What works in wellbeing for Personal Assistants (PAs) to disabled people? A systematic review

Aisha Macgregor, Obert Tawodzera, Richard Brunner, and Rhiann McLean.

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IMPACT is a £15 million UK centre for implementing evidence in adult social care. It is funded by the Economic and Social Research Council (ESRC) and the Health Foundation. Its Leadership Team is made up of 13 individuals, led by Professor Jon Glasby at the University of Birmingham. This team includes academics, people who draw on care and support, and policy and practice partners. IMPACT has also involved a broader consortium of key stakeholders from across both the sector, and the four nations of the UK.

IMPACT believes that 'good support isn't just about 'services' – it's about having a life.' In pursuit of this vision of adult social care, key objectives for the centre are to enable practical improvements on the ground and make a contribution to longer-term cultural change by:
- Increasing the use of high-quality evidence, leading to better care practices, systems and outcomes
- Building capacity and skills in the adult social care workforce to work with evidence of different kinds to innovate and deliver better outcomes
- Developing relationships between a wide range of stakeholders across the sector, to improve outcomes for people who draw on services and their families
- Improving understanding of what elements of evidence implementation do and do not work in practice, and using this to overcome barriers

To do this, IMPACT collaborates with existing adult social care policy and practice partners. IMPACT's work will also be embedded locally, regionally, nationally and across the UK.

Author information

- Dr Aisha Macgregor is an Evidence and Evaluation Research Fellow at IMPACT, based in the Faculty of Social Sciences, University of Stirling.
- Dr Obert Tawodzera is IMPACT's England South and West Midlands Project Officer, based at The University of Birmingham.
- Dr Richard Brunner is a Senior Strategic Improvement Coach at IMPACT, based in the Faculty of Social Sciences, University of Stirling.
- Rhiann McLean is a Senior Strategic Improvement Coach at IMPACT, based in the Faculty of Social Sciences, University of Stirling.

Acknowledgements

Executive Summary

Introduction

Personal Assistants (PA) to disabled people emerged from the disabled peoples' and independent living movements of the 1970s and 1980s. PAs are directly employed by the disabled person or their family, and support disabled people to live their lives in the way they choose: in the home, the community or at work. In Scotland, Option 1 of Self-Directed Support allows a disabled person or their family to opt for a Direct Payment, which enables them to directly employ one or more PAs. There are currently more than 5000 PAs working in Scotland, a small number in relation to the 211,510 registered social services workforce (SSSC, 2023). However, PAs have a vital and distinctive role in promoting the autonomy and independence of the disabled people and families who choose to employ them. There is limited understanding of the wellbeing needs of this population, who make up a growing proportion of the social care workforce in Scotland.

This evidence review resulted from a bid to IMPACT from stakeholders involved with Scotland's PA Programme Board, whose Wellbeing Subgroup has a focus on PA wellbeing. The review aims to address the question 'what works in PA wellbeing?'. The review specifically sought to find existing evidence about:
· What factors influence PA wellbeing?
· What interventions or supports can improve PA wellbeing?

Methods

A systematic search of international literature was conducted in February 2024 by the University of Birmingham Knowledge and Evidence Service. Forty-seven relevant pieces of research were found, predominantly from the UK and Scandinavian nations. This demonstrates that there is not a large evidence base on PA wellbeing. It is also important to note that proposals to improve PA wellbeing made in the literature were not based on tested interventions but were authors' conclusions based on their findings about the factors that affect PA wellbeing.

To 'ground' the evidence and interventions emerging from the literature search in lived experience and the Scotland-specific context, IMPACT recruited two expert groups of PA employers and PAs from across Scotland to discuss the emerging themes and help refine and contextualise the recommendations. While not seeking to be demographically representative, these expert groups were purposively selected to represent a range of backgrounds and experiences.

What does wellbeing mean in this context?

There is a lack of agreement on work-related quality of life in the social care sector, or on how to measure it. Whilst there are specific differences between PAs and other types of social care workers, Silarova et al (2022) identify key components of work-related quality of life for social care staff, which provides a useful starting point for thinking about 'what is PA wellbeing?'. They set out six key components of work-related quality of life: organisational characteristics, job characteristics, mental wellbeing and health, physical wellbeing and health, spillover from home to work, and professional identity.

What influences PA wellbeing?

There is no single profile for PAs, and indeed limited knowledge about what diversity exists in the PA population. Research suggests that Scotland's PA workforce is predominantly female, white, and over the age of 45. The literature review indicates an evidence gap in terms of understanding the experiences of PAs from diverse backgrounds, and on how protected characteristics interact with PA work and PA wellbeing.

Aside from this limitation, the systematic review found six themes important to PA wellbeing:
   a. Job satisfaction and perceptions of PA work
   b. Employment conditions and insecurity
   c. Access to training and support
   d. Isolation
   e. Relationships and blurred boundaries
   f. The nature of the work

a. Job satisfaction and perceptions of PA work
The evidence shows that PAs consistently report high levels of job satisfaction and can see the difference their work makes to their employers' lives. This likely has a positive impact on wellbeing. But the evidence also suggests that the PA role has low public recognition and has low professional status, likely associated with discriminatory attitudes faced by disabled people and weak public understanding of the PA role.

b. Employment conditions and insecurity
PAs often have poor employment conditions, including insecure work, low pay, lack of promotion structures, and lack of access to pensions, sickness leave, maternity leave, holiday leave and redundancy pay. Funding made available to PA employers through local authorities commonly constrains how much they can pay their PAs. Promoting fair pay and recognition is likely to help with financial stressors and could protect PAs from potential exploitation or precarious working conditions.

c. Access to training and support
A consistent finding from research is that PAs often lack access to adequate training and support. A recent survey of PAs in Scotland revealed that most PAs had not received recent training, and this was linked to low PA confidence to do their job well. The evidence suggests that access to training programs is likely to support the wellbeing of PAs, though it could also risk undermining PA employer choice and control. The literature also suggests that training and ongoing support to enable people to be good PA employers would support PA wellbeing.

d. Isolation
PAs largely work on their own, and the isolated nature of the work can have implications for wellbeing. Lone working restricts access to networks of peer support among PAs, especially when they are not part of a wider PA team. The space where PAs work also has consequences for wellbeing: the employer's home space becomes a workplace, leading to unique vulnerabilities and risks.

e. Relationships and blurred boundaries
The evidence shows that relationships between PAs and their employers do not usually follow a traditional employer/employee dynamic. PAs and their employers often spend long periods of time together in the private sphere of the home. This closeness can foster intimacy and trust, as well as mutuality and reciprocity, with employers also supporting PAs.

These relational dynamics are often valued and cited as being key factors that motivate people to become PAs and therefore has potential to support wellbeing. However, issues of frustration and dissatisfaction, control, and abuse can also be experienced by both parties. PAs must also navigate relationships with other professionals, including medical professionals, who may not understand or value their role. PAs may also have to navigate relationships with family carers or partners of supported people.

f. The nature of the work
PA work is often highly skilled and complex, involving a wide range of tasks and activities in the home and the community. Many PAs assist with intimate personal care, and some do complex health-related tasks such as administering medication, assistance with catheter care, and pressure sore prevention. Studies show that working with employers whose health is deteriorating can be physically taxing and emotionally demanding.

Conclusions

The UK and international evidence, grounded by the PA and PA employer expert group discussions, suggests that improving and sustaining higher wellbeing for PAs requires a combined strategy which addresses the material, relational and societal drivers of wellbeing for this workforce. There is limited evidence as to what precise combination of interventions would improve PA wellbeing, as recommendations emerging from the literature were based on evidence of the known drivers of PA wellbeing, rather than on tested interventions. However, the evidence highlights the relational aspect of the PA-PA employer dynamic, and so it follows that interventions to support PA wellbeing must also seek to improve PA employer wellbeing. A coproductive or codesign approach, involving PAs and PA employers, will maximise the potential for interventions working, and for accurately evaluating their impacts on both groups.

Recommendations to improve PA wellbeing in Scotland

The findings of the systematic evidence review have been discussed with the expert groups and with key PA and PA employer stakeholders in Scotland. The outcome is a range of proposed interventions likely to enhance PA wellbeing in Scotland. There is already a strong web of organisations, networks and bodies working to improve outcomes in the PA/PA employer 'space', with a strategic overview involving the Scotland-wide PA Programme Board and its sub-groups. Taking the recommendations forward in practice will be the work of these multiple stakeholders through continuing partnership and collaboration. Appendix 2 lists stakeholders that are already doing work in this area. The recommendations need to be carefully considered to ensure they do not undermine the ethos of the Independent Living Movement and the principles of personal assistance. All interventions should be evaluated, including in relation to protected characteristics.

a. Adequate, liveable wages that reflect the nature and value of PA work – so that people are more likely to take up the role. This may include opportunities to tier pay levels to reflect factors such as the complexity of each individual PA role, rurality, travel time, and unsocial hours. Additionally, PAs need easy access to support to maximise income, including through welfare benefits advice, as many PAs work part-time and/or have caring responsibilities. Additional benefits, such as discount cards or employee assistance programmes should be explored as part of the wider benefits package for PAs but should not be considered a replacement for fair pay.

b. A higher supply of PAs and an increase in PA diversity – so that PA employers can choose compatible PAs, and PAs and PA employers can have access to additional assistance in the event of sickness, annual leave, or changes in support needs. To maximise PA employer choice and control, there need to be systems developed to facilitate 'pools' of PAs to emerge, accessible to PA employers, enabling them to access PA 'cover', where needed.

c. Higher public awareness of and esteem for PAs - public campaigning, so that people are aware of the PA role in assisting disabled people to have independent living, and the complexity of the job. To develop parity of esteem for PAs with other allied professionals, there should be tailored learning across health and social care settings about the PA role, how it differs from other social care roles, and its distinctive contribution.

d. Opportunities for PAs to connect with other PAs across Scotland so that PAs can tackle isolation. There should be multiple avenues to connect with others, including online, anonymised, moderated spaces for discussion with peers, more informal opportunities to connect, as well as regular regional and online events. PAs need to be involved in the development and leadership of these initiatives to build a collective voice.

e. Stronger enforceable employment rights for PAs - notably in terms of working conditions (e.g. being paid for all the hours they are at work) and employee benefit packages (e.g. access to pensions, sickness, holiday pay, redundancy pay and maternity leave), with local authority funding and contracts accordingly. This may include engagement with regulatory frameworks, professional associations, membership bodies, and trade unions.

f. Consistently available and accessible information, training and support to maximise PA employers' awareness of their legal and 'best practice' obligations to support PA wellbeing, and support to access adequate local authority funding to align with these best practices.

g. Guaranteed, funded access to training and development that meets the individual needs of PAs and PA employers - both skills-based and for personal growth. Training delivery should maximise choice and may include joint training for PAs and their employers, training that PAs can access independently, and training that focuses on the unique relational element of PA work. To remove barriers to accessing training for PA employers and their PAs, time to access training should be included in Direct Payment allocations. Recommendations for how best to deliver training to PAs and PA employers in Scotland can be found in the 2024 Personal Assistant National Training Framework for Employers.

h. Access to a range of emotional supports tailored to PAs that reflect the unique needs and challenges of the role, including counselling services, mental health support and a dedicated Scottish-based helpline with specialist training on/awareness of the SDS landscape, the PA role and wellbeing challenges. PAs should have the opportunity to inform decision-making on the right structures and mechanisms for this specialist support.

i. A pathway for PAs to be able to pursue relevant formal qualifications, with the support of their employer, and have the opportunity to gain membership of appropriate professional associations.

j. Upskilling PA employers with the softer skills needed for effective people management (including work planning, anticipatory management, offering feedback on PA performance and contribution, recognition). Where these opportunities are already available (e.g. from Centres for Inclusive Living), improve publicity and opportunities for take-up.

k. Access to mediation and brokering for PAs and PA employers to navigate the relationship and blurred boundaries in the PA employer-PA dynamic.

l. Evaluation - all interventions seeking to improve PA wellbeing in Scotland need to be systematically evaluated for effectiveness and unintended impacts on the various subgroups in the PA space, including impacts on PA employers and on groups with protected characteristics. Evaluation activities should include PA employers and PAs, who should be paid for their time and expertise.

m. Presentation of these findings by the PA Programme Board Wellbeing Subgroup to the wider PA Programme Board to integrate actions into the Board's workplan, where relevant.

Research gaps and priorities

In the course of analysis of the systematic review, and discussion with the expert groups, priorities for further research have emerged. These include a need to understand different 'types' of PAs, the intersection of unpaid care and PA work, and self-employed PAs.

What works in wellbeing for Personal Assistants (PAs) to disabled people? A systematic review

Introduction

Setting the scene

Personal Assistants (PA) to disabled people emerged from the disabled peoples' and independent living movements of the 1970s and 1980s. These movements recognised that to change years of historic discrimination and institutionalisation, disabled people needed to have more choice and control over the assistance they have to live the lives they want (Shakespeare, 2014). PAs are directly employed by the disabled person or their family, and have a role that is qualitatively different from care and support workers employed by local authorities or other providers, shifting power to the disabled employer. In Scotland the role of PAs was recognised in law through the Self-Directed Support Act (2013). Option 1 of Self-Directed Support allows a disabled person or their family to opt for a Direct Payment, which is paid by the local authority directly to the disabled person or their family. This enables them to directly employ one or more PAs. PAs support disabled people to live their lives in the way they choose: in the home, the community or at work. The PA role is highly varied, as it focuses on the needs and aspirations of the individual.

Since 2021, how to enhance the wellbeing of the PA workforce has been of interest to Scotland's Personal Assistant Programme Board. The Board has commissioned two surveys of the PA workforce (Theakstone, Lawrence & Adderley, 2022; Lawrence et al, 2024) that have increased understanding of the high levels of job satisfaction experienced by PAs, alongside challenges, including over pay, access to training and support, job insecurity, and mental health. For disabled people to be assisted in the best possible way to achieve the outcomes they choose, the PAs that support them need to have good wellbeing: PA wellbeing supports PA employer wellbeing. Enhancing PA wellbeing should make the job role even more attractive, so increasing the supply of and diversity of people entering the PA workforce. This should in turn enhance choice and control for disabled people.

In 2023-24, the PA Wellbeing Subgroup of the PA Programme Board submitted a bid to work with IMPACT, a UK centre for implementing evidence in adult social care. The PA Wellbeing Subgroup bid sought to better understand the evidence base on PA wellbeing in order to make evidence-informed interventions to improve PA wellbeing, while maintaining PA employer choice, control, and wellbeing. IMPACT established a twelve-month 'Demonstrator' project, employing two part-time researchers through the University of Stirling (Richard Brunner and Rhiann McLean) to lead the project. Stakeholders from the PA Wellbeing Subgroup worked with IMPACT to shape the parameters of the review. This report examines the evidence of what supports PA wellbeing, and makes a set of recommendations for the PA Wellbeing Subgroup of the PA Programme Board to take forward in Scotland.

Section 1: What is the issue?

The Personal Assistance (PA) model originates from the Independent Living Movement and was developed as a radical alternative to care based on asymmetrical power relations that resulted in disabled people's oppression (Porter et al, 2020; Watson et al, 2004). Instead of being passive recipients of care, personal assistance enables disabled people to be in control by directing what support they receive and by whom (Lakhani et al, 2018).

The personal assistance model varies across countries. In the UK, for example, personal Assistants are distinctive, differing from other care workers in that they are not employed by an organisation. Instead, they are directly employed by the person with support needs through a direct payment or personal budget (Porter et al, 2022) or alternatively, work on a self-employed basis (Lawrence et al, 2024; Woolham et al, 2019a). In Sweden, however, Personal Assistants can be employed through the municipality, or directly employed by the person through a direct payment (Westberg, 2010).

One reason for employing PAs directly is to reconfigure the relationship from one of care to assistance or help, and in doing so shift the balance of power (Watson et al, 2004). Personal Assistance is often portrayed as an instrumental, transactional relationship, and thus curtailing the emotional components of care, though this stance has been challenged by research underpinning the relational dynamics inherent in the PA/employer nexus (Shakespeare et al, 2017; Watson et al, 2004; Fleming et al, 2019).

Personal assistance has been positioned as a mechanism to support human rights realisation for disabled people (Angelova-Mladenova and Fernandez, 2024) by promoting autonomy and facilitating independent living (Fleming et al, 2019). The right to live independently and be included in the community is underpinned by Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (Angelova-Mladenova and Fernandez, 2024). Yet tensions exist between disabled people's rights to live on an equal basis with others and the ways in which PA wellbeing is potentially compromised because of how it is currently operationalised (Neumann and Gundersen, 2019).

Previous literature reviews have highlighted core issues that may impact PA wellbeing, yet there are notable gaps in the evidence base. A scoping review by Manthorpe et al (2011) explored evidence on people with learning disabilities employing family members as PAs. However, relational dynamics were not represented in the evidence in this context.

A rapid review on employment of PAs in the UK also highlighted key issues that have potential to impact wellbeing, including poor recognition and visibility of the role, isolated working, and issues related to employment terms and conditions (Wallace et al, 2022). Insufficient literature from the perspectives of PAs themselves, and a lack of evidence on how PA wellbeing intersects with protected characteristics such as age, gender, and ethnicity were highlighted by the review (Wallace et al, 2022). This is a serious shortcoming given that PA work is often gendered, with women constituting a large proportion of the PA workforce (Skills for Care, 2023; Lawrence et al, 2024). Further, whilst this review provides important insights, it was limited to a five-year search period and did not include international literature and so only provides a snapshot of the existing evidence (Wallace et al, 2022).

To our knowledge, no reviews exist which specifically focus on understanding what factors promote and restrict PA wellbeing. This systematic review seeks to address this gap by

synthesising the published evidence on what works in PA wellbeing and so provide insights for policy and practice.

Personal Assistance in Scotland

The introduction of the Self-Directed Support (Scotland) Act 2013 (SDS) marked a significant shift in the policy landscape in Scotland (Pearson et al, 2018). SDS requires that people have choice in how their support is provided, with four options being available to select from. Direct Payments are one option available that enable individuals to employ a Personal Assistant (Manji, 2018). Whilst Direct Payments were previously available under the Community Care (Direct Payments) (Scotland) Act 2002, it was up to individuals to request these, rather than these being offered proactively by Local Authorities (Manji, 2018).

The impetus for change towards SDS centred on promoting personalisation, which seeks to enhance choice, control, and inclusion, marking a departure from previous resistance to the marketisation of care (Pearson et al, 2018; Manji, 2018). Yet, SDS was introduced in a context of austerity cuts, performance management, and cost efficiency measures (Pearson et al, 2018). Research demonstrates a divergence between policy rhetoric focused on empowerment, and implementation that promotes the status quo (Pearson et al, 2018). Manji's (2018) qualitative study highlighted concerns about becoming an employer amongst some participants, and some existing Direct Payment users received cuts to their package of support (Manji, 2018). This is an important backdrop for understanding PA wellbeing, since issues that affect people who draw on care and support are also likely to impact PAs.

There are more than 5000 Personal Assistants working in Scotland, a small population in relation to the 211,510 registered social services workforce (SSSC, 2023). Within this population, some PAs may be directly employed by a disabled adult, some may be employed by a family member to support a disabled adult, and some may be employed by a parent of a disabled child. There was a two-fold increase of self-employed PAs responding to the annual Personal Assistant Workforce Survey (Lawrence et al, 2024), which may indicate more self-employed PAs entering the workforce. Whilst there is a need for greater data on the PA workforce in Scotland, the PA Workforce Survey conducted in 2023 reported that PAs are predominantly white, over the age of 45, and female, with a majority providing unpaid care to a friend or family member alongside their PA role (Lawrence et al, 2024). Further, the number of PAs working on a self-employment basis almost doubled between 2022 and 2023, though it is unclear if this may be the result of people with support needs not wanting to take on the responsibility of being an employer (Lawrence et al, 2024). This review seeks to explore how different characteristics intersect with the nature and conditions of PA work to shape PA wellbeing.

Conceptualising wellbeing

Conceptualisations of wellbeing predominantly focus on either a 'hedonic' approach centred on happiness and pleasure or a 'eudaimonic' approach based on optimal functioning and growth (Bartels et al, 2019; Cooke et al, p2016). The former are often measured according to subjective happiness, whilst the latter includes self-acceptance, positive relationships, autonomy, mastery, purpose in life, and personal growth (Bartels et al, 2019). Models combining these two perspectives have been developed to measure general wellbeing (Ruggeri et al, 2020) and Bartels et al (2019) argue that this should be extended to conceptions of workplace wellbeing (Bartels et al, 2019). Yet, wellbeing is also shaped by social and structural factors (Putra et al, 2023) and these must be considered in definitions of workplace wellbeing.

Work-related quality of life is also related to workplace wellbeing, though there is a lack of consensus on how work-related quality of life is defined and measured, particularly in the adult social care sector. Silarova et al's (2022) scoping review addresses this gap by identifying key components of work-related quality of life for social care staff. Whilst there are unique differences between PAs and other types of social care workers, this framework provides a valuable starting point for analysing PA wellbeing. Six key components of work-related quality of life are identified: organisational characteristics, job characteristics, mental wellbeing and health, physical wellbeing and health, spillover from home to work, and professional identity. Each key component has several sub-themes, for example, 'job characteristics' consists of: job–person match; autonomy/control at work; time; responsibility for people; learning and growth opportunities/self-actualisation; meaningful work and feedback from work (Silarova et al., 2022). The analysis reinforces that there is as yet an absence of agreement on work-related quality of life in this sector, or on how to measure it.

Supporting wellbeing has potential to benefit both PAs and PA employers. In Scotland, PAs report high job satisfaction, particularly in the relational aspects of the job (Lawrence et al, 2024). Personal Assistance can also benefit PA employers and unpaid carers, improving satisfaction and levels of unmet need (Mayo-Wilson et al, 2008). Given the extent of recruitment and retention problems in the social care sector more broadly, promoting PA wellbeing is also vital for ensuring that there is a sufficient workforce to meet the needs of people who draw on care and support (Silarova et al, 2022). Despite differences between PAs and other social care staff, key learning about what promotes PA wellbeing could also inform approaches to supporting the wider social care workforce. This evidence review therefore seeks to present a model of what works in PA wellbeing.

Section 2: Methods

This evidence review aims to address the question 'what works in PA wellbeing?'. It specifically sought to explore:

- What factors influence PA wellbeing?
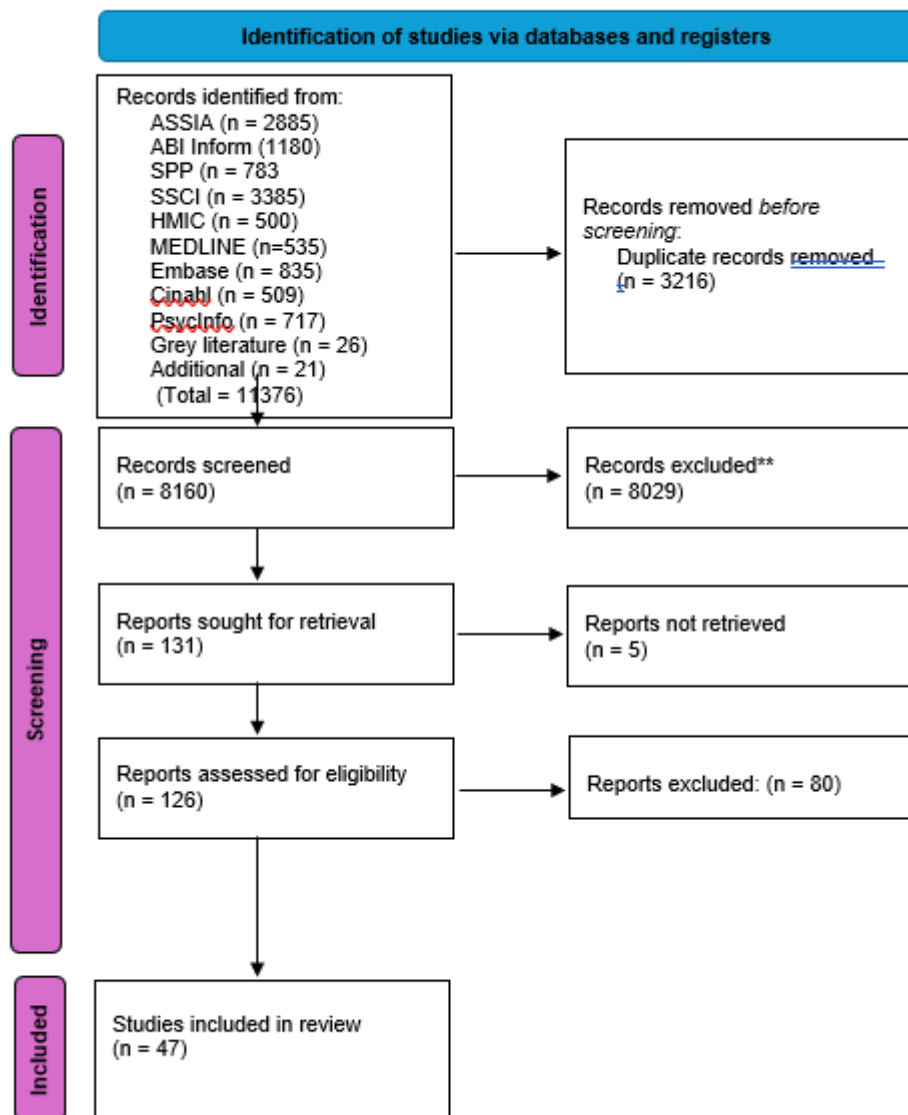- What interventions or supports can improve PA wellbeing?

A systematic search of the literature was conducted by the University of Birmingham Knowledge and Evidence Service. The databases used were: Social Policy and Practice, Social Science Citation Index, Health Management Information Consortium, and Applied Social Sciences Indexes & Abstracts, ABI Inform, MEDLINE, Cinahl, Embase, and PsychInfo. Search terms were adapted for each database. Terms included "personal assistant", "personal assistance*", "professional carer*", "direct payment", "wellbeing", "well-being", "health*", "mental health*", "psychosocial wellbeing", "protection", "rights", "security", "happ*", "satisfact*", "safety", "working condition*", "purpose*", "flourish*", "retention*", "absent*", "power*", "ethic*", "emotion*", "absenteeism", "trends", "sick*", "stress*", "lonelin*", "distress*", "insecur*", "isolat*", "ill*", and "recruit*".

Diagram 1 presents a PRISMA diagram of the search. A total of 11,329 articles were identified. A further 26 items were identified in a grey literature search, and an additional 21 items were identified through existing networks. Titles and abstracts were screened against the inclusion and exclusion criteria and 131 were examined in full. A total of 47 items were included in the final review. These were predominantly from the UK and Scandinavian nations. A data extraction proforma captured information about what works in PA wellbeing, alongside recommendations to support PA wellbeing, and was subsequently thematically analysed.

An assessment of methodological rigour was undertaken for each article (see Appendix 1). The proforma included an assessment of methodological rigor, based on quality criteria from the Joanna Briggs Institute Manual for Evidence Synthesis which has tailored questions for different study types. The majority of items were of high quality (n=26), whilst 15 were medium quality, and six were of low quality. High quality items were methodologically robust and had only minor limitations, medium quality items had some important limitations (for example, no discussion of ethical issues), and low-quality items had major limitations (for example, very little information about methods).

Limitations were apparent across the evidence base, with suggestions for improvement based on research recommendations, rather than being tested interventions. Further, overall, studies did not frame PA issues in terms of wellbeing, despite discussing factors likely to impact wellbeing.

Diagram 1: PRISMA

Identification of studies via databases and registers

Identification

Records identified from:
ASSIA (n = 2885)
ABI Inform (1180)
SPP (n = 783
SSCI (n = 3385)
HMIC (n = 500)
MEDLINE (n=535)
Embase (n = 835)
Cinahl (n = 509)
PsycInfo (n = 717)
Grey literature (n = 26)
Additional (n = 21)
(Total = 11376)

Records removed *before screening*:
Duplicate records removed (n = 3216)

Screening

Records screened (n = 8160)

Records excluded** (n = 8029)

Reports sought for retrieval (n = 131)

Reports not retrieved (n = 5)

Reports assessed for eligibility (n = 126)

Reports excluded: (n = 80)

Included

Studies included in review (n = 47)

Inclusion and exclusion criteria

To be included, articles had to have been published in English since 2000. Additionally, they had to specifically focus on the Personal Assistant workforce; social care workers, support workers, and business personal assistants were excluded. Personal Assistants were defined as workers employed directly by people to provide care and support, or undertaking work on a self-employed basis. Geographical criteria were applied, with articles originating from Scotland, England, Wales, Northern Ireland, Australia, the Netherlands, Switzerland, Norway, Sweden, Denmark, Finland, Belgium, Slovenia, and Iceland being included. Systematic reviews were also excluded, and all items had to have an empirical component, with purely theoretical papers being excluded.

Co-production

The oppression of disabled people has been compounded by research which silences experiential knowledge and which pathologises and individualises disability (Stone and

Priestley, 1996). To address this common power imbalance, key stakeholders in PA wellbeing in Scotland were involved in commenting on the emerging evidence, themes and recommendations. PA employers, including disabled people, and PAs from across Scotland were invited to join separate online expert groups to advise on interpretation of the emerging evidence review findings and recommendations. Each group met four times between February 2024 and July 2024 to review the evidence and comment on its salience and relevance to ensure that the research and recommendations were relevant and grounded in their lived experiences. All participants were paid by IMPACT for their time, including preparation time, and IMPACT also paid for any reasonable adjustments, including PA support where preferred. See Appendix 3 for full details of the expert groups and how they operated.

Limitations

There are two key limitations to the evidence review. Firstly, the included studies are generally not framed around the concept of PA wellbeing, instead they focus on factors that shape PA wellbeing (such as relationships and working conditions). Secondly, recommendations made in the studies cited in Section 3 are not based on proven interventions, but rather are the authors' inferences based on the findings of their studies. The interventions proposed in the reviewed literature are therefore yet-to-be-tested strategies, rather than proven evidence-based practices. However, they are strongly informed by secondary evidence combined with empirical data about the working lives of PAs. Section 5 lists recommendations to enhance PA wellbeing in Scotland, alongside a set of research gaps and priorities. These are drawn from analysis of the evidence review themes conducted with the PA and PA employer expert groups, and with other key PA and PA employer stakeholders in Scotland. This process aimed to maximise the applicability of the final recommendations made in this review to the Scottish context. Systematic evaluation will be needed to understand the impacts of interventions to determine whether – and the extent to which - they make a tangible difference to the wellbeing of PAs.

Section 3: Findings

This section presents findings from a systematic review of the evidence on factors that influence the wellbeing of PAs. The themes are: job satisfaction and perceptions of PA work; employment conditions and insecurity; access to training and support; isolation; relationships and blurred boundaries; and the nature of the work. Finally, the intersections between PA wellbeing and protected characteristics are considered. Each theme is organised with the first subsection outlining issues that affect PA wellbeing, and the second subsection presenting recommendations emerging from the literature. It is important to note that propositions in the literature to improve PA wellbeing were not based on tested interventions but were authors' conclusions based on their findings about the factors that affect PA wellbeing. It is therefore unclear what effect the proposed interventions would have on PA wellbeing in practice. It is also important to note that the suggested recommendations in the literature sometimes sit in tension to the ethos of choice and control that underpins PA work. These issues are explored in Section 4, the discussion and conclusion. Section 5 lists a set of recommendations and interventions that are specifically applied to the Scotland PA/PA employer context. These are informed by the work of the expert groups and by discussion of the systematic review evidence with other key stakeholders in Scotland.

a. Job satisfaction and perceptions of PA work

How people feel about the work they undertake is likely to impact on levels of happiness and overall wellbeing. The literature demonstrates that PAs often report high job satisfaction (Leece, 2006; Reid Howie Associates, 2010; Scottish Centre for Employment Research (SCER), 2018; Manthorpe et al, 2021; Lawrence et al, 2024), indicating that the nature of the work has potential to positively influence wellbeing. The SCER (2018), for example, found a high level of job satisfaction amongst PAs in Scotland, with a large majority being either very satisfied or satisfied, though this was based on a small sample size. Focus group data attributed this to both dissatisfaction with previous employment and reward from providing high quality care and support (SCER, 2018). This was also reflected in the PA Workforce Survey conducted in 2023 in Scotland which reported that job satisfaction was mentioned as having a positive impact on mental health and wellbeing in the free text comments (Lawrence et al, 2024). The same survey also reported that a large majority of PA respondents (86%) felt proud to be a PA (Lawrence et al, 2024), which is significant given professional identity is a key component of wellbeing (Silarova et al, 2022).

Flexibility and autonomy are frequently cited as key features that PAs value as this can suit their circumstances, including accommodating people with family responsibilities (Reid Howie Associates, 2010; Shakespeare et al, 2017; Theakstone et al, 2022; Wallace et al, 2022; Skills for Care, 2023; Cominetti, 2023; Lawrence et al, 2024). The presence of autonomy and control at work is associated with work related quality of life (Silarova et al, 2022), so this is likely to positively contribute to PA wellbeing.

Having a strong sense of fulfilment and purpose is also likely to impact wellbeing (Silarova et al, 2022). Building quality relationships and developing knowledge and understanding of their employer's personal needs and preferences, alongside being able to support employers to achieve personal outcomes, was perceived as highly rewarding in a mixed methods study in Wales (Wallace et al, 2022). This aligns with findings from a qualitative study with 105 PAs in England which highlighted that PAs valued the relational aspects of the work and making a positive difference (Woolham et al, 2019a), and echoes findings from the most recent PA Workforce Survey in Scotland which reported that PAs value the

rewarding nature of the work and the relationships they develop with their employers (Lawrence et al, 2024).

Skills for Care (2023) workforce data also shows lower turnover rates amongst PAs compared with independent sector care workers. Building close bonds with employers is highly valued (Reid Howie Associates, 2010; Theakstone et al, 2022; Cominetti, 2023) and this relational aspect was cited as a key reason why PAs remain in their roles in a survey conducted with around 1000 PAs in England (TLAP, 2022).

Yet, there is a paradox within the evidence between perceptions of value and the rewarding nature of the work discussed above, and low status emphasised in the literature (Norrie et al, 2023). This was reinforced in a survey conducted in England by TLAP (2022) which highlighted the low social value and recognition associated with PA work. Graby's (2018) study of PAs and employers in the UK associates the material and cultural devaluation of PA work with disablism, noting that poor pay stems from the lack of financial provision for disabled people. This was linked to distrust and paternalism embedded in assessments of need which shape the allocation of budgets, which in turn affects the level of pay that employers are able to offer PAs (Graby, 2018). Additionally, the cultural conflation of disability with dependency has negative consequences for the image and attractiveness of PA work (Graby, 2018).

Perceptions of value regarding the PA workforce was also illustrated in a qualitative study focused on the impact of Covid-19 on PAs. Woolham et al (2020) demonstrated that although health and care workers were held in high esteem during the Covid-19 pandemic, there were concerns about the longevity of public appreciation, though there was hope that this would lead to a more positive societal image of PAs (Woolham et al, 2020). However, participants described how inadequate access to PPE for PAs was symbolic in reinforcing their low status, and that poor guidance, training, and support left them feeling overlooked (Woolham et al, 2020).

Suggested recommendations for Job satisfaction and perceptions of PA work
The literature paints a conflicting picture when it comes to PAs. On one hand, studies consistently find high levels of job satisfaction stemming from the rewarding nature of their work, which likely has a positive influence on overall wellbeing (Lawrence et al., 2024; Manthorpe et al, 2021; Reid Howie Associates, 2010). However, there seems to be a paradox with the low professional status and lack of social value often associated with the role (Norrie et al., 2023). Reconciling this disconnect is important for fostering a heightened sense of identity, pride, societal appreciation, and wellbeing among PAs.

It is important to consult PAs on what resonates as meaningful appreciation and validation (Skills for Care, 2023; TLAP, 2022). The evidence advocates for personal assistants to have autonomy in conducting assessments about their wellbeing needs, with local authorities, employers, and support agencies prioritising the facilitation of peer-led assessments (Priestley et al., 2010).

Reshaping societal perceptions could go a long way in enhancing PA wellbeing. Public awareness initiatives that showcase how PAs support disabled people to live independently may help dispel misconceptions rooted in prejudice and assumptions about dependency (Graby, 2018; Woolham et al., 2020). Highlighting the transformative impacts PAs have on

autonomy, dignity and quality of life, could instil a sense of value, positive recognition and improved wellbeing.

Educational provision is also recommended to validate PA roles and boost wellbeing. Incorporating PA-focused modules in healthcare, social services and disability support curricula could cultivate deeper understanding of their unique responsibilities and person-centred philosophies (Reid Howie Associates, 2010; National Development Team for Inclusion, 2010). This has potential to foster greater respect, empathy and validation for the profession.

Formalising and elevating the professional standing of PAs is also recommended in some literature. Suggestions include formal qualifications for PAs, and the use of professional associations and regulatory bodies to enhance training and oversight while conferring a sense of prestige to the role (Cairncross & Crick, 2014; Glendinning et al., 2000).

As the literature shows, the quality of relationships between PAs and employers significantly impacts job satisfaction and wellbeing. Recommendations include providing joint training on conflict resolution, problem-solving and managing emotions (Porter et al., 2022). The literature indicates that vetting for value/personality compatibility (Shakespeare et al., 2017) and offering mediation support for sensitive conversations (Wallace et al., 2022) may further strengthen these dynamics.

Through public awareness, education, professional formalisation, and nurturing positive PA-employer relationships, the literature suggests a cultural shift has potential to enhance PA wellbeing (Woolham et al., 2019a). This has potential to boost morale, job satisfaction, overall wellbeing, and foster deeper societal appreciation for PAs' role in supporting independence, dignity and quality of life for their employer (Lawrence et al., 2024).

b. Employment conditions and insecurity

Poor employment conditions can have a detrimental impact on the wellbeing of PAs (Roland et al, 2022). PAs often receive low pay (Leece, 2006, 2010; Unison, 2012; Figgett, 2017; Graby, 2018; Norrie et al, 2023; Wallace et al, 2022), inconsistent rates (Theakston et al, 2022; Wallace et al, 2022), and higher levels are available in other sectors which require less demanding work (TLAP, 2022). A lack of opportunity for progression has also been highlighted (TLAP, 2022), reinforcing the need to consider how to facilitate career progression for PAs (Norrie et al, 2019). There are also inequities in pay depending on funding source, with PAs funded by personal health budgets in England receiving higher wages on average than those employed through a direct payment (Skills for Care, 2023).

Low rates of pay are compounded by the lack of security that often accompanies PA work. PAs are often precarious workers (Leverton et al, 2022a; Woolham et al, 2020; Wilcok et al, 2020), with a portion having no contracts and poor employment terms and conditions (Beer et al, 2013; Leverton et al, 2022a; Leece, 2006; Figgett, 2017; Manthorpe et al, 2010; Woolham et al, 2019a; Norrie et al, 2023; Roland et al, 2022; Theakston et al, 2022; Woolham et al, 2020; Wilcock et al, 2021; Wallace, 2022). A study by Woolham et al (2019a), for example, reported that PAs frequently lack secure contracts, sometimes have unclear job descriptions, and are regularly excluded from employee benefits including pensions, sickness, maternity, holiday, and redundancy pay.

Furthermore, it is common for payments to stop during disruptions to care, including due to hospitalisation or death (Woolham, 2019a; Norrie et al, 2023). Working conditions during the Covid-19 pandemic further illuminated the financial vulnerability of PAs (Norrie et al, 2023), with some having work suspended (Woolham et al, 2020; Leverton et al, 2022b; Norrie et al, 2021), including due to employers deciding to hire family members who were more trusted to reduce the risk of spreading infection (Leverton et al, 2022b; Manthorpe et al, 2021). Poor employment conditions can also affect health related behaviour amongst PAs, with Wilcock et al (2021) demonstrating how lack of sick pay may impact decisions about whether to work during periods of illness.

The financial insecurity of PAs can be situated within the wider macro context, which is shaped by inadequate funding and exacerbated by austerity measures (Figgett, 2017; Graby, 2018). Pay rates are set at local authority level, and the level of budget a person receives impacts how much they can pay (Theakstone et al, 2022; Wallace et al, 2022; TLAP, 2022). As highlighted above, Graby (2018) demonstrates how the material disadvantage of PAs is tied to cultural misrecognition of disabled people, with the conflation of disability and dependency framing care and support work as undesirable.

Suggested recommendations for employment conditions and insecurity
In light of these challenges, the reviewed evidence highlights the need for measures to ensure fair compensation and adherence to legal and regulatory frameworks governing PA employment. Addressing these factors is posited as a step towards providing PAs with the security and favourable working conditions necessary to thrive in their roles.

Firstly, the notion of 'fair compensation' emerges as a recurring theme across the evidence base, with multiple sources advocating for improved pay rates, enhanced wages, and better compensation for PAs (Figgett, 2017; Glendinning, 2000; Roland et al., 2022; TLAP, 2022; Skills for Care, 2023). These recommendations underpin the necessity of adequate, liveable wages that reflect the invaluable nature of PA work. Fair compensation extends beyond remuneration alone, encompassing reasonable working hours, comprehensive benefits packages, and overall favourable terms of employment (Leece, 2010; Glendinning et al., 2000; Manthorpe et al., 2010). Joining a trade union may provide PAs with support and information, also offsetting isolation (Unison, 2012). By ensuring that PAs are appropriately compensated, employers may cultivate a sense of stability and appreciation among this workforce, alleviating financial stressors and contributing to heightened job satisfaction and overall wellbeing (Glendinning et al., 2000; TLAP, 2022; Figgett, 2017). It is suggested that promoting fair compensation may enable employers to shield PAs from potential exploitation or precarious working conditions (Woolham, 2019a; Cairncross and Crick, 2014).

Some reviewed literature promotes adherence to legal and regulatory frameworks governing PA employment. Woolham et al. (2019a) support HMRC registration and encourage compliance with employment legal requirements. Additionally, Cairncross and Crick (2014) highlight the need for background checks as part of this compliance effort. However, these suggestions have implications for employer choice and control, a key issue discussed in the discussion and conclusion.

c. Access to training and support
A consistent finding in the literature is that PAs often lack access to adequate training and support (Ahlström and Wadensten, 2012; Lawrence et al, 2024; Norrie et al, 2019, Norrie et al, 2023; Theakstone et al, 2022; Unison, 2012; Woolham et al, 2019b, Woolham et al,

2020). The 2023 PA workforce survey in Scotland reported that only 24% of PAs had received training to support their role as a PA in the last year, and just over half felt they had enough training to do their job well (Lawrence et al, 2024).

Although greater autonomy and in work experience can support professional development (SCER, 2018), PAs report insufficient training on how best to support their employer, and this can create insecurities (Ahlström and Wadensten, 2012). Having responsibility for people and the fear of getting it wrong are examples of issues that affect wellbeing in Silarova et al's (2022) model of work-related quality of life, suggesting that insufficient training and lacking confidence about how to provide support might impact PA wellbeing.

One of the reasons for poor availability of PA training is due to limited funding. In Scotland, 40% of respondents to the 2023 PA survey noted that training was paid for by either PAs or their employers (Lawrence et al, 2024). This was reinforced by Norrie et al (2019) who highlighted that poor training availability is impacted by a lack of ringfenced funding. Another key issue relates to autonomy, with employers wanting to direct how their support is provided. Perceptions that training would undermine PA employer autonomy were reported in Norrie et al's (2019) study. This was echoed by Glendinning et al (2000) who highlighted tensions between disabled people's desire for PAs to have a basic level of training to enable them to undertake the role, whilst not so much that it eroded their choice and control.

Some studies specifically focused on access to training and support during the Covid-19 pandemic. Minimal guidance, training and support created new training needs and generated perceptions of being undervalued (Norrie et al, 2021, 2023; Woolham et al, 2020), though new opportunities for training also opened that were previously unavailable (Norrie et al, 2023). Concerns about infection control and the risk to their employer were highlighted as causing significant anxiety and stress which negatively impacted wellbeing (Woolham et al, 2020). PAs also reported having to manage mental distress and difficult behaviour from their employer due to the pandemic (Norrie et al, 2023), illustrating a need for further support to prevent negative consequences for PA wellbeing.

The literature also focuses on training for employers and the importance of support with tasks including recruitment, payroll, taxes, and national insurance (Graby, 2018; Cairncross and Crick, 2014; SDSS and The Alliance, 2020). Leverton et al's (2022a) qualitative study with seventy PA employers in England also reported poor access to training and support on being an employer, with some employers being worried about whether they were acting in accordance with employment law. Hamilton et al's (2015) study conducted in England highlighted that whilst unpaid carers often provide support with training and supervising PAs, there were concerns that this resulted in a reduction in formal support provision, underpinning the need for resource allocation systems that are carer neutral.

Concerns have also been raised about the ability of some disabled people to manage the requirements of being an employer (Priestley et al, 2010). A need for ongoing support to enable people to be good PA employers has been highlighted (Arksey and Baxter, 2012; Glendinning et al, 2000). Priestley et al's (2010) study on local cultures and their impact on the implementation of direct payments in the UK described how practitioners in one site were worried about the ability of users to manage a direct payment, and had concerns about the potential for poor treatment of PAs. It should be noted, however, that this was only identified in one out of eight case study sites, so may be reflective of risk management cultures in that particular Local Authority (Preistley et al, 2010).

However, issues relating to being an employer are also echoed in a study focused on the early implementation of self-directed support for people who experience mental distress in Scotland (Ridley and Jones, 2002). Ridley and Jones (2002) highlighted potential difficulties with managing finances and relationships due to the fluctuating nature of mental distress (Ridley and Jones, 2002). Mental health service users described being anxious about the responsibilities of being an employer, particularly managing paperwork and finances, though this was based on experiences of the early implementation of self-directed support in Scotland (Ridley and Jones, 2002). Nevertheless, it does pinpoint the need for adequate assistance to support people to meet their obligations as employers.

Despite there being clear support needs for employers, inequities in the availability of training and support between PAs and employers have also been highlighted, with the former having more access to help. This has potential to disadvantage PAs in the event of a dispute with their employer and may have negative implications for PA wellbeing (Woolham et al, 2019b). A need for further support to help broker conversations on sensitive topic areas between PAs and employers has been identified (Wallace et al, 2022).

Inequities within the PA workforce have also been reported. Woolham et al's (2019a) study in England highlights differences in access to support depending on employment type. Self-employed PAs had access to independent legal advice services through their insurance, whilst similar support was non-existent for directly employed PAs (Woolham et al, 2019a).

Suggested recommendations for access to training and support
The literature highlights the importance of training programs in supporting the wellbeing of personal assistants (PAs), though the potential for this to undermine employer choice and control has also been highlighted (Norrie et al, 2019; Glendinning et al, 2000.

Cairncross and Crick (2014) advocate for tailored educational and support opportunities that cater to the distinct needs of both PAs and their employers. TLAP (2022) and Skills for Care (2023) reinforce this, advocating for training, support and development initiatives designed specifically for PAs' unique challenges. However, literature highlights the need to move beyond skill-building to nurture personal growth and equipping PAs with coping tools to navigate the complexities of their roles (Manthorpe et al., 2011; National Development Team for Inclusion, 2010; Theakstone et al., 2022).

The evidence also indicates that support, guidance, and peer networking should complement formal training. For example, Manthorpe et al. (2011) emphasise the role of peer support networks in fostering PA wellbeing. Woolham et al. (2019b, 2020) recommend providing informal support, networking opportunities, and tailored emotional resources to address PAs' unique challenges. Wilcock et al. (2021) stress the requirement for access to mental health services and "well-being programs tailored to the unique challenges faced by care workers, including PAs". Similarly, Reid Howie Associates (2010) and TLAP (2022) flag the need to address the lack of peer support and social opportunities and actively promote dedicated peer networks.

d. Isolation
PAs often work on their own and the isolated nature of the work can affect wellbeing (Ahlström and Wadensten, 2012). Lone working restricts access to networks of peer support amongst PAs (Wallace et al, 2022), especially when individuals are not part of a wider PA

team (Wilcock et al, 2021). Even when individuals are part of a team, this can be hampered by confidentiality requirements (Glendinning et al, 2000).

Studies highlight an absence of emotional support for PAs (Manthorpe et al, 2011). This was reinforced by a qualitative study in Sweden which showed that the lack of a wider community created feelings of loneliness and the level of responsibility associated with lone working was a source of stress, making some PAs feel powerless (Ahlström and Wadensten, 2012). Further, a lack of peer support was a key issue exacerbated by lockdowns during the Covid-19 pandemic (Woolham et al., 2020).

The spatial aspect of PA work also has consequences for wellbeing. The employers home space becomes a workplace, leading to vulnerabilities that are absent in more traditional workspaces (Cairncross and Crick, 2014). Risks associated with lone working can erode protection in the event of abuse or violence and there is less likely to be a witness where such circumstances arise (Cairncross and Crick, 2014).

Suggested recommendations for Isolation

The reviewed evidence recommends initiatives and support structures to mitigate isolation and vulnerability associated with PA work. Firstly, fostering opportunities for peer support and networking is recommended (Manthorpe et al., 2011; Unison, 2012; Woolham et al., 2019b, 2020). Establishing dedicated platforms, events, or support groups that facilitate knowledge-sharing among PAs may alleviate feelings of loneliness and provide a sense of community. Additionally, integrating PAs within broader teams, where feasible, may enhance access to peer support and collaborative working environments (Wilcock et al., 2021).

The provision of emotional support tailored to the unique needs of PAs is also recommended (Manthorpe et al., 2011; Ahlström and Wadensten, 2012). This may include access to counselling services, mental health support, or dedicated helplines that offer guidance and a listening ear. By addressing the emotional toll of solitary and high-responsibility work, it is envisaged that these support mechanisms could bolster PA wellbeing and resilience.

Recognising the vulnerabilities associated with working in private households, the reviewed literature also suggests the implementation of robust safety protocols and protective measures (Cairncross and Crick, 2014). These may include background checks - though as mentioned earlier, this has implications for employer choice and control - risk assessments, and clear reporting mechanisms for incidents of abuse or violence. Additionally, providing PAs with access to conflict resolution training or mediation services may equip them with the necessary skills to navigate challenging situations and maintain a safe working environment (Cairncross and Crick, 2014).

e. Relationships and blurred boundaries

The evidence shows that relationships between PAs and their employers rarely reflect a traditional employer/employee dyad (Leverton et al, 2022a). Relationships have been likened to friendships or simulating familial relationships due to the proximity and embedded nature of the work (Arksey and Baxter, 2012; Leece, 2010; Manthorpe et al, 2010; Porter et al, 2022; TLAP, 2022; Shakespeare et al, 2017). The temporal and spatial dimensions of PA work can result in formation of social relations as opposed to being merely task oriented or instrumental as people spend long periods of time together in the private sphere of the home (Porter et al, 2022; Shakespeare et al, 2017). This closeness can foster intimacy and trust, as well as mutuality and reciprocity, with employers also supporting PAs (Graby, 2018;

Figgett, 2017; Manthorpe et al, 2021; TLAP, 2022; Shakespeare et al, 2017). These relational dynamics are often valued and cited as being key factors that motivate people to become PAs (Wallace et al, 2022; Reid Howie Associates, 2010; Lawrence et al, 2024; Porter et al, 2020); relational dynamics therefore have potential to support positive wellbeing.

Issues related to the blurring of the private/public sphere are exemplified in Bahner's (2012) small scale qualitative study which examined the struggle for sexual recognition for disabled people with PAs in Sweden. Although PA employers adopted approaches to secure privacy, tensions were evident between disabled people's right to sexual expression, sometimes seeking support to enable them to engage in sexual activity, and PAs not feeling comfortable with their employer having sex in close proximity (Bahner, 2012).

Yet, studies demonstrate that some employers purposely maintain professional boundaries (Figgett, 2017; Graby, 2018). Likewise, some PAs prefer to keep their private life personal, and choose not to disclose information to their employer (Shakespeare et al, 2017; Glendinning et al, 2000). The blurring of boundaries between the professional and personal and the informality of PA relationships can have a negative impact on PAs (Graby, 2018; Leverton et al, 2022a; Porter et al, 2022; Shakespeare et al, 2017; Woolham et al, 2019a). This can include PAs working unpaid hours or feeling a sense of responsibility to work additional paid hours (Leece, 2010; Ahlström and Wadensten, 2012; Woolham et al, 2019a; Porter et al, 2020; Theakston et al, 2022).

A UK based qualitative study with 58 disabled people and PAs reveals how PA relationships are often bound with emotion work and involve conflict or 'troubles', particularly where differences of opinions exist about what appropriate boundaries constitute (Porter et al, 2022, Shakespeare et al, 2017). This includes personal troubles resulting from clashes in personalities and values; practical troubles arising from issues related to PA performance, management style, and working conditions; and proximal troubles emanating from the closeness of working conditions (Porter et al, 2022; Shakespeare et al, 2017). This also echoes Graby's (2018) findings that whilst PA relationships are often positive and shaped by mutuality and reciprocity, issues of frustration and dissatisfaction, control, and abuse are also experienced by both parties in the PA nexus.

The negotiation of power within relationships also has implications for PA wellbeing. Fluid power relationships arise as PAs are reliant on their employer for income, whilst PAs can also hold power over their employer (Graby, 2018). Nordic studies have highlighted issues with PAs being in a subordinate position, lacking control (Ahlström and Wadensten, 2012), with the ideal PA being constructed as an invisible provider of service (Neumann and Gundersen, 2019). In one Swedish study, the PA/employer relationship was described as encompassing 'incomplete mutuality', due to the ways in which PAs and PA employers depend on each other (Ahlström and Wadensten, 2010).

Power relations are further complicated when people employ family members to be their PA (Arskey and Baxter, 2012). As Manthorpe et al (2011) noted, employing family members can be complicated, particularly for people with learning disabilities whose families are actively involved in decision-making in their lives.

Suggested recommendations for relationships and blurred boundaries
The evidence highlights the role that supportive organisational structures and positive relationships can play in cultivating PA wellbeing and job satisfaction. Establishing robust

supportive infrastructures in this context requires concerted efforts from multiple stakeholders, including local authorities, brokerage agencies, user-led organisations, employers, and the personal assistants themselves (Leverton et al., 2022b; Woolham et al., 2019b).

Porter et al. (2022) recommend training on problem-solving, conflict resolution, and emotional management for both parties. Shakespeare et al. (2017) emphasise compatibility and suggest assessing for shared values and personalities to foster positive working dynamics. Wallace et al. (2022) propose brokerage support services to facilitate sensitive conversations, mitigating strain or conflict that could undermine wellbeing. This is reinforced by Norrie et al (2023) who recommend that brokerage agencies provide group mentoring and mediating support services. SDSS and The Alliance (2020) advocate for a free, independent national helpline for self-directed support users. Such a resource could provide guidance and support for PAs and employers alike, cultivating a supportive ecosystem for PA wellbeing.

Employers should be made aware of the support available and how to access it to address identified knowledge gaps and employment law (Graby, 2018). Simultaneously, support agencies and user-led organisations should prioritise outreach to create avenues for meaningful dialogue with PAs and their employers.

f. The nature of the work

PA work is often highly skilled and complex (Thompson and Pickering, 2021) and can involve a range of tasks including activities of daily living and intimate personal care (Ahlström and Ahlström and Wadensten, 2012; Graby 2018; Wilcock et al, 2021). Participants in a Swedish qualitative study described the coping skills they adopted when providing intimate personal care, and the labour involved in negotiating time pressures and managing their stress to prevent it having a detrimental impact on their employer (Andersson et al, 2022).

Personal Assistance can also involve health-related activities. This was exemplified in one study citing administering medication, assistance with catheter care, and pressure sore prevention (Wilcock et al, 2021). Studies show that working with people whose health is deteriorating can be challenging (Wilcock et al, 2021), can sometimes be physically tasking (Ahlström and Wadensten, 2012), and can be difficult when supporting people with challenging behaviour (Andersson et al, 2022). Indeed, participants in Wilcock et al's (2021) study of directly employed care workers reflected that supporting people with deteriorating and fluctuating health conditions can be emotionally demanding.

The difficult nature of PA work can be compounded by a lack of knowledge and training regarding how best to support PA employers (Ahlström and Wadensten, 2012). A study of PAs in Sweden, for example, described feelings of sadness and 'mental fatigue' and reported that insufficient knowledge about their employer's illness and a lack of understanding about how best to support them created feelings of insecurity (Ahlström and Wadensten, 2012), again underlining the importance of adequate support and training identified throughout this report.

Role expectations also shifted significantly during the Covid-19 pandemic (Woolham et al, 2020). Woolham et al's (2020) study demonstrated how PA work altered in response to lockdowns which disrupted what people were able to do. PAs also provided significantly more emotional support, alongside help to meet healthcare needs, shopping, and

technology, and this was the source of stress for some PAs. Infection control also became an important part of the role which caused stress and anxiety (Woolham et al, 2020; Norrie et al, 2023). A study examining PA work during the pandemic, for example, found that PAs experienced stress due to the increased risk to their own health and the responsibility of protecting their employer, and despite this, there was a lack of resources available to support PA wellbeing (Norrie et al, 2023). Thus, changing demands in response to the pandemic, accompanied by a lack of adequate support, created stress, which detrimentally affects wellbeing.

Suggested recommendations for the nature of work

The reviewed evidence highlights the need for comprehensive measures to address the unique support requirements of PAs. Firstly, providing targeted training and knowledge development opportunities is recommended, equipping PAs with specialised knowledge and skills tailored to diverse aspects of their work. This could enhance PA confidence, competence, and preparedness for their multifaceted roles (Andersson et al., 2022; Wilcock et al., 2021; Woolham et al., 2020; Norrie et al., 2023) and could include intimate personal care, health-related tasks, supporting individuals with challenging behaviours or deteriorating conditions, and infection control.

Secondly, the evidence recommends establishing robust supportive structures and resources to address the emotional, psychological, and physical demands inherent to PA work. Access to counselling services, peer support networks, dedicated mental health resources, and occupational health support may provide essential outlets for PAs to process emotional challenges, foster resilience, manage physical strain, and promote overall well-being (Manthorpe et al., 2011; Wilcock et al., 2021; Ridley and Jones, 2002; Woolham et al., 2020; Norrie et al., 2021).

Thirdly, support mechanisms should be adapted in response to evolving role expectations and changing circumstances, such as those experienced during the Covid-19 pandemic. Implementing flexible and responsive support systems that prioritise ongoing needs assessments and timely adjustments may equip PAs with necessary resources, guidance, and coping strategies to navigate unpredictable situations effectively, mitigate stress, and maintain well-being amidst heightened demands (Woolham et al., 2020; Norrie et al., 2023). Lastly, fostering collaborative partnerships between PAs, employers, support agencies, and relevant stakeholders is suggested. Through open communication, inclusive engagement, and co-creation processes, stakeholders may collectively identify emerging needs, address knowledge gaps, and develop tailored solutions that empower PAs and enhance their work experiences while ensuring priority is given to their well-being (Norrie et al., 2021; Leverton et al., 2022b; Priestley et al., 2010).

g. Equality, Diversity and Protected characteristics

Reid Howie Associates (2010) highlight employers' limited access to equal opportunities policies for PAs, and limited awareness of equality issues more widely. Whilst the reviewed evidence often provides a breakdown of participant demographic information, there is a lack of active consideration of how wellbeing intersects with protected characteristics. For example, Leverton et al (2022a) purposely sought to recruit people from minority ethnic groups and ensure a diverse range of voices were included, though the analysis does not consider differences amongst these groups. This is echoed by Wallace et al (2022) who reinforce the lack of publications specifically focused on how variables such as age, ethnicity, and gender impact the lives, work, and experiences of the PA workforce. There is a

notable lack of literature focusing on experiences of PA migrant workers in the UK. Similarly, no literature was identified that specifically focused on experiences of Gypsy/Travellers communities.

This suggests that there is an overall gap in understanding the experiences of PAs from diverse backgrounds and on how protected characteristics interact with their work and wellbeing.

There is evidence that there is a lack of diversity in Scotland's PA workforce. Lawrence et al, (2024) examined age, gender, and disability among PAs in Scotland and found the respondent pool to be largely homogenous, with PAs being predominantly female, white, and over the age of 45. The lack of recognition and visibility of the PA role, as well as occupational isolation and lack of support networks, are identified as key issues for the PA workforce (Wallace et al, 2022), indicating that there may be challenges in achieving equality and inclusion. This highlights the need to improve outreach to underrepresented groups and expand the diversity of the workforce in Scotland.

The voices of disabled people are often included in evidence on PAs, though this is often from the perspective of being an employer (e.g. Figgett, 2017; SDSS and The Alliance, 2020). There are exceptions to this, with Lawrence et al (2024) reporting that just over a fifth of PAs in Scotland considered themselves to have a disability, which reflects characteristics of the wider population. This was lower in England at 6%, with the proportion of disabled care workers in England being even lower (1%), although the data may be an artefact of the reporting mechanism with PAs answering the questions directly, whilst employers answered on the behalf of care workers (Skills for Care, 2023).

In relation to mental health, there was a slight reduction in the percentage of people responding to the PA workforce survey in Scotland who rated their mental health as very poor or poor, reducing from 18% in 2022 to 14% in 2024 (Lawrence et al, 2024; Theakstone et al, 2022). The authors note that it is too soon to infer an improvement trend (Lawrence et al, 2024).

The gendered nature of care is particularly visible amongst PAs. This is evident in Skills for Care (2023) workforce data which shows that 82% of PAs identified as female in England, with similar results reported in Scotland, with 79% identifying as female (Lawrence et al, 2024). Norrie et al (2019) highlight that training can be difficult for PAs to fit into their lives, particularly when people have family responsibilities, an issue that is often more acute for women.

A high proportion of PAs are also unpaid carers. The PA Annual Workforce Survey in Scotland reported that over half (57%) of respondents provided unpaid care or support outside of their PA role (Lawrence et al, 2024). Self-directed support legislation allows for direct payment holders to hire family members, in select circumstances, to support them. This means there is also a population of PAs who are likely to undertake both paid and unpaid care. Lawrence et al (2024) conclude that more work is needed to understand the impact of unpaid caring on PAs, and what supports can be provided to address their needs. Suggested recommendations for protected characteristics

Specific recommendations do exist in the evidence to support PAs that are also unpaid carers. The evidence base advocates for the implementation of flexible scheduling arrangements, tailored work-life balance initiatives, and the provision of resources to assist

PAs in managing the complexities of unpaid care responsibilities alongside PA work (Glendinning et al, 2000; Leece, 2010; Manthorpe et al, 2010).

There is a clear gap in evidence on how PA wellbeing intersects with wider identities. Further research is required to understand PA wellbeing according to protected characteristics.

Section 4: Discussion and conclusion

This systematic review aimed to examine and synthesise the evidence base to a) understand what factors impact PA wellbeing and b) identify strategies and recommendations to improve PA wellbeing. The review demonstrates that although core issues facing the social care workforce (Silarova et al, 2022) also impact PAs, PAs have distinct wellbeing needs. These coalesce around pay and employment conditions, the nature of relationships with employers, and inadequate access to training and support due to issues relating to funding and autonomy. Progress is needed to ensure that the benefits of PA work remain, whilst enhancing employment conditions to maximise wellbeing (Woolham et al, 2019a).

PAs report high job satisfaction and having a sense of purpose and fulfilment is likely to benefit wellbeing outcomes. PAs play a unique role in supporting people with diverse needs to live in a way that they choose, and making a difference to people's lives was perceived as rewarding (SCER, 2018; Wallace et al, 2022). Building close bonds with employers and having a high degree of autonomy and flexibility are also attributes that PAs value (Woolham et al, 2019a; Reid Howie Associates, 2010; Theakstone et al, 2022), and are key factors likely to also have a positive impact on PA wellbeing. These factors align with the meaningful work, autonomy/control at work, and compassion satisfaction sub-themes within Silarova et al's (2022) 'job characteristics' component of their model of work-related quality of life.

Despite high job satisfaction, a personal sense of value amongst PAs is not reflected in wider societal status, with PAs often having low visibility and recognition (Graby, 2018; Wallace et al, 2022). This applies to cultural recognition (how PA work is valued) and material recognition (financial renumeration) (Graby, 2018). There is strong evidence that PAs regularly have poor employment conditions, including low pay, access to pensions, sickness, maternity, holiday, and redundancy pay. Further, PAs are often precarious workers, with a portion having no contract (Leverton et al, 2022a; Norrie et al, 2023; Woolham et al, 2019a; Wilcock et al, 2021). Financial precarity was further magnified during the Covid-19 pandemic, which reinforced existing vulnerabilities (Leverton et al, 2022b; Norrie et al, 2023; Woolham, 2019a) as payments and work ceased for many PAs (Leverton et al, 2022b; Woolham et al, 2020). This evidence reinforces Silarova et al's (2022) examples of pay, benefits, and job security to illustrate the 'working culture' sub-theme of the 'organisational characteristics' component in work related quality of life for social care staff.

PAs also frequently lack access to adequate training and support (Norrie et al, 2019, 2023; Theakstone et al, 2022; Unison, 2012; Woolham et al, 2019b, Woolham et al, 2020), an issue compounded by the isolated nature of PA work (Ahlström and Wadensten, 2012; Wilcock et al, 2021; Cairncross and Crick, 2014). Tensions exist between the purpose of PAs in supporting independent living, with employers directing how work should be carried out, and PAs acting in accordance with external training guidelines. Further, the absence of ringfenced funding reduces incentives for employers to pay for PA training (Norrie et al, 2020; Woolham et al, 2019a), highlighting tensions between the needs of PAs and their employers and how this intersects with wider systemic financial constraints and policy choices at both state and local authority levels. Training is inherent to the 'learning and growth opportunities/self-actualisation' sub-theme of the 'job characteristics' component of Silarova et al's (2022) work related quality of life model.

Relational dynamics between PAs and PA employers also influence PA wellbeing, in both positive and negative ways. The proximity and temporal character of PA work generates

benefits including intimacy, trust, mutuality, and reciprocity (Graby, 2018; Figgett, 2017; TLAP, 2022; Shakespeare et al, 2017). Yet, this can blur boundaries between the personal and professional which can result in PAs doing unpaid work (Theakstone et al, 2022; Woolham et al, 2019a) and which can significantly impact relationships (Porter et al, 2022; Shakespeare et al, 2017). While Silarova et al (2022) highlight the importance of the job-person match, the relational dynamics between PAs and their employers are distinctive from that of the wider social care workforce. Specific support is required to help PAs and PA employers navigate relational issues, including brokerage and mediation to support conflict resolution (Shakespeare et al, 2017; Porter et al, 2022; Wallace et al, 2022). Further wellbeing needs relate to supporting work/life balance, including support for PAs with informal caring responsibilities, and greater use of mental health and wellbeing resources. Further research is required to test these out in practice and assess what impact they have on PA wellbeing outcomes.

The need to improve compensation and ensure employment practices are legally compliant is also essential (Figgett, 2017; Skills for Care, 2023). Improved pay and conditions are required to foster greater security and stability for PAs and so to improve their wellbeing outcomes. As the literature highlights, poor pay and conditions are impacted by the wider structural context (Graby, 2018). Greater financial support is therefore recommended to bridge the gap and enable PA employers to fairly compensate PAs for the work they undertake.

Finally, there is insufficient research on the ways in which protected characteristics intersect with PA wellbeing. Providing a breakdown of participant characteristics in research and evaluations is not sufficient; analysis should go further to consider how different facets of PAs identity shape experiences and outcomes.

The evidence reviewed offers a range of suggested recommendations aimed at enhancing the wellbeing of PAs. However, it is important to note that propositions in the literature to improve PA wellbeing were not based on tested interventions but were authors' conclusions based on their findings about the factors that affect PA wellbeing. It is therefore unclear what effect the proposed interventions would have on PA wellbeing in practice. Further, any interventions need to be carefully considered to ensure they do not undermine the ethos and progress of the Independent Living Movement. For example, the need for comprehensive training and support could erode choice for PA employers in directing how their support is provided (Norrie et al, 2019; Glendinning et al, 2000). Similarly, whilst role autonomy for PAs may support their wellbeing, a fundamental purpose of personal assistance is to promote self-determination for PA employers (Angelova-Mladenova and Crespo Fernandez, 2024). Any intervention focused on training or enhancing PA autonomy would have to simultaneously promote the self-determination and independence of their employer.

The use of background checks and regulation for PAs is also potentially at odds with the ethos of personal assistance. Whilst this may aim to formalise the PA profession, this could reduce the pool of PAs and the autonomy and flexibility associated with PA work (Norrie et al, 2023). Debate over regulation in Scotland is ongoing, with proponents arguing that it will offer enhanced security for PAs and PA employers, advance parity in terms of pay and conditions with the wider social care system, and enable access to support and training for PAs (Scottish Government, 2023). However, significant concerns have been raised, including negative impacts on recruitment and the potential for over-regulation that may encroach into the private space of the home (Scottish Government, 2023; Elder-Woodward, 2023, 2024). Any changes around regulation would therefore have to be carefully considered and co-produced to avert any negative wellbeing impacts on both PAs and disabled people.

Section 5: Recommendations for practice and research

The findings of the systematic evidence review have been discussed with the expert groups and with key PA and PA employer stakeholders in Scotland. The outcome is a range of proposed interventions likely to enhance PA wellbeing in Scotland. There is already a strong web of organisations, networks and bodies working to improve outcomes in the PA/PA employer 'space', with a strategic overview involving the Scotland-wide PA Programme Board and its sub-groups. Taking the recommendations forward in practice will be the work of these multiple stakeholders through continuing partnership and collaboration. Appendix 2 lists stakeholders that are already doing work in this area. The recommendations need to be carefully considered to ensure they do not undermine the ethos of the Independent Living Movement and the principles of personal assistance. All interventions should be evaluated, including in relation to protected characteristics.

Recommendations to improve PA wellbeing in Scotland

a. Adequate, liveable wages that reflect the nature and value of PA work – so that people are more likely to take up the role. This may include opportunities to tier pay levels to reflect factors such as the complexity of each individual PA role, rurality, travel time, and unsocial hours. Additionally, PAs need easy access to support to maximise income, including through welfare benefits advice, as many PAs work part-time and/or have caring responsibilities. Additional benefits, such as discount cards or employee assistance programmes should be explored as part of the wider benefits package for PAs but should not be considered a replacement for fair pay.

b. A higher supply of PAs and an increase in PA diversity – so that PA employers can choose compatible PAs, and PAs and PA employers can have access to additional assistance in the event of sickness, annual leave, or changes in support needs. To maximise PA employer choice and control, there need to be systems developed to facilitate 'pools' of PAs to emerge, accessible to PA employers, enabling them to access PA 'cover', where needed.

c. Higher public awareness of and esteem for PAs - public campaigning, so that people are aware of the PA role in assisting disabled people to have independent living, and the complexity of the job. To develop parity of esteem for PAs with other allied professionals, there should be tailored learning across health and social care settings about the PA role, how it differs from other social care roles, and its distinctive contribution.

d. Opportunities for PAs to connect with other PAs across Scotland so that PAs can tackle isolation - there should be multiple avenues to connect with others, including online, anonymised, moderated spaces for discussion with peers, more informal opportunities to connect, as well as regular regional and online events. PAs need to be involved in the development and leadership of these initiatives to build a collective voice.

e. Stronger enforceable employment rights for PAs - notably in terms of working conditions (e.g. being paid for all the hours they are at work) and employee benefit packages (e.g. access to pensions, sickness, holiday pay, redundancy pay and maternity leave), with local authority funding and contracts accordingly. This may include engagement with regulatory frameworks, professional associations, membership bodies, and trade unions.

f. Consistently available and accessible information, training and support to maximise PA employers' awareness of their legal and 'best practice' obligations to support PA

wellbeing, and support to access adequate local authority funding to align with these best practices.

g. Guaranteed, funded access to training and development that meets the individual needs of PAs and PA employers - both skills-based and for personal growth. Training delivery should maximise choice and may include joint training for PAs and their employers, training that PAs can access independently, and training that focuses on the unique relational element of PA work. To remove barriers to accessing training for PA employers and their PAs, time to access training should be included in Direct Payment allocations. Recommendations for how best to deliver training to PAs and PA employers in Scotland can be found in the 2024 [Personal Assistant National Training Framework for Employers](#).

h. Access to a range of emotional supports tailored to PAs that reflect the unique needs and challenges of the role, including counselling services, mental health support and a dedicated Scottish-based helpline with specialist training on/awareness of the SDS landscape, the PA role and wellbeing challenges. PAs should have the opportunity to inform decision-making on the right structures and mechanisms for this specialist support.

i. A pathway for PAs to be able to pursue relevant formal qualifications, with the support of their employer, and have the opportunity to gain membership of appropriate professional associations.

j. Upskilling PA employers with the softer skills needed for effective people management (including work planning, anticipatory management, offering feedback on PA performance and contribution, recognition). Where these opportunities are already available (e.g. from Centres for Inclusive Living), improve publicity and opportunities for take-up.

k. Access to mediation and brokering for PAs and PA employers to navigate the relationship and blurred boundaries in the PA employer-PA dynamic.

l. Evaluation - all interventions seeking to improve PA wellbeing in Scotland need to be systematically evaluated for effectiveness and unintended impacts on the various subgroups in the PA space, including impacts on PA employers and on groups with protected characteristics. Evaluation activities should include PA employers and PAs, who should be paid for their time and expertise.

m. Presentation of these findings by the PA Programme Board Wellbeing Subgroup to the wider PA Programme Board to integrate actions into the Board's workplan, where relevant.

Research gaps and priorities for Scotland

In the course of analysis of the systematic review, and discussion with the expert groups, priorities for further research have emerged:

- Understanding the different 'subgroups' of PAs, and trends in the PA population including protected characteristics.
- Understanding the paths of progression for PAs who wish to pursue the role as a long-term career, rather than as a short-medium term job.
- The experiences of and wellbeing drivers for PAs who are acting as PAs to family members, to understand more about the intersection of PA relationships with unpaid care responsibilities.

- Better understanding of the wellbeing needs and distinctions between directly employed and self-employed PAs.
- Better understanding of the wellbeing supports PAs may need in response to advances in technology-enabled support.
- The wellbeing experiences of PAs working with PA employers that are navigating the transition from children's services into adult services.
- Awareness of and effectiveness of the PA employer and PA handbooks, as these are central tools for sharing information on best practice for the PA role.
- Further work to examine where PA wellbeing drivers and barriers mirror or differ from those of the wider social care workforce.

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Appendix 1: Assessment of Methodological Rigour

Author(s)	Year	Rating
Ahlström, B and Wadensten, B	2010	Medium
Ahlström, G, Wadensten, B	2012	Medium
Andersson, K, Lovgren, V, Ahnlund, P and Kalmnan H.	2022	Medium
Arksey, H, Baxter, K	2012	High
Bahner	2012	High
Beer, G, Paxman, J, Morris, C	2013	Low
Cairncross, L, Crick, A,	2014	Medium
Cominetti, N	2023	Low
Figgett, D	2017	Low
Glendinning, C, Halliwell, S, Jacobs, S, Rummery, K, Tyrer, J	2000	Medium
Graby, SD	2018	High
Hamilton, S, Szymczynska, P, Clewett, N, Manthorpe, J ,Tew, T, Larsen, J, Pinfold, V	2015	High
Hultman, L, Bertilsdotter Rosqvist, H, Elmersjö, M and Koziel, S	2023	Medium
Lawrence, J, Adderley, J, Hirst, K	2024	Medium
Leece, J	2006	Medium
Leece, J	2010	Medium
Leverton, M, Samsi, K, Woolham, J and Manthorpe, J.	2022a	High
Leverton, M, Samsi, K, Woolham, J, Manthorpe, J	2022b	High
Manthorpe, J, Samsi, K, Norrie, C and Woolham, J.	2021	High
National development team for inclusion	2010	Low
Neumann, C, B, Gundersen, T	2019	High
Norrie, C, Luijnenburg, O, Moriarty, J, Samsi, K, Manthorpe, J.	2023	High
Norrie, C, Woolham, J, Samsi, K and Manthorpe, J.	2021	High
Norrie, C, Woolham, J, Samsi, K, and Manthorpe, J	2019	High
Porter, T, Shakespeare, T, Stockl, A	2022	High
Porter, T, Shakespeare, T, Stockl, A	2020	High
Priestley, M, Riddell, S, Jolly, D, Pearson, C, Williams, V, Barnes, C, Mercer, G.	2010	Medium
Reid Howie Associates	2010	High
Ridley, J, Jones, L	2002	Medium
Rodrigues, R.	2020	High
Roland, D, Allan, S, Chambers, E, Smith, D, Gousia, K.	2020	High
Scottish Centre for Employment Research	2018	High
SDSS and The Alliance	2020	Medium
Shakespeare, T, Porter, T, Stockl, A	2017	High
Skills for Care	2023	Low
Theakstone, DD, Lawrence, J and Adderley, J.	2022	High
Thompson, J, and Pickering, S.	2021	High
TLAP	2022	High
Unison	2012	Medium
Wadensten, B and Ahlström, G.	2009	Medium
Wallace, S, Llewellyn, M, Garthwaite, T, Randall, H and Sullivan. S.	2022	High
Westberg, K.	2010	High
Wilcock J, Manthorpe J, Moriarty J and Iliffe, S.	2021	High
Woolham J, Samsi K, Norrie C and Manthorpe, J.	2020	High
Woolham, J, Norrie, C, Kritika, S, Manthorpe, J	2019a	Medium
Woolham, JG, Norrie CM, Samsi K and Manthorpe, J.	2019b	High
Zaviršek, D. and Fischbach, S.	2023	Low

Appendix 2: Stakeholders active in the PA wellbeing space in Scotland

Note: while not exhaustive, below is a list of national, regional and local organisations, networks and bodies that have influence and a role in the PA wellbeing space, whether directly or indirectly. The evidence outlined in this systematic review may be of interest to the stakeholders listed below. Some of these bodies may have a role in mobilising the recommendations emerging from this report.

- PA Programme Board Wellbeing subgroup (and other subgroups as appropriate)
- PA Network Scotland
- Self Directed Support Scotland
- Scottish Government: Ethical commissioning, Wellbeing and PA policy team
- Scottish Government: Direct Payments funding agreement group
- Direct Payments Model Agreement Subgroup (Scottish Government, COSLA, local authorities and HSCPs)
- Independent Living Fund Scotland
- Local Disabled People's Organisations (DPO)
- Local independent support organisations (ISO)
- Centres for Inclusive Living (CILs)
- Support in the Right Direction (SIRD)-funded projects
- Community Brokerage
- Independent Living Group PA (ILG PA)
- Local authorities
- Health and Social Care Partnerships (HSCP) and Integration Joint Boards (IJB)
- Partners involved in 'Make an imPAct' campaign
- My Job Scotland
- Carers Centres
- Fair Work Commission
- Relevant trade unions
- Scottish Qualifications Authority (SQA)
- The Scottish Social Services Council (SSSC)
- NHS Education for Scotland (NES)
- Social Security Scotland

Appendix 3: PA and PA employer expert groups

The team undertaking this review believe that people with lived experience have a vital role to play in the use of evidence. The Disabled Peoples' Movement and Independent Living Movement campaigned for years for the right to personal assistance, and from the outset of this project the team was clear that PA employers were central to the success of this work. In January 2024, Rhiann McLean and Richard Brunner, who led the IMPACT Demonstrator project on PA Wellbeing in Scotland, convened two online expert groups; one for PA employers and another for PAs. All members were asked to remain anonymous, and for confidentiality to remain within each group.

The purpose of these groups was to:
- examine emerging evidence from the systematic review
- 'ground' the evidence in the real life of PAs and PA employers in Scotland
- identify potential gaps in the evidence to allow the IMPACT team to refine searches (for example, on self-employed PAs)
- make sure that the IMPACT leads considered how the review findings/recommendations impact on PA employer wellbeing as well as PA wellbeing (seeking the 'win-win')
- help IMPACT prioritise recommendations to inform guidance and policy for PA employers, PAs, and other local and national professionals and bodies in Scotland.

The groups did not seek representativeness, seek a consensus, or seek unanimity. Instead, the aim of the conversations was to facilitate a range of voices, seek diversity, draw out contradiction and nuance, hear lived experiences that might place limits on generalisability of emerging themes, and raise questions that would allow us to interrogate the emerging findings of the evidence review.

Group composition

The groups were recruited in December 2023 through existing PA and PA employer networks. Interested people contacted the IMPACT leads directly to discuss potential participation. The PA employer group had nine members, and the PA group had eight members. The meetings were held on the Zoom online platform.

While not seeking to be demographically representative, these expert groups were purposively selected to represent a range of backgrounds and experiences, and included:
- rural, urban and island perspectives
- a range of different support needs
- disabled employers employing PAs for themselves, employers employing PAs on behalf of adult family members, employers employing PAs for their children
- PAs directly employed by disabled people, PAs employed to support disabled children, PAs employed by their own friends and family, PAs working for more than one employer
- both directly employed and self-employed PAs.

Group activities

Over the course of their involvement, group members:

- attended 4 facilitated two-hour online meetings between January 2024 and July 2024
- were sent written summaries of emerging evidence themes with reflection questions in advance of each meeting, and were expected to read and think about this evidence before the meeting, to enable informed discussion
- were invited to claim a participation payment of £25 an hour for 4 hours, including two hours advance reading, plus expenses e.g. to pay for PA support to enable participation.
- were encouraged to put thoughts in writing if they could not attend a particular meeting, or if they had reflections after a meeting.

It is worth noting that in the PA group, members repeatedly expressed satisfaction at meeting other PAs, and for the rare opportunity of being able to talk together about experiences (e.g. 'This has been amazing, just talking about our experiences, it is in itself helping my wellbeing.') This happened to a lesser extent in the PA employer group, and is a soft indicator of PA isolation, which is a theme in the evidence review.

Ways of working

- the IMPACT leads supported people to get online for the meetings, doing individual 'practices' where helpful, and being available in the meeting room 15 minutes before start-time
- the IMPACT leads invested in 'beginnings' and 'endings' for the groups. To set the tone at the outset of the group, time was dedicated in the first meeting for in-depth introductions, and opportunities to ask questions about the work. Across all sessions, time was spent at the start to 'tune in' to each other's voices, and have a chance to connect as people
- the fourth session was dedicated to final comments on the systematic review summary report, reflections on how the group had gone for people, and discussing a list of opportunities for PAs and PA employers who may be interested in involvement in similar groups
- ground rules were proposed by the IMPACT leads, including an interruption rule, which allowed the leads to seek clarity, refocus conversation and keep to time
- the meetings were two hours long with a protected ten-minute break. Some participants engaged through the chat function, some sent written points in advance, to be read out at the meeting
- the time available in each group was limited, not every theme in the evidence review was able to be discussed in detail, and members still had more to say
- the Zoom discussions were recorded with consent from participants, for the sole purpose of enabling reflection and active listening by the IMPACT leads
- at meeting three, the IMPACT leads gave the groups feedback as to how their reflections had influenced the writeup of the evidence.

Examples of learning from each expert group are summarised below (non-exhaustive).

a. the PA expert group helped the IMPACT leads realise that:
- PA wellbeing is imperative to enabling their employer's wellbeing. However, PAs are focused on their employer's wellbeing, rather than their own.

- There is no 'single type' of PA for whom all interventions to improve wellbeing aimed at PAs will work. There are (at least) three cohorts of PAs: those employed by family, by friends/neighbours, and those PAs employed by people they did not previously know. Also, some are directly employed, some are self-employed. Therefore, interventions to improve PA wellbeing may need to be framed and evaluated in terms of their intended impact on wellbeing in specific ways (e.g. aimed at which group of PAs/employers, for what wellbeing goal…).
- There is not a simple or single 'free market' in PAs. Some PAs are employed by family members, specifically because the family member does not wish anyone else to play the role; or because the family speaks a minority language, so sourcing an appropriate PA that is not a family member is very difficult.
- It can be unclear who is responsible for PA wellbeing. For employed PAs it should be for the employer to initiate conversations about wellbeing and training needs (as in every other workplace). For self-employed PAs it may be a different dynamic, with the PA needing to be more proactive.
- Paying for interventions to support wellbeing: in other jobs, support, supervision, training, mentoring and so on would be done in the employer's time. Direct payments should account for this.

b. PA employers helped the IMPACT leads realise about PA wellbeing:
- There is no 'single type' of PA employer for whom all interventions to improve wellbeing aimed at PAs will work. There are 3 types of employer (at least): for self, for disabled family members, and for disabled children. Therefore, interventions to improve PA wellbeing may need to be framed and evaluated in terms of their intended impact on wellbeing in specific ways (e.g. aimed at which group of PAs/employers, for what wellbeing goal…).
- It is hard for employers to know the wellbeing status and needs of their PAs. And questions were raised about how they should they measure wellbeing (e.g. some kind of wellbeing indicator tool?). What might 'soft' indicators for PA wellbeing be (e.g. having a PA working for you for a reasonable amount of time, evidence of your PA being excited/enthusiastic when at work)?

Combined group points

Running the two expert groups in parallel allowed the IMPACT leads to view the same evidence from different perspectives, and draw conclusions such as:
- PA employer wellbeing and PA wellbeing are likely symbiotic. It is difficult to imagine one without the other. Wellbeing for both is needed in order to maximise wellbeing for each.
- Training for employers and training for PAs could go together more often.
- Disabled people have rights – PAs have rights too.

We sincerely thank both PA wellbeing expert groups for their essential contribution to this project, and for their professionalism and commitment to the work.

Richard Brunner and Rhiann McLean, August 2024.