

# **THE FORGOTTEN WORKFORCE: RECRUITING AND RETAINING PERSONAL ASSISTANTS**

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A survey of people supported  
by a personal assistant

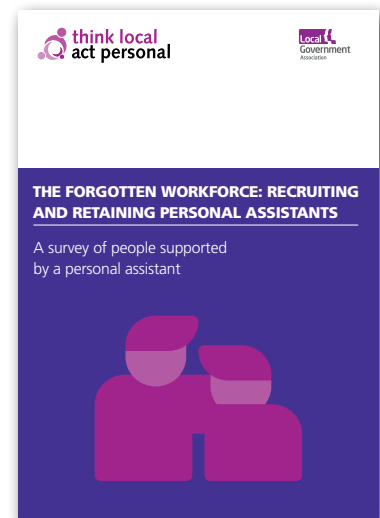


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## SUMMARY

What has been people’s experience in relation to recruiting and retaining a Personal Assistant (PA) between March 2020 and January 2022? This report, based on a survey response of nearly 1,000 people who employ a personal assistant, describes the challenges faced by people trying to find the support they need in an increasingly fragile market experiencing shortages of social care staff across the whole sector.

We find that PA recruitment has got harder, both in terms of a shortage of applicants and their suitability for the work. Low pay, poor terms and conditions, and restrictions by funders on what people can pay PAs are the primary drivers for this, alongside the impact of the Covid pandemic.

This report brings people’s real experiences to life and should be required reading for social workers and all those who work with direct payment recipients. Our findings should be a call to action for councils, NHS funders and government.

## FOREWORDS

I've employed personal assistants to support my two autistic (now adult) children since they were young teenagers. From a time when we only had a few hours support a week from one personal assistant, to now – a team of six. Being a personal assistant is a unique role and I've recruited an amazing range of people over the years. People who love my kids, who go the extra mile to help them get the gloriously ordinary lives they deserve, who problem solve, think on their feet and fight our corner. They work in our family home, they become part of the family.

Almost everyone I have employed over the last 13 years is still part of our lives, even when they have moved on to other things and live in different places. Two people have gone on to do degrees (one in social work and one in youth work) that they tell me they wouldn't have thought of doing had they not worked as a personal assistant.

Being an employer is hard work, plenty of rules and regulations to get right and the responsibility of making sure that people get paid, are well supported, and have opportunities to learn and grow. All this alongside navigating life as a disabled person or family carer. In the survey that informed this report, people shared their stories of how the system at best doesn't offer the support that people need to do this well, and at worst actively gets in the way.

This report has a wealth of incredibly sensible and achievable recommendations for change, and I look forward to both central government and local authorities responding in equally sensible ways.

**Tricia Nicoll**

Parent carer and member of the Survey Design Group

**“ To recruit a PA, the system is set up almost as though to make it impossible. It is as though a carrot is being dangled, and as you get closer, it is being pulled away. ”**

The Care and Health Improvement Programme<sup>1</sup> and Think Local Act Personal have worked in partnership with a group of people supported by personal assistants, and organisations that support them, to co-produce a survey exploring people's experience of recruiting and retaining PAs during the period of the Covid-19 pandemic.

This important report is based on a survey response of nearly a thousand people supported by PAs. We heard some individual examples of the system working well during this time.

Whilst it's heartening to hear that some people supported by a PA are finding it easier to retain workers than in other parts of the care sector, the report also paints a stark, and at times uncomfortable, picture of the challenges faced by those using direct payments to employ a personal assistant. People rightly value the control and choice that employing a personal assistant provides, but many shared experiences that fell far short of these principles and we heard of some practices that restrict people's ability to manage their support as flexibly as they would like. Much of the report reinforces the messages in our recent joint work with TLAP, about the need to **reduce bureaucracy in direct payments oversight**.

All of us with responsibilities for the provision of care and support should consider this report as a call for action. People responding to the survey were keen to offer constructive suggestions about how local and central government could work with them to ensure that the PA workforce is not 'the forgotten workforce' and these form the basis for the recommendations in the report. We want to work together with people who draw on care and support to tackle the barriers identified here. There is a long way to go, but it is the right way to go.

**Simon Williams**  
Director of Social Care Improvement  
Care and Health Improvement Programme

**“ [We need to] show that the government/country values people with disabilities and their inclusion in society so that people want to work as a PA. ”**

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<sup>1</sup>The Care and Health Improvement Programme is a partnership of the Local Government Association and the Association of Directors of Adult Social Services

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## EXECUTIVE SUMMARY

There are around 70,000 people in England who draw on care and support and employ a personal assistant (PA)<sup>2</sup>, usually through taking a direct payment or personal health budget.

What was their experience of recruiting and retaining a PA between March 2020 and the end of January 2022?

The Local Government Association (LGA) and Think Local Act Personal (TLAP) worked with people supported by a PA to undertake an online survey with people supported by a personal assistant to explore the issues they faced. Nearly 1,000 people participated – a very good response to a survey of this type. Our survey respondents provided many helpful and constructive suggestions for action that can be taken by local and central government to help with PA recruitment and retention.

### Based on what people told us, we conclude that:

- ▶ Low pay outstripped every other factor people said is making PA recruitment more difficult. Councils, government, and the NHS need to do more now to address this.
- ▶ The system is not working as intended under the Care Act, where people's PA support is funded by councils (through a direct payment) or the NHS (through a personal health budget).
- ▶ People are not clear how the calculation of their direct payment or personal health budget is arrived at, or what costs associated with recruiting and employing PAs are included.
- ▶ PA recruitment is getting harder, and this is part of a broader trend, it's not just pandemic-related.
- ▶ There are severe shortages of PAs. Restrictions on what people can pay PAs by council and NHS funders is effectively pricing many out of their local PA market, meaning some people are being left with no PA support for long periods of time.
- ▶ People have taken on PAs they know are not right for the job and are having to compromise on their support because of PA shortages.
- ▶ People's quality of life and mental and physical wellbeing have been affected by shortages of PAs, as well as the pandemic, with many describing themselves and their unpaid carers as "exhausted".

**Findings from a national survey co-designed by people supported by a personal assistant**

**“ PAs do a fantastic job, a lifeline to families. Without them we'd have more families moving family members into care homes. PAs are the forgotten and a light needs to be shone on them now. ”**

<sup>2</sup> <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/Individual-employers-and-personal-assistants.aspx>

- ▶ Low pay is linked to poorer terms and conditions for PAs compared to other parts of the care sector and the NHS. These factors combine to deter people with the right skills, values, experience and training from working, or remaining in work, as a PA.
- ▶ Traditional ‘time and task’ approaches, rather than those based on outcomes, are limiting the pool of PAs able to work the fixed times set by some funders.
- ▶ The job of a PA is not socially valued or well understood; this also contributes to recruitment difficulties.
- ▶ People supported by a PA are more likely to retain their PA than employers in other parts of the care sector.
- ▶ People want more council and government help with PA recruitment, training and employer support.

### Key survey findings

77% of people who had needed to recruit a PA had found it more difficult	69% said people were taking jobs with better pay rather than PA jobs	59% think it's harder to find PAs with the right skills, values or training
<b>88% detailed multiple negative impacts on them of the pandemic</b>		
Of those who needed to use agencies, 66% think it's been harder to find workers, and 62% have found it more expensive	Low pay, poor terms and conditions and insufficient hours were key factors in PAs leaving	44% of people think it's been harder to retain their PAs since March 2020, whilst 47% said it was about the same

### Headline recommendations

The recommendations in the report come from the findings of the survey and are grouped into four themes: funding; support for people who employ personal assistants; information and advice; and quality assurance and oversight.

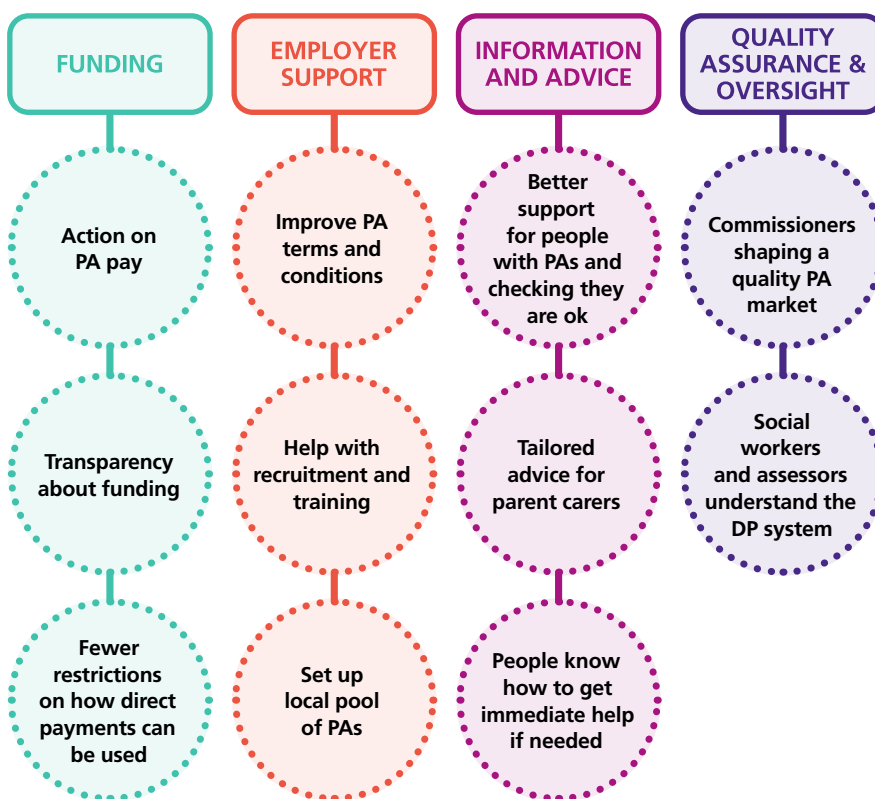
- ▶ The most urgent action is for funders to enable PA pay to reflect local market conditions, and to review any local practice that unduly restricts what people can pay their PA and which people experience as funders ‘setting’ pay rates which limit the pool of available PA support.
- ▶ Greater transparency about how direct payment or personal health budgets are arrived at is needed, and this should include the costs related to finding, employing and training PAs.
- ▶ Funders should reduce unnecessary restrictions on how direct payments and personal health budgets can be used by people supported by a PA.

**“ Even a one per cent pay rise per year will support retain[ing] staff. No increase in four years means that the wages being paid is not increasing in line with the cost of living. ”**

**“ I feel the main thing is pay. I started with a direct payment five years ago and the pay hasn't gone up by one penny since then. ”**

- ▶ Local and central government and the NHS need to offer more help with PA recruitment, training and employment advice.
- ▶ Commissioners need better oversight of their local PA market. They should also be proactive in checking the quality, reliability and standard of support provided by those they commission to assist people supported by PAs.
- ▶ People who find themselves without PA support, or have concerns about their PA, must know how to get immediate help.
- ▶ Social workers and assessors need a better understanding of how their local direct payments system should operate.

“ [I] worry about them leaving, worry about paying them enough so they don't leave, trying not to do anything that may get their back up so they leave. ”



This report aims to shine a light on the needs of people who employ personal assistants and to acknowledge the valuable role PAs play as part of the wider social care workforce. Our findings support **calls from sector leaders** such as Skills for Care, ADASS, the LGA, TLAP and the Social Care Institute for Excellence in calling for better pay and working conditions.

It is clear from the survey that for many people, their experience falls short of the intentions set out in the Care Act for people to have maximum choice and control over their care and support. The report provides a clear and compelling case for action and improvement in the context of implementing the social care white paper, **People at the Heart of Care: adult social care reform**.

“ No one with the right skills will work for minimum wage, so as soon as I think I have found someone I lose them as they can't afford to live on the given wage. ”

# 1 | WHY WE DID THE SURVEY

During the winter of 2021, there were many stories in the press, on social media and in meetings, about how employers in residential and nursing homes, or who support people at home, were struggling to recruit and retain enough staff to continue to provide care safely. To better understand these pressures, the government carried out a **workforce survey of care providers registered with the Care Quality Commission (CQC)**.

As this survey was only for employers registered with the CQC, people supported by a personal assistant did not take part. But some organisations, groups and people supported by a PA told us that they were hearing about and experiencing similar recruitment and retention problems.

We felt it was very important that the voices of the 70,000 people<sup>3</sup> supported by a PA in England were heard. There was a lot of support for a survey to explore how widespread the challenges are and provide evidence for the changes needed to enable people to continue living the lives they want with the support they need from a PA. At the end of this report, we have summarised the key actions people were seeking from local and central government, together with the NHS.

**There are about 70,000 people who are supported by a Personal Assistant (PA) in England. Nearly 1,000 of them completed our survey**

## THE SURVEY OBJECTIVES:

- 1 To collect evidence to confirm whether what we were hearing anecdotally about challenges in recruiting and retaining PAs was accurate.
- 2 To co-design the survey with people who are supported by a PA, for people who are supported by a PA.
- 3 To gather information that we could share openly and freely about the challenges and possible solutions.
- 4 To provide feedback for councils and government about what people who are supported by a PA would find most useful in tackling recruitment & retention challenges.
- 5 To offer a collective opportunity for people supported by a PA to share their experiences during a very challenging time for them, and to help shape central and local government policy as it affects people supported by a PA.

<sup>3</sup> <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/Topics/Individual-employers-and-personal-assistants.aspx>



## 2 | HOW WE DID THE SURVEY

It was important that our survey was designed by people who are supported by a PA, for people supported by a PA. To achieve this, we convened a Survey Design Group made up of people who employ PAs and organisations that support them. This approach ensured that the survey was fully co-produced, relevant, accessible, and reached the people it was intended for, as well as policy makers, commissioners, funders and frontline workers who can use it to make the changes we call for. We are grateful for the design group's support and active contributions.

We all felt that the survey would have the best chance of success if people could help let others know about it through their own networks. We didn't want to rely on councils or the NHS to distribute the survey as they don't always know who has a PA in their area, though some did help send it out for us. With limited time and resources, we were only able to run an online survey. We recognised that not everyone is able to complete an online survey, so we also offered people the alternative of joining an online discussion session, supported by In Control.

The scope of our survey is set out in the appendix. The survey was open to anyone who employs PAs, or who is supported by a self-employed PA, and who pays for their PA with a direct payment, personal health budget or from their own money. This included adults of all ages as well as children and young people who are supported by a PA.

### **Explanatory note: pay capping**

What people were able to pay their PAs was the single biggest issue for people in the survey. People frequently used the term 'pay capping' to refer to their experience of funders determining what they could pay their PA.

**“ [working as a PA] is still considered a job that only the desperate for money take, or those that have a passion to help. The status of the PA is poor and needs elevating. ”**

## 3 | WHAT RESPONSE RATE DID WE GET?

995 people participated in our online survey: there were 982 survey responses and 13 participants who joined the discussions with In Control. This is a very good response for an online survey and represents a good sample of those we were trying to reach. The survey ran between December 2021 and January 2022 and asked about people's experiences between March 2020 and January 2022.

We had a broad range of responses in terms of geographical spread, who was being supported, and the type of PA support being provided. Some respondents were supported by a team of PAs. We collected a combination of quantitative (yes/no) and qualitative (free text) responses. Almost everyone answered every question, most giving extra information and personal stories where they could. This suggested a high level of interest in the topic of PA recruitment and retention. 400 people told us they would like to see our findings once they are published.

We found the stories that people shared with us were full of constructive insights and ideas about how things could improve, and we heard about some very positive experiences of PA support, despite the many pressures felt during the pandemic period. But we also heard about the huge stress and worry people supported by a PA experienced during this time, and the many adverse impacts on them and their families arising from increasing difficulties in recruiting and retaining PAs to support them.

We wanted to do justice to those who'd taken the time to tell us about their experiences and because of the number of responses we received, it's taken time to analyse the results.

We have provided numbers of responses throughout this report where we have felt it's helpful. Numbers have been rounded to the nearest percentage point. We have used people's quotes to bring to life many of the points made throughout the survey. We've only managed to use a small proportion of the responses people gave us and would be happy to provide more detail on specific topics raised in the survey on request.

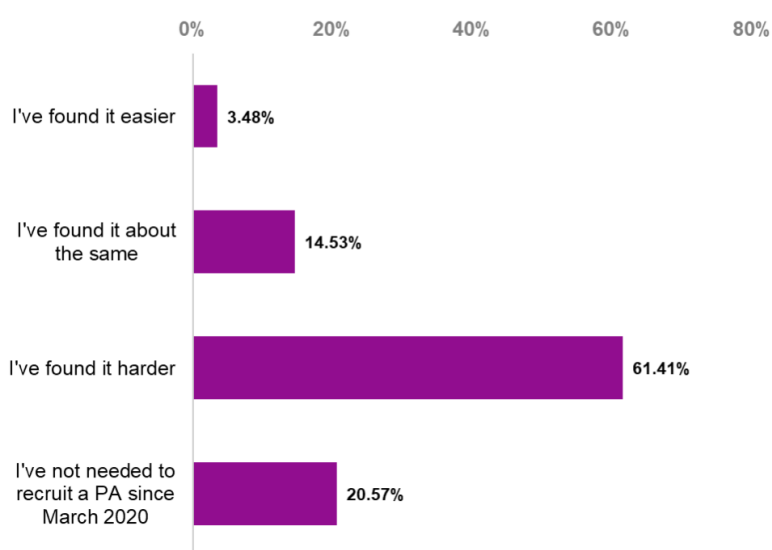
**995 people participated in our survey – a very good response**

# 4 | OUR SURVEY FINDINGS

## 4.1 PA RECRUITMENT

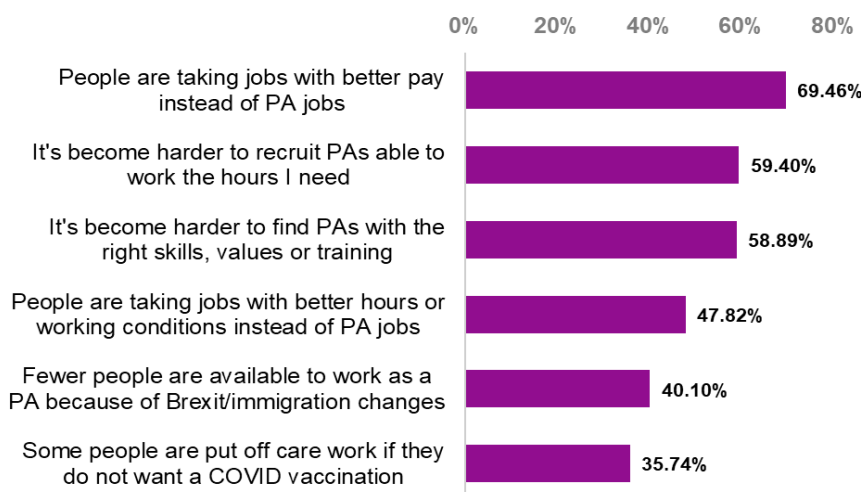
Of those who needed to recruit a PA between March 2020 and January 2022 (776 people), 600 of them (77%) said they had found it harder to recruit PAs. People were clear that this is part of a broader trend and was not just related to the pandemic.

**Question 1. Since March 2020, have you found it easier or harder to recruit (find) your personal assistants (PAs)?**



We asked people why they felt it had become harder for them to recruit a PA. People could tick more than one reason. These are the main factors people say are affecting PA recruitment:

**Question 2. Reasons its been harder to recruit personal assistants**



### IN THIS SECTION:

- 4.1 PA recruitment
- 4.2 Retaining PAs
- 4.3 Using agencies for PA support
- 4.4 Reasons PAs leave
- 4.5 The impacts of the pandemic

**77% of people have found it harder to recruit personal assistants since March 2020**

## Personal assistant pay is too low

Low pay was by far the biggest factor people told us was making things harder. People said low pay has made working as a PA uncompetitive compared to other kinds of work, both in other care roles which can offer better pay, hours, terms and conditions, and non-care work, such as retail or hospitality that can pay similar or higher wages for work that is less physically and mentally demanding.

*“Care support workers are now in demand. I am for ever shown adverts for other jobs [by PAs] or told they’ve been offered to go and work in other [jobs] in particular the NHS, doing bank work, or other jobs, as they are able to offer more money.”*

Everyone who commented on pay throughout the survey said PAs should be better paid, and felt very strongly that PA pay should more accurately reflect the demands of the role and the skills and experience needed to be a good PA. Most people reported that their PAs were paid at a flat rate (often minimum wage) regardless of length of service, experience or specialist skills *“By far the most difficult issue is that Direct Payments do not pay an hourly rate remotely in line with the skill set required of a typical PA - which simply means it’s impossible to employ anyone unless they are willing to take a significant cut in their hourly rate! This makes no sense whatsoever since Direct Payments is willing to pay substantially more per hour to ‘care provider companies’ who then pay their staff minimum wage. Typical PA rate £16 per hour. Maximum Direct Payments will pay: £13. Typical hourly rate of care company: £21.”*

People said their PAs were worried about rising costs of living and felt that an annual cost of living increase should be built into their direct payment or personal health budget. *“Even a one per cent pay rise per year will support retain[ing] staff. No increase in four years means that the wages being paid is not increasing in line with the cost of living.”*

Respondents voiced feelings of frustration when their direct payment and personal health budget funders required them to set PA pay at rates which meant they struggled to compete for support with people who could afford to pay more. *“You MUST recruit and retain carers by increasing pay and conditions of employment. I can pay my carers £10 per hour to provide personal care and [my cleaners] £15 for cleaning. This is madness. Carers work long, unsocial hours for low pay. Many leave and the workload falls on the remaining staff forcing*

**“ Recruitment is difficult. The pay, which is low, does not entice experienced carers. If they can get the same rate, or even more, working in Aldi without the same level of responsibility, they will choose to work elsewhere. ”**

**“ No one with the right skills will work for minimum wage, so as soon as I think I have found someone I lose them as they can’t afford to live on the given wage. ”**

*them to work longer hours. In the end, dispirited and crushed by the workload, they leave."*

These pay rates were almost universally felt to take little or no account of current or local market conditions for PAs, and many people gave examples of how PA pay had not increased for years. Some said they'd topped up their PA's wages, or in some cases paid for extensive furlough, out of their own savings rather than risk losing a good PA, but many people did not have the money to do this. *"I feel the main thing is pay. I started with a direct payment five years ago and the pay hasn't gone up by one penny since then."*

People felt that limits on pay rates were a false economy and described how perverse it seems to them that funders prevent them from paying their PAs more, yet could end up paying much higher agency rates, or, if care broke down completely, for hospital admissions or even permanent residential care as a result of PA shortages.

People also described how the support from a directly employed personal assistant led to much better outcomes for them than having to use agency support because of PA shortages. *"I have experience of both a directly-employed PA (accountable to me) working with one young person: and an agency-provided (and accountable to the agency) support worker. Both the quality of provision and calibre/training of the worker directly employed by me has been infinitely better and substantially cheaper to the taxpayer, than the agency-provided service."*

A lot of people told us they lived with constant worry about what would happen to them if they were unable to recruit or replace a PA who left. We cover this, and other adverse impacts resulting from PA shortages, in more detail later.

People also described how the 'churn' or turnover of PAs resulting from low pay was disruptive for people with complex needs who benefited from regular support from familiar, trusted faces. *"I found that there was a high turnover of staff disruptive to a routine, and very unsettling for elderly parents with dementia."*

Some people described being put under pressure to raise pay by PAs who knew there were local shortages. There is an ever-present risk of people training up their PAs, only for them to leave for jobs with higher wages, better terms and conditions or

***“ If I lose my PAs, the council will have to pay an agency to cover my care which is a lot more expensive than a PA, even with a pay rise. ”***

***“ 11 never turned up for interview after many conversations. 8 took application forms to complete to get their benefits. And 3 started with us...[they] got training and then left to go back to previous jobs as offered a higher wage or incentive. ”***

other inducements. More than one person described their PAs effectively being poached by other employers in the care sector or by agencies.

*“We are competing with care homes for staff - we have had people apply, but when they give in their notice, the care home immediately offers more pay and better hours so the person withdraws from the job.”*

### It’s getting harder to find PAs to work the hours needed

354 people (almost 60% of respondents to question 2) said they were finding it harder to recruit PAs able to work the ‘fixed hours’ that had been decided by their funders as suitable to meet their support needs. These hours tended to be structured along traditional ‘time and task’ lines with specific hours allocated to certain tasks, very much like home care, rather than being based on outcomes and enabling people to use their direct payment or personal health budget flexibly in ways which worked best for them.

People told us that these ‘time and task’ approaches by funders, combined with low rates of pay, was acting to limit the pool of people able to support them. We were given several examples where being limited to specified hours split across the course of a day, and being unable to pay PAs travel costs or time, meant finding PAs able and willing to work the hours allocated was very difficult. *“PAs will not do four x 30 mins slots per day due to travel costs - most are looking for a block of 2-3 hours per day.”*

People said they felt that their funders and commissioners were unrealistic about the likelihood of finding PAs willing to work split hours. They wanted much more flexibility to manage their hours in a way which made it more attractive for PAs and suited them better too. *“Providing appropriate funding so we are able to pay a good wage and get the right number of hours, instead of having to decide which needs will get met within the time I can afford, would be amazing and also help with PA retention.”*

Many people described how unfair they felt it was that funders would not allow them to pay their PAs extra to work unsocial hours including evenings, overnight, weekends and public holidays as they would in other jobs, and thought that this should be factored into direct payments and personal health budgets by funders.

**354 people said they were finding it harder to recruit PAs able to work the ‘care hours’ needed**

**“ My PA did not like doing two visits per day and said it was not worth her while to come back for an hour at tea-time. It is very difficult to recruit staff for short shifts as most people are not prepared to do it - but I cannot compromise as I need support at that time of day and I can’t offer more time due to budget limitations. ”**

Other people mentioned how the combination of low pay and the limited hours on offer could mean people were better off on benefits than working as a PA. *“Some of our carers claim universal credit ...I have one lady who is on her own, wants part time work to give her some income, but because she hasn't got any children, they take 67p off every pound she works.”* This is something worth further investigation and discussion with government to see if any of these barriers can be reduced.

Several people also said that some PAs could only work during term-time, and that a lack of affordable childcare and decent public transport meant the available pool of PAs to work unsocial hours or on non-school days could also be very limited.

### Shortages of PAs with the right skills, values, or training

351 (59%) people told us they were finding it harder to find the right PAs for them. Low pay, poor terms and conditions and the low esteem in which care work is held were all felt to discourage people with the right skills, experience, values and training from taking up work as a PA. One person said that despite the wide range of skills and experience needed, PAs *“...are very often viewed as plain manual workers. This gives little or no encouragement for anyone to do this job and sadly, on top of this, you can work in a large supermarket and earn more money, have a career structure and earn a management position. Hence getting PAs in the future will continue to be difficult for many elderly and disabled people across the country.”*

People said that the role of a PA was often not well understood by jobseekers or by employment and recruitment agencies, meaning some people came for interview who were totally unsuitable for the role. Others described the impacts of people applying for PA jobs solely to retain their Job Seekers Allowance.

Most people said that they had to organise PA training themselves, with no extra funding included in their direct payment or personal health budget. They wanted more help with this from local and central government. *“We are currently seeking a new PA. [The] time I have spent with advertising, interviewing, creating documents for our PA unpaid, then training, is madness. I do this all in my limited personal time for free.”*

**“ It has become progressively more difficult over the last 15 years... unsocial shifts, nights, learning disability with challenging behaviour, lone working - what's not to like?! ”**

**59% of people think it's harder to find PAs with the right skills, values or training**

*"I'd like a way of training people without it affecting our budget. We have a high failure rate with new recruits either finding the culture of a single person service and the isolation that staff can feel when lone working is not for them, or we find they are not up to it. We should be part of a programme of helping to develop a wider workforce."*

Several people also said that interviewing for a PA online during the pandemic, rather than face-to-face, had made it more difficult for them to match someone to their individual needs. *"It requires people who are patient, caring and committed to this type of work. The PAs who have left our employment typically have not exhibited these characteristics for any length of time and often have a poor attitude towards a good work ethic and personal responsibility."*

### **There's not enough recruitment support from councils, NHS funders and government**

333 people said they needed more support with PA recruitment from councils, NHS funders and government. *"For years (decades) there has been talk of a council facilitated list of experienced PAs, or PA brokerage. It never materialised."* Some people said they'd not really understood what they were taking on when agreeing to a direct payment or personal health budget to employ a PA. *"In many cases the support from the local authority ends once everything has been set up, but things go wrong if the employer lacks the understanding with undertaking their responsibilities, or lacks the confidence needed - there is plenty of written guidance out there...but in reality, DP support helplines and services are trying to support the employer resolve something which has already happened and could have been avoided."*

Although most people said they had to manage PA recruitment themselves, none said that the costs of PA recruitment were included in their direct payment or personal health budget. *"Advertising in most cases costs money - many local authorities (my own included) do not include any funding for the cost of advertising, and this makes the recruitment very difficult."* Some people said they managed to find PAs by word of mouth or adverts in shop windows, but the majority, even people with many years' experience of PA recruitment, said they were finding recruitment harder than ever before.

Where some recruitment help was on offer to people from councils and the NHS, views on the value of this were mixed. One person described their council's PA website as "out-of-

**“ In one year many people have applied for the jobs I posted but only 10% turn up to interviews. This is because they only have to apply to get the Job Seekers allowance, no one checks if they went to the interview ... it wastes our time and money... [the system] needs a good overhaul. ”**

**A third of people said they needed more support with PA recruitment**



date”, another was given a “shopping list” of PAs who they couldn’t contact or who were charging more than they were able to pay. Several people said they were signposted by their funders to agencies whose rates were above what they were allowed to pay. Another person described being told if they couldn’t recruit, to fall back on unpaid carers. *“We have had no support in finding someone suitable to support my daughter. When we ask for help, we are told to pay a friend or family member. If I had a friend or family member that was in a position to help us, I wouldn’t have asked for respite!”*

*“I’ve been without the PAs I need for 6 years. The local council have done nothing other than mess with my direct payment and continue to ask for more forms to be completed. They seem to have NO understanding of the local market and no interest in supporting me to find PAs. They rely on my unpaid carer stepping up.”*

Some people were keen that councils take on the job of PA recruitment themselves, and 120 people called for councils to arrange the vetting and training of a local pool of ‘trusted’ PAs who could offer a range of support from emergency cover to highly specialist and skilled support.

*“I am firmly of the view that the recruitment and retention efforts need to be brought back in-house, within local authorities. All responsibility has been farmed out to an independent agency who has no real investment in whether my arrangements are working for me or not. I am left to sort out the mess. Direct payments and PA arrangements only work when there is a sufficient supply of suitable PAs in the market. If there is not, we not only have lost any ‘choice’ but we are left with trying to create a market that does not exist. This is very harmful and dangerous for individuals with direct payments.”*

Some of the most positive feedback in the survey was about the recruitment and employment support from councils’ in-house direct payment teams. Other council and NHS funders have commissioned local or national organisations to recruit, employ and manage PAs, or to provide services like payroll or advice on recruiting and managing PAs. People’s experiences of the support provided by these organisations were very mixed and they felt funders and commissioners should seek regular feedback from them about how effective these organisations were in providing the right help. *“The council has a contract with a third sector organisation to provide support to direct payments*

**“ Finding, and most especially, retaining PAs has been very difficult. This has been worse since March 2020 but has always been difficult. This then severely impacts both my life and that of my family. ”**

**“ I have gone from a soul-destroying poor quality of care from the agency to employing my own PA and regaining my dignity, and quality of life... I am deeply grateful to the direct payment local team for all they have done for me... This is the system working at its best within very challenging circumstances. ”**

*recipients but although they offer tea and sympathy, the business support seems to be pretty basic. They would have to up their game a fair amount to provide a decent service."*

People felt it was unfair if funders limited who could be supported by these commissioned organisations meaning, for example, people self-funding their PA support were excluded from this source of help.

### **Not enough oversight of the PA market by funders and commissioners**

Several people commented on how unrealistic and lacking in knowledge funders and commissioners seemed to be about their local PA market and about the effects that competition, low pay and poor terms and conditions were increasingly having on their ability to recruit and retain a PA. One example given to illustrate this was how people were prevented by their funders from using a self-employed PA<sup>4</sup>, significantly limiting the pool of PAs available to them and creating inequalities in the market as self-funders can contract with whomever they choose. One person described how their council contracted with self-employed PAs, even though they were not allowed to do so, with the effect of further depleting the pool of available support. *"In our area, people who leave care agencies are becoming self-employed micro providers on much better pay than being an employed PA. They have control of the hours they work, their pay. The downside is social workers who cannot find capacity from their commissioned providers (e.g. home care) swamp local micro providers with commissioned work, so people with DPs have no [PA] provider market to buy from!"*

People were keen that councils revisit local policy on the use of self-employed PAs as this could have a positive impact on PA shortages.

Another respondent said it was important that funders and commissioners did not frame recruitment as a failure on the part of individuals, but as a failure of commissioners to ensure a sufficient supply of PAs to meet demand. *"We are told it is our problem if we can't find PAs - when in reality it is a commissioning failure."*

**285 people said they felt PAs were choosing jobs with better hours, terms and conditions, and career development**

<sup>4</sup> <https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Information-for-individual-employers/Before-your-PA-starts.aspx>

## People can't offer PAs better terms and conditions and working hours

*"Two main reasons (I) have lost staff over the years are pay [or] they have moved on to progress their career (nurse training for example)."*

Most people who commented on PA pay in our survey also said that sick pay, additional payment for unsocial working hours, paid holiday, and a retention payment where needed, should be built into budgets by funders when calculating direct payments and personal health budgets. The inability to pay PAs for sickness absence or isolation was highlighted by many as a significant limiting factor in PA recruitment, and many PAs could not afford to go unpaid if the person they supported had to isolate or go into hospital. A retention payment would allow people to hold onto good PAs in these circumstances.

## The job of a PA is not socially valued or well understood

People told us how they worked hard to make the role of a PA interesting and rewarding, but low pay, with no reward for length of service, little or no allowance for PA training, and little opportunity for career progression, often limited the length of time a PA would stay in the role. *"It is very difficult as an individual employer to offer any great career structure for my carers."*

Many survey respondents felt that PA recruitment challenges are exacerbated by the low esteem in which the type of support provided by a PA is held. People felt evidence of this low esteem was most apparent in the way funders limited what their PA could be paid (often minimum wage), despite the skills, often specialist experience, and knowledge and training needed by many to work as a PA, often alone, and meeting complex and diverse needs.

Several people referred to the government's **Workforce Recruitment and Retention Fund**, managed by councils, as an example of how people supported by PAs are invisible to local and central government, and the rest of the care system. The fund was intended to provide extra employer support for recruitment and retention during the pandemic period, including people supported by a PA; however no-one in our survey appeared to have benefitted from additional support from the fund. *"The PAs are not recognised as a part of the social and health care system... I know that in the pandemic, some care homes and care companies have given their employees a pandemic bonus that says to the carers that they are valued. Unfortunately, this is impossible for the PAs because the system will not allow this."*

**“ I train them up, they become skilled and experienced, then they leave to take better paid roles or do further studies in the disability field. ”**

**“ For people of working age, the job as a PA is not identified as a recognised skilled job or held in any high esteem. ”**

The low public esteem in which care work is held was inextricably linked by many survey respondents to a widespread lack of understanding of what a PA does. *“People also don’t know what a PA is... they either think it’s a nice chat and cup of tea or wiping bums. They don’t understand it’s about all of life.”*

One person described how they tried to ensure their PA teams felt valued and had a stake in the support they were collectively providing by involving them in interviewing prospective PAs and making decisions between themselves about managing rotas. This person was rewarding their skilled, qualified, and experienced PAs of many years from their own pocket. *“I have always tried to be fair, and I personally fund an annual pay rise although it is usually just pence, but it shows some commitment on my part.”*

### PA shortages due to Brexit and immigration changes

More than a third of people responding said they have found fewer people are available for PA work following Brexit or immigration restrictions, and called for action by government to make it easier for individual employers of PAs to recruit and sponsor people from abroad to work as a PA.

*“Add live-in carers to the shortage occupation visa scheme or create a new visa scheme with no cost barrier or minimum salary requirements for live-in carers. My carers are specialist and do meet the skilled workers visa requirements, but the cost of using that scheme is too much for me and is limited to two years...you need to know if the person can do the job and live with you first before you commit...”*

### PAs don’t want the Covid vaccination

Although most people wanted their PAs to be vaccinated, 36% of people answering this question said that they believed new PAs were put off the role because they believed they’d need to have the vaccination.

### PAs are afraid of catching Covid

Some people felt their PAs were afraid of catching Covid from them, despite the precautions they had put in place to keep everyone safe. Several people said PAs were also afraid of catching Covid and passing it onto their own families who were clinically vulnerable. Others described how they had to support their PA to manage their anxieties about catching Covid. People also described how they had struggled to get free PPE at the start of the pandemic from both the council and the NHS.

**“ How can you recruit to a post that people have no understanding or knowledge of? Many people perceive a PA as someone who works for a company director. ”**

**239 people (40%) think fewer PAs are available because of Brexit or immigration changes**

**36% of respondents said that Covid vaccination was putting people off PA work**

### Transport problems and no allowance from funders to pay PA travel or travel time

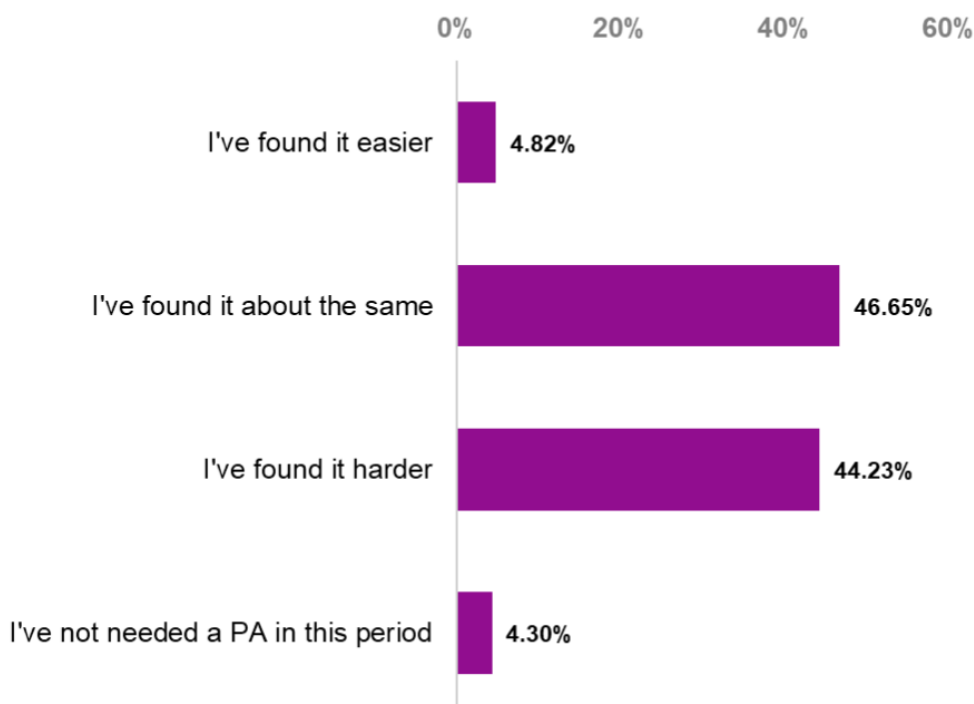
There is a cluster of transport-related issues affecting PA recruitment. These include the challenges of finding a person who can drive, and problems with funders over whether people could refund their PA for mileage or travel costs incurred while providing them with support from their direct payment or personal health budget.

People living in rural areas with limited public transport said they found it very challenging to recruit PAs, particularly ones who needed to work split or unsocial hours. People said they weren't usually permitted to reimburse the costs of travel to and from the PA job, even where this involved 'split' hours involving multiple journeys and travel time, making this one of the main reasons PAs found it wasn't worth their while financially to take these split hours on. *"PAs are poverty workers who often can't afford to live in our city as it's so expensive. Once they move out, it's not worth the [unfunded] cost of a bus or train into the city for only a few hours' work."*

**“Transport is very problematic for the PAs because they work unsociable hours, and these hours are when the bus services are not running.”**

## 4.2 RETAINING PAS

**Question 4. Since March 2020, have you found it easier or harder to retain (keep) your Personal Assistants (PAs)?**



**44% think it had been harder to retain their PAs**

Given what people told us about the challenges of recruiting PAs, we fully expected to hear that people were also finding it harder to retain their Personal Assistants. Only 46 (5%) of people said it had got easier. 422 people, more than one third (44%), said that it had been harder. A slightly larger number of 445 (47%) people said it had remained about the same. This contrasts with the workforce survey in which 70% of employers found it much more challenging to retain staff now, than they had the previous year. It may be worth further work to better understand the factors that encourage PAs to stay in their PA role, compared to other jobs in the care sector, and how these can shape future recruitment efforts.

People who had long-term PAs, in some cases for many years, frequently talked about qualities like loyalty, trust and mutual respect which had led to them forming a positive working relationship, and in some cases an enduring friendship, with their PAs.

Throughout the survey, people emphasised the benefits of having regular PAs who got to know them and their routines and preferences. Some described how they'd all worked as a team during the pandemic to keep each other safe. *"It's been extremely challenging. PAs have had to adjust to new enhanced deep cleaning, wearing PPE, new routines in care. It took a lot of thought to keep the client engaged and supported throughout this time, it was a very long winter, and the staff rose to the challenge. They baked a lot of cakes."*

Several people told us how their PAs had gone "above and beyond" in the pandemic period, describing how their PAs had limited their own social contact outside work, in some cases forming a bubble with the person or family they supported, or even moving into their home temporarily.

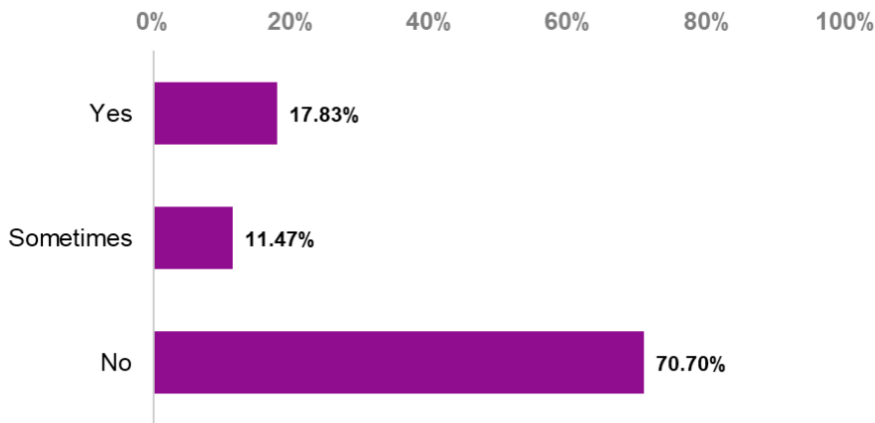
### 4.3 USING AGENCIES FOR PA SUPPORT

We asked a question on whether people ever used agencies to provide regular or occasional support such as emergency cover. There was a mixture of responses to this question with some reporting their experience of using care provider organisations with others referring to recruitment and employment agencies. It was not possible in all cases to distinguish between the two types in the responses given and so for the purposes of the quantitative analysis they were grouped under the single category of 'agencies'.

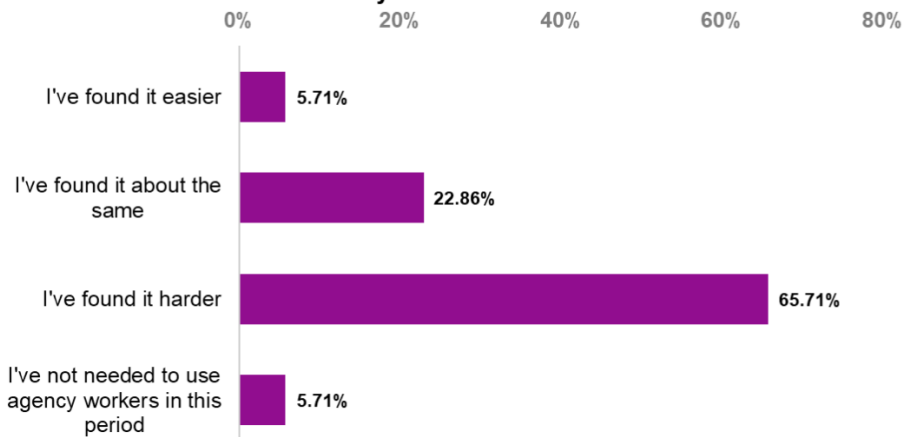
#### People with long-term PAs talked of loyalty, trust and mutual respect

**“ My PA only looked after people who were shielding and gave up her visits to her grandchildren to keep me and other clients safe. She was incredible! ”**

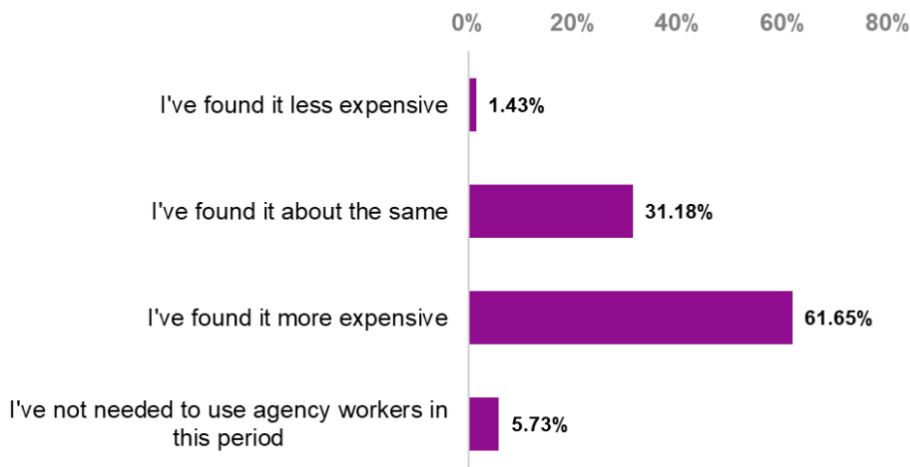
**Question 5. Do you use agencies as well as Personal Assistants?**



**Question 6. Have you found it easier or harder to get agency workers when you need them since March 2020?**



**Question 7. Have you found it less or more expensive to get agency workers when you need them since March 2020?**



### Agencies are unaffordable for most people with a direct payment or personal health budget

678 (70%) of respondents answering this question did not use PA support from agencies, either regularly, or on an occasional basis such as for emergency cover. Most people said agencies charged above the rates they were allowed to pay, though some reported funders still signposted people to them. *“All the agencies I was given to help find PAs were far too expensive, even though the contact details were given to me by my Continuing Care Support Worker who told me that they could not charge more than £15 per hour. The agencies were all charging way above that amount, making the situation impossible, especially when they realise that my needs are complex, above just basic care. Their charges escalate way above the budget.”*

Of those who did use agencies, 184 (66%) people said it had been harder to get agency PA support since March 2020, and 172 (62%) of those said it was also more expensive. Some people’s direct payment or personal health budget had run out early because they’d had no other option than paying more, and they feared being left without support as a result.

### Funders and commissioners should check the quality, reliability and standard of care provided by agencies

People said they wanted direct payment and personal health budget funders and commissioners to do more to check the quality and standards of services provided by agencies, especially those they are signposting people to. In the most concerning cases, people told us they had been left without support by agencies.

Despite the higher PA pay rates reportedly offered by agencies, people described the supply of PA cover as being under constant pressure. One person said they felt *“considerable stress from not having enough PAs to cover absences and having to employ agencies for the first time ever, then the agencies letting me down”*. Another said, *“We dismissed a PA for gross misconduct but then have had to cover the hours ourselves as local care agencies had no capacity to send any cover PAs.”*

### Agencies are affecting the supply of affordable PA support

People were also concerned that agencies were taking affordable PA capacity out of the local market by offering better rates of pay, with one reportedly offering a sign-on bonus of £2,000 and other perks.

**“ You have to work around agencies rather than them work around us and our needs ”**

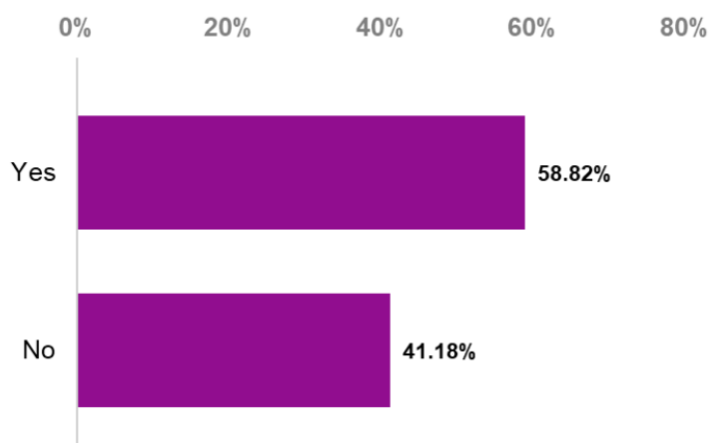


Of those who did use agencies, a few did report a positive experience. *“Now we have a consistent PA through an agency, it is amazing...our daughter...really looks forward to the visits from the PA and spending time together and it’s starting to give her some independence away from the family.”*

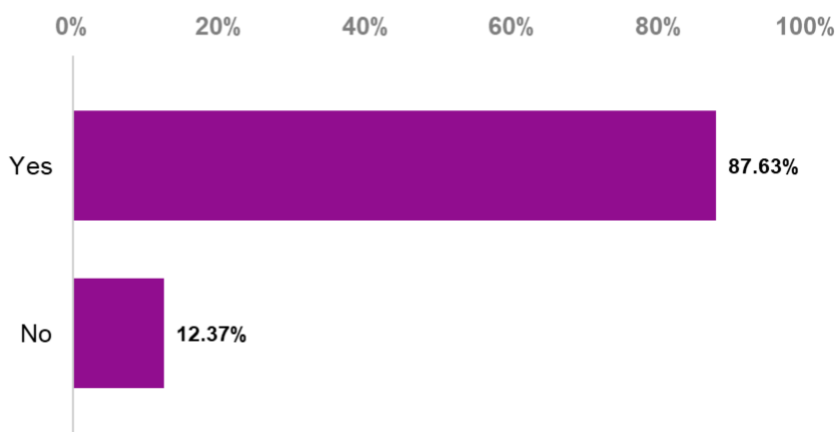
#### 4.4 REASONS PAs LEAVE

We asked whether PAs had given the people they support reasons for leaving their job as a PA. Almost 60% of those responding to this question said one or more of their PAs had left between March 2020 to January 2022, and of those who left, 88% had given a reason for why they were leaving.

**Question 8. Have any of your Personal Assistants left since March 2020?**



**Question 9. Did the Personal Assistants who left tell you why they were leaving?**



**Low pay, poor terms and conditions and insufficient hours were key factors in PAs leaving**

The reasons PAs most often gave for leaving was a change in personal circumstances or commitments, followed by “other reasons”. These other reasons mostly related to low pay, working hours, working conditions and lack of career development or progression, reinforcing what we heard elsewhere in the survey.

### Low pay, poor terms and conditions and insufficient hours were key factors in PAs leaving

By far the biggest factors in ‘other reasons’ PAs gave for leaving was low pay, allied to job insecurity and not getting paid if they (the PA) had to isolate, were ill, or if the person they supported went into hospital, and the impact low wages had on their state benefits. More than one person had a PA who used a food bank. *“I’ve had three people at food banks and one person who worked with no coat in winter and holes in her shoes for months. That’s just ridiculous.”*

Other PAs had left because the hours on offer were insufficient for it to be financially viable for them. *“PA left due to Covid, got no reply to job adverts. A family member helped for a few months, then tried to advertise again. Had two people do the trial then say they would start work. Quit before finishing their first day. One was due to not being paid mileage to drive to work. Other was because it’s a small amount of hours. No other applications. Social services have been zero help in getting someone, they also haven’t offered any other solutions. They didn’t show any care at all that I was without help for months.”*

### PAs or PA employers found this was not the right job for them

42 people said their PA had left saying PA work was not the job for them, and people used this to illustrate how the role and demands on a PA are not well understood. If we combine this with the 32 PAs whose contracts were terminated by the person they support, we can see why it’s so important there is a much better understanding of the PA role, and how being a PA differs from other sorts of care work.

### PAs were experiencing mental ill-health

At least 25 PAs had told the person they support they were leaving their job because they were experiencing mental ill health with stress, anxiety and depression all being mentioned.

**One person described low paid PAs as “poverty workers.”**

*“Although I still have my PA, I have had to allow them to shield/ isolate for the vast majority of the Covid lockdown due to their own anxieties about working with me. I have also been put under pressure to continue paying for a service that I am not getting because it is not their fault that they cannot work. This has therefore left a lot of pressure on my family, as well as [me] being highly isolated during this time. However, I felt I did not have a choice because otherwise I would lose that PA.”*

Several people made a case for PAs having access to the mental health and wellbeing support which is on offer to other parts of the care sector and the NHS<sup>5</sup>, and for people they support to know how to refer PAs, and themselves, if necessary, to these sources of support.

### **PAs are returning to a previous jobs or education**

Some people reported that during the pandemic they had been able to recruit people furloughed from their jobs, which ranged from cabin crew and hairdressers through to students not in college or university. As we were carrying out the survey, people were beginning to return to their furloughed jobs or full-time education so it's very likely that this extra supply of people will begin to dry up.

### **Other reasons PAs gave for leaving**

Fear of catching Covid, or passing it on to their own families, or the person they supported, was another reason given by PAs for leaving. Difficulties with affordable childcare, transport, Brexit and changes to immigration rules were also given as reasons for PAs leaving.

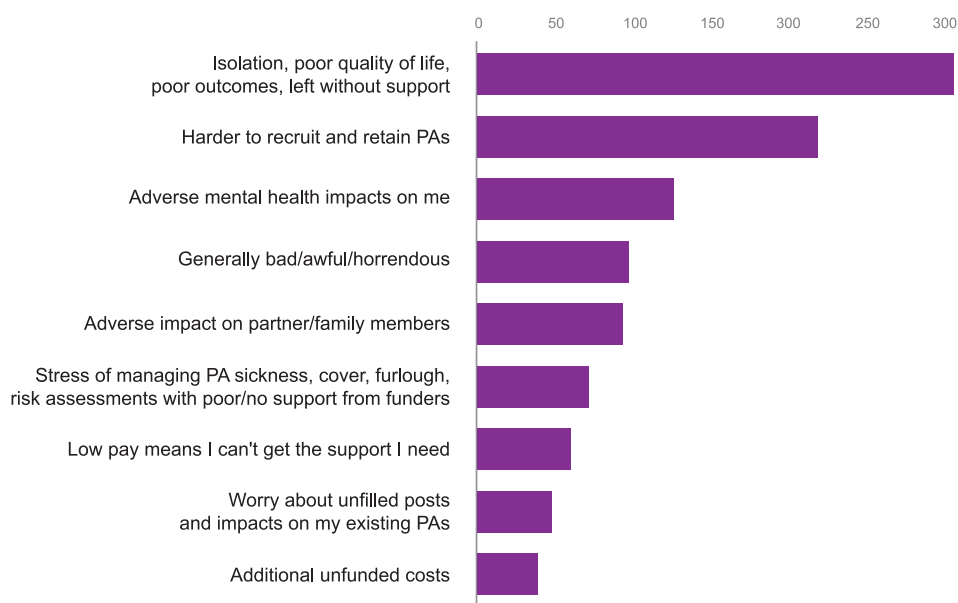
**“ My PAs are really nice people, but they’ve found it very stressful because they’ve wanted to protect me, so have themselves felt the pressure to not go out, so they don’t catch Covid and pass it on to me. I suspect this has contributed to one leaving, but I don’t know for sure. ”**

<sup>5</sup> <https://www.gov.uk/government/publications/health-and-wellbeing-of-the-adult-social-care-workforce/health-and-wellbeing-of-the-adult-social-care-workforce>

## 4.5 THE IMPACTS OF THE PANDEMIC

We wanted to hear first-hand what the impacts of living through the pandemic period had been for people supported by a PA. We have grouped the free text answers to this question into broad themes to capture the most frequently mentioned impacts.

**Q12. As a person supported by a PA, what have the impacts been on you, good or bad, since March 2020**



We used a word cloud to capture the words most frequently used in the survey to describe these impacts.



### Good impacts during the pandemic period

96 (12%) of people said the impact on them of living through the pandemic period had been positive, or they had seen little change. *"I feel we are extremely fortunate to have had the support [local council and CCG] have given during this time. My husband had another mild stroke in January 2020. GP not helpful but social services were on the spot immediately and provided all the equipment and support I required for many*

790 people used the free text option to tell us about their experiences during Covid.

96 (12%) people said the impact on them of living through the pandemic period had been positive, or they had seen little change

*months including the support to employ an additional carer. I was advised to contact X recruitment agency who gave me advice and advertised for my husband's new carer. I had no stress whatsoever."*

Some people were able to use their direct payments flexibly during the pandemic to achieve a good outcome, one person describing how they were able to use it *"to pay a table tennis coach for a safe 1-1 lesson instead, which didn't give me respite as I had to be in attendance, but it was great for my child to have exercise, and be coached in something he's talented at, feel the esteem of playing well, and it gave him a break from me!"*

One person described in detail what it's like when the system is working well. *"I have found the access to support and information from direct payments team to be key in retaining and employing PA cover. I interviewed a stand-in holiday PA on a Friday afternoon...she accepted the post, I emailed the local direct payment team supporter, and the contract had been drawn up and sent by the Monday morning. Outstanding! This enabled me to employ a PA within a week turnaround. That cover has been in place for weeks and worked extremely well. Had I not had that standard of support from direct payment team, I would have not had a PA covering my care."*

### **Negative impacts during the pandemic period**

Some positive individual examples aside, the majority who responded to this question (88% or 694 people) detailed often multiple adverse impacts on them, their PAs, their families, their quality of life and health and wellbeing outcomes during this time.

#### **People were fearful about not being able to recruit a replacement PA**

The attrition caused by worry or fear about not being able to recruit if their PA left is a constant theme throughout the survey. One person summed it up as, *"[I] worry about them leaving, worry about paying them enough so they don't leave, trying not to do anything that may get their back up so they leave."*

*"...fear of losing my regular main PAs who have been with me for over 10 years because of the difficulty I see and hear from all my disabled friends with recruiting PAs."*

***“ I have found my particular local council to be good ...Life can come back when you find genuinely caring people. ”***

**Nearly 700 people detailed multiple, often adverse, impacts on them during the pandemic**

**People felt isolated, and some were left without PA support for long periods of time, with serious consequences for some**

304 people described how lonely or isolated they felt during lockdowns or when they were shielding. 160 people described being left without PA support, some for long periods of time. This had consequences for some people that potentially had safeguarding implications including injury, mental ill-health, hospitalisation, pressure sores, risk from unsuitable PAs or insufficient agency support, and care or unpaid carer breakdown. One person told us, *“I have had to go very long periods without help, making me isolated, housebound and vulnerable. I could not go to many appointments hence put in risk of my health, as there was no one to go with me. I had numerous falls downstairs and otherwise. I cut myself trying to prepare meals. I suffered burns whilst cooking, had no way at times to access the community.”*

Other people said they’d either given up trying to recruit a PA, or that long after being given a direct payment or personal health budget they were yet to recruit anyone and remained unsupported. *“Twenty-one months without having a PA, initially because they were not wanting to work for Covid safety reasons, then they quit for better pay in non-care work, then next PA never started due to another lockdown being imposed and having an immuno-suppressed child of their own, then couldn’t recruit another. We’ve now given up as the stress, work and admin for me as a parent-carer was eclipsing any benefit I may have got from the respite care.”*

**Pressure on PA teams where people can’t recruit a replacement**

People also talked about the impacts that gaps in their PA team had on their remaining PAs to cover unfilled hours. Some PAs had left their job as a direct result of being unable to sustain the additional support needed to cover for long gaps in PA teams. *“I have a budget for two carers, but the lack of the ability to recruit a second or third carer has made the situation intolerable for the first carer to remain doing the job of two people.”*

**People have taken on PAs they know are not right for the job and are having to compromise on their support because of PA shortages**

One of the other consequences of difficulties in recruiting PAs was that some people, out of desperation, took on PAs they

**160 people described being left without PA support, some for long periods of time**

**“ ...Inability to manage health. Burden on family. Isolation. Loneliness. Returning to the hospital more frequently. ”**

knew were not right for them, but felt it was a choice between being left completely unsupported or supported by someone less than ideal for the job. *“I desperately scrambled to find cover and took on short term people and people with poor references because I had no other options. There is NO support locally for those struggling to recruit and no agencies who take on complex PA situations (disabled mum with child).”*

Some people also described how shortages meant some PAs could, *“dictate to us about what they will or won’t do, they are better than no one! If another leaves, we will likely end up in hospital. We had a bad experience, leaving us feeling very vulnerable because we were trying to hold on to someone who was totally unsuitable to this type of work.”*

### People experienced poorer health and wellbeing outcomes and quality of life

Shielding, and the closure of regular activities, groups, services and amenities, had all contributed to a deterioration in people’s wellbeing, skills and confidence.

*“I have lost confidence and went through difficulties when two PAs left to work at higher paid care jobs. The team is back up to full numbers again now, but I am very nervous and am just waiting for news of a PA leaving. I miss out on loads when my care team is low, and I don’t like seeing my PAs overworked and tired, it makes me feel uneasy asking them to do things when I know they are exhausted.”*

Another person said, *“All my available income goes on PA wages. No visits to cinema or theatre or dining out with friends or family for same reason. If their wages need to increase again, I despair of surviving and may have to go to a care home as a last resort.”*

### People found it harder to recruit and retain PAs, and this is not just Covid-related

As noted earlier, people told us they had found it harder to recruit, and in some cases to retain, PAs during the pandemic period. Many also said this was part of a broader trend, and not just linked to Covid pressures. People also said that Brexit and immigration rules had also noticeably impacted on their ability to recruit PAs.

**“ The quality of the people who are coming forward to be PAs is just not as good as it used to be...all of this is really distressing for me and it weighs on my mind almost every day. ”**

**“ It’s always a good feeling when you get a good carer who can stay for a decent amount of time... Even when you get a good carer, you don’t know how long they’ll stay, meaning you’re constantly worrying about having to get new carers. ”**

## Adverse mental health impacts on people supported by a PA

125 people described specific mental ill health consequences they had experienced. This included stress, worry, anxiety, low mood, depression, despair, burnout, and feeling they could not cope. A further 97 people described their experience simply as “bad,” “awful” or “horrendous.”

Many people described themselves and their unpaid carers as “exhausted” and having “given up” being able to get the PA support they needed, with inevitably poorer outcomes for them, their independence, their unpaid carers, and family life. One person described how lockdown and isolation led to them developing agoraphobia, others that they now need counselling. Another person said they felt like a ventriloquist's dummy who only came alive when their PA arrived at their home.

Several people told us that they had to provide mental health support to their PA, and many said they worried about the impacts of the pandemic on their PAs.

## Adverse impacts on unpaid carers and family life

Almost 100 people said that there had been adverse impacts on their partner, unpaid carers and family life, and that unpaid carers had to step in because they could not recruit and retain PAs. A married couple both had hospital admissions after being left without adequate PA support. Some people described health, carer or family breakdown, or partners or family members having to give up full-time work to provide unpaid care due to shortages of PA support. *“I have to fill the gaps in my childcare due to lack of PAs /agency workers’ absence. Both of us feel exhausted and tired and not able to take the kids out much. I have now ended up resigning from my job.”*

*“...both myself and my partner employ PAs and I act as a carer when we have no one. The lack of PAs has impacted on our relationship, and the health of us both, but mostly me. We have to rely on family which erodes my privacy and takes away the control over our lives which having a full PA team allows.”*

*“It is relentless and exhausting. My daughter needs help with all aspects of personal grooming, including night-time care and incontinence. She never goes anywhere except school without us; her world has shrunk. Looking after her while ill with Covid myself was traumatic. Thank goodness my husband and I were ill one after the other, rather than at the same time.”*

**125 people described specific mental ill health consequences they had experienced**

**“ Since PA left, struggle to cope. Few replies to adverts in local online newspaper. One came for two weeks, was not up to the job. The whole thing made me feel depressed as I can’t manage my life. ”**

**Almost 100 people said that there had been significant adverse impacts on their partner, unpaid carers and family life**



## Stress from managing PA sickness, cover, furlough, and risk assessments

The pandemic period brought additional demands and extra costs for people supported by a PA. People described the stress and practical problems they experienced trying to manage PA sickness, PAs who had to isolate, shield, or furlough, and the extra burden on them as employers to undertake risk assessments and keep their PAs safe. The lack of sick pay for PAs who were ill or isolating due to Covid highlighted the concerns about sick pay expressed elsewhere in the survey.

The lack of contingency funding or flexibility within direct payments or personal health budgets, during this period was mentioned several times. *"I asked the council if I could use my direct payments flexibly under the pandemic guidance to purchase equipment to help me meet my social [support] needs. They said no, I appealed, they said no, then they said yes and reduced my direct payments which is in direct contravention of the pandemic guidance. I did not receive the email informing me of their decision and it caused me a lot of stress and anxiety when I realised my funding had been cut."*

Some people were critical of the lack of Covid-specific support from councils and NHS funders and said they found them hard to contact for advice on things like PPE, testing, vaccination and isolation payments for PAs. *"We have gone periods of time without care or any support offered...the council did not answer our calls, the social worker would not visit our home, and everyone hid under the Covid banner, even to explain the emails left unanswered."*

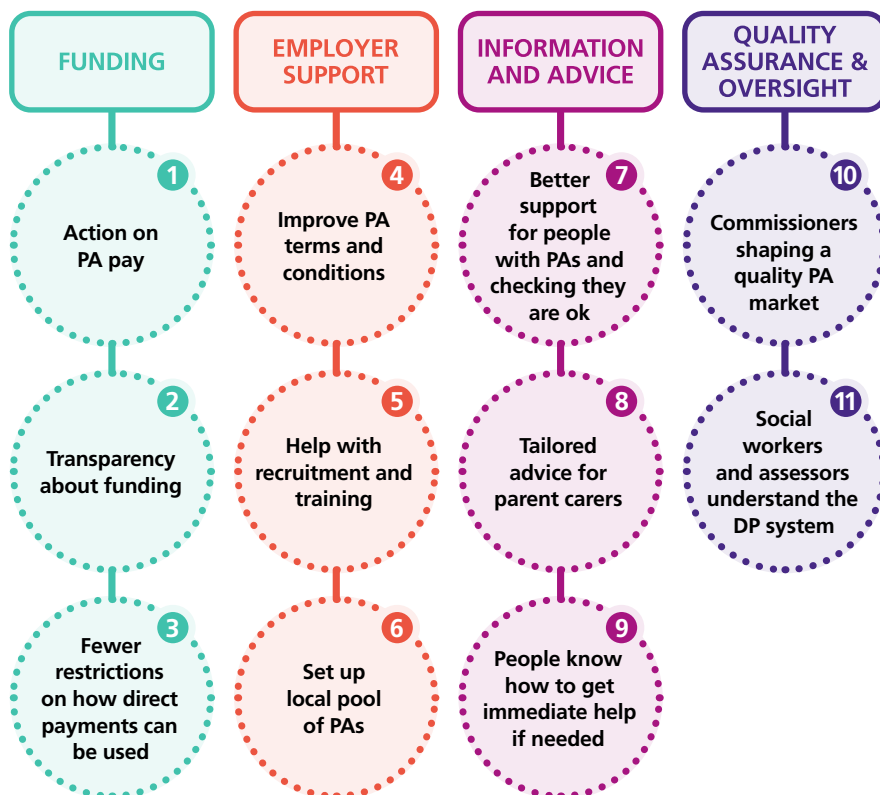
Other impacts mentioned included funders cutting hours because people were assumed to need less support during the pandemic. *"It's been difficult as the support planner from my council cut my hours from 35hrs per week to 26hrs. She told me when I start going out, I can just ring up and the hours would be put back on my assessment. I rang today and I have to wait for another assessment. It's been very hard."*

**“ I don't know how much longer we can sustain this without either myself or my partner completely collapsing. ”**

**“ Several times I have had to pay for PA out of my own [funds] to cover self-isolation periods and I have had no cover. So, paying for care that hasn't been received. ”**

# 5 RECOMMENDATIONS FOR ACTION

Recommendations for local councils and central government to support PA recruitment and retention



Almost 80% of people provided recommendations for councils and government, and most people provided more than one suggestion

## Direct payments: a lean or a mean system?

*“The [PA] system needs overhauling from start to finish and much better customer care and accessible systems. Systems are built not on lean systems thinking, but on mean systems thinking, functional to the bone, but lacking in kindness.”*

One of the best examples of ‘mean systems thinking’ came from someone who described not being allowed to pay for their PA’s coffee in a café from their direct payment *“[Please] provide money in budget for PA expenses... If we go out, my PA is expected to buy their own drink if I sit in a cafe. I can’t sit alone as need help to lift cup, so I have to buy them a drink...it adds up when I have limited income.”*

People mostly talked about their direct payment or personal health budget in the context of what funders would not, or would, allow them to do. This lack of control and flexibility was most strongly expressed as frustration over the way funders restricted what people could pay their PA, even if this made it difficult or impossible for them to recruit anyone.

**“ The [PA] system needs overhauling from start to finish and much better customer care and accessible systems. Systems are built not on lean systems thinking, but on mean systems thinking, functional to the bone, but lacking in kindness. ”**

People felt that limits on what they can pay seems to be underpinned by assumptions that PA support is inherently cheaper than other forms of care, and that it is a minimum-wage level job. It also appears that for some people, whilst the burden of recruiting, employing, and training PAs has shifted to them as individual employers, the associated costs are not routinely included in their direct payments or personal health budgets.

One person set out their ask of local and central government. *"Promote the work of a PA as being different and [an] interesting part of the workforce nationally. Advertise specific to PAs and not generic carers. Local government funding to publicise PA work and back local databases we can all access in coordination with support schemes or similar. More funding to [give] our staff a pay rise each year, and a good starting rate of pay in line with their skills and responsibilities."*

### **Key actions which people in our survey said could be taken by local councils and central government to support PA recruitment and retention**

**A total of 662 people said action on pay is urgently needed**

#### **1 Action on PA pay**

- ▶ Low PA pay outstripped every other factor people told us is making PA recruitment more difficult for them.
- ▶ A total of 662 people said action on pay is urgently needed. Action on pay would include reviewing people's experience of limiting PA pay and enabling people to offer a fair rate of pay that is competitive in their local care market and more accurately reflects the skills and experience needed by their PAs.
- ▶ A few people said that unless council and NHS funders maximise flexibility on pay, government should step in and set a national PA pay rate (or establish a National Care Service) as this is the only way to ensure PAs are paid fairly and equally for the work they do, compared to those in similar roles in the sector; a national pay rate would also eliminate the disruption to local PA markets caused by variance in PA pay set by different councils.
- ▶ Increases in PA pay should not mean people's 'care hours' are cut to cover these increases.

## 2 Transparency on how direct payment or personal health budgets are arrived at, and more information about what costs are included

- ▶ Everyone should know the basis on which their direct payment or personal health budget has been calculated and what is included.
- ▶ The costs associated with PA recruitment, support and training should be included in budget calculations.
- ▶ Contingency funding should be built into direct payments and personal health budgets.
- ▶ Sufficient hours should be allocated to meet all eligible needs and people should be able to manage this in ways which make it financially viable and attractive for people to work as a PA.
- ▶ Allowing payment for PA sickness, and a retention payment if people go into hospital, will improve recruitment and retention.
- ▶ Free or funded PPE should also be included.

## 3 Fewer restrictions by funders on how direct payments and personal health budgets can be used

- ▶ People should be free to use their direct payments and personal health budgets flexibly to meet agreed outcomes in ways which work best for them, without unnecessary restraints imposed on how their direct payment or personal health budgets should operate.
- ▶ Traditional 'time and task' approaches should not be used to limit or restrict the way people's needs are met.
- ▶ People should not have to choose which of their eligible support needs are met to remain within budget limits set by funders.
- ▶ Funders need to demonstrate greater openness and trust towards people supported by a PA to use their direct payments responsibly within agreed budgets.
- ▶ Barriers such as only being allowed funding for one Disclosure and Barring Service (DBS) check a year should be reviewed.

## 4 Improve PA terms, conditions, and public esteem

- ▶ PAs deserve terms, conditions and benefits in line with similar jobs in other parts of the care and health system, including sickness and holiday pay, pay for working unsocial hours

**“ The relentless propaganda about how ‘special’ care workers are I feel has really harmed our and our care staff’s dignity as professional people who do a proper job and do it well - they aren’t heroes or martyrs and we are not the cause of their martyrdom. ”**

and Bank Holidays, paid mileage when providing support, and public transport costs and travel time reimbursed where appropriate e.g. in cases of split visits over the course of a day or where recruitment is proving especially difficult.

- ▷ Government needs to do more to recognise PAs as a skilled, valued, and experienced workforce, raising their profile and public esteem accordingly. Councils and government should use their 'soft' power to raise the profile and awareness of PA job options, building on a more positive, less stereotyped view of what working as a PA involves.

**“ [Councils could meet] basic PA training needs - safeguarding, medication training, food hygiene, health and safety with easy access programmes, and new recruits [could] join training provided by health and social care for other staff. ”**

### **5 Help with PA recruitment, training and employer support from both local and central government**

- ▷ More investment is needed in national or local recruitment hubs for PAs, with advertising through a range of channels, including broadening recruitment to attract PAs with specialist skills or experience.
- ▷ Some people suggested a council or NHS sponsored one-stop shop or PA Hub for recruitment, vetting, PA training, and peer to peer support for people supported by PAs, especially those new to the role of employing PAs.
- ▷ 189 people voiced support for a coordinated and free training support offer at both national and local level for PAs, as well as people starting out as a new employer.
- ▷ PAs should be able to join free training for staff in other care roles.

### **6 A local pool of PAs people can draw on, open to all**

- ▷ More than 120 people wanted councils to actively develop a local pool of vetted PAs able to offer a range of types of support which they could draw on.
- ▷ Any pool should be open to all, regardless of how their support is funded or who is supported.

### **7 Better support for people employing PAs, and regular checking that people are ok**

- ▷ 128 people wanted more support from councils, government and NHS funders, with access to accurate and reliable information and support about employment-related matters and sources of wellbeing support for PAs.
- ▷ Council and NHS funders need to check regularly that people are still managing their support ok, or if they need any additional help or guidance.

**8 Tailored advice and information for parent-carers employing PAs**

- ▷ Funders need to do more to help parent-carers find suitable PA support for their children and young people and provide tailored help with employing and managing PAs.
- ▷ Skills for Care funding to support adult social care funded employers of PAs should be extended to include those PAs who support children and young people.

**9 People who are left without PA support, or are worried about their PA, need to know how to get help right away**

- ▷ Everyone supported by a PA, and their unpaid carers, should know exactly who to contact at the council or the NHS, including out of office hours, if they are left without PA support for any reason.
- ▷ People should know what to do if they have concerns about the actions or behaviour of their PA, including how to raise a safeguarding concern.
- ▷ Everyone supported by a PA should know how to get access to mental health and wellbeing support for their PAs, and for themselves, if needed.

**10 More assurance and oversight of the local PA market by commissioners**

- ▷ Commissioners have a duty to ensure a sufficiency and diversity of PAs to meet demand and should exercise more oversight of their local PA market. This includes the effects that competition, and limits on what people are able to pay, are having on people's ability to recruit and retain PAs.
- ▷ Government should ensure councils have enough funding to enable them to achieve the expectations set out in Care Act Guidance (chapter 12) about direct payments, but should also hold councils more to account for fulfilling these duties, including how they shape and manage the local PA market so that there is genuine choice in how support needs can be met.
- ▷ Commissioners should seek regular feedback about the quality, standard and reliability of support on offer from those they commission to assist people supported by PAs.

**11 Better understanding by social workers and assessors of the direct payments system**

- ▷ Better training and understanding on the part of social workers and assessors and Continuing Health Care workers

**“ I am the same legal employer as a big company. It means I have to know everything a big company does and treat my staff the same - when one became pregnant I had no idea what to do. But turned out I had to act the same as a company who have a huge HR department - how am I supposed to know all the laws and rules?! ”**

about how direct payments and personal health budgets operate is needed to ensure that people are given accurate and consistent information, and that the principles of independence, choice and control underpinning direct payments are understood.

## CONCLUSION

We know what good, personalised care and support looks like in practice, through TLAP's **Making it Real** framework. Our report indicates that the reality of people's experience has a long way to go to match the ideal described in Making it Real and we need to close this gap.

The numbers of people who told us they had been left with no PA support for long periods of time is concerning, as are the mental health and wellbeing impacts on people of not being able to recruit and retain the support they need, when they need it. People who have been recruiting PAs for many years said it was more difficult now than it has ever been. Others had not been able to recruit a PA since getting their direct payment or personal health budget and had given up hope of ever finding anyone suitable. People who did have support in place worried about being able to replace a PA who left. Some had to compromise on the quality of PAs they were willing to accept otherwise they would have no-one, others had to choose which parts of their support plan would not be met to stay within the budget set by their funders.

It was very clear from the quantitative data, and the stories people told us, that the direct payments and personal health budgets system is not working as set out in the Care Act for many people. Few people in our survey saw themselves as having the choice and control they wanted over how they could use their direct payment or personal health budget to meet agreed outcomes in the best way for them and we need to work together to improve this situation.

**“ We need to make social workers more educated and held accountable. I have had one tell me I COULDN'T pay my PA minimum wage, that I had to pay them UNDER minimum wage!!! ”**

**Many people who completed the survey offered their suggestions so that more people have the opportunity to personalise their care and support. We should see this as an agenda for change.**

# APPENDIX – SURVEY SCOPE

## THE SCOPE OF OUR SURVEY:

- 1 We focused on PA recruitment and retention as that's where we were hearing pressures were greatest, and also to complement other workforce surveys.
- 2 The online survey had to be accessible for use on mobile devices and screen-readers and written in plain English.
- 3 We wanted it to be simple and easy for people to complete.
- 4 The survey questions covered the pandemic period from March 2020 to the end of January 2022. We agreed that we'd not focus purely on the effects of the pandemic as some people said their PA recruitment and retention challenges were not necessarily pandemic-related, though it had exacerbated things.
- 5 We asked a mixture of yes/no questions and more open questions where people could tell us their stories.
- 6 We didn't ask people for any personal information so that no-one one participating could be identified, meaning we could share our findings widely and openly.
- 7 The survey was open anyone who employs PAs, or who is supported by a self-employed PA, and who pays for their PA with a direct payment, personal health budget or from their own money. This included children and young people who are supported by a PA, as well as adults of all ages. We defined a personal assistant as a person who provides support services but is not provided through a care agency, and included private support workers and private care assistants.
- 8 We agreed that our main way of distributing the survey would be through the networks of people involved in the survey design. This approach turned out to be absolutely critical to the success of the survey.
- 9 We told people how they could get a copy of our findings once they were published.

## USING FINDINGS FROM OUR SURVEY

Please feel free to share and reference the findings, headlines, and recommendations from the survey. All we ask is that you credit the Survey Design Group, Think Local Act Personal and the Local Government Association.

Because people gave us so much feedback about their experiences, we've only been able to use a small proportion of what people told us in this report. If you're interested in looking at any of the issues highlighted in this report in more depth, or have any specific queries about the survey, please feel free to get in touch with [liz.greer@local.gov.uk](mailto:liz.greer@local.gov.uk) or [martin.walker@tlap.org.uk](mailto:martin.walker@tlap.org.uk)





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We'd also like to thank everyone supported by a PA who took the time to complete the survey and provide us with such a rich picture of the realities of living through a very challenging time.

## **Useful resources**

**[Better Direct Payments: from insight to action](#)**

**[Improving Direct Payments Oversight](#)**

**[Direct payments: working or not working?](#)**

**[Personal Budgets Outcome Evaluation Tool](#)**

**[Social Care Innovation Network](#)**

**[Personal budgets minimum process framework](#)**

**[The 3 R's of Social Care Reform](#)**

**[Payment Cards as a means of managing a personal budget](#)**

**[thinklocalactpersonal.org.uk](http://thinklocalactpersonal.org.uk)**

**[info@tlap.org.uk](mailto:info@tlap.org.uk) [@tlap1](#)**

**[local.gov.uk](http://local.gov.uk)**

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Designed by Matt Crane – [mattcrane@outlook.com](mailto:mattcrane@outlook.com)