, if they've got this training need, that training need, the NHS withhold a chunk of the budget and they can say 'Actually, yes, there's money in there for doing that and yes, you definitely need that'. With local authorities, it all has to be met out of your budget. So, if your PA is being trained, then you've got to pay their salary for a day and you're without care for a day'....they ring fence it; local authorities don't: they give all the Direct Payment to the client and they expect them to build up a small contingency, and it's getting more and more difficult because you don't know what the contingency will cover...and if they build up too much contingency then it gets taken back off them'.

KI Interviewee 16

For PHBs, ring-fenced funding to meet training needs was determined following a professional assessment and such training was generally paid for because NHS care is free to end users. Though acknowledging this may remove control over training away from the employer, it was also reported that the funding amounts given to DP funded employers, though notionally sufficient to cover learning and development costs, in practice were often insufficient (it was not clear if this referred to Skills for Care funding for learning and development for PAs). This meant that for some external training was not possible unless paid for by other means, *even* if needed or desired. The cost of travel and lack of funding for PA time to attend training were also seen as obstacles unless Skills for Care support was obtained. Finally, some participants took the view that opportunities for training - even if funding were available and the employer wanted their PA to receive it - were not always easy to come by even though Skills for Care provides some funding to User-led organisations for learning and development. Most local authorities were said to be unable to afford to underwrite the costs of on-going PA training via a formal training programme. Skills for Care funding, though available to *employers* to pay for learning and development of their PAs, involved what some key informants perceived as bureaucratic hurdles to jump in order to access. Skills for Care (2018 p.95) has reported that only 27% of PAs had engaged with Care Certificate training compared with 42% amongst care workers. With the exception of self-employed PAs, training and its funding are the responsibility of PA employers if they wish to arrange it.

National representation

Several participants referred to the absence of any national organisation that would represent the interests of PAs as some kind of professional association as noted above. Major barriers to the creation of such an organisation were also mentioned. The first was that the low pay of most PAs meant that any membership

organisation that depended on subscriptions for revenue would find it hard to attract members. Second was the 'fragmentary' nature of the role – whereby the PA worked for individual employers and not an organisation – made them 'hard to reach' for any prospective membership association:

'I know that UNISON did attempt to set up some models for organising PAs and I know of one or two other projects that looked at it, but it's been very, very difficult to give any kind of structure or framework to that. And in parts, service users, you know, they guard their privacy and the idea that the PAs would all sit in a room and start slagging them off is, like, something they're not very keen on encouraging. So there's no real impetus coming from anywhere to support those PAs; agencies are not interested in providing support to individual PAs because they're competitors in the market, so I think there is no huge drive by anybody to do this...'

KI Interviewee 26

Local networking for support

In a couple of local areas, local organisations funded to help establish Personal Assistant jobs had set up networking opportunities for PAs. These were online or at meetings held every couple of months. The amount of use made of these resources seemed to vary. Meetings may have been more useful for people recently starting work as PAs but the fact that these often occurred in the evenings, sometimes in areas that were several miles from where a PA might work, were barriers to attendance according to key informants.

c. Key informant views about initiatives planned or underway to support or develop the PA role

Key informants were asked if there were any initiatives within their own organisations that were intended to support or develop the PA role. Though most acknowledged the needs, most also said none were currently taking place. This was usually because either they did not have the funding to do so (it was not clear if they had applied anywhere for funding), or because they saw their role as primarily one of supporting employers. Amongst those working in organisations that did provide training for PAs, some said this was offered even though it was not funded, and some admitted existing arrangements were in jeopardy because of continuing cuts to local authority funding. Initiatives that were mentioned include the following:

PA toolkit/guide

One key informant worked for Skills for Care that had been funded by the Department of Health and Social Care to develop an online 'information hub' for employers and PAs¹². This was available in a range of different formats, but details of uptake were not available:

'...we've been doing lots of work around PA employment and supporting Personal Assistants. All of the information that we have available is on the information hub for individual employers and PAs. So that includes – for individuals the Personal Assistant's toolkit is our flagship product, really... that's very well used and very popular and we have an online version of that, an easy read format, as well as a hard copy booklet and a DVD that we can give out to people...we get great feedback on that. We've got a 'Working as a PA Guide', we've got things about learning and developing your PAs, We've got things, just other general stuff that we do about, you know, we'll kind of have other work around the organization as well in terms of recruitment and retention and data collection which will include, as much as we possibly can, information about individual employers and personal assistants.'

KI interviewee 1

However, another key informant, though acknowledging the contribution that Skills for Care had made to developing information that could be used by PAs and employers, felt that without further input from disabled people, particularly in relation to dissemination, its impact was diluted in respect of employers:

'I suppose there's the problem that organisations like Skills for Care have is that they kind of operate in this environment where they want to provide all this information, and although they have things like the PA Framework ... it feels a little sterile and it feels – that involvement of the user-led aspect of it is lost in their delivery of their materials.'

KI interviewee 18

PA registers

A few key informant participants said the organisation in which they worked had, or was developing, an online PA register. These seemed to be developing in isolation from one another, collecting different kinds of information and with different arrangements for sharing information that was collected. Some registers appeared to have been less successful than others: the report will return to this topic below.

¹² https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Information-hub.aspx?utm_source=EmpPApage&utm_medium=Website&utm_campaign=Employing%20your%20own%20care%20and%20support.

Training

A small number of participants described being involved in helping employers to write funding applications to Skills for Care for training of their PAs. One also referred to securing bespoke training for both the employer and the PA. It was suggested that one advantage of providing training to both employer and PA simultaneously was that it addressed some of the logistical problems that otherwise prevented PAs attending.

PA support networks

Some key informants mentioned local plans to set up arrangements to enable PAs to get in touch with one another to reduce their occupational isolation. Not all PA employers reportedly welcomed this:

Interviewer: *'And often there is no supervision?'*

Key informant: *'...yes, whereas yes, a lot of PAs who don't – they're employed by the person and some of those employers don't necessarily want them to go outside of their – where they are. So, it's – they don't want them to get supervision or advice from anybody: they want to keep them to themselves and even when I...when I decided to launch a PA network, I had a lot of lash-back from the employers, saying 'Oh, well, these PAs are going to get together and have a talk about me and they're going to compare how much they're earning' – and I've been to numerous [network meetings] and never once does a PA do that, and everything is confidential and it's done on a very – much more peer support – it's peer support virtually.'*

KI Interviewee 20

Awareness raising of PA role

Demand for PAs varied in different geographical areas according to the experiences of some key informants. To address low awareness and low demand, attempts had been made to raise the visibility of the PA role amongst the general public to promote interest in the job. This involved a range of different strategies, including use of local and social media.

Pre-existing initiatives

These were more frequently mentioned by key informants. Arrangements to support employers and PAs have already been discussed. One local authority had established an arm's-length organisation that offered a range of services which included formal registration arrangements for PAs. To register, applicants are required to undertake free basic training on a range of topics. The training is provided by the local authority. DBS checks are also carried out. Registered PAs are expected to be self-employed and so checks are also made to ensure they are also registered with HMRC. The register, containing details about the PAs, is made available to people who wish to recruit a PA. Networking opportunities are also

available in the form of periodic meetings which PAs may attend to share experiences. Strict protocols govern the sharing of personal information about the people the PAs work for. There were concerns that funding cuts would lead to the curtailment of some of the things this organisation provided and no robust independent data about cost-effectiveness appeared to be available.

Several Centres for Independent Living and user led organisations also offered some support to PAs though none as extensively, as noted above in the section on disputes and problem resolution. In light of the criticisms made by some disabled people such a well-resourced organisational model may not be universally supported, because of the status of the PA as self-employed rather than employee, and because of misgivings about the value of formal training compared with employer-led training. The views of PAs about such a model would be helpful to hear.

10. Training and support for employers

Several parts of key informant interviews also focused on what employers of PAs needed access to in order to be good employers. Needs and unmet needs for support in the employer role were very frequently mentioned. The kinds of support, its quality, and availability were frequently expressed concerns and their limits were thought to impact on PAs.

Information and advice

Information and advice for employers were most frequently mentioned as deficient. Participants felt that this was patchy (only available in some geographical areas); of variable quality (some felt it was difficult for employers to know what 'good advice' looked like); and in some places was absent. One participant referred to people who had a Direct Payment in her local area being left to 'sink or swim' and though there was general concern expressed at the lack of 'user-friendliness' of much printed or online information, the informational needs of people with learning disabilities or dementia were mentioned particularly. These comments did not necessarily refer to information provided by local NHS organisations or local authority adult services departments, but also to information from government departments for employers, which was written with particular employment situations in mind that were difficult to relate to PA employment. One participant argued powerfully that 'information packs' provided by local authorities, NHS organisations or government departments did not enable many disabled people to overcome lifetime experiences of marginalisation, discrimination and disadvantage:

'What I find quite interesting is, when I've engaged in an advocacy role or when I've done research and I've engaged with individuals and families who have no experience of it whatsoever and are being very passive and dependent in the system – what I mean by that is that they've had that kind of notion of passivity and dependency reinforced by professionals saying 'We know best, you listen to us. You shut up'. Then what you've got is people saying 'Oh, I've got no idea. What do I do? What are contracts? How do I give a contract? What's my responsibility as an employer?' And all of this is highlighted. But the problem is...that what a responsible local authority can – you can quite easily see it being 'Oh, shit, okay, we need to give all this information out, make it into a nice accessible pack, leave it on the coffee table when you've talked about PAs, there you go. Well, that's not an accessible way to provide information.'

KI Interviewee 18

Another key informant made a very similar point, but from a different context and with very different implications:

'...if you've got an older person with lots of issues and something crops up, if they were to call an advice line and talk to someone professional it's highly likely that they wouldn't really get what was going on even then. I think there's certainly a role there for those tricky issues of HR...'

KI Interviewee 7

Ability to access 'good employer' training

Smaller numbers of key informants from organisations such as Centres for Independent Living said they organised 'good employer' training courses from time to time. These were only available in the areas served by the organisation, but some courses were not well attended. Reasons for this were unclear. Since these courses were free of charge, cost was not a factor. It was suggested that the cost of travel and difficulty entailed in travelling for some disabled people may have been barriers. The lack of 'value' some employers may attach to training has already been mentioned and may also have been a relevant factor. A couple of organisations said they offered training to employers even though they were not funded to do so because they felt strongly that this kind of support was needed. Several participants mentioned that there was even less support available to self-funders even though this is not excluded by Skills for Care funding of training for PAs. One participant felt that local and regional variation in the availability and quality of support to PA employers suggested the need for a national, centralised 'hub' for advice to employer and PA alike. Many participants emphasised how important it was for new employers to have training and advice to avoid later costly and stressful mistakes in managing their PA.

Recognition that some people would be unable to manage even with ample support

Some participants felt that current arrangements were such that people with health or care needs might effectively feel 'forced' to have a DP or PHB to employ a PA in order to obtain support or care of the right quality. Several commented that the employment of a PA 'was not for everyone'. There were, though, differences of opinion between participants over what proportions of people might manage employment responsibilities. It was clearly the experience of participants that some disabled people would manage with or without support to employ a PA. Others felt that most people with health or care needs would be able to take on employment responsibilities with support. In this regard, the diffuse and patchy nature of support and guidance was seen as a serious obstacle to people becoming PA employers: one participant said it was important for people to have confidence that support would be there for them if things went wrong. A minority of participants, by contrast, thought that in practice, even with very large amounts of support, it would be difficult for some people to take on meaningful employment responsibilities. The great majority of participants felt more advice

and support were needed, and that at the present time, both the availability and the quality of advice and support – though good in some places - were generally patchy and inadequate.

Advice about drawing up job descriptions and person specifications and contracts for PAs

Many participants said that locally, and in other areas, arrangements were in place to ensure job descriptions and person specifications were drawn up. For some of the organisations employing those interviewed, this was a ‘core’ responsibility. In some, these were based on templates, but because of the highly variable nature of employer needs, goals and requirements, they were often substantially ‘customised’. One local authority participant also drew on support from the local authority’s Trading Standards Department to assist in writing these documents. These same organisations were often also responsible for working with the prospective employer in drawing up the contract of employment. Amongst this sample of participants, arrangements for providing job descriptions, person specifications and contracts seemed common, and unmet need was thought to be low. Some concern was expressed by other key informants about the imprecise content of documents in general and particularly the contract of employment.

Organising payment and payroll

Support with pay was another employment responsibility that was, in the view of key informants, generally met if the employer wanted to use it. Typically, payroll companies, outsourced or commissioned by a local authority were able to ensure that PAs were paid properly if employers availed themselves of their services. Most of these arrangements did not draw much comment, though one participant referred to one payroll company that they felt was very inefficient and caused significant problems for employer and PA alike. This appeared to be an isolated local example.

Calculating hours of work and overtime, holidays, time off in lieu, and sick pay

These tasks were seen by participants as being the primary responsibility of the employer, who typically would then notify the payroll company. This was not, however, always a straightforward task. Sometimes an employer might have a team of PAs, and PA shifts might vary from week to week and actual hours worked in a given day might also vary according to the employer’s requirements. Though payroll companies were usually felt to respond promptly to information provided by the employer, they relied on employers instructing them and providing the necessary information. Some key informant participants emphasised that this was one reason that better ‘induction’ training for new employers could be so valuable. One participant said that their organisation now used volunteers to offer advice and support about this to employers who needed it but this was an isolated example and no PA reported that their employer received such help.

National insurance and pensions

Though most participants felt that payroll companies and non-commissioned services available in the voluntary sector such as disability rights organisations were able to offer advice and support, it was acknowledged by key informants that many employers made what were described as 'innocent mistakes' through lack of awareness of legal requirements or other non-intentional mistakes.

Hiring self-employed PAs

Potential pitfalls of hiring self-employed PAs have been referred to above. Several key informant participants emphasised how important it was for people who wished to pay a self-employed PA to make sure that this was arranged properly and acknowledged that this did not always happen. Some participants managed organisations that provided work opportunities for self-employed PAs. The level of support available varied according to the amount of funding provided by the local authority rather than any charges to the PA or employer. In one organisation, funding covered the cost of running a PA register, and this registration was conditional ensuring that prospective PAs undertook mandatory training to provide them with core skills. At the time of the fieldwork, this was provided free of charge, the costs being underwritten by the local authority. Disclosure and Barring Service (DBS) checks were also made and paid for, and checks to ensure that, as self-employed workers, PAs had taken out liability insurance and were registered with HMRC for tax purposes. Participants associated with this scheme expressed concern that without these protections in place, employers could be exposed to risk: for example, because tax liabilities might transfer to them if the self-employed PA did not register with HMRC or was not accepted as self-employed. A small number of participants expressed particular concern that some employers - for example, self-funders - might seek to avoid employment responsibilities by paying cash for care within a local 'hidden economy' which could put them at particular risk of colluding with illegal activities such as benefit fraud or employing people without the right to work in the UK.

Support with employment and disciplinary issues

Disciplinary issues were probably the most frequently mentioned employment concern by key informants. Participants emphasised that the close working relationships that could be so rewarding to employer and PA alike also meant that any conflicts that might occur were more intense and difficult to resolve:

'They don't recognize; they don't see it coming, like an employer might. They don't nip poor behaviour in the bud because they fear losing their staff; they don't want to upset them, and things do bubble under the surface and boil over. Usually, it works well: these are rare occurrences. But I've seen this time and time again and they want to dismiss somebody, but they haven't done anything procedurally to warn them about their behavior or try to put it right. Yes, people can get into

disciplinary and grievance; they don't know how to handle the grievance. It'll be 'Right, if you're not happy, just leave' and it can get quite disappointingly fraught'.

KI Interviewee 16

Many key informant participants drew attention once more to the importance what they described as clear boundaries in the employment relationship to ensure neither side took advantage of the other, though some felt that the having no or little experience of being an employer, lack of support and knowledge of employment responsibilities allied to the close working relationships that developed could, and did, blur boundaries. This made it much harder for employers to discipline PAs, and several participants said that time and resources were spent on offering advice to try to resolve problems, or, rarely but sometimes, to support employers through an employment tribunal process.

The advice that participants said they would give about where an employer should seek help varied. Participants from some organisations felt that they could provide advice to employers particularly if the employment problems were not long-standing. (It was also pointed out that often employment problems were not brought to anyone's attention until matters had reached a crisis.) If problems could not be resolved by dialogue and conflict resolution, many participants said they would advise employers to seek professional advice from the legal advice line of their insurance company (covering employer liability) though some also felt that insurance companies were 'risk averse' and their processes were lengthy, and stressful. Some participants would discourage people from seeking advice from their local authority because staff there were insufficiently knowledgeable about employment law. The Arbitration and Conciliation Service (ACAS) was also mentioned as a reliable source of advice by some participants based on feedback from people whom had sought its advice.

11. Interest in expanding the PA role to take on more health-related tasks

a. PA perspectives

Only a few PAs (n=16/17%) did not already carry out some form of task that could be described as 'health related' and a quarter (n=22/24%) said 'a lot of their time' was spent on health-related tasks. There was considerable interest in opportunities to expand the 'health' role further, with many PAs (n=59/63%) expressing such interest and a further 7/7% unsure but wanting to know more. Many (n=68/73%) also felt that if they were to take on the role of supporting people with health as well as care needs, they would need training to feel confident in their ability to carry out such new tasks. Some said they would want an enhancement to their pay for acquiring new skills, and the need to properly demarcate their role from the activities of community-based health professionals was also mentioned:

'I would want the satisfaction that I'm learning more and I'm doing more things, but at the same time I think with that you have to look at the bigger picture, and if I'm doing more nursing-related things, I would expect more money and more recognition, because I think there is a shift where people are expected to do more and more, and it does save the government money, which is good, but then it's not fair that if you look at what people do, they are taking on roles and they're not being recognised for it. So, I think if you're doing the things a nurse would do, you're not qualified as a nurse, you haven't done the degree, I would expect some kind of recognition, both financially and in qualification to say that I'm more qualified than just standard PA, that I can do these extra additional things.'

DM550163

b. Key informant perspectives on scope for the PA workforce to be employed by people with Personal Health Budgets

Key informant interviews also addressed the topic of Personal Health Budgets (PHBs), the scope for the PA workforce to be employed by people who had a PHB and some of the implications for pay, conditions and training.

Though some participants felt that the ultimate objectives of PHB and PB funding were the same and so in theory, at least, the source of funding should not make a difference, most accepted that it did. These same differences were viewed both positively and negatively by different participants and are explored below.

Resources, needs and training

These were key concerns. Several participants drew attention to the arrangements through which PAs could be employed through PHBs which were considerably different to those for Direct Payment funded or self-funding PAs. The main differences were that as PHBs are NHS funded, there was a legal obligation to fund all assessed need (in adult social care, assessed need is regulated by eligibility criteria and a means test to manage demand and local authority resource availability). There was also an obligation to ensure that PAs funded by PHBs and who carried out tasks that were clinically focused (for example, the kinds of tasks that might be carried out by a Health Care Assistant) received training to ensure they were competent to carry them out. This could be formal or peer training:

'With the NHS, if they've got this training need, that training need, the NHS withhold a chunk of the budget and they can say 'Actually, yes, there's money in there for doing that and yes, you definitely need that'.

KI Interviewee 16

Participants described how community-based nursing staff were generally responsible for ensuring competence in whatever clinically related tasks might be needed and needed to 'sign off' the PA if they were competent. This was not always straightforward. First, some participants referred to a reluctance of some community nursing staff to assess for and 'sign off' PAs. In part, this might have been related to a reluctance to accept accountability but it was also suggested that they did not have time to train and assess PAs because of other more pressing clinical tasks. Second, some participants, who had tried to arrange formal training in clinical tasks or procedure said that they found it hard to find the right training in their area. Third, the control over training and establishment of a competence framework was considered unhelpful by some disabled participants, who felt that managers responsible for introducing PHB arrangements saw it as another form of service delivery rather than primarily as funding support to meet not just health needs but provide support to all areas of the employer's life. In practical terms, some participants said such arrangements might also make PAs less 'malleable' as they would be trained to carry out given clinical tasks to a standard required by the NHS and periodically monitored. No equivalent monitoring arrangements were required from local authorities. Some participants suggested that the imposition of competency standards might differ from how an employer might wish the tasks to be completed (e.g. wearing of gloves, use of hoists), thereby removing an element of control from the employer.

Deciding what can and cannot be paid for with a PHB

One matter that illuminated the question of control over the PHB was whether it could be spent on things for which there was no evidence of clinical effectiveness,

such as aromatherapy, homeopathy or other alternative therapies delivered by a PA. Though NHS staff might balk at the cost-benefit of providing financial support to pay for therapies for which there was no evidence of effectiveness, placing restrictions on the kinds of things on which the budget could be spent might also be seen as an example of the NHS restricting the freedom of budget holders to spend their money as they saw fit.

Though the concept of evidence-based medicine is now strongly rooted in the NHS¹³, it has received less attention in social care. One participant said that their organisation (not part of the NHS) might fund 'alternative' therapies (for which no evidence for clinical effectiveness existed) but was unsure if Clinical Commissioning Groups would do the same. One participant referred to the potential need for risk assessments to be carried out for PHB funded 'interventions' if no clinical evidence for effectiveness for the intervention existed.

Role demarcation

Demarcation was felt by some key informant participants to be a problem arising from these differences. Participants referred to potentially difficult scenarios: for example, where PHB funded PAs and DP funded PAs worked for the same employer, which might be a potential source of conflict if one PA was paid more, but spent time doing clinical and non-clinical tasks at the employer's request. There was also a more general concern amongst some key informants that disputes could arise in determining whether a task was 'clinical' or 'non-clinical'. Some participants felt there could be scope for offering clinical training for PAs if an employer's health had deteriorated and a PHB was provided. However, it was also felt that though some PAs would be keen to extend their skills, other would not, and some thought it might be difficult for an employer to release their PA to enable them to receive training, because DP funding was insufficient to pay for it. Local authorities were not obliged to train PAs or ensure their competence (some did but most did not); and because of difficulties in accessing clinical training in some areas. A small number of participants also expressed concern about the hypothetical fate of a PA should the meeting of an employer's needs require a PHB rather than local authority Personal Budget. They felt that because responsibility for training rested with the funder, not the employer, if an existing PA did not wish to undertake training to become employed via a PHB they would probably have to resign, with attendant potential loss of a close working relationship between the employer and a PA that could have been built over a number of years. Such worries were generally based on possibilities rather than experience.

¹³ The term 'evidence informed' rather than 'evidence based' is now sometimes used: this is another potential challenge to evidence driven protocols and may need to be more clearly defined and debated.

Pay and conditions for PAs paid from PHBs

These were seen by most participants as different and it was agreed that PHB funded PAs should receive higher pay to reflect what was seen as their higher levels of skill. In contrast with responses from some key informant participants over the possibility of spending PHB money on alternative therapies, others noted that in some areas NHS funders seemed to have a more relaxed view about how the PHB was spent. Thus, in practice, the completion of non-clinical as well as clinical tasks would be permitted. These participants felt this was a common sense solution that avoided the need for arguments over demarcations between health and care tasks. However, there was also concern that some local NHS organisations did not recognise any skill differentials through higher pay, which made it hard to recruit PAs to work for people with PHBs in some areas:

'In [name of organisation] there is...no difference in pay between somebody who gets a Personal Budget and somebody who gets a Personal Health Budget...it's often a standard rate which can often be difficult for a place to attract staff, because if you've got a Personal Health Budget and you need somebody for example with skills and experience that veers towards more clinical support – nursing type element, then that's going to be really difficult to find somebody to do that for the same rate of pay as you would for a more general Care Assistant, Personal Assistant role'.

KI Interviewee 24

This was not an isolated problem:

'One thing that is worth saying is that if the tasks do change quite often the funding doesn't reflect it. So, in other words, the hourly rate that the health service is giving matches the hourly rate the local authority is giving....at times you think OK, so these people now perform all these additional things, but there's very few of the rest of us who would be told 'we're up-skilling your job' but we're not going to give you any money to do it'.

KI Interviewee 26

There was concern – particularly from participants in some parts of the country - that pay did not reflect local market conditions and therefore made it particularly hard to recruit PAs funded from *either* kind of budget source.

Portability of role

A couple of participants saw an opportunity for PAs to achieve a measure of recognition of their skills or competence if clinical training was accredited or recognised in some way. It was suggested that social care funded PA employees, at the present time, might acquire high levels of skill, but these might reflect the

very specific requirements of their employer and so would not necessarily be transferrable. Recognised or accredited skills were perceived to potentially offer more 'portability' in employment arrangements.

Training

Though mention has already been made of different training requirements for PHB PAs, some participants also observed that Direct Payment funded PAs often did not receive any formal training or learning or development opportunities. Several reasons were given - some of which the report has already mentioned - including lack of perceived value of formal training (because it might encourage the PA to perform tasks in ways that did not suit the employer); because Direct Payment funding amounts were insufficient, in reality, to cover training costs; and because of difficulties in some parts of the country to find or access suitable training.

'Topping up' the budget

Augmenting a personal budget with private funding from savings or other income was allowed for Direct Payment (DP) funded employers but not those who were PHB funded. The rationale for this was reported to be that although local authority eligibility criteria meant that not all assessed needs would necessarily be met by a DP, the NHS funded PHB was intended to meet all identified needs.

Insuring PHB PAs

Insurance was raised by just one participant who felt that, in practice, clear boundaries between PHB and DP funded tasks or between PHB funded PAs and local primary care clinical staff would inevitably be blurred which might possibly make obtaining insurance cover more difficult:

'There's obviously the on-going issue with insurance, and where people are – PAs are doing clinical – well, so firstly there's the issue of 'Is this a health-care task? Who does this? Is there an expectation that the PA does this or does this need to be done through Primary Care services...?' And then getting insurance for that in place, getting the insurance paid for and determining competency – because often trying to get somebody to sign off to demonstrate competency in a healthcare task is quite a challenge....There is insurance available for health-care tasks but it's only valid...if somebody is deemed competent to perform that task: that's how the insurance company mitigates the risk....often people don't want to sign their name to a piece of paper to say 'this person is competent'.'

KI Interviewee 24

12. Personal Assistants and other community health and care professionals

a. The experiences of PAs

Few direct comments were made by PAs about working relationships with other practitioners, although references were made about being supported by GPs, social workers or district/community nurses: for example, in persuading an employer to move into a care home or to go into hospital in their best interests.

Some PAs were aware that care workers could have a poor reputation and might not always be treated respectfully by other professionals:

Interviewer: *'I guess that there'll be a group of community-based professionals that will be supporting the lady you're employed by? Do you feel part of a team, or...? I mean, do they ever seek your advice, or because you know that person really well?'*

PA: *'It depends on the individual, to be fair. Sometimes, unfortunately a lot of support workers and PAs, they get a bad reputation, or are treated unfairly, but I think it just depends on who you are dealing with, and I think if they see that you genuinely care and have a relationship with that person, it'd be silly for them not to seek out your opinions, or ask you things... because obviously, you do spend a lot of time together.'*

Interviewer: *'Does that happen to you though? I mean, do you feel that you're, as it were, the bottom of the feeding chain?'*

PA: *'Yeah. Yeah... Definitely...'* [Interruption]

Interviewer: *'You know, as a... like a very junior member of a community-based team, or, you know, you're shut out from some things? Is that?'*

PA: *'Yes, you can be. They assume that you don't want to be in the role, and you're just there for convenience, and that you shouldn't be considered... And, unfortunately... Sometimes they can be right, but it's just a stupid assumption to make, because you don't know the individual, but... how they came to do the role, and why they're there... Unfortunately... Yeah, it is. It's so much the case in a lot of places. There's a lot of... Even with maybe the family that you come to deal with, a lot of them don't like you being there, but you're there because the person needs you.'*

DM550237

Another PA noted that in contrast to care work, the PA role provided a lot more scope for effective team working to assist clients:

'I liaise with so many professionals it's unbelievable, and experience, you get to do more, you're restricted so much more when you're with home care than we are with this job. My client is quite troubled in some areas of her life and this causes problems and so liaising with all these people. I'm the middleman really. If they were to go straight to the client they would get such a negative response and it would all fail whereas if they come to me and express their concerns I can then go to the client and I can put it in a way that works for some reason, but then again that's why we've been match made... They've basically told me that, you know, they just don't know how I do it, they couldn't, she'd be lost by now if it weren't for me and I'm not blowing my own trumpet: it's fact.'

DM550238

b. Key informant views on the co-ordination of the PA workforce with other community professionals

Over time PAs are likely to know their employer better than other community-based professionals. As such, they might be valuable sources of information from which an employer might benefit. For example, a PA might be able to spot subtle changes in their employer's physical or mental health long before other professionals, enabling earlier intervention and forestalling a later crisis or emergency situation. However, there was little report of any kind of integration or communication between them. There were several reasons for this.

Employer objections

Concerns of employers about privacy were the most obvious and frequent obstacle to the closer working of PAs with other community professionals:

'I would not see it as a generalised responsibility for the PA. I think it's very much up to the individual as to where they share that information with the PA about the services they engage with and...the level of input they want from their PA...I think at the outset the expectation should not be on the PA to be involved...unless the PA user wishes them to do so, because it changes some of that relationship then, because – for many people I've worked with...they talk about professionals and service deliverers as 'them and us'....and so I think it's very much a case of allowing or ensuring the disabled person is in the driving seat of co-ordinating that input and that information'.

KI Interviewee 18

Several participants, particularly those who themselves were PA employers, felt extremely strongly their PA should always respect confidentiality and privacy, and that not to do so would be a gross breach of trust. (One or two participants felt that there might possibly be exceptions to this: for example, the reporting of

safeguarding concerns, or where there was recognised impaired capacity.) They felt that the only time a PA should disclose anything about them to anyone was with their clear consent. One participant felt that employer permission was essential because the PA was not a 'service deliverer' but an 'extension of the employer' and within this context, as well as breaching trust, information disclosure without consent would affect the power dynamics within the PA/employer relationship:

'...when you start to provide additional roles in the initial development of the PA which involves them being aligned or closely aligned in those discussions with service providers or the professionals, it changes the power dynamic between the disabled person and the PA themselves'.

KI Interviewee 18

Another participant also framed information sharing in relation to power dynamics, suggesting that technically the PA's role was to meet needs and not express opinions, but that if they had opinions (relating to the welfare of their employer) these should be shared with the employer who would decide if they were valid. Another maintained that a more appropriate focus would be for the PA to work on empowering the employer to provide information if they had the capacity to do so.

Ambiguity of PA status among community professionals

Though concerns of employers were probably the most frequently voiced concern, some also drew attention to the ways in which other community professionals viewed PAs. Several key informants said that in their experience health and adult social care professionals did not see PAs as fellow professionals:

'...they are an invaluable untapped resource about both the person but also stuff that's going on in and around communities because they're really good at sort of supporting people to live those good, full lives, normal lives in the community. So, because they're a Personal Assistant...they're not - I don't know what it is, but they're not recognised, by the 'system' in the sort of way commissioned services are'.

KI Interviewee 3

Some went further and suggested that PAs were regarded as unskilled care workers, and therefore even if permitted to do so by their employer, they were generally not seen as having a great deal to contribute in case conferences or other fora:

'The problem sometimes come with those professionals not thinking the PA knows...they don't know anything. It comes with the attitude 'Oh well, they're just

this non-professional person that comes and helps a person' so it's a – the retraining of the sector....to recognise the fact that 'hey, this person is probably spending more time with that person than anybody else: they're going to notice changes in health...changes in mood, or if depression is setting in. They're going to notice these changes more than anyone else, and especially if there is no family that are involved'.

KI Interviewee 20

One participant suggested that a reason for the exclusion of PAs (in this case the respondent was referring to PAs funded by PHBs) was that health professionals excluded PAs 'because they like to be able to work with people they've got some element or influence or control over', but this person did not see the greater integration of a PA within a community team as necessarily removing control because the person (employer) remained at the centre.

Whatever reasons there may have been for the exclusion of PAs from closer working with other health and care professionals, one impact was to reinforce their sense of isolation within the workplace (which was a theme of many of the PA interviews), and their sense of disconnectedness:

'There's a lot of things like Age UK and all those sort of things that you can talk to and the carers' hub and things like that you can get connected to and stuff, but sometimes you do feel like you're the only one. You're the only one that's doing this job, you're the only one that's really caring... I think also when they [the employer] have family, I think the family, they disconnect themselves from... even though you're the PA, you should be doing all of it, if that makes sense. They don't really want to get involved. We're paying you for this, so this is what you're doing. It does become quite lonely'.

DM550180

'It feels quite contradictory, probably, what I'm about to say, but there's massive risks and massive difficulties, or barriers to being a PA, as there is with any job, I guess, and I think the barriers to being a PA and what has been a reason why I've always done other work alongside it, is because I think it can be incredibly isolating, because you're working one on one for eight hours. And, if he's in bed or is unable to go out that day, or you're trying to do a task like shopping and he's unable to focus, it can be incredibly difficult. And so... but the plus side is that you feel very supported by a team, and you know that it's not about... you're not being judged by the outcome because you can't make him perform in a better way; all you can do is assist him with whatever it is you can do... Whereas with my other jobs, the sessions I do with somebody are probably much more intense... But, basically, the sessions are much more engaging, I think that's what I'm looking for, so you can have a conversation, you can get tasks done, you can achieve your

outcomes and you move on, but the lack of support outside that network is also what makes you think, oh, this bit isn't so good, because you never get to see the other members of the team at all, so you work in isolation in the support worker job. So, both roles can have elements of isolation with them'.

DM550191

Connections between Personal Assistants working for people with Personal Health Budgets

These reflected differences in approach to the use of PAs to support people who had a PHB and needed clinical support or care. Here, the necessity for PAs to have received competence based training to ensure they had the necessary skills and knowledge to discharge this role meant a greater 'connection' with some community health professionals, who were responsible for providing training for PAs in basic clinical tasks and signing them off as competent to carry out these tasks. There was at the same time a recognition of the difference of the PA role:

'...you can work towards being part of a team can't you, but to a point, because...the PA is employed by that person and not by the Health Team.'

KI Interviewee 41

13. Barriers and facilitators to the development of Personal Assistants in the social care workforce

a. PA perspectives

Reasons for growth

Dissatisfaction with working for home care agencies was a huge impetus for the development of the PA role as a segment of the social care workforce according to our interviewees. Most PAs wanted the freedom to care for their employers in a meaningful way and setting oneself up as a PA was one way to do this.

Obstacles to growth

Many PAs drew attention to the administrative or emotional responsibilities that accompanied the role:

'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. Some are through [name of service organisation], some are through social services, some are through themselves. I think it's relying on other people for that. And the other thing I think sometimes... it's not always the worst thing, because I have got people I can contact, but it is just you and the client quite a lot, and I think sometimes it's just not having somebody that you can almost have a supervision with or that you can say, this is what I'm doing, what do you think?'

DM550147

b. Key informant perspectives

Most, but not all participants felt that there had been a sustained growth in the proportion of PAs in the social care workforce. Skills for Care (2018) figures also suggest that this may be based on an assumption that a clear majority of people receiving a DP will want a PA, but participants identified other factors that both promoted and inhibited growth.

Reasons for growth

Probably the most frequently expressed reason for growth in the PA workforce was increased demand for and take up of the role. This was, though, largely an

outcome, and it was itself the product of several different pressures and flexibilities. These included policy shifts toward greater self-care and control; the emergence of more 'rights based' approaches to service delivery and changes in attitude by local authorities and social workers/care managers: towards promotion of both Direct Payments and PAs. Greater awareness of the potential for taking on a PA and training about the mechanisms of setting up such arrangements were also sometimes cited as reasons for these changes in attitude:

'More personal budgets/Direct Payments awarded; better training about personal budgets for social workers involved in the assessment process. It's (also) more widely known about'.

KI Interviewee 31

Some participants felt that growth was encouraged locally because of the potential of PAs to save public money: they believed PAs were cost effective compared to agency care but also because they acquired deep knowledge and understanding that a PA might acquire about their employer might mean earlier intervention if changes in their need occurred. One participant suggested growth had continued in their local area because the right 'market conditions' existed, and another felt that local campaigns to secure PA provision, combined with wider awareness raising with the general public, had also been facilitative. Additionally, both employers and PAs were attracted to this kind of arrangement because of negative and unsatisfying experiences with local care agencies:

'I know PAs I work alongside have left what would be, sort of, traditional care jobs to have a bit more flexibility and control over their own destiny and how they are caring for people as well'

KI Interviewee 29

However, a few mentioned the greater ability of people in need of care and support to afford to pay for a directly employed care/support worker from their own income, saving and resources.

Obstacles to growth

Mention was also made of factors that inhibited growth of PA numbers. Some participants felt that there had been limited demand in their area and thought some of this might have been because of low public awareness. It was also suggested that prospective employers declined opportunities to have a PA because they did not wish to take on employment responsibilities. In part, this was attributed to insufficient levels of support from the local authority or commissioned service because of continuing public sector austerity:

'...there's the cuts as well within local authorities that is becoming even more the case these days. I have been in touch with a particular support organization who have recently had their budget cut by the local authority by 60% which means that they're not able to offer a certain level of support to people employing PAs in their local area. The support varies, as you'll know, around the country and it depends which local authority you get your support from'.

KI interviewee 1

But it was also seen as a 'second wave' factor in the sense that early more enthusiastic supporters of Direct Payments had now mostly secured PAs and fewer people were now so committed to this approach to service delivery. One participant referred to 'zombie personalisation'¹⁴ as a factor, in which genuine choice and control were not available. A small number of participants cited Skills for Care figures as evidence of continuing growth but whilst one suggested that actual numbers of PAs within the workforce was likely to be higher than 'official' figures suggested because of a large 'invisible' (i.e. informally working) number of people working as PAs, another suggested that the Skills for Care figures may have been based on inaccurate assumptions about the proportions of people with a Direct Payment choosing to employ a PA and that the true figures were lower:

'...in 2010 the government made it a more formal policy that people should be on a Direct Payment by default...and there was a massive growth of numbers...over the next five years, but initially Skills for Care assumed that all those people were employing PAs....and then they started surveying and finding that no, the majority of the increase was down to people using a Direct Payment to purchase regulated services. And I think what that was about was local authorities chasing a target...getting more people on Direct Payments'.

KI interviewee 30

There were well-defined differences of opinion about how extensive the use of PAs should be. On the one hand, some felt strongly that the number of people who had a PA was much lower than it should be:

'...in terms of the numbers of people who should be using Personal Assistants or actually have it offered to them in terms of their assessment procedures and so forth, it's woefully inadequate in terms of having people who should access it'.

KI Interviewee 18

By contrast, others felt that PAs were not the 'answer' for all:

¹⁴ This term was first used by Duffy S. (2014) *After personalisation*. In: Needham C, Glasby J (eds.,) **Debates in Personalisation**. Bristol: Policy Press, 167-184.

'I think it's definitely not right for everybody: I would definitely say that. So there are some people, just because they need support, doesn't mean they're necessarily going to be a good employer. So we can't forget that alongside having a PA, which brings a lot of advantages, there are things where you have to become an employer... I know there's the self-employment thing, but I think that's a separate thing. It's that, yeah, you have to be – you're their manager, so you deal with any issues. You have to deal with holidays ... and the hours. If you don't have a payroll service you have to calculate tax, National Insurance. So yeah, not everybody is a natural employer. Some people are amazing employers and it works really, really well, and some people don't have those skills'.

KI Interviewee 37

Both 'demand' and 'supply' problems were claimed to hold back PA growth. Shortage of supply was attributed to the high cost of living in certain local areas/regions (which meant PAs could not afford to live in the area) and high costs of travel for PAs working in rural areas. Another 'supply side' problem was turnover among PAs. Turnover was attributed to bad employment experiences, poor pay, poor conditions and lack of role recognition, particularly amongst other social care or health professionals. Lack of information about the PA role was cited as a problem for both prospective employers (reducing demand) and for prospective PAs (reducing supply). Some concern was expressed that local adult social care teams were apparently making 'inappropriate' use of Direct Payments which meant that the level of support needed to enable a person to employ a PA was so intensive as to make it not a cost-effective approach, whereas in some areas, choice was thought to be eroding as it became more difficult for people *not* to have a PA.

Discussion

Limitations and strengths of the study

The challenging nature of recruitment of PAs for this study meant that the sample, though very large for a qualitative study, was opportunistic rather than purposive, and self-selection bias cannot be excluded from the PA dataset. People who were secure in their immigration status, tax status and who were committed to care work might be expected to be more likely to agree to take part than others. The sample group might also represent more financially stable individuals with the interest, language skills, and time to devote to participating. We also had no way of determining whether the PA employers we contacted passed on our request for an interview to their PA, or how the organisations that acted as intermediaries selected the PAs they contacted on our behalf.

Additionally, since little is currently known about the demography of the PA workforce, we could not establish quota or other sampling arrangements that might ensure representativeness of our sample. We do know in comparison with other recent studies, there are differences in the composition of our sample, but these may also be the result of different sampling biases. For example, the surveys of PAs and employers carried out by Skills for Care (Skills for Care, (SfC) 2017; 2019) were based on a very large samples, but the samples from both surveys were drawn from two service organisations and an online survey. Despite securing a low response rate, the size of the response suggests a low response bias for the two organisations that supported the study and therefore that findings will be reliable among these two organisations. As noted above, our own quantitative data on PA demography was quite similar: the mean age of our sample was 44.8 compared to 44.4 years (SfC 2017) and 45.7 (SfC 2019); on gender, our sample was 87% female compared to 83% (SfC 2017; 2019) The ethnic breakdown of our sample was similar to the second Skills for Care survey (85%: their first survey was 78%) and nationality was also similar (in our sample 92% British compared to 91% (2017) and 93% (2019). However, there were also marked differences. Both 2017 and 2019 Skills for Care surveys included no self-employed PAs, and, over half their PAs were family members or friends of the employer (the percentage cited in SfC 2017 was 52%; in SfC 2019 it was 56%). In our study only 18% of PAs were related to their employer. These variations may reflect the specific profile of the PAs in contact with the two organisations that supported the Skills for Care survey. If this is so, then it may be that the greater heterogeneity of our sample may better reflect PA employer relationships in these respects.

The present study has furthered understanding of the nature of employer/PA relationships, what it is like to work as a PA, and PA employment terms and conditions. In these respects, our study aligns more closely with another recent but smaller study of 25 PAs and 36 PA employers by Shakespeare et al., (2017) and the doctoral study conducted by Graham (2015) covering eight PAs supporting learning disabled people. Though both are based on smaller numbers than our own study they offer important insights into the dynamics of PA employer relationships, and many of the findings of our study closely correspond with these earlier studies. However, our study has the unique value of asking about employment terms and conditions which are points of great interest for policy makers and, of course, for PAs.

For key informant interviews, we deliberately sought to identify people likely to offer different perspectives based on their occupational roles and personal values. It was clear from the richness of the data collected from interviews that our sample of informants was highly knowledgeable about several relevant topics but had different, sometimes conflicting views and perspectives; indeed, it is also possible that the sample failed to incorporate all of these.

In summary, our study is the largest qualitative study of social care PAs to date in the UK and offers the rare opportunity to hear from PAs about their work conditions and terms of employment.

Several important findings emerged from the data. These are discussed below in two sections. In the first, we refer to 'surface' themes. These were usually immediately obvious from our interviews. The second we refer to as 'underlying' themes. These refer to matters which, though mentioned by many participants, seemed to be linked in some way to surface level concerns.

'Surface' themes

Job satisfaction, morale and pay

This study found that people working as PAs compared their role favourably with other forms of care work because of opportunities to build mutually fulfilling relationships with employers. Not all, however, had worked in social care previously. However, those PAs who had previous experience of care work spoke of having more time with their employer and not being constantly under pressure. Overall, the great majority of PAs derived considerable satisfaction from their role. Our findings support conclusions from other studies that there may be less job turnover amongst PAs than other care workers (Skills for Care 2017) although we did not interview those who had left this type of work. Our study supports the idea that their morale may be higher (this was not assessed by any scale that could be compared and there may be a risk of bias from our sample). However, some PAs

felt that comparatively low pay meant that they did not think they would continue to work indefinitely in the role, and the view was also expressed that if they were given specific training to enable them to work for employers with PHBs, then these enhanced skills should be rewarded with more pay. In practice, however, PAs might find themselves paid for partly from a PHB and partly from another budget such as a DP, and it several thought it would be impossible for PAs or employers to demarcate the role so that funding from one source was spent on health or care tasks respectively.

Though at face value these are positive findings, comparison with the recruitment and retention problems of general care work creates the risk of 'lowering the ceiling rather than raising the floor'. For the number of PAs to continue to increase in a context in which there is evidence of considerable slow-down in care sector growth (Skills for Care 2018, p.4) more may need to be done to support this process. This will include improving awareness of the PA role as an employment or self-employment option, for the development of accredited training for specialist PAs working for people with PHBs (and for pay differentials to incentivise people to do the training) as well as improvements to employment terms and conditions – at a minimum, ensuring these are legal. We discuss these matters below.

It could be argued that self-employment, rather than direct employment of PAs reduces choice and control for the employer; that tax, insurance, and other employment conditions, such as holiday entitlements sick pay will produce poorer working conditions. There are also risks associated with the hiring of PAs who are not HMRC registered or insured. However, the findings in this report suggest that employment conditions of directly employed PAs are often poor anyway, and a self-employment option may offer more choice and control to PAs themselves. Our study found no evidence to suggest that self-employed PAs were less satisfied with their working conditions. Local Authority funded registration schemes to verify that prospective PAs are HMRC registered and insured would reduce potential risks to employers. This can be done, for example, the agency Support with Confidence in East Sussex requires verification of these as a condition of registration. It carries out DBS checks and offers basic training for prospective PAs who wish to work with it, who are all required to be self-employed.

Visibility

Despite high job satisfaction overall in our sample, the social care PA role is not widely known according to our participants. People may be unlikely to choose it as an occupational role simply because they do not know it exists. Our study found that many PAs started work following conversations with friends or colleagues and 'word of mouth'. The study also confirmed what might be suspected: that the term is easily misunderstood. Key informants who were PA employers drew

attention to recruitment problems they had experienced where unsuitable applicants would apply thinking that the role involved secretarial or office work. The role was also said to be poorly understood by professionals working in community teams: some respondents felt that there was an assumption that PAs were effectively unskilled care workers. This was something PAs felt significantly downplayed their skills and experience; it may also downplay social care work more generally.

Improving the 'visibility' of the role will require co-ordinated national, regional and local activity. Nationally, government sponsored or led advertising campaigns to support local recruitment, including use of newspaper and 'trade' media advertisements, and social media might help promote the role. The evaluation of the 2019 Social Care Recruitment Campaign funded by the Department of Health and Social Care will have important information about the effectiveness of such media campaigns. At the start of this study, an early objective was to explore the role of local authorities in promoting the development of PAs. It became apparent as the fieldwork progressed that in most of the geographical areas from which our PA sample came, the local authority role was very small, and indirect. In some places this had been through the funding or commissioning of local user led organisations or Centres for Independent Living, but this funding was evidently in decline. These third sector organisations could be well placed to promote and support the PA role, but dependence on local authority grant income brings a precarious existence. In the course of our study two such local organisations were about to close, and others were closely reviewing their financial commitments because of uncertainty about whether grants would be reduced or removed in the next financial year. Whether it would be possible for some to obtain alternative sources of funding is moot but seems unlikely. This level of uncertainty makes it difficult for staff in these centres to plan beyond the short term. If national campaigns are to require local organisations to provide the operational support for people who may respond to advertising promoting the PA role, then reliable funding of local organisations will be essential. For other social care or health related roles social care employers are far easier to identify and many have local or regional bodies or run their recruitment processes online.

Recruitment

It was not always easy for employers to recruit PAs. The lack of visibility or understanding of the role has been mentioned, but it was also reported that other things made it hard for a prospective employer. Lack of experience in recruitment was one factor. Support with recruitment was available in some areas but not everywhere. As noted above, the degree of support available to PA employers was largely dependent on the availability of local authority financial support to Centres for Independent Living and user led organisations, and the energy and commitment of people working in these organisations.

Recruiting the right person to work as PA was generally seen as particularly important because of the often cited 'unique' relationship between PA and employer; one element of which is importantly informed by our findings that most PAs work for more than one person. Traditional approaches to recruitment were described by some key informants as expensive and time-consuming because of the need to sift out unsuitable candidates. Informal approaches were often favoured over the formal: shop window advertisements and word of mouth seemed to work better for employers than approaching a Job Centre, for example. Informal conversations with applicants over a number of meetings, rather than a single formal interview, and focusing on values and attitudes - not skills and experience - seemed to be favoured by employers and of course, enable PAs to make judgements about whether they wished to take up the work with an individual.

Local support for employers who wish to recruit a PA is likely to be essential for most prospective employers who lack experience of hiring staff or whose family members are not able to assist. In Wales this is highlighted as available to both people receiving local authority funding but also for self-funders:

'If you receive direct payments, you will be supported through the recruitment process and provided with the information needed to be a good employer. You will also receive help to deal with any problems which might arise.

Remember, you can still ask for support and advice from your local council even if you are paying for your own personal assistant'.

(Dewis Cymru undated)¹⁵

It is important to acknowledge that the nature of the PA role means that local but also international recruitment will be likely amongst some employers and these need to be accepted and supported (not all international care workers require visas, see Christensen and Manthorpe 2016). However, it is also important that recruitment practices are fair, non-discriminatory, and legal so that PA work gains a good reputation and credibility. Local support for employers could be audited or inspected by the Care Quality Commission as we suggest as a policy option elsewhere.

PA registers

Registers of PAs were seen as useful to both employer and PA, but only if they were properly managed and regularly updated. There was also evidence that care

¹⁵ <https://www.dewis.wales/recruiting-a-personal-assistant>

was needed over what information was provided, and how the register operated, to prevent misunderstandings, discrimination or misuse.

Some registers were designed so checks could be carried out on PAs as a condition of registration. This seemed particularly valued in one scheme, where registered PAs were required to be self-employed. However, mandatory checks on, for example, Disclosure and Barring status, HMRC registration (for tax purposes) and employment insurance were not favoured by some informants who were employers, who strongly felt that individual employers should be left to make their own decisions and without oversight. Such a permissive regime runs the risk of colluding with poor or precarious working conditions and undermining government efforts to ensure employment law is respected.

Local authorities in the areas from which PAs were recruited varied in the support they made available to third sector organisations: some did not pay the cost of setting up a register, and some other registers were reportedly not always kept up to date because of resourcing limits. Local authorities seem to be best placed to pay for the set-up and running costs of registers, but those that are not already doing so may be unlikely to pay for a register unless mandated to do so. Our evidence suggests registers are an important resource when properly set up and managed, and should be encouraged, alongside other approaches to recruitment. There are now several models of these in operation and setting up a register may not be as expensive an endeavour as previously.

There is no national 'template' as to what information should be collected and made available on a register, or who should have access to what is collected. Centres for Independent Living and user led organisations may help those considering whether to set up a register about structures processes and content. Skills for Care would be well positioned to review and co-ordinate existing guidance, enlisting support from its existing PA Framework Group, and drawing in others as needed. (see: www.skillsforcare.org.uk/iepahub, and <https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Resources/Information-for-local-authorities-NHS-and-support/Other-useful-resources/Developing-a-local-network/Developing-a-PA-register.pdf>).

Few participants in this present study expressed concern about privacy and confidentiality in respect of registers, partly because they were largely unaware of their potential. However, guidance should also include advice about compliance with the General Data Protection Act and other relevant legislation to ensure registers are non-discriminatory and not open to abuse by either employer or PA.

The linking of registers with access to training and background checks on PA registrants is controversial in that some disabled employers and others believe

that these remove control from the employer. In practice, only one scheme included in our study was able to link training in this way because it had negotiated an arrangement with the local authority to use its training resources. Though this would be an effective way of ensuring PAs have core skills, this training initiative may have been more valued by PAs than employers, because employers were reported to attach more importance to values than skills. Training is discussed separately below.

There is a strong case for mandatory Disclosure and Barring Service (DBS) checks of PAs. Ideally, the check should not remove the ability of the employer to choose whether to employ a PA from the employer, even if the check reveals that the PA has a criminal record. This is the situation if the PA applies for a basic check themselves. LAs or local NHS organisations (or delegated organisations such as a User-led organisation) that carry out checks on behalf of individual employers have responsibility for acting on the information received as this rests with the organisation requesting the check: it has a duty to act on the information revealed, and cannot pass the information on to an individual employer in order for them to decide on suitability. Nor can PA employers organise their own checks: they can only request a check is made by the LA or the NHS (or delegated authority) or ask the PA to obtain one. At the present time, the decision as to whether checks should be *insisted upon* rests with individual LA or the NHS services. This is likely to be a powerful disincentive to PA employers to request background checks, and it may therefore be preferable, within current legislation, for LAs and NHS organisations to ensure that people seeking to work as PAs are checked. It stands in contrast to child-minders who are able to arrange DBS checks through Ofsted.

The question of checking a family member was not the focus on our study but this is required when a relative is acting as a proxy for the care user in respect of receiving Direct Payments and this does not appear to raise particular controversy (see Laybourne et al. 2016). Checks to ensure HMRC registration and employment insurance cover are a policy option in circumstances where an employer chooses to hire a self-employed PA. Currently, public funds seem to be sometimes used to pay people, mainly women, who may not be paying tax, contributing to their own pension, or have appropriate insurance cover.

Compliance with regulations, and safety requirements

At the present time, there is almost no regulatory oversight of the PA role. PAs and employers are not inspected by the Care Quality Commission in contrast to the registration and inspection of home care agencies. We found two local authorities which promoted basic standards by linking PA registers with an accreditation system, but this did not appear to be widespread. For PAs funded by Personal Health Budgets from the NHS, there was, however, a system of competency-based training. Such a permissive regime stands in contrast to other European cash for

care developments (Gori and Luppi, 2019) where there are increasing moves to provide more oversight or input into how much freedom there is to use such funding; the furtherance of professional information and advice or counselling to older people and families about such options, and growing attention to the integration or relationship between the delivery of such options and other parts of the publicly funded long-term care system.

Lack of external training and regulatory oversight may create an environment in which unsafe practice is not challenged, other than by the employer, indicating the potential for directly employed care workers to change the structure of care work (see De Roit and Moreno-Fuentes (2019) for international comparisons) Our study did not find widespread evidence of unsafe practices (observational studies would be needed here), but we did find some: for example, a PA being shown by her employer how to give her an injection, of the PA who chose not to wear protective clothing due to a wish to avoid 'medicalising' their relationship with their employer, and of the PA who used her own car to transport a person without additional support for lifting, and possibly without insurance cover. These kinds of practices would not necessarily be covered in contracts of employment (if there was a contract) and sometimes appeared not to be negotiated but assumed by the employer as part of the requirement of 'flexibility'. PAs might either willingly overlook this or, even if they feel some requested tasks make them uncomfortable, they do them anyway because they feel they have no real choice.

These examples varied in relation to the probability of harm occurring and the severity of harm but were all potentially avoidable risks. Our study lacked input from social workers who approved the care plans to be funded through Direct Payments for PAs, but another study (Stevens et al., 2014) explored this area and noted that not all care plans covered adult safeguarding preventive measures. Adult safeguarding services did not feature strongly in our data; indeed, their existence was only noted by one PA who reported minimal interest in his situation (see pages 75-78). This confirms evidence from both Scotland and England that there are few safeguarding referrals concerning PAs (Hunter et al., 2012; Manthorpe and Samsi 2013; Ismail et al., 2018).

Both employers and PAs may benefit from access to clear information about safe practice, and what both parties may need to do to comply with relevant regulations and guidance, although information is not of course always taken up or regarded as personally relevant. In our view it would not be appropriate to recommend the extension of Care Quality Commission inspections to PAs and employers: quite apart from the lack of evidence to justify this, it would be likely be impracticable but the quality of local authority support for the arrangements of publicly funded PAs could be explored by the Care Quality Commission. An alternative policy option may involve encouragement of local authorities to offer

more light touch oversight: through the funding of proactive guidance and support from staff working in Centres for Independent Living and user led organisations that might also be taken up by self-funders. The general insularity of the PA - employer relationship also means that neither are exposed to others with whom ideas and experiences can be shared. Local third sector organisations could play an important role in creating opportunities for employers and PAs to form separate networks: protected spaces for discussions. These would need to be moderated to ensure ground rules – for example, for PAs to respect the privacy of their employer - but they could create opportunities for informal learning, also uncovering and challenging poor practices, exploitation and safeguarding concerns.

Employment conditions

Though for most PAs, job satisfaction seemed high, this was despite, in several cases, less than ideal conditions of employment some of which were reported as exploitative. Though many PAs worked part-time, most were not contributing to a pension; holidays and sick pay entitlements were not clear, and neither were arrangements for sick pay, which also potentially left employers either at risk or at the least inconvenienced if the PA was unable to work. As with other parts of the social care workforce, these inequalities are gendered; with women forming most of the home care workforce, however it is deployed. Skills for Care (2017) reported that PAs took less sick leave than other care workers (an average of 2 days annually, compared to 5.2 days for care workers). Though this could offer evidence of higher job satisfaction or better health among PAs (something inferred in the Skills for Care report) our findings suggest it could also reflect the absence of sick pay arrangements or the pressure for ‘presenteeism’ – felt obligations to work when sick or financial necessity to do so.

Many PAs lacked a written contract, had a contract that was vaguely worded, or one that did not reflect the actual role. Many PAs also carried out unpaid overtime and other kinds of ‘invisible labour’: in almost all cases willingly. The requirement that PAs work flexibly meant patterns of work amounted to a ‘zero hours’ contract, which suited some PAs but not others. PAs also spoke of tolerating ‘bad’ employer behaviour, seeing this behaviour as a manifestation of illness, pain or disability, though some also mentioned the need to defend certain boundaries to prevent exploitation and to challenge racist or other forms of grossly unacceptable behaviour. Others have described the emergence of a ‘precariat’ class of low paid, precarious workers becoming the norm in some sections of the health and social care workforce (Malin, 2017) and the PA workforce may share some of these characteristics, indeed domiciliary care often encompasses a formal and informal labour process (Bolton and Wibberley, 2014).

Responsibility for conditions of employment normally rest with the employer. The study identified several local organisations (representatives of these were some of our 'key informants') that had developed and organised support for employers, but *no* support for PAs was found. Some offered basic informal advice and there was some support in one scheme that organised core training for PAs but if problems occurred, PAs generally said they would 'walk' (leave their job). Where there was clear evidence of abuse there seemed nowhere for PAs to turn. Such a situation parallels the lack of collective bargaining arrangements in social care more generally (outside local authority employment) (Hayes, 2017a) and the pressure sometimes put upon PAs to trade as self-employed despite the limits to protection that this status brings (ibid page 12).

Though only a few examples of exploitation and abuse were found, where it did occur it seemed to have had serious consequences for the PAs concerned. Poor employment practices, lack of employment protection and the absence of support for PAs were contributory factors. The report has already noted resistance to oversight or regulation by some employers; there may be room to debate this further with care using representatives to inform policy makers if such views are being moderated over time.

Though there is general good practice information or guidance available for both PAs as employees/self-employed workers (e.g. SCIE 2012, Disability Rights UK 2018; ACAS, undated, Leicester County Council 2014) for budget holders as employers (e.g. Skills for Care, Haringey Council 2016; ACAS, undated) and for proxy budget holders (Mental Health Foundation 2015, Laybourne et al., 2015), little up-to-date information is available about how widely this is used, and whether those who have used it found it relevant and helpful. Our study found that far more support was available for employers than PAs which put PAs at considerable disadvantage in the event of a dispute with their employer. Unionisation of the PA workforce would be one way of establishing more equitable arrangements; another option for policy makers is the registration of care workers as being undertaken in Wales (building on the Social Services and Wellbeing (Wales) Act 2014 which is professionalising the homecare workforce by registration, enhanced employment security and intervening in working time arrangements). Another option might be the creation of a national professional association to represent PAs though this might only be an option taken up by few and would not necessarily have any bargaining rights. Shakespeare et al., (2018) differentiates 'strained' relations between PA and employer from those that have become 'fractured'. This suggests the need to establish good employment practices from the start, to prevent disputes by maintaining open and positive channels of communication, and to deal quickly with strains before fracturing occurs and the relationship is irreparably damaged. These are easy to recommend but less easy to implement. However, early support by social workers or care co-

ordinators at the time of setting up a PA arrangement may help and is in line with the preventive principles of Making Safeguarding Personal and the Care Act's (2014) provisions for social workers to provide social work services such as counselling.

Access to training for employers and PAs

Employer training. Training for employers was seen by some key informants as very important because many prospective employers had no previous experience of this role. Some Centres for Independent Living and user led organisations had organised training events for employers, and one national and other local organisations had developed 'good employer' guidance and training respectively. However, employer training was reportedly not well attended. It is possible that some employers may have found it difficult to attend due to illness or disability, but also because some employers may not have seen training as their priority. The outcomes of training do not appear to have been evaluated and we suggest that more work on what makes for effective training might be appropriate rather than to repeat the trope that 'more training is needed', especially since this often seems to refer to the imparting of information and advice.

External training can, of course, provide information and foster skills that may enable employers to avoid difficulties in managing their relationship with their PA(s) and encourage good employment practices. Improving access to training would involve planning courses carefully to ensure they are fun to attend as well as informative: perhaps combining it with a social activity of some kind; advertising and marketing the event extensively; choosing venues that are disability friendly and arranging programmes so PAs can attend (to provide support if this is needed), and arranging (and possibly paying for) specialist transport to and from the venue. One policy option is that consideration might be given to making 'one off' training compulsory for new employers whose funding comes from the public purse: such requirements are present in other jurisdictions to help ensure that employers of potentially vulnerable home care workers are fully informed of their employer responsibilities (e.g. Singapore's mandatory Employers' Orientation Programme (EOP) for people employing a foreign domestic worker for the first time or who have changed workers frequently)¹⁶.

PA training. Basic training or skills development for novice PAs is also important although most PAs in this study had care work experience. In the absence of any form of external supervisory arrangement, skills training, for example, can guide PAs on how to carry out tasks without injuring themselves and be part of Health and Safety at work assurances (limited as these are in domestic employment

¹⁶ <https://www.mom.gov.sg/passes-and-permits/work-permit-for-foreign-domestic-worker/eligibility-and-requirements/employers-orientation-programme-eop>

settings). It is particularly important for PAs employed by people funded with PHBs where specific clinical practices may need to be followed but we have little evidence that the present system is working. This present study confirms that many of such practices are accepted as being part of social care as they are funded by DPs, e.g., stoma care and PEG feeding (see Bolton and Wibberley 2014, for example) and so a two tier system of skills assurance is quietly unfolding (PBs and PHBs overlapping in task).

Training opportunities for PAs are patchy (resembling social care more broadly). In some areas no training appeared to be available, but it was also reported that some employers were reluctant to pay for it (unlike training for PAs funded by the NHS through PHBs, funding for training for PAs through a DP is not ring-fenced). Thus, paying for training might mean less money is available to pay for care or support. It was also reported that, in some places, employers' attempts to save money from DP as a contingency fund could create problems, because it was not made clear by the local authority what contingencies such a fund could cover, and if too much money was set aside it might be clawed back. It was not always known that Skills for Care administers Workforce Development Fund monies for training that employers can apply for (see www.skillsforcare.org.uk/funding). Some employers expressed misgivings that training might encourage PAs to do things 'by the book' – and not work flexibly and intuitively. Ring-fenced training for PAs whose employers were funded by NHS PHBs removed any disincentives for employers to pay for training but may have been more overtly necessary because of well-defined clinical skills required for PAs to safely work with employers with health-related needs. However, the absence of control over funding for training challenges the view of some disabled employers who felt strongly that the PA should do things 'their' way rather than the 'prescribed' way. Solutions to these concerns may involve initiatives to encourage employer 'buy in' by supporting the co-production of the design and possibly delivery of training offered to PAs to ensure it reflects employer values and there is shared control over content. Extending the use of ring-fenced funding for training used for PHBs to DP users would clarify funding arrangements but would remove control over some of the budget from employers. A ring-fenced training budget would have to cover travel costs and the cost of back-filling the PA post to enable the employee to attend the training.

Underlying issues

Many of the 'surface' issues identified in this report can be understood within the context of two underlying concepts: 'control' and 'boundaries'; some of these related to Labour Process Theory (see Edwards 2010) and others to the gendered

nature of care work (Hayes 2017b) within a socio-legal context. These will now be discussed.

Boundaries

Our findings confirm the conclusions of others (Shakespeare et al., 2017) that relationships between employers and PAs have very fluid boundaries. This potentially offers both major advantages over other forms of care and support work, but also potentially serious disadvantages. However, other studies of home care work draw similar conclusions about boundaries (Abrams et al. 2019; Hayes 2017b; Johnson 2015) and indeed these are discussed as present in care homework (Dodson and Zinavage 2007).

The idealised advantage to employers is that fluidity and ‘plasticity’ make possible much greater levels of personalised care and support, which offer benefit to employer and PA alike. Employers have an opportunity to develop and ‘mould’ their PA so the latter can offer seamless, unobtrusive and sometimes intuitive kinds of support or care, enabling employers, within the constraints of available funding, to lead more independent and empowered lives than possible through a more orthodox care arrangement. For the PA, too, it has been suggested that fluidity offers opportunities to make a difference to the life of their employer: something many PAs greatly valued. Our findings suggest that though this was something that some employers and their PAs felt they were able to achieve; it was not always possible to attain and that compromises have to be made and that such ideals may be hard to realise.

In particular, our findings about the lack of clarity around where boundaries lie and that these could become very problematic are both real and symbolic elements of the PA role and its terms and conditions. Some key informants drew specific attention to this: for example, by emphasising the need for clear contracts which outline the key expectations of the PA role. Some of this was based on their experience of trying to support PAs without clear job descriptions of their role when disputes occurred. Though clarity may be desirable should things go wrong, this clarity may be at the expense of the flexibility desired by the PA and their employer. Employment of family members as PAs present particular challenges for both employer and PA, because it is likely to be especially difficult to establish and maintain clear boundaries, and for these to be defended by either the PA or the employer. However, our study contained more examples of such tensions in relation to PAs who were migrants and may have lacked the experience, ability and confidence to address boundary work. As noted, for many PAs, the work is not their first experience of employment and many had care work experience where boundary questions or negotiations are likely to have arisen.

Clear but flexible job descriptions may be oxymoronic. Achieving a mutual understanding of the role and expectations of both parties, through discussion and negotiation, may be more realistic. However, our findings suggest that this may not be easy to achieve in practice for several reasons. First, employers may not have a clear understanding about what they want. Some PAs commented that what they did was very different in practice to what was originally discussed in their job interview. Second, an employer with fluctuating physical or mental health will require corresponding adjustments to the role of his or her PA. Third, to be effective, the PA may need to work with other family members who may have different agendas to their immediate employer. Boundary 'spanning' – the ability of the PA to negotiate and construct a role that is acceptable to more than one person - may be essential in these circumstances if they are to work effectively. Fourth, the negotiating position of most PAs was weak: PAs did not belong to a trades union, had no professional association, and there was - mostly - very little support or guidance available for them. Such isolation seemed more intense for some of the migrant PAs but other PAs were more confident that alternative employers were easy to find should the current arrangements become untenable. The 'idealised' PA relationship sometimes gives the impression that this is long-standing; our study found that PAs often juggled their employment commitments and several, consciously, were not over-reliant on one source of income. Their rights to redundancy payments and being 'laid off' (if their employer was hospitalised for example) were not many and such eventualities featured in their accounts of needing diverse income streams to compensate for lack of redeployment options immediately. The limits of employment rights in care work overall have been explored by Hayes (2017 a and b) among others, who observes that directly employed care workers are excluded from comprehensive protections.

Many PAs referred to the importance of having clear boundaries: around the tasks they were willing or not willing to do, around the times they were willing to work, and how far they were prepared to share information about their own personal lives with their employer. Though our study found few allegations of exploitation or abuse of PAs by their employers, where this occurred, it appeared to be because the absence of clear boundaries enabled the employer to take advantage. How boundaries are negotiated, where they lie and for what reason, and how and why they change are fertile areas for further research. Changes to the way in which contracts are set up may also be needed to address possible problems with boundaries. First, policy makers could consider making sight of contracts mandatory if the PA's time is paid for with public funding, even if they are employed on a part-time basis and over a small number of hours. One way of doing this would be to amend the Care Act 2014 guidance. Second, these contracts may need to specify as far as possible the full range of task and duties of the PA which could be done by the local authority representative agreeing the care plan

(a social worker or care co-ordinator). Third, it may be necessary to review them more regularly than in other employment relationships to allow for changes to care needs and the need for the PA to take on different tasks from time to time (this again could be part of local authority monitoring). The aim would be for the contract to accurately reflect the purpose of the role and its content. This oversight could be carried out by the local authority, but employers may find it more acceptable if this was a delegated responsibility of a Centre for Independent Living or user led organisation; providing of course that PAs see such bodies as impartial. Funding would be needed to enable them to do this. Training and support needs of employers and PAs, mentioned above, are also relevant here.

Control

Interviews with PAs and key informants suggested that choice and control were important principles and enticements for PA employers. There was a strongly held view that, for example, background checks on PAs, such as Disclosure and Barring checks, should not be carried out by local authorities or their proxies, but by employers themselves, and at their discretion. This desire for control and to act in a legally different way to other employers in the social care sector also extended to control over recruitment of PAs, their employment, and their access to training. Some employers mentioned that people with no previous experience of care work appeared to be favoured because of concerns that PAs with a care background might have a 'carer mentality' at odds with the PA role. Related to this, values were often seen as more important than previous experience or skills. However, this may be more aspirational than real as our study found that most PAs had care work experience. Employers who took part as key informants were also concerned that external training might lead their PA to adopt procedures for certain tasks that were not the way they wanted such tasks to be carried out. They did not favour the 'professionalisation' of the PA role because it seemed to shift the locus of control too much from employer to employee. This was not borne out in the accounts we received from PAs. Many of them had prior social care experience and training; and a third were undertaking, or had undertaken, the Care Certificate. The notion that care workers of any type should have a role in shared ownership of the care system and its development and improvements was not articulated. This stands in contrast to the commitment made by the Welsh Government (2018) that shared 'ownership' of the care system (including care workers as well as care users) is essential.

Employer control over PAs also extended to some concerns that PA networking - in which PAs might discuss issues within a 'safe' environment for example - would undermine trust because any disclosure would be a breach of confidentiality. There appeared to be some distrust of approaches to peer learning and reflection which are at odds with the evidence that human relationship work is emotionally exhausting and stressful and that it needs to be valued by compassionate mutual

support and exchange (see, for example, the role of Schwartz rounds¹⁷). The isolation of PAs is not unique to their situation as home care work is often undertaken with little contact between employees (Unison 2013).

Finally, control extended to the links that were possible between PAs and other social care and health professionals, because their first loyalty was to their employer: in most circumstances, PAs described only being able to share information with permission from their employer about what could be discussed with others. In practice there may be more negotiation but this is an important area in the roll-out of PHB funding and clinical imperatives.

Though control is an important principle, employers are also citizens and citizens function within wider communities and society within a network of rights responsibilities and accountabilities. The virtual absence of any form of regulatory framework for PAs and employers is problematic because control should be exercised with reference to wider societal obligations. Though only a small minority of PAs described abusive behaviour by their employer, there is no reason to suppose that PA employers will be any different from the general public in their moral outlooks and values. However, our study suggests that PAs are at a considerable disadvantage compared to their employers in the event of a dispute, and need access to similar levels of support, and protections. Control by employers therefore could be mitigated by PAs having:

- (d) Access to legal and employment advice from trades union, or professional association or, providing the potential conflict of interest can be effectively managed, third sector organisations that support PA employers.
- (e) Access to training or skills development, possibly extending current funding and training arrangements used within the NHS for Personal Health Budgets for Direct Payments and encouraging those organisations approving DPs (local authorities) to work with PA employers to develop plans to support their PAs.
- (f) The ability to form local networks and associations to provide greater transparency to their work and the opportunity to discuss elements of their role in a moderated, but protected environment. Such developments could be part of local employment or economic initiatives rather than a local authority adult social care obligation and shared with NHS bodies in the development of integrated working.

PA role typology

¹⁷ Point of Care Foundation <https://www.pointofcarefoundation.org.uk/our-work/schwartz-rounds/benefits-of-rounds/>

PAs and key informants both drew attention to the uniqueness of the PA role, but there was some evidence to suggest that these unique relationships could be typologised to a limited extent, according to whether the PA and their employer saw the PA role as being a *companion*, or paid friend, or a *physical extension* of the employer: essentially, someone available to do things the employer is unable to do because of their disability. Neither role was reported in 'pure' form by PAs but aspects of the relationship between them and their employer enable some basic observations to be made. Each type of role preference appeared to have advantages and disadvantages. The desire for the PA to act as a companion could meet the needs of people who may be excluded, isolated and lonely, but may lead to boundaries being crossed unless care is exercised by the PA especially. PAs fulfilling this role may need to consider how much of their own non-working life they wish to share with their employer, how willing they may be to do the kinds of things a friend, rather than an employee, would do. There is a risk of misunderstanding so careful and regular negotiation of boundaries is likely to be needed.

The employment of PA as 'physical extension' is rooted in disability ideology but may overlook the 'human element': the relationship that will occur between employer and employee (Shakespeare et al., *ibid.*) and of course which is not just confined to PAs. PAs may find working in this way less satisfying unless there is due acknowledgement by the employer of this human relationship and a sense of mutual obligations. Our findings further suggest that the intensification of care work is not simply around tasks (Unison 2013) but encompasses emotional intensification of the employer/worker bond. This has gendered as well as moral dimensions. We noted that several of the situations that give rise to PAs' concerns about their work were not so much to do with the individual care user/employer but concerned relationships with their family members, some of whom were legitimately the employer but others of whom were present in the PA workplace or care user's home. This triadic relationship could ease but also give rise to tensions. We heard from a few PAs of circumstances that suggested that migrant PAs faced further disempowerment.

Can everyone be a potential employer? Balancing benefits with costs

The PA model may well be appropriate for some employers, but it is not always the 'best' option for others and our study suggests that these tensions need to be more widely recognised. In some contexts where employees or PAs are vulnerable (for many different reasons) the use of a managed register, broker or agency with responsibilities to represent PAs might be more appropriate. The 'sink or swim' approach to DPs may need to be moderated by further engagement from local authorities where public funding is involved.

Conclusions

The findings of this study suggest that social care Personal Assistants offer a good opportunity to deliver person-centred, relationship-based care and support. They can also offer an opportunity to provide support that embodies the aspirations of some disabled people for support that can act as an unobtrusive extension of their own body. In both cases, they can support independence and well-being. However, our findings have also suggested that they are not a panacea, may not be the only way of achieving these aims and are problematic in certain respects.

First, unregulated and unmonitored situations and the invisible and private nature of the work present significant potential risks to both employer and employee, and to the use of public funds. Other research has drawn attention to risks to employers: indeed, one study conducted in the United States (US) amongst women with physical disabilities or physical and cognitive disabilities found that rates of physical and sexual abuse were roughly twice the national rates for women without disabilities (Powers et al., 2002), and disabled men (Saxton, et al., 2006). Though there are major differences in the characteristics of PAs in the US and England, the unregulated nature of PA-employer relationships means abuse is likely to be more difficult to identify. Our research has also identified accounts of abuse by employers of PAs. Though the number of cases identified were very small, PAs were even less 'protected' than their employers because any local support available was intended to support and advise employers, not PAs, an issue also identified elsewhere (Cairncross and Crick, 2014).

Second, the use of PAs funded by the NHS may represent a fundamental challenge to the ethos of the NHS by challenging the allocation of resources currently based on clinically led and defined need, based on evidence, with one that is consumer driven and in which the PA employer, not the clinician, allocates resources once an initial assessment of need has been established. The findings of our study are timely and relevant to the roll-out of PHBs. Whether these concerns are more apparent than real require further studies.

Third, the introduction of Direct Payments as the 'default' option for people requiring adult social care support or care is widely claimed to support the long-term policy goals of choice, control and independence. However, critics have drawn attention to the risk of 'responsibilisation' – the transfer of responsibility for the provision of care and support from the state to sometimes vulnerable people, and without adequate support (Clarke et al., 2006, Ferguson, 2007, Daly, 2012). Evidence to date suggests that though Direct Payments (and with it, an opportunity to employ a PA) are clearly what some want, others do not. There is, for example, no substantial evidence to suggest that older people overall fare

better with Direct Payments, and this study has shown that though PAs can play a transformative role in the lives of some, its responsibilities can also be a cause of stress for people who need support in their working lives.

Our findings, therefore, suggest a need to:

- reconcile the legitimate aspirations for control by disabled people with the avoidance of exploitation and abuse,
- the need for training to be part of the DP care plan and monitoring arrangements to avoid unsafe practices and to enhance skills, while respecting the concerns of employers about the inappropriateness of some training and
- create safe and less isolated working environments for PAs while also respecting the employer's right to privacy and confidentiality.

PA support, to be successful, may need to acknowledge that PAs are both different from and similar to care workers in regulated settings: different because they are directly employed, and develop closer and more mutually appreciated working relationships with employers, but similar too. For example, there is some job turnover (though apparently less often than in other care work), they usually work for several employers or clients, and they need to travel to and from their place of work.

Acknowledging the different working conditions and the closer relationships that are sometimes built between the PA and their employer is important. But our study has also pointed to a need for better information about some aspects of these working conditions: for example, the impact of their lack of contracts, pensions, holiday and sick pay and so on. Our study provides timely evidence that there are potential breaches of employment law and though, in the main, these are likely to be the result of inexperience than maleficence on the part of some employers, they are likely to have consequences for employers as well as their PAs at some point: being a care or support user will not protect employers from law enforcement. We caution against idealising PA work and seeing it as disconnected from other parts of social care.

This report presents policy options for central government directly and for local government indirectly. We also suggest that there is scope within Care Act Guidance to make Local Authority roles more supportive of PAs and employers than they are in some geographical areas. Oversight is justified where public money is concerned though to address concerns of employers this should not be disproportionate and be respectful towards the nature of the working relationships that are so valued by employers and PAs alike.

In a few local areas, we noted that Centres for Independent Living, User-led organisations and other local third sector organisations provide support for employers, but nearly all were not funded to provide equivalent support for PAs. This may be a role for local authorities (who have access to training, legal advice, and so on). Funding existing local third sector organisations that support employers might be another way to achieve this but risks a conflict of interest and the perception that the organisation has become 'the local authority's police'. Some PA employers were also supportive of their PA joining a trades union.

In the future we will be able to make comparisons of PA work with other social care work where employment conditions and relationships are changing. This includes Wales, which will offer the opportunity to see if the professionalisation of care work is impacting on social care and potentially improving home care workers' conditions. Comparing these different approaches to care delivery and employment arrangements may be another fruitful area for future research.

References

- Abrams, R., Vandrevalla, T., Samsi, K., and Manthorpe, J. (2019). The need for flexibility when negotiating professional boundaries in the context of home care, dementia and end of life. *Ageing and Society*, 39(9) 1976-1995, doi:10.1017/S0144686X18000375
- Apteligen (2014). Evaluation of Third Sector Health and Social Care Brokers. <http://www.apteligen.co.uk/wp-content/uploads/2015/08/TSB-Evaluation-Final-Report-FINAL-ENGLISH-FOR-PUBLICATION.pdf>
- Baxter, K. and Glendinning, C. (2015). People who fund their own social care. Research Report. SSCR Scoping Review. NIHR School for Social Care Research, London.
- Baxter, K., Rabiee, P., and Glendinning, C. (2013). Managed personal budgets for older people: what are English local authorities doing to facilitate personalized and flexible care? *Public Money and Management*, 33(6) 309-406, doi.org/10.1080/09540962.2013.835998.
- Bolton, S. C and Wibberley, G. (2014). Domiciliary Care: The Formal and Informal Labour Process. *Sociology*, 48(4) 682-697.
- Cairncross, L., and Crick, A. (2014). Research on abuse and violence against the social care workforce: focus on personal assistants. Leeds, Skills for Care, <https://ipc.brookes.ac.uk/publications/Research-on-abuse-and-violence---PAs-301014-FINAL.pdf>
- Christensen, K., and Manthorpe, J. (2016) Personalised risk: new risk encounters facing migrant care workers. *Health, Risk and Society*, 18(3/4) 137-152. <https://doi.org/10.1080/13698575.2016.1182628>
- Clarke, J., Smith, N., and Vidler, E. (2006). The indeterminacy of choice: political, policy and organisational implications. *Social Policy and Society*, 5(3) 327-336.
- Currie, R., Kinn, A., Thompson, R., and Hamilton, S. (2016). An Evaluation of My Support Broker: Research Data and Analysis, Volume 2. London, McPin Foundation. <http://mcpin.org/wp-content/uploads/McPin-MSB-report-volume-2-Final.pdf> [Accessed 26.07.19]
- Dale, S., and Brown, R. (2007). How does cash and counselling affect costs? *Health Services Research*, 42(1/2) 488-509.
- Da Roit, B, and Moreno-Fuentes, F.J. (2019). Cash for care and care employment: (Missing) debates and realities. *Social Policy and Administration*. Advance access 1–16. <https://doi.org/10.1111/spol.12503> .
- D'Astous, V.A., Samsi, K., Vandrevalla, T., Adams, R., and Manthorpe, J. (2019). What are the gaps in our understanding of the experiences of home care workers providing end of life care for people with dementia? *Dementia: The International Journal of Social Research and Practice*, 18(3) 970–989.
- 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) 179-190.

Department of Health. (2011). Working for personalised care: A framework for supporting personal assistants working in adult social care, Department of Health, London,

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215508/dh_128734.pdf

Disability Rights UK (2018). Disability Rights Factsheet F2. Being in Control: getting Personal Assistants (PAs) <https://www.disabilityrightsuk.org/being-control-getting-personal-assistants-pas> [accessed 23.07.19]

Dodson, L. and Zinbarg, R. M. (2007). It's like a family' caring labor, exploitation and race in nursing homes. *Gender and Society* 21(6) 905-28.

Doyle, M., Lapanjuuri, K, and Toomse-Smith, M. (2017). The Hidden Economy in Great Britain, Research Report 478, HM Revenue and Customs. London.

Edwards, P. (2010). Developing Labour Process Analysis. In: Thompson P, and Smith C. (eds.) *Working Life*. Palgrave, London, pp. 29-46.

Fisher, K., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C. A'egher, L. & Thompson, D. (2010). Effectiveness of individual funding approaches for disability support, FAHCSIA Occasional paper 29, Canberra.

Ferguson, I. (2007). Increasing user choice or privatising risk? The antinomies of personalisation. *British Journal of Social Work*. 37 (3) 387-403.

Glendinning, C, Halliwell, S, Jacobs, S, Rummery, K, and Tyrer, J. (2000). *Buying Independence: Using Direct Payments to Integrate Health and Social Services*, Policy Press, Bristol.

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (2000), New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance. *Health and Social Care in the Community*, 8, 201-211. doi:10.1046/j.1365-2524.2000.00242.x

Graham, K.E. (2015). Cash payments in context: (self) regulation in the new social relations of assistance' *Disability and Society*, 30(4) 597-613. DOI: 10.1080/09687599.2015.1037951.

Gori, C. and Luppi, M. (2019). Regulating the delivery of cash-for-care payments across Europe. *Social Policy and Administration*, 1-12. <https://doi.org/10.1111/spol.12500>

Guldvik, I., Christensen, K., and Larsson, M. (2014). Towards solidarity: working relations in personal assistance, *Scandinavian Journal of Disability Research*, 16:sup1, 48-61, DOI: 10.1080/15017419.2014.897644.

Hayes, L. (2017a). 8 Good Reasons Why Adult Social Care Needs Sectoral Collective Bargaining. Institute for Employment Rights, Liverpool.

Hayes, L. (2017b). *Stories of care, a labour of law, gender and class at work*, Palgrave, London.

Hunter, S., Manthorpe, J., Ridley, J., Cornes, M., and Rosengard. A. (2012). When self-directed support meets adult support and protection: findings from the evaluation of the SDS test sites in Scotland. *The Journal of Adult Protection*, 14(4) 206-215.

Kremer, M. (2006). 'Consumers in charge of care: the Dutch personal budget and its impact on the market, professionals and the family', *European Societies*, 8(3) 385-401.

Haringey Council (2016). Fact sheet on employing Personal Assistants. https://www.haringey.gov.uk/sites/haringeygovuk/files/direct_payment_factsheet_employing_personal_assistants.pdf.

HDG Consulting (2010). Evaluation of Direct Employment Project, HDG Consulting Group, Melbourne.

Henwood, M., and Hudson, B. (2007). Review of independent living funds by independent consultants for the Dept. of Work and Pensions, Sheffield, UK.

Hudson, B. and Henwood, M. (2009). Working for people: the workforce implications of Putting people first – a report for the Department of Health, Melanie Henwood Associates, Towcester.

Independent Advisory Committee for the NDIS (2017). Risks related to poor employment practices for self-managing participants, Canberra, <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b19e67eaa4a99e99b2e3ace/1528424066616/Attachment%2BD-Risks%2Brelated%2Bto%2Bpoor%2Bemployment%2Bpractices%2Bfor%2Bself-managing%2Bparticipants.pdf>

Ismail, M., Hussein, S., Stevens, M., Woolham, J., Manthorpe, J., Aspinall, F., Baxter, K. and Samsi, K. (2017). Do personal budgets increase the risk of abuse? Evidence from English national data, *Journal of Social Policy*. 46(2) 291-311.

Laybourne, A. H., Jepson, M. J., Williamson, T., Robotham, D., Cyhlarova, E., and Williams, V. (2016). Beginning to explore the experience of managing a direct payment for someone with dementia: The perspectives of suitable people and adult social care practitioners. *Dementia*, 15(1)125–140. <https://doi.org/10.1177/1471301214553037>

Leece, J. (2007). Direct payments and user-controlled support: the challenges for social care commissioning, *Practice*, 19(3) 185–198.

Leece, J. (2010). 'Paying the piper and calling the tune: power and the direct payment relationship', *British Journal of Social Work*, 40(1) 188-206.

Leicester County Council (2014). Become a Personal Assistant. <https://www.leicestershire.gov.uk/adult-social-care-and-health/working-in-care/become-a-personal-assistant>

Malin, N., (2017). Developing an analytical framework for understanding the emergence of de-professionalisation in health, social care and education sectors. *Social Work and Social Sciences Review*, 19(1) 66-162.

Manthorpe, J. and Samsi, K. (2013). Inherently risky? Personal budgets for people with dementia and the risks of financial abuse: findings from an interview-based study with Adult Safeguarding Co-ordinators, *British Journal of Social Work*, 43 (5) 889–903.

Manthorpe, J, Martineau, S., Ridley, J., Cornes, M., Rosengard, A., and Hunter, S. (2015). Embarking on self-directed support in Scotland: a focused scoping review of the literature, *European Journal of Social Work*, 1 (1) 36-50.

Mental Health Foundation (2015). Indirect payments for people who lack capacity: How are they working in practice? <https://www.mentalhealth.org.uk/publications/indirect-payments-summary-findings-report> .

NHS England (2019). The NHS Long term plan <https://www.england.nhs.uk/long-term-plan/> [accessed 28.07.19]

Pearson, C., Ridley, J., and Hunter, S. (2014). Self-Directed Support: personalisation, choice and control. Policy and practice in health and social care. Dunedin, Edinburgh. ISSN 1750-1407.

Powers, L. E., Curry, M. A., Oschwald, M., Malet, S., Eckels, K., and Saxton, M. (2002). Barriers and strategies in addressing abuse within personal assistance relationships: a survey of disabled women's experiences. *Journal of Rehabilitation*, 68 (1) 4-13.

Ritchie, J. and Spencer, L. (1994). Qualitative data analysis for applied policy research in A. Bryman and R. G. Burgess [eds.] 'Analysing qualitative data', (pp.173-194). Routledge, London.

Saxton, M., Curry, M.A., McNeff, E., Limont, M., Powers, L., and Benson, J. (2006). We're all little John Waynes: a study of disabled men's experiences of abuse by Personal Assistants. *Journal of Rehabilitation* 72(4) 3-13.

Shakespeare, T., Porter, T., and Stöckl, A. (2017). Personal Assistance Relationships Power, ethics and emotions, Report on ESRC Project ES/L007894/1. University of East Anglia, Norwich, www.careappointments.co.uk/reports/PersonalAssistanceRelationshipsReport.pdf [accessed 28.07.19]

Social Care Institute for Excellence (SCIE) and Skills for Care (2012). Personalisation for personal assistants (PAs), London, SCIE. <https://www.scie.org.uk/personalisation/practice/personal-assistants> [accessed 28.07.19]

Skills for Care (2016). The size and structure of the adult social care sector and workforce in England. Leeds, Skills for Care <https://www.skillsforcare.org.uk/Documents/NMDS-SC-and-intelligence/NMDS-SC/Analysis-pages/Size-and-Structure-2017.pdf> [accessed 28.07.19]

Skills for Care (2018). The state of the adult social care sector and workforce in England. Leeds, Skills for Care, <https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/publications/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx> [accessed 28.07.19]

Skills for Care (2019) Individual employers and the personal assistant workforce, 2019 Skills for Care survey research, Leeds, Skills for Care, <https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/Individual-employers-and-the-PA-workforce.pdf>

Skills for Care (undated) Individual Employer and Personal Assistant Hub www.skillsforcare.org.uk/iepahub [accessed 28.07.19]

Skills for Care (undated) Developing a PA Register.
<https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Resources/Information-for-local-authorities-NHS-and-support/Other-useful-resources/Developing-a-local-network/Developing-a-PA-register.pdf>.
[accessed 28.07.19]

Skills for Care (undated) Workforce Development Funding
www.skillsforcare.org.uk/funding [accessed 28.07.19]

Stevens, M., Manthorpe, J., Hussein, S., Ismail, M., Woolham, J., Samsi, K., Baxter, K. and Aspinall, F. (2014). 'Risk, Safeguarding and Personal Budgets: exploring relationships and identifying good practice', NIHR School for Social Care Research, London. Available from: <http://www.kcl.ac.uk/sspp/policy-institute/scwru/pubs/2014/reports/Stevens-et-al-2014-Risk-Research-Findings.pdf>

Unison, (2013). Time to Care
<https://www.unison.org.uk/content/uploads/2013/11/On-line-Catalogue220152.pdf> [accessed 28.07.19]

Welsh Government, The (2018). A healthier Wales: our plan for Health and Social Care. <https://gweddill.gov.wales/docs/dhss/publications/180608healthier-wales-mainen.pdf> [accessed 28.07.19].

kcl.ac.uk/policy-institute
@policyatkings

kcl.ac.uk/scwru
@HSCWRU

<https://doi.org/10.18742/pub01-005>