

WHAT WORKS IN PA WELLBEING

A 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. 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 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.

Scotland's PA Programme Board has a sub-group with a focus on PA wellbeing. In 2023-24, members of the Wellbeing Subgroup made a bid to IMPACT for a twelve-month 'Demonstrator' project find out 'what works in PA wellbeing?'. As part of this project, in collaboration with key stakeholders from the Wellbeing Subgroup, a team from IMPACT (Dr Aisha McGregor, Dr Obert Tawodzera, Dr Richard Brunner and Rhiann McLean) carried out a systematic evidence review that aimed 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 Feb 2024 by the University of Birmingham Knowledge and Evidence Service. Forty-seven relevant pieces of research were found, mainly 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. It is therefore unclear what effect the proposed interventions would have on PA wellbeing in practice. This suggests that more research is needed on PA wellbeing, and that any interventions seeking to improve PA wellbeing in Scotland should be evaluated.

To 'ground' the evidence 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. Each group met online four times between February and July 2024 and each member was paid for their involvement, and for any reasonable adjustments. The groups discussed the emerging themes and helped to refine the recommendations. While not seeking to be representative, members of the expert groups had a wide range of backgrounds and experiences. These included: a. rural, urban and island perspectives; b. disabled employers employing PAs for themselves, people employing PAs on behalf of adult family members, and people employing PAs for their children; c. PAs directly employed by disabled people, PAs employed to assist disabled children, and PAs employed by their own family; d. PAs working for more than one employer; e. both directly employed and self-employed PAs.

What does wellbeing mean in his context?

It is important to consider what is meant by wellbeing in the PA 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 six 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?'. These are: organisational characteristics, job characteristics, mental wellbeing and health, physical wellbeing and health, spillover from home to work, and professional identity.

What influences PA wellbeing?

The systematic review found six themes important to PA wellbeing:



PA Wellbeing Subgroup stakeholders also had an interest in any evidence about the wellbeing of PAs from groups with protected characteristics.

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.

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.

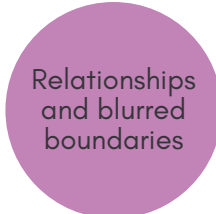
Access to training and support

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.




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 amongst 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.



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 in the PA relationship. PAs must also navigate relationships with other professionals, including medical professionals, who may not understand or value their role. PAs may have to navigate relationships with family carers or partners of supported people.



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.

A gap in the evidence: protected characteristics

Research indicates that Scotland's PA workforce is predominantly female, white, and over the age of 45. The systematic review indicated that PA employers have limited access to equal opportunities policies for PAs. There was a gap in the evidence in terms of understanding the experiences of PAs from diverse backgrounds, and on how protected characteristics interact with PA work and PA wellbeing.

Conclusion

The UK and international evidence, grounded by 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 PAs. 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 co-productive or co-design approach, involving PAs and PA employers, will maximise the potential for interventions working, and for accurately evaluating their impacts on both groups. Policy and practice choices need to strike the right balance between interventions that seek to improve wellbeing for all PAs, and more targeted interventions that will have a more significant impact on specific 'types' of PAs (e.g. unpaid carers who are also PAs), or PAs from groups with protected characteristics.

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 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 A 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 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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See full evidence at the [IMPACT PA Wellbeing Demonstrator project homepage](#)



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Appendix A: 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 the 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