

Self-employed personal assistants (SEPA)s in adult social care

A review of literature

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Self-employed personal assistants (SEPA)s in adult social care: A review of literature

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This work was researched and compiled by Sanah Sheikh of Social Care Institute of Excellence.

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1. Introduction

The Social Care Institute of Excellence (SCIE) were commissioned by Skills for Care to produce a review of the published literature around the following key themes:

1. National policy and regulation relating to using direct payments and Personal Health Budgets (PHBs) to engage personal assistants (PAs)
2. Trends and preferences for accessing care and support at home
3. Attitudes towards and support for using self-employed personal assistants (SEPAs)
4. How the local market for SEPAs operates
5. Support and guidance needed by SEPAs
6. Issues faced by and views of PA employers and people who engage SEPAs

This was timely, particularly because as a result of the pandemic, the profile of the PA role had been raised, but the issues of how people find, recruit and manage PAs were widespread and increasing. Recent reports published by Think Local Act Personal (TLAP) (2022) and Skills for Care (2022a) have highlighted these issues. Additionally, the PA role was being increasingly accessed by people not only receiving direct payments but also those in receipt of Personal Health Budgets (PHBs).

1.1 Methodology

An iterative approach to the literature search was taken, refining the search strategy, terminology and sources as and when needed. This helped ensure varied types of literature that covered all the themes were identified.

The full list of sources consulted are included in the table below:

Source	Type of organisation/repository
<ul style="list-style-type: none">• Google Scholar• Social Care Online• British Nursing Index• CINAHL• HMIC• EMCARE	Databases
Think Local Act Personal (TLAP)	Charity / partnership of 50 organisations

Source	Type of organisation/repository
Skills for Care	Charity / workforce development and planning body for adult social care
The Kings Fund	Independent charitable organisation working to improve health and care in England
Local Government Association (LGA)	National membership body for local authorities
Skills for Health	Not-for-profit organisation committed to the development of an improved and sustainable healthcare workforce
ADASS	Membership charity and leading social voice of Adult Social Care
NHS Confederation	Membership charity that supports healthcare system in England, Wales and Northern Ireland
Department for Business, Energy & Industrial Strategy	Government department
Department of Health and Social Care	Government department
NHS England	Leads the NHS in England
HM Revenue and Customs	Government department
Low Income Tax Reform Group	Part of the Chartered Institute of Taxation – an educational charity
London Self-Directed Care Forum	Network of professionals
<ul style="list-style-type: none"> • PSSRU (Kent) • NIHR HSCWRU (Kings) • SPRU (York) 	Research institutes
<ul style="list-style-type: none"> • Catherine Needham, University of Birmingham • Jill Manthorpe, NIHR School for Social Care Research 	Academics
Community Catalysts	Company that helps people and communities to start and run small enterprises and community businesses

We used a broad range of terminology in our searches to ensure that any potentially relevant literature was identified. This included:

- Personal assistants/assistance
- Support workers
- Private carers
- Personalisation
- User choice

The types of literature that we deemed could be potentially relevant were:

- Policies
- Guidance
- Research
- Articles
- Case studies
- Court cases

Finally, we restricted our search to literature published from 2015 onwards. However, we made an exception for legislation published before 2015 that was still applicable and relevant in 2022.

1.2 Included literature

After abstract and full text sifting, a total of 35 documents were identified for inclusion. The spread across the research themes is highlighted in the table below:

Research theme	Number of documents
1. National policy and regulation relating to using direct payments and Personal Health Budgets to engage personal assistants	7
2. Trends and preferences for accessing care and support at home	7
3. Attitudes towards and support for using self-employed personal assistants	8
4. How the local market for self-employed personal assistants operates	5
5. Support and guidance needed by self-employed personal assistants	4
6. Issues faced by and views of personal assistant (PA) employers and people who engage self-employed personal assistants	17 ¹

¹ Most of these reflected the views and experiences of people who directly employ PAs, rather than those who engage SEPAs.

The spread across types of literature is included below:

Type of literature	Number
Primary research - survey, mixed or qualitative	17
Policy / Guidance / Consultation	9
Articles	4
National statistics	3
Case study	1
Legislation	1

2. Theme one: National policy and regulation relating to using direct payments and PHBs to engage PAs

2.1 Overview of relevant literature

There were seven documents that addressed this research theme. Three of these were national policies on direct payments published by the DHSC, two were guidance on PHBs by NHS England and NHS Improvement, one was national legislation on direct payments in the NHS and one was guidance on PA working by Skills for Care. Sub-sections 2.2 to 2.7 summarise what we found.

2.2 Local authorities should provide information, advice and support for those employing PAs

According to the DHSC, the Care and Support statutory guidance (2022a) was last updated in January 2022. It is important to note that the language used in the Act relates only to the ‘employment’ of PAs using direct payments, that is, there is no mention of engaging SEPA. When it relates to using direct payments to employ staff such as PAs, the regulation focuses primarily on the responsibilities that local authorities have in ensuring that potential employers have the **support, advice and information** they need. The key points relating to this include:

- *Local authorities should help people who fund their own services or receive direct payments, to ‘micro-commission’ care and support services and/or to pool their budgets, and should ensure a **supporting infrastructure** is available to help with these activities.... This should include facilitating organisations that support people with direct payments and those whose care is funded independently from the local authority to become more informed and effective consumers and to overcome potential barriers such as **help to recruit and employ personal assistants** and to assist in overcoming problems and issues.*
- *The local authority should provide the person (and/or their independent advocate or any other individual supporting the person, if relevant and if the person wishes this) with appropriate **information and advice** concerning the usage of direct payments. This should include:*
 - *the difference between purchasing regulated and **unregulated services** (for example regarding personal assistants)*
 - ***signposting** to direct payment support and support organisations available; in the area (for example, employment, payroll, admin support, personal assistants, peer support)*

2.3 Local authorities need to be involved in contingency planning and provide access to training opportunities for PAs

The Care and Support statutory guidance (2022a) also highlighted the responsibility and role of local authorities in relation to **contingency planning** if a PA is sick or absent:

- *Where a direct payment recipient is using their payment to employ a personal assistant (PA) or other staff, the local authority should ensure that there are clear plans in place of how needs will be met in the event of the PA being absent, for example due to sickness, maternity or holiday. Local authorities still have **a duty to ensure needs are being met**, even if the person makes their own arrangements via the direct payment, so contingencies may be needed. Where appropriate, these should be detailed in the care and support plan, or support plan.*

There is also mention of the fact that local authorities should ensure that PAs are able to access **training opportunities**:

- *Training should take place at all levels in an organisation and be updated regularly to reflect current best practice. To ensure that practice is consistent – no staff group should be excluded. Training should include issues relating to staff safety within a Health and Safety framework and also include volunteers. In a context of personalisation, boards should seek assurances that directly employed staff (for example, **Personal Assistants**) **have access to training and advice on safeguarding**.*

2.4 Local authorities need to offer greater support to directly employed PAs and SEPAs

Guidance published by the DHSC (2022b) during Covid-19 for people receiving direct payments and PAs highlighted the need for greater support to be provided to PAs during this time. This also included SEPAs to a certain extent, although it is important to note that this guidance was withdrawn on 1 April 2022 when the government published its plan for living with Covid-19².

However, it can be interpreted as the beginning of a shift in attitudes towards direct payments and PAs by policy makers. Some of the key points made related to support with accessing **testing, vaccination and Personal Protective Equipment (PPE)**:

² [COVID-19 Response: Living with COVID-19 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/covid-19-response-living-with-covid-19)

- *The government consider all PAs to be key workers, **both now and in the future**...All health and social care workers are key workers, and should therefore be **vaccinated against flu** if they are directly involved in providing care and support to other people. This includes all personal care assistants/PAs, including self-employed PAs and those employed through self-funders...Neither individuals nor their PAs will have to pay for the flu vaccination for PAs – it will be paid for by the NHS complementary scheme.*
- *Directly employed or **self-employed PAs** who provide care that requires them to come within 2 metres of the person they support and who support adults over the age of 18 are eligible for regular testing.*
- ***Antibody testing** is now available across England and is also being provided free of charge to anyone employed in adult social care. Personal assistants who provide for the care and support needs of adults are eligible, across health and social care, and also when employed by self-funders.*
- *If you employ a personal assistant, you are **entitled to free PPE** for the COVID-19 needs of your personal assistant, in line with the guidance below on wearing the right PPE. You can access free PPE either through your local authority or CCG. If you're unsure of who is in charge of this distribution locally, you could contact your local authority or CCG who will assist you. You can also see a list of local contacts. The organisation funding your direct payment – either your local authority or CCG – has responsibility to ensure that you and PAs that support you have the PPE needed to keep safe. If you cannot access PPE through the routes set out above, they must support you to get the PPE you and your PAs need during this time, as quickly as possible, to keep you safe.*

The guidance also emphasised that any extra expenses incurred by PAs would need to be covered during this period, through additional funding if need be:

- ***Covering extra expenses faced by your PA during the pandemic (for example, car parking charges if unable to use public transport due to local lockdowns)** - In some circumstances, this will be appropriate and necessary in order for you to receive the care and support you require during the pandemic (for example, where public transport is reduced due to a local lockdown and a PA cannot reach your home without using their own car, but by doing so incurs car parking fees). It is vital that you continue to receive the care and support you need to remain safe at home, and the government recognises the importance of support delivered by key workers such as PAs. As an employer, you will need to consider whether the additional expense is essential, appropriate and cost-effective. If in doubt, or if additional funding will be needed, you should discuss this with your named contact at your local authority or CCG.*

2.5 Local authorities and Clinical Commissioning Groups (CCGs)³ need to be more flexible with regards to how direct payments are used

Two pieces of guidance were published by the DHSC (2022b, 2022c) during Covid 19 - one related to people receiving direct payments and PAs, and the other to local authorities and CCGs. These emphasised the importance of taking a flexible approach towards the care and support people receiving all forms of direct payments to maintain their wellbeing. Both were withdrawn on 1 April 2022, when the government published its plan for living with Covid-19⁴, but as mentioned above can be interpreted as the beginning of a shift in attitudes towards direct payments and PAs by policy makers:

- *The fundamental approach to payments should reflect the trust needed between providers and receivers of payments that the money will be used as intended to meet agreed outcomes for care, support and improved wellbeing. Payments should continue to be used flexibly and innovatively with no unreasonable restrictions placed on the use of the payment, so long as it is being used to meet eligible care and support needs.*

With regards to **flexibility in how PAs are engaged**, a number of scenarios were mentioned:

- *If your PA becomes sick or is unable to work, you or somebody on your behalf should try to organise different arrangements. For example, it may be **that another PA is willing** and able to take on further work to provide you with the care and support you need. If other arrangements cannot be put in place, it will be necessary to implement your contingency plan. For example, where they are sufficiently trained to do so, friends or family members may be willing to step in and support you to receive the care and support you need.*
- *In support of this during the COVID-19 pandemic, local authorities and CCGs should review local operating procedures and adapt or suspend those which prohibit or limit flexibilities that **enable family members, including those who live under the same roof**, to be employed as personal assistants and be paid through a direct payment or personal health budget for the period covered by the Coronavirus Act 2020.*
- *Consideration should also be given to allowing direct payment and personal budget holders to **pool funds** with others receiving these payments as part of a contingency plan in case care and support is interrupted, for example, because a personal assistant is unable to work.*

³ Clinical Commissioning Groups were replaced on 1 July 2022 by Integrated Care Systems (ICSs) as a result of the Health and Care Act 2022. See: <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/>

⁴ [COVID-19 Response: Living with COVID-19 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/covid-19-response-living-with-covid-19)

2.6 PHBs can be spent on any services agreed in the care plan that help meet needs

Legislation on PHBs by Gov UK (2013) and guidance associated with this legislation (NHS England, 2014) said that in principle:

- *A direct payment can be spent on a **broad range of things** that will enable the person to meet their health and wellbeing needs. A direct payment may only be spent on services agreed in the care plan. The term 'services'.... refers to anything that can be bought and which will meet someone's health needs. The care plan must be agreed by both the CCG and the person receiving care, or their representative. Before signing off the care plan, the CCG must be reasonably satisfied that the health needs of the patient can be met by the services specified in the care plan.*

However, the legislation also provided a list of '**barred**' services which include:

- ***A direct payment cannot be used to purchase** primary medical services provided by GPs, as part of their primary medical services contractual terms and conditions nor is a direct payment suitable for the following public health services:*
 - *vaccination or immunisation, including population-wide immunisation programmes.*
 - *screening,*
 - *the national child measurement programme*
 - *NHS Health Checks*
- *A direct payment cannot be used for urgent or emergency treatment services, such as unplanned in-patient admissions to hospital or accident and emergency.*
- *A direct payment cannot be used for surgical procedures*
- *A direct payment cannot be used to pay for any NHS charges, such as prescription or dental charges*
- *A direct payment cannot be used:*
 - *to purchase alcohol or tobacco,*
 - *for gambling,*
 - *to repay a debt (with the exception of debts relating to services specified in the care plan).*
- *In addition they cannot be used to purchase anything illegal or unlawful.*

2.7 Clinical Commissioning Groups (CCGs)⁵ need to provide a range of advice, information and support that people may need as employers

Legislation on PHBs by Gov UK (2013) and guidance associated with this legislation (NHS England, 2014; NHS England, 2017) very clearly outlined the information, advice and support that CCGs need to provide to people who use their direct payment to employ staff, recognising that for many people this may be their first experience of being an employer:

- *This support could include provision for payroll, training, information and advice on management of employment-related issues (for example, employment contracts, compliance with statutory requirements relating to sick leave, maternity leave, management of grievances, disciplinary procedures and dismissal).*
- *Where direct payments are being used to employ one or more people, the person receiving care, the representative or the nominee, should be made aware of their legal responsibilities as employers. CCGs should ensure that individuals are fully aware of their **responsibilities, and of any potential risks** and should be supported to manage them.*
- *There will also be **costs** associated with employing a member of staff directly, such as **National Insurance, training, insurance costs and emergency cover**. When setting the budget and agreeing the care plan, CCGs should ensure that the full cost of employing someone is included, and people must not be expected to bear any of these costs themselves.*
- *People should be informed of the local support available in relation to being an employer and the different options in relation to taking on staff, such as use of agencies. **Support services** may be provided by the NHS or local authority directly, by a commissioning support unit, **a user-led organisation or other private and voluntary sector organisations**. The costs of a support service can be paid for directly by the NHS or the local authority, or included in the budget. A support service can provide people with a range of advice and support, including*
 - *holding the direct payment*
 - *using it to pay for care and support services in line with the person's personalised care and support plan*
 - *payroll services and budgeting*
 - *recruitment of personal assistants*
 - *staff management and training*
 - *employment law and advice*

⁵ Clinical Commissioning Groups were replaced on 1 July 2022 by Integrated Care Systems (ICSs) as a result of the Health and Care Act 2022. See: <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/>

3. Theme two: Trends and preferences for accessing care and support at home

3.1 Overview of relevant literature

There were seven documents that addressed findings related to this research theme. Three of these were national statistics published by governmental bodies or other organisations, such as the Kings Fund. A further three were findings from primary research, surveys in particular and the final one also reported survey findings from a public consultation on the extension of PHBs and integrated personal budgets. Sub-sections 3.2 to 3.5 summarise what we found.

3.2 The uptake of Direct Payments and the employment of PAs

In their report on the personal assistant workforce, Skills for Care (2022a) noted that the number of direct payment recipients employing PAs initially rose by around 35,000 during the period of 2008 to 2013, which was in line with the increased uptake of direct payments. However, they estimated that the number of **direct payment recipients employing PAs had remained stable** at approximately 70,000 between 2014 and 2020. According to a survey of employers in the same Skills for Care report, individual employers in receipt of direct payments had, on average, 1.85 PAs each, creating around 130,000 jobs. A little more than half (53%) employed a family member or friend, while the rest employed people they did not know before they started in their roles.

Additionally, the Kings Fund (2022) reported that overall, 26.6% of people accessing adult social care used direct payments, down from 28.1% in 2015/16. This represented 38.4% of working-age adults and 15.3% of older people. Additionally, the number of people using direct payments was lower than in 2015/16 and had fallen for each of the past four years, as highlighted in Figure 1 overleaf.

Figure 1: Change in number of direct payment recipients compared to previous year
Change in number of recipients compared to previous year

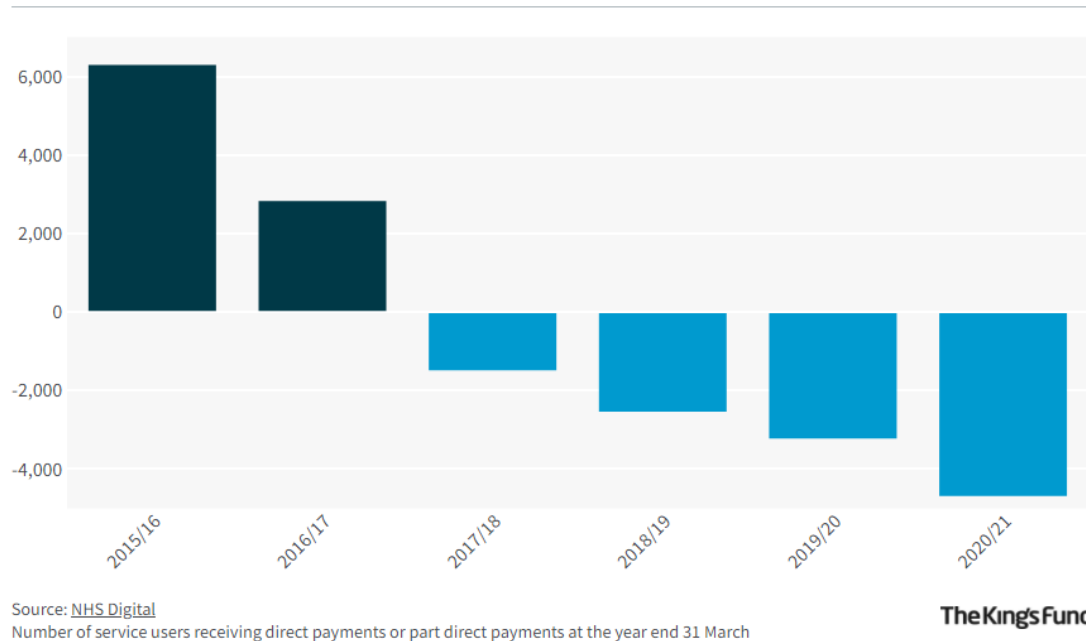


Image copied from *The Kings Fund Social Care 360 (2022)*

A few possible reasons for this decline were offered by the Kings Fund (2022). Firstly, that despite government guidance that local authorities should be as flexible as possible in their oversight of direct payments during Covid-19, this had made little difference. Direct payments, due to their very nature, require people to be more involved and take on more management and administrative responsibilities, and whilst some local authorities provide support with this, others do not and this can act as a deterrent for opting for a direct payment compared to a managed service. Additionally, if there is limited choice of local services on which to spend a direct payment, this may further dissuade people from wanting to take on the extra work required.

However, whilst the overall uptake of direct payments appeared to have declined, there was evidence to indicate that there had been an **upward trend in the uptake of direct payments amongst adults with learning disabilities**. Public Health England (2018) reported on the trends in adults with learning disabilities getting different types of social care support, as highlighted in Figure 2 overleaf.

Figure 2: Number of adults with learning disabilities aged 18-64 years in England supported by local authorities getting different types of long-term social care support during the year: 2009 to 2010 to time period 2017 to 2018.

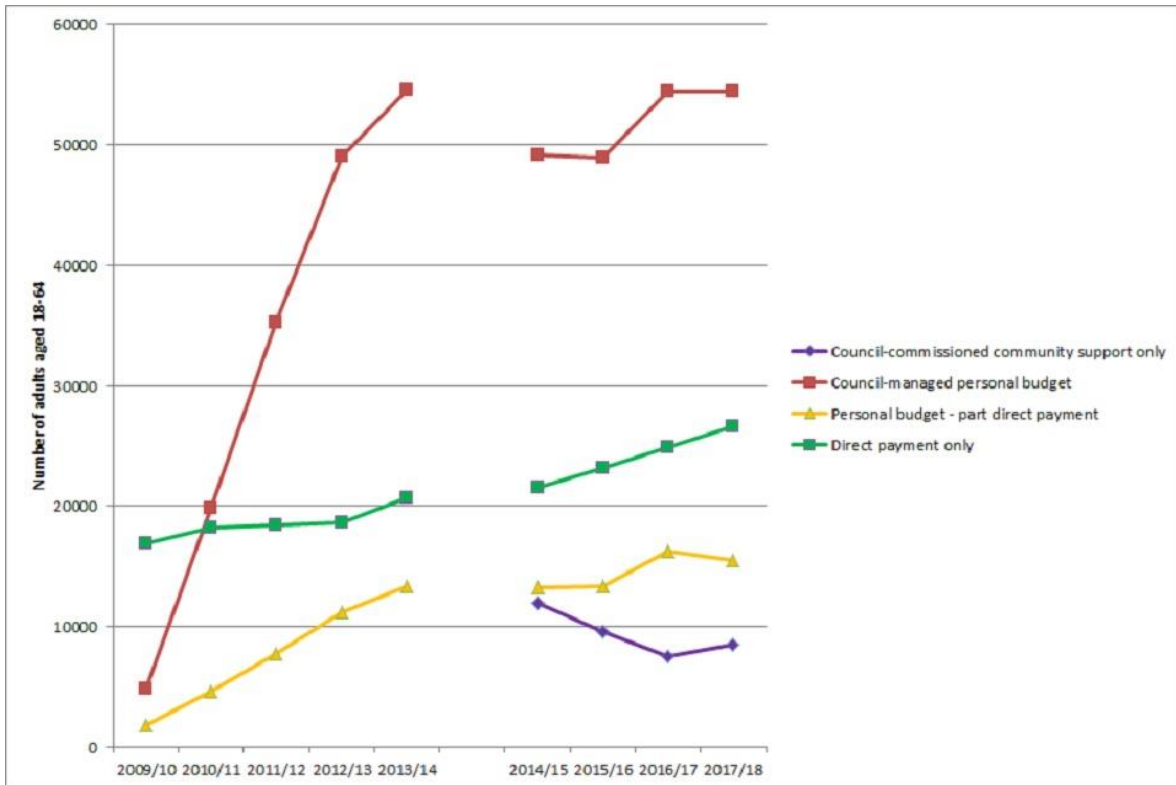


Image copied from Public Health England (2018) *People with learning disabilities in England. Chapter 5 - Adult social care.*

They specifically commented on the upward trend in the number of adults with learning disabilities getting long-term social care in the form of a direct payment only between 2017/18 and 2014/15 - an increase of approximately 1,660 people per year. They also commented that this was a faster upward trend from 2009/10 to 2013/14, when there was an increase of 944 people per year.

3.3 The uptake of and attitudes towards PHBs and the employment of PAs

According to statistics published by People Places Lives (2022) the number of people in receipt of PHBs in 2021/22 steadily grew from:

- 80,148 at the end of Q2, to
- 101,053 at the end of Q3, to
- 124,964 at the end of Q4.

The Q4 2021/22 data published by NHS England Digital (2022) showed that 22% of PHBs were delivered as a direct payment; 74% as a notional payments; and 5% as a third-party budgets.

This increase in uptake was in line with the findings of a public consultation run by the DHSC and the NHS (2019) on the potential extension of PHBs and integrated care budgets to a broader group of people. The findings demonstrated broad support for all proposals with an average of 83.5% of respondents agreeing with each proposal. The consultation also sought views on whether, when extending the right to a PHB, an additional right should be created to include an explicit right to have this budget managed through a direct payment. The questions on extending rights to direct payments were on average supported by 86% of respondents, demonstrating strong levels of support.

Finally, many responses to the consultation referenced the independence and freedom that people are able to achieve through adopting a more personalised approach. In particular, direct payments were identified as a mechanism that can really enable individuals to take the responsibility they want when managing their own care. This individual approach was thought to contribute toward recovery, as people feel invested in their treatment and care. A short case study, highlighting the employment of PAs was included:

“Darren is in his 40s with tetraplegia. His 24-hour care package enabling him to live at home was provided by a single agency, but he wanted more independence. He discussed with commissioners how he could go out with his carers to a wide range of social activities, and without them being dressed in uniform. Together they agree he will employ a team of personal assistants, using a personal health budget. He was supported to achieve this, and is now enjoying being able to socialise with friends.”
(DHSC and NHS England, 2019; pp.8)

Additionally, Skills for Care’s (2022a) survey of individual employers in receipt of PHBs and their PAs found approximately 25,000 people in receipt PHBs were individual employers and that they were employing around 75,000 PAs. Additionally, individual employers in receipt of a PHB had on average, 3.21 PAs each. PAs employed by people in receipt of PHBs were more likely to hold a relevant health or social care qualification (45%) compared to PAs employed to support social care direct payment recipients or self-funders (40%) or care workers (42%). The most common areas PAs employed by people in receipt of PHBs, supported their employer with, was mobility/moving and assisting (89%), followed by household duties (84%) and eating and drinking (82%).

3.4 Older people’s preferences for housing in later life

The international evidence on older people’s housing preferences has been growing in recent years. However, there has been a lack of such research in the UK. In order to address this gap Mulliner et al. (2020) conducted a survey of 767 UK residents aged 55+ of which 649 valid responses were included in the data set for statistical analysis. The findings indicated a **strong desire for independence in older age**.

More specifically, in order to gain a general view on preferences to ‘age in place’, respondents were asked to what extent they agreed or disagreed with five statements:

- 63% of respondents agreed that they want to ‘stay put in their current home’
- 29% agreed that they want to ‘downsize from their current home’
- 60% agreed that they are ‘aware of the different specialist housing options for older people’
- 25% agreed that they ‘want to move to such specialist accommodation’
- Almost 90% of respondents indicated a desire (agreement) to ‘live independently as long as possible’.

Other results indicated that in later life, the most preferred option for over a third of respondents was to live independently (37%). This was followed by supported living (17%), extra care housing (13%), retirement villages (12% and, nursing/care homes (9%), with the least preferred option being sheltered housing (5%). This is depicted in Figure 3 below which compares current living situations with current preferred options and preferences for later life.

Figure 3: Preference for housing setting

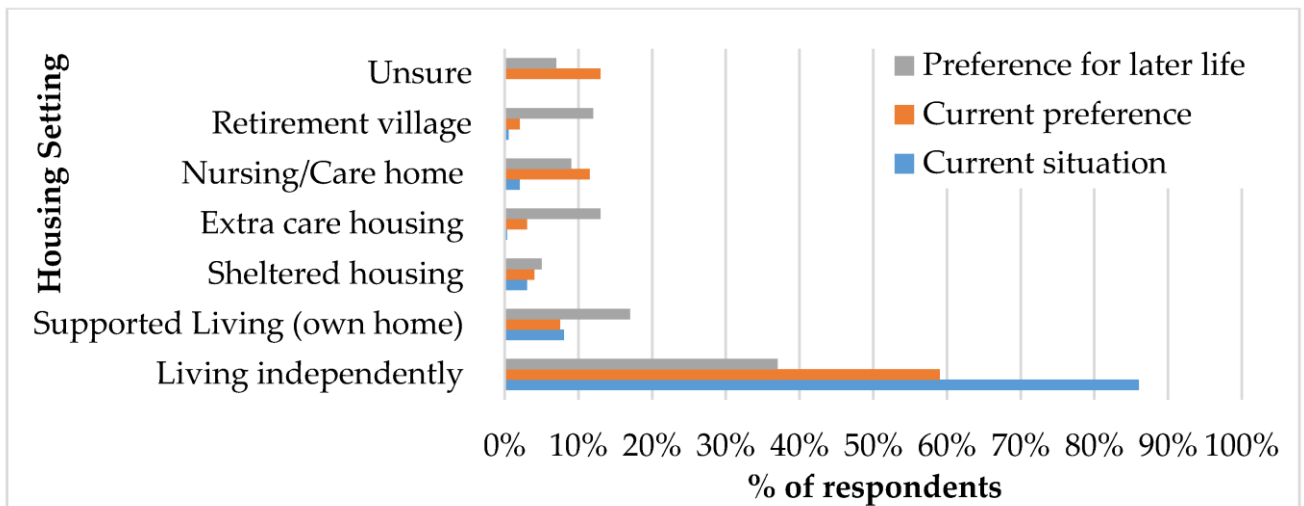


Image copied from Mulliner E., et al (2020)

The findings also indicated that people place significant importance on adaptations and support that will enable them to **stay independent and at home as long as possible**. For example, the 65–74 and 75+ age groups both placed a significantly higher level of importance on having ‘assistive technology within the home’, a home with an ‘adaptable design to facilitate ageing in place’, and ‘storage space for wheelchair or scooter in comparison to the youngest age group (55–64). The authors argue that *‘this is not surprising given that there is extensive research indicating that most older people prefer to continue living in their own home for as long as possible’* (Mulliner et al., 2020; pp. 13).

3.5 Upward trend in adults with learning disabilities choosing to live with family / friends

In addition to older people indicating a strong preference for staying in their own homes as long as possible, there was also evidence to indicate that **adults with learning disabilities were also increasingly choosing to live with family and/or friends** rather than in other settings. Statistics published by Public Health England (2018) indicated that in 2017/2018 the most common living situation for working age adults with learning disabilities getting long-term support from the council was settled living with family/friends. This was an increase of 1,127 people per year from 2014/2015. There was also an upward trend from 2009/2010 to 2013/ 2014 - an increase of 2,625 people per year. Moreover, from the period 2014/2015 to 2017/2018 the number of adults with learning disabilities living in residential care has steadily decreased. This is highlighted in Figure 4 below.

Figure 4: Number of adults with learning disabilities aged 18-64 years in England in accommodation 1 April - 31 March: 2009 to 2010 to the period 2017 to 2018

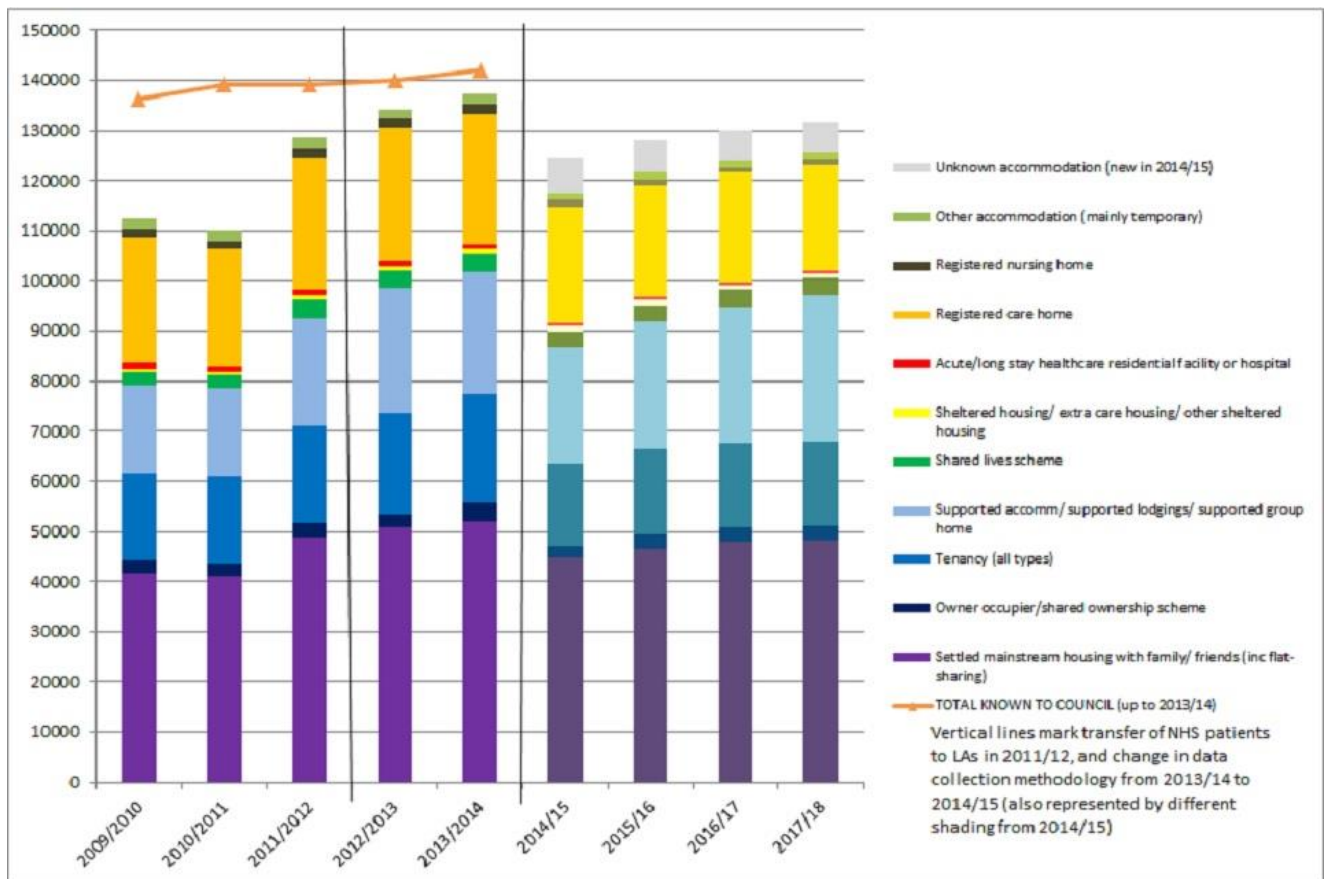


Image copied from Public Health England (2018) *People with learning disabilities in England. Chapter 5 - Adult social care.* Public Health England

4. Theme three: Attitudes towards and support for using SEPAs

4.1 Overview of relevant literature

There were eight documents that addressed findings related to this research theme. Six documents consisted of findings drawn from primary research, either surveys or a mix of surveys and qualitative research. Four of these studies were primary research conducted with PAs and other stakeholders including local authorities and other organisations that support and/or work with PAs. However, only one of these focused specifically on SEPAs. The others included a mix of directly employed and SEPAs, with the latter usually accounting for a small part of the sample. The other two studies focused on the experiences of community micro-enterprises, which often consisted of sole-traders whose roles and responsibilities very closely aligned with those of PAs, and were therefore considered relevant for inclusion. The literature also included two pieces of advice and guidance regarding the employment status of PAs. Sub-sections 4.2 to 4.4 summarise what we found.

4.2 Benefits and added value of being SEPAs / sole traders

Self-Directed Support Scotland (SDSS) (2021) carried out a small-scale survey of SEPAs, those who engage them, local authority staff and other stakeholders. Of a total sample of 39 respondents seven were SEPAs. Although the number of respondents is very small there was a great deal of consensus amongst them about why they had set up as self-employed and the added value and benefits they associated with this status. The key benefit identified was that of **flexibility**. This flexibility was associated with being able to:

- set one's own hours and manage one's own time
- to take on other work or roles when they want or need to
- respond to their clients' needs more effectively
- choose the clients they want to work with
- set one's own hourly rates

Another reported benefit was being able to **maximise their income**, for example by working more hours and multiple roles. Whilst the flexibility associated with choosing clients and responding to their needs also resulted in **deeper connections** with their clients.

Many of these views were also echoed in studies conducted with community micro-enterprise schemes by the New Economics Foundation (2020) and Needham and Glasby (2021). Those working as sole-traders, with a close approximation to PA roles, identified two important advantages of moving away from more traditional jobs in social care.

The first was **autonomy** - the participants very much appreciated being able to choose who they support and how they support them. Many described having had bad experiences working with hierarchical care agencies whose culture of 'whistle-stop care' and 'time and task' model had forced them to rush from one client to another, thereby providing inadequate support. Operating as sole-traders or small micro-enterprises enabled them to be flexible and responsive to people's needs. In the words of one commissioner, this results in a 'distributive model of leadership', where decision making is devolved to the lowest possible level: that of the people engaged in the activity of giving and receiving care. They develop the support together. One sole-trader described an example of how she has gone in to provide a meals service, and then went further than that because of the perceived need:

“Took this new man on. Dementia. It was a, like, holiday cover. His sister’s gone away. Says, ‘Will just go and, you know, do his dinner for me? Just put the vac round?’ He’s got a dog. Cause he’s got dementia, every time the dog barks, he feeds him. So he’s just barking all the while, so he’s just giving the dog food. And [his sister] says, ‘Just do his dinner and go.’ So now, what I do, put his dinner in when I get there, wash up, wipe the sides down, put it on the plate, put the vac round, and when that’s cooled down, give him his dinner and take the dog for a walk. Stops the dog barking and he can eat his dinner in peace. And he’s ate at least three-quarters of his dinner every day.”

(Needham and Glasby, 2021; pp.9)

The second advantage was having **more control over work time**. Again, those who had previously worked for home care agencies described getting burnt out because of long, high pressure shifts. Being self-employed enabled them to decide their own hours and organise their workload in a way that suited them.

The New Economics Foundation (2020) report noted that these benefits helped to explain why micro-entrepreneurs **found their work more rewarding**. They reported that since setting up a micro-enterprise, four in five (81%) of those surveyed reported an increase in the extent to which they feel that what they do in their life is valuable and worthwhile. Similarly, three in five (61%) of those surveyed said that their **work-life balance** had improved since setting up a micro-enterprise.

4.3 Issues and risks associated with working with SEPAs

In the limited literature on this topic there were a few key but important themes that emerged. Firstly, Woolham et al (2019) in their semi-structured interviews with PAs and other stakeholders drew attention to the risks employers ran by working with people who may claim to be self-employed but were in fact **not registered with HMRC**. For example, some stakeholders worked in organisations that managed PA registers where PAs were invited to effectively 'self-register' and where no information provided was verified and no background checks are made. Instead, potential employers were advised to verify all information and conduct checks themselves. This **responsibility of verification** was also highlighted in the Low Income Tax Reform Group (LITRG) guidance (2022) on ascertaining whether PAs are self-employed or not. The authors state that:

“It is very important to understand that it is your responsibility to correctly decide the ‘status’ of your PA (that is, whether they are employed or, less commonly, self-employed) based on the specific working arrangements between you, so that you can operate PAYE if you need to. You cannot just pick a status because it is either better for you or because the PA wants to be self-employed or because the PA states they are self-employed for the work they do for others.”

(LITRG, 2022; pp.2)

Another risk is that while PAs may have registered with the HMRC they **did not actually meet the criteria for being self-employed**. In both these cases **tax liabilities and national insurance contributions** can be transferred to people engaging SEPAs as the former can in fact be deemed to be employers. With respect to this the LITRG state:

“Tax law can override what either you or your PA intended. This means that even if you have a contract with your PA that says they are self-employed, if the facts indicate otherwise, HMRC can decide that they must be treated as your employee. Be aware that employment status is not a choice. There have been cases where a court has ruled that a carer who was previously considered ‘self-employed’ is in fact legally an employee.”

(LITRG, 2022; pp.2)

This is also echoed by Skills for Care (2017; pp.22) in their guidance on understanding the employment status of PAs where they state, *‘If an employment status is determined as wrong (by HMRC), individuals and their employers may have to pay unpaid tax and penalties, or lose entitlement to benefits.’*

Stakeholders in the study conducted by Woolham et al (2019) also referred to a 'hidden' or 'black market' of PAs who receive cash in hand as payment which can put people at particular risk of **colluding with illegal activities** such as benefit fraud or employing people without the right to work in the UK. One stakeholder described one such experience:

'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'.

(Woolham et al., 2019; pp.55)

Some stakeholders felt that **PA registers could be used as a form of a 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 was also an effective way for PAs to secure employment.

These findings were also echoed in a survey of and focus groups with PAs and gatekeeper organisations conducted by the Scottish Centre for Employment Research (2018). In addition to the risk of employers being faced with large HMRC bills for unpaid National Insurance contributions that they had assumed a PA was paying, the study also identified the precarious situation of PAs who are self-employed and could for example lack a contingency fund or be paid maternity leave.

4.4 Attitudes towards engaging SEPAs

There was little, but **mixed evidence** on the extent to which local authorities and NHS bodies support and permit people receiving direct payments or PHBs to engage SEPAs. For example, in their small-scale survey of SEPAs, local authority staff and other stakeholders, Self-Directed Support Scotland (2021) found that when asked if their local authority permits the use of a direct payment to contract with a SEPA, the majority of respondents (23) said yes, ten were unsure, three said no and three said only in exceptional circumstances.

In another survey of local authorities and NHS organisations conducted by Skills for Care (2016) respondents reported a mixed number of employment models where local authority respondents were more likely to report the existence of SEPAs compared to NHS organisations (73% compared to 50% of NHS respondents). Respondents from NHS organisations were more likely to report that a traditional care agency or an organisation taking employment responsibility existed (74% and 70% respectively vs the 51% and 41% reported by local authorities). However, it is important to note that whilst these figures provide a picture of prevalence, they do not in fact provide any information on frequency or extent of use of SEPAs.

The same study reported that the employment status of PAs remains a **contentious issue and reported attitudes varied** from '*I want us to have a policy that we will not entertain the use of self-employed PA*' to '*We have embraced this – they (PAs) have to provide evidence of this*' (Skills for Care, 2016; pp.11).

The authors report that in practice it was likely that the self-employment of individual PAs was being considered on a **case-by-case basis** and sites were providing employers and their PAs with advice and guidance as well as conducting their own checks - include seeing the results of an employment status indicator check, evidence of registration with HMRC and checking national insurance numbers, to validate employment status.

5. Theme four: How the local market for SEPAs operates

5.1 Overview of relevant literature

This research theme aimed to identify the operating models of organisations that support and link SEPAs to job opportunities and to each other. It also aimed to understand how local networks of PAs are supported and managed with local authority and clinical commissioning group areas. There were only five documents identified as relevant to this research question including a mix of primary research, guidance and case studies. Sub-sections 5.2 to 5.4 summarise what we found.

5.2 User-led organisations (ULOs)

Guidance published by Skills for Care (2017b) provides a clear overview of the different ways in which people can engage PAs. For those who want to keep the choice and control offered by employing a PA, without the responsibility of becoming an 'employer', Skills for Care suggest working with a ULO. With this arrangement ULOs tend to take full responsibility for employing PAs, but service users retain the choice and control over who's employed and what they do. Two examples of ULOs and their operating models are provided:

- **ibk initiatives** - a family led social enterprise in Sheffield that aims to transform education and support so disabled young people and their families are included in their communities and enabled to live meaningful lives. They do lots of work including supporting families and individuals to recruit PAs and can also be more involved in the management of and even directly employing PAs.
- **Possibility People** - a user-led organisation in Brighton (previously called The Fed Centre for Independent Living) who have been running their Continuing Independence Service for a couple of years. They believe this service is perfect for people who want the chance to have control over their support, but don't want the responsibility of being an employer. As well as supporting people to directly employ their own PAs, Possibility People also provide a model of employment that can be considered as a bridge between a traditional domiciliary care agency and being an individual employer.

Both these ULOs stress the importance of similar values and practices. For example, there is a lot of emphasis placed on personalisation and **person-centred approaches**. For example, Possibility People '*provide a bespoke service to individuals who want to employ PAs and take time to find out about them, their families and friends, discuss their needs and learn about their lifestyle and things they like.*'

All the necessary **quality assurance and safeguarding checks** are also conducted by these ULOs, including DBS checks, ensuring the correct insurance is in place, checking references and the right to work in the UK. Finally, both organisations also recognise the importance of their continuing involvement in the relationship between service users and PAs, through some type of **supervision and oversight**. For example:

- ibk initiatives believes that supervision is key and is one of the reasons this model of employment works so well. They offer supervision services and they feel it really makes a difference to support the PAs and help the individual to be a 'good employer'. It also means that issues can be addressed early on before they become a bigger problem.

It is also interesting to note that Woolham et al (2019) in their in their semi-structured interviews with PAs and other stakeholders found that participants felt that it was important for PA registers to either be managed by ULOs or co-produced by them. They felt that this would confer greater legitimacy to the register and that user ownership or participation would lead to better quality management and experience.

5.3 Local authority registers or noticeboards

The literature also included good practice case studies of PA registers or noticeboards managed by local authorities. These included:

- The Personal Assistant Noticeboard – Portsmouth City Council (Skills for Care, 2016)
- The Isle of Wight Personal Assistant Hospital Discharge Initiative and PA Hub (Local Government Association (LGA), 2020)

Learning gained about the success and sustainability of these two initiatives also highlight similar factors. For example, both initiatives stress the importance of **working in partnership with ULOs**:

- Portsmouth City Council - The importance of maintaining the focus on enabling and empowering individuals which was possible through working with SPECTRUM in Southampton. The involvement of DPOs were fundamental in building the right foundation for the Noticeboard.
- Isle of Wight – The new approach has been sustained by working collaboratively with the local user led organisation to support the day-to-day management of the scheme

The importance of supporting, **advising and guiding service users and their families** was another important enabler. Similarly, providing a **person-centred** service was also stressed:

- Portsmouth City Council - Always put the person in need of care and support at the centre of any new service and the steps you will take to get there.

Finally, both initiatives also stressed the importance of **investing time and resource** in building and embedding a successful register. This can include dedicated recruitment activities, investing in PA market development team, and engaging with front line staff to raise awareness and support them to build their confidence to discuss the service with service users.

5.4 Other models that facilitate the engagement of SEPAs

A few other operating models were briefly mentioned in the literature. The first was described by Skills for Care (2017b) as **introduction agencies or online-market places**. These agencies 'match' potential service users with SEPAs based on shared interests and care needs as well as location and availability. Whilst we know anecdotally that this model is growing rapidly across the country there was little further detail provided in the literature.

Another model briefly described by Skills for Care (2017b) is where more **traditional domiciliary care agencies** offer a 'personal assistant' service. The prevalence of such a model was surprisingly high at 63% across local authority and NHS survey respondents (Skills for Care, 2016). In practice the services offered by these agencies are likely to be varied and include:

- the use of a domiciliary care agency's services to meet gaps in support; for instance, where a PA cannot be recruited to cover a small number of hours
- domiciliary care agencies offering more 'personalised' services; for instance, greater insistence on a single named carer per client or care workers undertaking tasks outside of the care plan, at the direction of the client
- agencies or organisations, taking on the role of the 'employer' but giving control and management of a PA to the person in need of care and support

Finally, a small number of respondents from the same study - 10% of local authority respondents and 2% of NHS respondents - reported the existence of **pools of PAs** selling their services to employers as a group (Skills for Care, 2016).

6. Theme five: Support and guidance needed by SEPAs

6.1 Overview of relevant literature

There were only four documents identified that were relevant to this research theme. Again, this is not surprising given the dearth of research that has been conducted specifically relating to the experiences of SEPAs. Three documents drew on findings from primary research, either surveys or a combination of surveys and qualitative fieldwork with PAs and other stakeholders. However, only one of these focused specifically on SEPAs. The other samples included a mix of directly employed and SEPAs, with the latter usually accounting for a small part of the sample. The last study focused on the experiences of community micro-enterprises, which often consisted of sole-traders whose roles and responsibilities very closely aligned with those of PAs and was therefore considered relevant for inclusion. Sub-sections 6.2 to 6.6 summarise what we found.

6.2 Financial support

Woolham et al (2020) conducted telephone interviews with 41 PAs about the impact of Covid on their work and personal lives. The sample included SEPAs but there is no indication of how many. Findings relating to this group tended to focus on the difficulties they faced in accessing financial support or compensation during this time. In particular, they found that they did not qualify for the Government **furlough scheme** and the only **sick pay** they qualified for was statutory sick pay which they felt was insufficient as compensation for lost income. In fact, some SEPAs reported that they did not receive any pay if they were not working. They found themselves having to draw on savings or in some situations in more dire circumstances:

“So I'm in my overdraft. I don't want a grant, I don't want to have to put myself into that situation where I'm paying something back, so yeah, and in fact our son who has recently got a management trainee position with (XX), he's the only one with income, so if we need to, we'll have to rely on him because he's been furloughed.”
(Woolham et al., 2020; pp.22)

Another expense that this group was unable to get support for was **PPE**. Being self-employed they were expected to pay for this themselves. The costs of PPE had escalated - both because prices had risen due to scarcity, and also because more was being used. Some accepted the situation as it was and took it upon themselves to source PPE, but for others it caused resentment, particularly given the low pay that many PAs receive.

Only those SEPAAs who were in touch with a **brokerage service** managed by a voluntary sector organisation were able to access some financial support, for example the organisation was able to **support group applications for furlough** for these SEPAAs.

In a survey of PAs conducted by Woolham et al (2019) where approximately one third of the sample was self-employed (34 out of 105 respondents), findings indicated that 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.

6.3 Advice and support when problems arise in working relationships

Findings from Woolham et al's survey (2019), where approximately one-third of the sample were self-employed, indicated that PAs have **no organisation or body to turn to for advice and support in case they become involved in a serious dispute** with the person they support. Whilst many respondents couldn't envisage such a situation arising, they also couldn't identify any available dispute resolution procedures. Some wrongly assumed that perhaps the organisation that put them in touch with their employer would help them whereas stakeholders from these organisations said that they would be unable to offer this support due to a conflict of interest or lack of funds or expertise.

Similarly, the authors also reported that there is an absence of places for PAs to report any abuse or exploitation experienced from the people they support. Those who had encountered such problems noted that there were few specialist places for them to go.

They tended to mention some more general sources of legal advice like the Citizens Advice, ACAS, or the small claims court but also felt that that these organisations might not understand the nature of their roles. Although reports of such behaviour were rare, where it did occur it could have a devastating impact on the PA, in part because of this very absence of support.

6.4 Training and development support

In a small-scale survey where only seven of a total sample of 39 respondents were in fact SEPAAs, Self-Directed Support Scotland (2021) found that when asked what support they would most like, all identified **access to training and development opportunities** as being of primary importance. More specifically, Woolham et al.'s survey (2019), where approximately one-third of the sample were SEPAAs most wanted training for more complex and technical tasks such as:

- Helping the employer with medical tasks (medications, dressings) – One PA discussed ‘sorting out’ an employer’s ‘needle’ who had epilepsy and another mentioned using an Epi-Pen. Another PA had given injections
- Checking and looking after/cleaning equipment essential for the employer
- Providing massage/helping with exercises to improve mobility and comfort

6.5 Access to PA registers and or introductory / brokerage agencies

The Self-Directed Support Scotland survey (2021) reported that all seven SEPA respondents stated that they would voluntarily register to be on a PA register as they felt that this would support them in their role. **Training and development** was the main reason for this, followed by **job opportunities, quality assurance and financial incentives**. Moreover, Woolham et al (2019) reported that PAs like being on a register or with a brokerage agency as it often corresponds with being **viewed as a vetted** and therefore safe provider. Such registers often require or conduct a number of checks including but not limited to DBS checks and HMRC registration checks and this was regarded as good practice. Moreover, access to training was again mentioned as a benefit of being part of these models.

Some respondents were keen to state that **local authorities and other organisations have an important role to play in vetting** candidates and verifying that they are HMRC registered and insured. The Support with Confidence scheme in East Sussex was mentioned as an example of good practice – 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.

6.6 Peer support

Woolham et al (2019) reported that **occupational isolation** was common amongst PAs who were usually lone workers with few opportunities to meet other PAs for support. In fact, some reported that employers were reluctant for them to meet others as they feared potential breaches in privacy or that their PA may be exposed to ideas from others that may challenge the ‘status quo’. This was also echoed in a study conducted with community micro-enterprise schemes by the New Economics Foundation (2020) where sole traders also reported that a risk of being self-employed is in fact that the conditions can be very isolating.

A solution to this is support for PAs to set up and operate as a network. For example, the authors report that in Somerset the micro-entrepreneurs have worked collaboratively and formed a **self-organising network**. This comprises various different local groups that communicate via WhatsApp and meet once a month to support each other, share good practice, and introduce each other to people looking for care and support.

As a network, the micro-enterprises are also connected via the council's 'village agents' programme, which employs people to serve a cluster of parishes and act as first point of contact for local residents who need information and support. The village agents have become an important source of referrals for the micro-enterprises

7. Theme six: Issues faced by, and views of, PA employers and people who engage SEPAs

7.1 Overview of relevant literature

There were 17 documents that were relevant to this research theme. However, it is important to note that most of these reflected the views and experiences of people who directly employ PAs, rather than those who engage SEPAs. The literature consisted of 12 research studies - either surveys or mixed methods studies with people employing PAs, people working as PAs, service users specifically in receipt of direct payments or PHBs, local authorities and other stakeholders. There were also five articles and/or short pieces of guidance which discussed a range of issues including but not limited to, law and guidance around being an employer, the potential regulation of PAs and a consultation on the extension of PHBs. Sub-sections 7.2 to 7.7 summarise what we found.

7.2 Challenges recruiting PAs

One of the most prevalent themes across the literature is that of the ongoing challenges faced by service users in recruiting PAs. In fact, a recent survey conducted by Think Local Act Personal (TLAP) (2022a) of nearly 1,000 people who employ PAs found that **recruiting PAs has got more difficult** over time. 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.

A number of factors were identified in the literature as having made recruitment harder. The biggest factor was that of **low pay** which respondents said made working as a PA uncompetitive compared to other care roles which can offer better pay, hours, terms and conditions. The same was considered true of work in other industries, for example retail or hospitality that can pay a similar or higher rate for work that is less physically and mentally demanding.

Respondents using direct payments or PHBs to employ PAs expressed frustration about **flat rates or a 'cap' on rates** which meant they struggled to compete with people able to pay more or recruit skilled and qualified people (Graby and Homayoun, 2019; Skills for Care, 2016; TLAP, 2022a). One respondent commented:

“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.”

(TLAP, 2022a; pp.05)

People also felt that the caps and limits on pay for PAs is partly a reflection of the fact that the **role is not socially valued** and often held in **low esteem**, despite the skills, specialist experience, and knowledge and training needed by many to work as a PA often alone and meeting complex and diverse needs. The **‘time and task’ model** adopted by funders also makes it harder to find PAs to work the hours needed and is very much in direct conflict with the ethos of direct payments and PHBs which is about outcomes and enabling people to use their budgets flexibly and in a way that meets their needs. Respondents felt that all these factors - low pay, the low esteem in which the role is held, poor terms and conditions - worked together to discourage people with the right skills, experience, values and training from taking up work as a PA. In fact, many respondents reported experiences of how some people who came for interviews were totally unsuitable for the role (Skills for Care, 2016; TLAP, 2022a).

Some respondents in the survey conducted by TLAP (2022a) were also concerned that **introductory agencies** were affecting supply by taking affordable PA capacity out of the local market by offering better rates of pay. Additionally, more than a third of respondents said they have found fewer people are available for PA work **following Brexit or immigration restrictions**. This was also echoed by Graby and Homayoun (2019) in their article on direct payments and how well they are working for people with disabilities. They report that PAs employed by people tend to be citizens of other EU countries, who are often more likely than British citizens to apply for, and to put up with, poorly-paid work.

This issue of **insufficient ‘supply’** of PAs is also felt to be a reflection of unrealistic and ill-informed funders and commissioners - one example given of this was how people were prevented from using a SEPA, significantly limiting the pool of PAs available to them and created inequalities in the market as self-funders can contract with whomever they choose (TLAP, 2022a). Another study conducted by Skills for Care (2016) with local authorities and NHS organisations found that when asked if a good supply of PAs existed locally, three-fifths of both local authority respondents and NHS respondents said there wasn’t (57% and 58% respectively). Interestingly, a majority from both groups of respondents reported that a good supply of people “could potentially” be recruited as PAs existed. This disconnect between actual and potential supply was attributed to a range of reasons. For example, the fact that the PA role is not socially valued and can be misunderstood and the fact that the ‘time and task’ model discussed earlier can make recruiting PAs to smaller packages of care very difficult. Additionally, respondents also reported that it can be difficult to recruit PAs for more complex care and health tasks.

There is also evidence across the literature that the recruitment of PAs is difficult because of a **lack of support from local authorities and NHS funders**. For example, although most people say they had to manage recruitment themselves, no one said that the associated costs of this recruitment were included in their direct payment or PHB.

Some people said that they had found PAs through word of mouth or adverts in shop windows and others said they were signposted by their funders to agencies whose rates were above what they were allowed to pay. What people really want is for funders to work proactively and collaboratively to **establish a pool / register of PAs** that people could choose from and to work with local skills and employment partnerships to promote being a PA as an employment choice (Skills for Care, 2016; TLAP, 2022a; TLAP, 2022b).

“For years (decades) there has been talk of a council facilitated list of experienced PAs, or PA brokerage. It never materialised.”
(TLAP, 2022a; pp.9)

7.3 The importance of values-based recruitment

Another key theme relating to recruitment that emerged in the literature is the importance of values-based recruitment with respect to engaging with PAs. An article published by TLAP (2020) defines values-based recruitment as being *‘aimed at finding people who are willing and interested in helping others in some shape or form irrespective of their age, educational level, previous occupations or available time. It is considered to be effective at finding individuals that have the qualities to be great carers, that for a myriad of reasons are not considering a career in care work.’* Many people who use direct payments or PHBs report that it is the persons’ values and finding someone whose **capabilities and interests** match their needs is more important than their qualifications (Skills for Care, 2016; TLAP, 2022a).

This was also echoed by Woolham et al (2019) in their semi-structured interviews with PAs and other stakeholders, where **‘personal chemistry’, shared values and outlooks** were emphasised as being key to successful recruitment, much more so than specific skills or experience.

7.4 Retainment and turnover of PAs

TLAP’s (2022a) survey of people who employ PAs asked respondents the reasons provided by PAs who left their jobs. The reason most often given was a **change in personal circumstances or commitments**. Other reasons related to **low pay**, not getting paid if they were ill, or if the person they supported went into hospital, and the impact low wages had on their state benefits. Others left because the **hours offered were insufficient** to be financially viable job option for them. 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.”
(TLAP, 2022a; pp.19)

Another key reason for leaving was that PAs found that the **job was not right for them**. PAs who left because the nature of the work was not right for them used this to highlight how the role and demands of PA work is not well understood or defined. Some PAs told their employers that they were leaving because of **mental health issues**, often mentioning stress, anxiety or depression in particular. Some people reported that during the pandemic they had been able to recruit people furloughed from their jobs, and therefore **returning to these old jobs** was also often a reason given for leaving.

The respondents also described how although they tried to make the role interesting and rewarding, the **low pay, no reward for length of service, little opportunity for career progression and/or training** often limited the length of time that a PA would stay in the role. Finally, people described the negative impact of the **turnover of staff**, particularly for people with complex needs or challenging behaviours:

“I found that there was a high turnover of staff disruptive to a routine, and very unsettling for elderly parents with dementia.”
(TLAP, 2022a; pp.06)

Interestingly a survey of PAs conducted by Woolham et al (2019), where approximately one third of the sample was self-employed (34 out of 105 respondents), identified a host of **different reasons** provided for changing employers. The most frequently mentioned reason (by n=33/31%) was the **death of the employer** which the authors note has not been highlighted in other research. Other reasons cited included **unreasonable demands and expectations** or **abusive behaviour** by the employer (n=13/12%) or a **move by the employer into residential care** (n=10/10%).

Some reasons related to changes to the circumstances of the employer, for example, **relatives being able to take on a greater caring role, changes in need, and reductions in the employer’s/client’s direct payment**.

With respect to turnover, Skills for Care (2022a) in their survey of **individual employers in receipt of direct payments** and their PAs reported that the **turnover rate of PAs was 18.2%**. Additionally, Skills for Care (2022b) in their survey of **individual employers receiving PHBs** and employing PAs report that the **turnover rate of these PAs was 21.3%**. These turnover rates are **considerably lower than care workers** in the independent sector at 39.1%.

The authors suggest several reasons including the close relationship between PAs and their employers, differences in the work carried out by the two roles, and better terms and conditions for PAs, supporting these claims with the following findings:

- Around 21% of PAs in social care were on zero-hours contracts and around 15% of PAs employed by people in receipt of PHBs were on zero-hours contracts. This was much lower than care workers in the independent sector (35%).

- The mean hourly pay rate for PAs in social care was £10.21 (as at February 2021) and mean hourly pay rate for PAs employed by people in receipt of PHBs was £10.20. This was much higher than the mean hourly rate for care workers in the independent sector (£9.20 as at December 2020)

7.5 The relationship between employers and their PAs

There is evidence in the literature from PAs and their employers about the importance of good relationships between the two based on **informality, friendship and being able to ‘get along’** (Porter et al, 2020; TLAP, 2020; TLAP, 2022a, Woolham et al., 2019). This is in line with the earlier findings reported relating to the importance of values-based recruitment.

This type of relationship has in part been attributed to the fact **that intimate tasks and the disclosure of personal information** are two aspects of the role that precipitate informal or personal relationships. Additionally, spending **prolonged periods of time** in one another’s company, and the fact that a PA’s **workplace is their employer’s home space** are also seen as further drivers of informality. Additionally, **continuity of care**, and **having the same PA for a long time** is also seen as fostering loyalty, trust and mutual respect which has led not only to good working relationships but enduring friendships between employers and their PAs.

At the same time, Porter et al (2020) in their qualitative research with 58 people with disabilities and their PAs also identify some **challenges associated with these informal relationships**. For example, **exerting discipline, giving orders or acting assertively** when support provided is unsatisfactory can be very difficult and feel inappropriate within such close relationships. Similarly, there is also the possibility for **emotional entanglements** as a result of **blurred boundaries**. As one employer who fell in love with his PA described:

“there weren’t clear boundaries, which neither of us set...it got very confusing for both parties’.

(Porter et al, 2020; pp.199)

The authors report that the problem of boundaries is a common theme in the literature on PAs and their employers, and one which can cause conflict and discord if left unattended. It is for this reason they believe that PAs should receive more information and guidance about boundaries.

7.6 Support available to employers of PAs

There are **mixed findings** across the literature about the level of support and advice available to employers and their satisfaction with it. For example, the National Audit Office (2016) report that **82% of local authorities have reported gaps in the support** they provide to users and PAs even though the Care Act requires authorities to give users who employ a PA advice on their responsibilities. However, Skills for Care (2022a) in their survey of individual employers in receipt of direct payments and their PAs reported that half the employers surveyed had accessed information via their local authority, with another 46% from direct payment/user led/voluntary sector organisations and 9% from a peer network. Moreover, **over half (57%) of individual employers said that they were satisfied** with the level of information and support that they could access. However, a further 28% were 'neither satisfied nor dissatisfied', which highlights an opportunity for further improvements.

Woolham et al (2019) in their semi-structured interviews with PAs and other stakeholders highlighted that several interviews focused on what employers of PAs need access to in order to manage their responsibilities. Stakeholders most frequently mentioned information and advice for employers as being **deficient**. It was also felt to be **patchy** and of **variable quality across different areas**, and in some places **completely absent**.

Moreover, Skills for Care (2022a) in their survey of individual employers in receipt of direct payments and their PAs report that the majority of employers (90%) had not undergone any training to help them in their role as an employer. This figure was 79% for individual employers in receipt of PHBs with PAs (Skills for Care, 2022b).

Skills for Care (2016) in their mixed methods research with approximately 50 Clinical Commissioning Groups in England indicated that the **support provided to people with PHBs is better than that provided by local authorities**. Across 90% of survey responses from NHS organisations the NHS was directly providing at least some of the employment support. This was most likely to include information about employing a PA and rates of pay. On the other hand, reported levels of support from local authorities to PHB holders were relatively low. Additionally, training for PHB holders new to an 'employer' role was reported as available by four-fifths of respondents; although the extent to which this represents support with recruitment, interviewing, HR and management as opposed to more traditional training and learning is not clear.

Additionally, the number of respondents indicating that peer support or mentoring was available to PHB holders is significantly higher than the figures reported in social care in previous years and is higher than the availability of 74% that local authorities reported in 2015. Nine out of ten respondents to this survey indicated some local provision. However, it is important to note that the relatively small number of PHB holders makes it easier to identify and communicate with people and the NHS does not face the same challenge in reaching self-funders that local authorities have.

Finally, in an article written by Which? (2021) on employing private carers the authors also emphasise that direct employment, rather than going through an agency can come with the absence of other key support. For example, an employer can be left without a replacement if the carer is absent from work, whereas an agency will usually find cover. Additionally, agencies provide employers with the added protection of staff training and vetting as well as an established complaints procedure to resolve any issues that may arise.

7.7 Disadvantages and advantages of engaging with SEPAs

Self-Directed Support Scotland (SDSS, 2021) carried out a small-scale survey where eleven of a total sample of 39 respondents were in fact people who engage with SEPAs. When asked about the disadvantages of contracting with them a number of key themes emerged. Many were concerned with **staff turnover** and how a SEPA can resign without being held to a **notice period**, and the length of time it can take to recruit a new one. Others mentioned the **difficulty getting cover** if a SEPA is sick or has an emergency.

“Difficult to get cover. Holidays can usually be covered by existing team, if we get enough notice, but sickness and other emergency leave is very problematic and I (daughter) often end up covering shifts myself, and my health isn't so good.”
(SDSS, 2021; pp.5)

Another key theme was that of the **lack of clarity and guidance** from local authorities. As one respondent commented:

“The difficulty is not with the PAs themselves. The difficulty has been in convincing, cajoling, and myth-busting with local authorities. The barriers and hurdles that already stressed people are having to deal with in order to get even four hours of care from their chosen SE PA, is not acceptable.”
(SDSS, 2021; pp.3)

Other disadvantages mentioned included the risk that SEPAs may not have the **required training**, that they are not bound by employment law, and as discussed earlier the fact that people who engage them can still be **found liable by the HMRC** for taxes and penalties even if the PA is registered as self-employed. However, the authors report that it was interesting to hear from one respondent who said there is *‘no more risk than when contracting the services of any self-employed professional. Most self-employed people will do the extra mile as its their name, reputation and future business that will be harmed if they do not perform as per the agreed contract. When both parties understand the expectations and responsibilities it works well’* (SDSS, 2021; pp.5).

With regards to making a decision to engage with SEPA, 80% of those who do engage them said that they explored the advantages and disadvantages of being an employer and of contracting with a SEPA.

When asked about the benefits of doing so **flexibility** was identified as a key theme, but not discussed further by the authors. Other benefits mentioned included not having to deal with **employment related processes** (payroll, paperwork) and costs (sick leave, maternity leave) and **more control** over the PAs they engage.

8. Conclusions

A key finding of this review is that there is a dearth of published literature about the experiences and needs of SEPAs and the people that engage them. Similarly, there is also little research evidence about how the market for SEPAs operates both locally and nationally. At the same time, we know anecdotally that the market for SEPAs is growing as they are seen by some as a possible solution to fill the gap in available PAs.

In fact, this gap in PAs available for direct employment was a key theme across the literature reviewed. Service users have reported that recruiting PAs has got more difficult over time and report a number of reasons. The low pay associated with the role or the flat rates or 'cap' on rates by local authorities are seen as a barrier. Additionally, the role is not socially valued and often misunderstood, and the hours offered are insufficient to make the role of a PA financially attractive.

The findings of this review highlighted that national legislation relating to using direct payments to engage PAs relates only to the direct 'employment' of PAs, that is there no mention of engaging SEPAs. However, guidance published by the DHSC during Covid-19 highlighted the need for greater support to be provided to PAs during this time. This also included SEPAs to a certain extent, for example in relation to access to testing, vaccination and PPE. This can be interpreted as the beginning of a shift in attitudes towards direct payments and PAs by policy makers. Additionally, legislation and guidance on Personal Health Budgets says that in principle direct payments can be spent on a broad range of things but provides a 'barred' list of services which could be viewed as more permissive compared to social care direct payments.

The limited literature highlighted some important risks and issues associated with engaging SEPAs. These primarily related to the fact that while PAs may have registered as self-employed with the HMRC they do not actually meet the criteria for being self-employed, and therefore tax liabilities and national insurance contributions can be transferred to people engaging SEPAs, or their funders. There is also little but mixed evidence on the extent to which local authorities and NHS bodies support and permit people receiving direct payments or PHBs to engage SEPAs - attitudes can vary from complete support to absolutely no tolerance.

At the same time, there was also a recognition of the benefits of engaging SEPAs. From a service user perspective, the benefits relate primarily to not having to be an employer and therefore not having to deal with associated processes (payroll, paperwork) and costs (sick leave, maternity leave). From the perspective of SEPAs, a key benefit to working in this way is flexibility - setting one's own hours, choosing which clients they want to work with, responding to their clients' needs more effectively and taking on other roles when needed.

Given the lack of an established market for or consistent policies towards SEPAs they also face challenges and identify a need for support and advice. For example, they struggle to access training and development opportunities and access job opportunities via PA registers or introductory agencies. They also have no organisation or body to turn to for advice and support in the case of a serious dispute with a client or if they face any abuse or exploitation. Additionally, challenges faced by those engaging SEPAs can include difficulty finding cover if a PA is sick, the lack of a need for a notice period and the lack of clarity and guidance from local authorities about how to engage with SEPAs.

Whilst SEPAs can clearly be seen as one of the options for individuals that require support to live an independent life, it is clear from this review that there is a need for better support, advice and guidance for SEPAs, individuals who engage them as well as the as organisations involved in funding direct payments across health and social care. The dearth of relevant literature highlighted in this review also means that further research is needed to understand how the market for SEPAs operates on a local level as well as a need to better understand the experiences of, and support and guidance needed by all stakeholders involved.

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Skills for Care
West Gate
6 Grace Street
Leeds
LS1 2RP

Telephone: 0113 245 1716
Email: info@skillsforcare.org.uk
Web: www.skillsforcare.org.uk