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research article

What factors affect well-being for personal assistants to disabled people? An ethics of care analysis of a systematic review

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Personal assistants (PAs) emanate from the independent living movement and were introduced in response to disabled people's oppression, rooted in discrimination, institutionalisation and asymmetrical forms of care. PA schemes allow disabled people to directly employ a PA, enabling choice and control over how and by whom support is provided. Empirical research demonstrates the complexity or 'troubles' entangled in PA–employer relationships, alongside the poor employment conditions often experienced by PAs. Yet, there is a lack of understanding of how such issues affect PA well-being. This systematic review of 47 items explores factors that affect and can support well-being outcomes for PAs. A search was conducted in February 2024. Items were included if they focused on the PA workforce, were published since 2000 and originated from Scotland and comparable nations. Three key findings are discussed through an ethics of care lens: interdependence and the significance of being attentive to the needs of both PAs and employers; the unique PA–employer relationship, which can support or hamper well-being; and the paradox between the rewarding nature of the job and its low public status. This article concludes that improving PA well-being is an important outcome for both PAs and PA employers and requires both structural and cultural change.

Keywords personal assistants • well-being • ethics of care • systematic review

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Background

The introduction of personal assistants (PAs) to disabled people emerged from the disabled people's and independent living movements of the 1970s and 1980s, particularly the pioneering efforts in Sweden and the UK, leading to the establishment of the Assistance Allowance Act 1994 and the Community Care (Direct Payments) Act 1996, respectively. Emerging in response to institutional abuse, the lack of civil rights and assumptions of dependency (Shakespeare, 2006), personal assistance 'is opposed to traditional forms of care' (Porter et al, 2020: 191). Personal assistance continues to be framed as a policy driver in the transition from institutional care to community-based models of support (European Commission, 2010).

PAs are a 'cash-for-care' policy initiative, where local authorities offer direct payments in place of traditional services, and are theoretically grounded in the recognition that disabled people need to have more control over their own assistance (Shakespeare, 2014). Cash-for-care has also been conceptualised through the lens of economic efficiency, despite conflicting evidence about these claims (Katzman et al, 2019). However, the co-option of the model as a neoliberal tool to cut costs is juxtaposed with its roots in the disabled people's movement (Ferguson, 2012).

PA programmes have emerged across Europe, Japan, Thailand, Taiwan, Korea, Costa Rica, Australia and the Caribbean (Bregaglio Lazarte, 2021). Despite recognition of personal assistance as 'one of the most significant innovations in disability policy in the Global North over the last several decades' (Mladenov, 2019: 3), policy development in the Global South continues to be impacted by poverty (Goodley and Swartz, 2016), inequalities, political barriers and the lack of coordinated representation from disabled people's organisations (Grech et al, 2023). Different cultural interpretations of independent living also impact the effectiveness of PA programmes (Chou et al, 2021).

Approaches to personal assistance vary significantly, and some schemes do not involve direct payments; for example, in Slovenia and Bulgaria, disabled people can recruit PAs but do not directly hold the money to pay them (Angelova-Mladenova and Fernandez, 2024). The development of effective PA programmes has been widely affected by cost-cutting and cost-controlling efforts (Mladenov, 2019), and inadequate budgets impact the quality and outcomes of PA programmes (Nally et al, 2021).

Regulation and registration mechanisms vary across countries and are often framed as protective measures, intended both to reduce the risk of abuse against disabled people and to improve the quality of care provided by the PA workforce (Angelova-Mladenova and Fernandez, 2024). There has, however, been debate around the mechanisms of regulation due to their potential to constrain the freedom of disabled people to match with PAs of their choice (Scottish Centre for Employment Research, 2018; Woolham et al, 2019b).

In Scotland, the PA role is recognised in law through the Social Care (Self-Directed Support) (Scotland) Act 2013. Under Option 1 of self-directed support, a disabled person or their family may choose to receive a direct payment, paid by the local authority directly to the disabled person or their family if eligibility criteria[1] are met. This enables people to directly employ one or more PAs.

Ethics of care

Many activists view 'care' as complicit in disabled people's oppression, with care constituted as a potent disciplinary mechanism invoking high levels of surveillance and medical scrutiny (Watson et al, 2004; Hughes et al, 2005). The discourse of care has historically been harnessed to legitimise paternalistic and dehumanising treatment, including institutionalisation (Lynch et al, 2009). Further, the dominance of a dyadic framing of care has resulted in the reification of the personal tragedy imaginary of disability, creating a dualism between 'self-sacrificing' carers and disabled people configured as 'burdens' (Morris, 2001; Watson et al, 2004). Early feminist literature on the gendered construction of care positioned disabled people as dependants and care as intrinsic to women's subordination (Morris, 2001). This negated the intersecting identities and experiences of disabled women while ignoring the fluidity within caring relationships, where people give and receive care (Morris, 1998). This was evident in a survey of PAs in Scotland, which used a self-selective sampling; it reported that PAs are predominantly female (79 per cent) and also carers (57 per cent), while around a fifth have a disability or long-term health condition (Lawrence et al, 2024).

The language of care has been rejected by the disabled people's movement in favour of personal assistance as a vehicle for independent living, shifting power so that disabled people are in control rather than passive recipients of care (Shakespeare, 2006). In its original formation, the PA model was based on an instrumental, depersonalised approach (Hughes et al, 2005; Neumann and Gundersen, 2019). Yet, a transactional framing silences the affective domain and contradicts empirical literature identifying the blurred boundaries and close relationships that can manifest between PAs and employers (Shakespeare et al, 2017; Porter et al, 2020).

This systematic review utilises ethics of care theory to interpret PA–employer relationships. An ethics of care is based on a relational ontology and pays attention to the 'personal and particular' (Flower and Hamington, 2022: 8). Care is conceived as a political project (Tronto, 1993; 2013; Barnes, 2016), recognising how structural inequality shapes micro-level caring practices (Urban and Ward, 2020). It provides a mechanism to examine policy and practice, connecting everyday experiences of care with the wider social and political context (Barnes, 2016).

Although care is a contested concept, we adopt Fisher and Tronto's (1990: 40) broad conception of care as 'a species activity that includes everything that we do to maintain, continue, and repair our "world" so that we can live in it as well as possible. That world includes our bodies, our selves, our environment, and of which we seek to interweave in a complex, life-sustaining web.' This definition starts from the position that care is enacted through a network of relationships. Relationality operates at the interpersonal level, examining caring relationships and foregrounding affection, emotion, trust and power (Barnes, 2016), acknowledging that people can be both care providers and receivers and can engage in mutual and reciprocal relationships (Lynch et al, 2009; Ward, 2016). The relational focus also requires examination of the particularities of care: the conditions, structures and systems that shape how care operates (Tronto, 2013). This is important because the PA–employer relationship is nested in the wider social care context, underpinned by inadequate funding and a shortage of workers that, as shown later, may limit choice and control in terms of employing PAs, while insufficient remuneration and precarity may hamper PA well-being (TLAP, 2022).

Tronto's (1993; 2013) framework provides a mechanism to examine caring relationships. It comprises stages of caring and principles that need to be met for good care to be achieved. This includes caring about with attentiveness (recognising needs), caring for with responsibility (accepting responsibility to meet needs), care giving with competence (achieving good care outcomes), care receiving with responsiveness (responding to the views of the person receiving care) and caring with solidarity (building trust and challenging unequal power dynamics) (Tronto, 1993; 2013).

An ethics of care also departs from the disabled people movement's rejection of 'care' by positioning it as a valuable social good (Lynch et al, 2009). An ethics of care is based on interdependency, recognising the shared experience of vulnerability, with care providing the basis for equality because all human beings are equal by virtue of the need for care (Tronto, 2013). Shakespeare (2006), however, critiques the tendency to romanticise care and omit abuses of power. Yet, an ethics of care recognises that all caring relations are grounded in power dynamics; making these visible provides a way to assess care quality (Sevenhuijsen, 1998; Tronto, 2013). Further, good care cannot be achieved without responsiveness to the views of the person receiving care; hence, Tronto's (1993; 2013) framework promotes autonomy. An ethics of care places emphasis on examining power within the context of PA–employer relationships while not reductively prioritising the needs of one party over another.

Care is also positioned as fundamental to justice. While an ethics of care initially dichotomised these two entities of care and justice, in more recent years, ethics of care scholars have focused on their entangled nature (Urban and Ward, 2020). Tronto (2013: 12) calls for a caring democracy to 'recast issues of inclusion, dependency, and creating more just democratic societies'. For too long, care, including personal assistance, has been eclipsed by a neoliberal focus on economics and needs to be recast as a fundamental political priority focused on the concrete allocation of responsibility to meet care needs (Tronto, 2013).

Thus, the ethics of care's relational ontology, multifaceted conception of care grounded in wider contexts, and positioning of care as a social good and an essential question of justice make it a valuable theoretical framework for understanding PA–employer relationships. Adopting a pluralistic view of care recognises that meeting the well-being needs of PAs is not only an important end but will also better assist PA employers to live in a way that they choose.

Methods

The aim of this systematic review is to investigate what works in promoting and enhancing the well-being of PAs (Macgregor et al, 2024). The review seeks to identify interventions designed to improve the well-being of PAs, and by exploring the unique challenges and opportunities within this workforce, the study aims to provide actionable insights to support the well-being of PAs. The review focused on two research questions:

RQ1: What factors influence PA well-being?
RQ2: What interventions or supports can improve PA well-being?

The review forms part of the programme of work of IMPACT, the UK centre for implementing evidence in adult social care. 'Evidence' for IMPACT consists of insights from research, lived experience and practice knowledge (Tawodzera and Glasby, 2025). It follows Nutley et al's (2013) principles of 'consilience', where smaller-scale studies and those of lower quality can be combined to produce recommendations in adult social care.

Search strategy

A systematic search of the literature was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al, 2009). The Knowledge and Evidence Service at the University of Birmingham systematically identified relevant publications. Searches were conducted across multiple databases: Social Policy and Practice, Social Science Citation Index, Health Management Information Consortium, Applied Social Sciences Indexes & Abstracts, ABI Inform, MEDLINE, Cinahl, Embase and PsycInfo. Search terms were tailored for each database and included such keywords as 'personal assistant', 'personal assistance*', 'professional carer*', 'direct payment', 'well-being', 'psychosocial wellbeing', 'mental health*', 'protection', 'rights', 'security', 'working condition*', 'stress*' and other related terms.

Inclusion/exclusion criteria

As a Scottish project, the focus of the systematic review was on systems and approaches comparable to the Scottish PA model. The review focused on studies from Scotland, England, Wales, Northern Ireland, Australia, the Netherlands, Switzerland, Norway, Sweden, Denmark, Finland, Belgium, Slovenia and Iceland. Articles were included in the review if they were published in English from 2000 onwards and specifically focused on the PA workforce. PAs were defined as individuals directly employed by people to provide care and support or as self-employed workers. Exclusions applied to studies on social care workers, support workers and business personal assistants.

Data extraction and quality assessment

Identified studies were independently reviewed for eligibility. Initial screening focused on titles and abstracts, followed by a full-text review for those meeting the inclusion criteria. Data extraction was conducted using a standardised proforma,[2] which recorded key information. This included study characteristics, such as authorship, title, year of publication, type of study and geographical focus. Findings were documented to capture factors influencing well-being, proposed interventions and recommendations.

Quality assessments were performed using criteria from the Joanna Briggs Institute Manual for Evidence Synthesis, tailored to specific study designs (Aromataris and Munn, 2020). Each study was categorised as high, medium or low quality (see later). Where quality or eligibility was uncertain, discussions were held within the team to reach consensus. In relation to RQ2, the supports and interventions described in the literature have rarely been evaluated for their efficacy in improving PA well-being outcomes, demonstrating the limitations of existing studies. This review was conducted on the basis of an inclusive definition of evidence (Tawodzera and Glasby, 2025), bringing together diverse types of evidence, which did not enable the assessment of risk of bias. Instead, appraisal criteria were tailored to the type of study using JBI criteria (JBI, nd) (see the Online Appendix).

Analysis and co-production approach

The analysis was conducted collaboratively by all members of the research team, following established principles of thematic analysis (Braun and Clarke, 2006). Themes emerging from the reviewed publications were systematically identified and extracted, with each theme supported by a concise summary to illustrate its relevance and context.

To strengthen the interpretation of findings from this systematic review, acknowledge the roots of personal assistance in the independent living movement (Shakespeare, 2014) and reflect the significance of voice and the democratisation of knowledge production in an ethics of care (Groot et al, 2018), key stakeholders were consulted through workshops to support this review. Two separate expert groups across Scotland – PA employers (*n* = 9) and PAs (*n* = 8)[3] – provided feedback on emerging findings and recommendations. The groups met online four times between February and July 2024. Group members offered a range of perspectives on evidence emerging from the systematic review and highlighted tensions, which guided the research team to calibrate the evidence. A consolidated theme in both expert groups was that PA and employer well-being are interlinked: one is difficult to achieve without the other. This relationality is evident in the following analysis. Participants were compensated by IMPACT, which also facilitated reasonable adjustments, such as PA support, to maximise participation.

Results

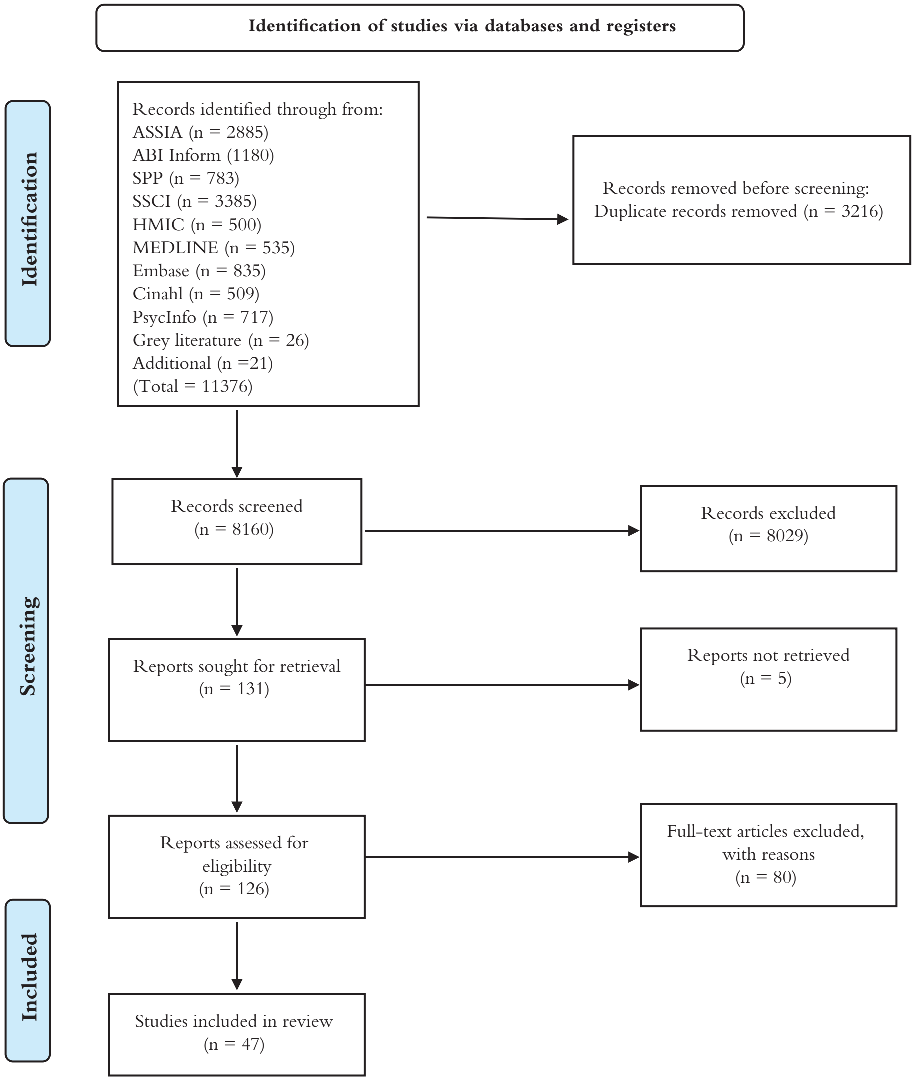
A total of 11,329 articles were identified through databases, alongside 26 items from grey literature and 21 items from existing networks. Studies were screened and selected, as shown in Figure 1. Following a full-text review of 131 items, 47 were included in the final review.

Characteristics of included articles

The 47 items were categorised by methodological rigour into high-rated (*n* = 26), medium-rated (*n* = 15) and low-rated (*n* = 6) research (see Table 1). High-rated studies demonstrated robust empirical foundations and theoretical coherence, while medium-rated studies exhibited moderate methodological limitations, such as constrained sample sizes or analytical scope. Low-rated studies were predominantly exploratory, with limited empirical substantiation.

Thematic analysis revealed six dominant research foci. The most prevalent theme, 'PA–client relationships and power dynamics' (*n* = 18), examines boundary management, intimacy and conflict resolution in care contexts. 'Direct payments and policy impacts' (*n* = 15) addresses self-directed support systems and employment conditions. 'PA work conditions and well-being' (*n* = 14) explores job satisfaction, occupational stress and structural vulnerabilities. A subset of studies (*n* = 8) investigates COVID-19's transformative effects on PA roles, including infection control and labour precarity. 'Independent living and disability rights' (*n* = 7) scrutinises autonomy barriers and care models, while 'training and support needs' (*n* = 6) evaluates educational gaps and supervisory frameworks.

Figure 1: PRISMA flowchart



The analysis constitutes an ethics of care interpretation of the PA literature. We have categorised the literature into three interlinked themes: 'attentiveness to the needs of all people in the caring nexus', 'relationality' and 'care as a valuable social good'. While these represent broader ethics of care concepts, the findings presented are necessarily limited to the themes found in the reviewed PA literature.

Attentiveness to the needs of all people in the caring nexus

Negating PA well-being is detrimental not only to PAs but also to the disabled people who employ them. Three themes from the reviewed literature engaged with this: access to training and support; isolation; and the nature of the work. While this

Table 1: Study characteristics

Author(s)	Year	Country	Method	Themes	Rating
Ahlström and Wadensten	2010	Sweden	Qualitative interviews: 32 PAs	Personal difficulties facing PAs, PAs' work experience, boundary management, balancing closeness and professionalism	Medium
Ahlström and Wadensten	2012	Sweden	Qualitative interviews: 30 PAs	PAs' experiences of work-related stress, coping strategies, training and empowerment	Medium
Andersson et al	2022	Sweden	Qualitative interviews: 11 care workers; 9 PAs	PAs manage intimacy and integrity, workplace support, relational and communicative strategies	Medium
Arksey and Baxter	2012	UK	Longitudinal qualitative interviews: 30 direct payment recipients	Direct payments, caregiver–recipient relationships, relational support networks	High
Bahner	2012	Sweden	Qualitative interviews: 10 individuals with disabilities who employ PAs	Agency in intimate care, PAs' discomfort	High
Beer et al	2013	UK	Qualitative interviews: 40 stakeholders on personal health budgets (PHBs)	Personal health budgets, well-being, challenges	Low
Cairncross and Crick	2014	UK	Mixed methods (literature review, online survey, stakeholder interviews): 30 stakeholders (including PAs) and survey respondents from agencies	Abuse and violence against PAs, support and training, resources	Medium
Cominetti	2023	UK	Secondary data analysis	Precarity and exploitation in PA employment, job satisfaction and autonomy, employment rights and support	Low
Figgett	2017	UK	Unspecified empirical research	Recruitment and retention of PAs, adult social care	Low
Glendinning et al	2000	UK	Qualitative interviews and focus group: 42 direct payment users; 14 PAs (in focus group)	PA job satisfaction and autonomy, challenges in employer–employee dynamics	Medium

(*Continued*)

Table 1: Continued

Author(s)	Year	Country	Method	Themes	Rating
Graby	2018	UK	Qualitative interviews: 13 PA employers and 14 PAs	PAs, independent living, employment contradictions	High
Hamilton et al	2015	UK	Qualitative interviews: 18 carers and 12 individuals with mental health disabilities	Direct payments, families, mental health, personal budgets	High
Hultman et al	2023	Sweden	Qualitative case studies (11 interviews): 4 young women	Role of PAs in disability, identity, space	Medium
Lawrence et al	2024	UK	Survey: 730 PAs in Scotland	PA mental health and well-being, training and development, experiences of becoming a PA	Medium
Leece	2006	UK	Comparative survey: 192 participants (PAs employed via direct payments versus local authority home-care workers)	Direct payments, job satisfaction, stress, PAs	Medium
Leece	2010	UK	Qualitative interviews: 32 participants (8 from each group): direct payments users, PAs, homecare users, homecare workers	Direct payments, PAs, client relationships, power dynamics	Medium
Leverton et al	2022a	UK	Qualitative interviews: 70 participants (PA employers and support professionals)	COVID-19, PA employment relationships, direct payments	High
Leverton et al	2022b	UK	Qualitative interviews: 15 support professionals across 11 organisations	COVID-19 impact, PA employers, social work practice, direct payments	High
Manthorpe et al	2021	UK	Qualitative interviews: 41 PAs in England	COVID-19, PA–client relationships, power dynamics	High
National Development Team for Inclusion	2010	UK	Policy/strategy framework (non-empirical)	Personalisation, mental health	Low
Neumann and Gundersen	2019	Norway	Qualitative interviews: 6 PAs and 11 supervisors	PA client working relationships, supervisors, user-controlled assistance	High
Norrie et al	2019	UK	Qualitative interviews: 105 PAs and 26 key informants in England	Personal health budgets, PA workforce, training needs	High

(*Continued*)

Table 1: Continued

Author(s)	Year	Country	Method	Themes	Rating
Norrie et al	2021	UK	Qualitative interviews: 41 PAs	PA experiences of COVID-19, infection control,	High
Norrie et al	2023	UK	Qualitative interviews: 38 PAs	COVID-19 impact, PA experiences, job security, regulations	High
Porter et al	2020	UK	Qualitative interviews: 58 participants (30 PA employers and 28 PAs)	PA–client relationships, power dynamics	High
Porter et al	2022	UK	Qualitative interviews: 83 participants (30 disabled individuals, 25 employers and 28 PAs)	Personal assistance, moral dilemmas, interpersonal conflict, relational dynamics	High
Priestley et al	2010	UK	Mixed methods (case studies, interviews, national survey): 8 national case studies, 21 policymakers/activists, 102 officers, survey of local authorities	Direct payments, independent living, welfare modernisation	Medium
Reid Howie Associates	2010	UK	Mixed methods (literature review, surveys, focus groups, interviews): surveys = 495 employers, 512 PAs; focus groups = 128 participants; interviews = 14 stakeholders	Self-directed support, PA workforce, training, support	High
Ridley and Jones	2002	UK	Mixed methods (focus groups, national survey): 23 service users/carers (focus groups); survey of Scottish local authorities	Direct payments, mental health users, independent living	Medium
Rodrigues	2020	UK	Qualitative interviews: 24 direct payment users	PA–client relationships, direct payments, satisfaction with care	High
Roland et al	2022	UK	Quantitative survey analysis: 2,428 PAs	PA absenteeism, turnover, long-term care, job characteristics	High
Scottish Centre for Employment Research	2018	UK	Survey: PA workforce in Scotland	PAs, self-directed support, fair work, employment relationships	High
SDSS and The Alliance	2020	UK	Mixed methods (interviews, focus groups, survey): 104 self-directed support users (interviews), 58 (focus groups), 460 (survey)	Self-directed support, user experiences, social care	Medium

(*Continued*)

Table 1: Continued

Author(s)	Year	Country	Method	Themes	Rating
Shakespeare et al	2017	UK	Qualitative interviews: 60 participants (30 disabled people and 30 PAs)	PA relationships, employment conditions, boundaries and emotion work	High
Skills for Care	2023	UK	Survey: 2,982 individual employers and 1,646 PAs	PA employment, personal budgets, direct payments	Low
Theakstone et al	2022	UK	Quantitative survey: 865 PAs in Scotland	PA workforce, job security, wages, support	High
Thompson and Pickering	2021	UK	Mixed methods (online survey, interviews): survey = 116 employers and 13 PAs; interviews = 21 individuals in Sheffield	PAs, person-centred support, employment relationships	High
TLAP	2022	UK	Survey: 995 individuals who employ PAs	PA recruitment, retention, direct payments, COVID-19 impact	High
Unison	2012	UK	Non-empirical	PAs, direct payments, social care needs	Medium
Wadensten and Ahlström	2009	Sweden	Qualitative interviews: 26 individuals with disabilities who employ PAs	PA–client relationship, PA experiences, autonomy	Medium
Wallace et al	2022	UK	Mixed methods (rapid review, survey, interviews): survey = 192 PAs and 138 employers; interviews = 8 PAs, 12 employers and 10 stakeholders in Wales	PA employment, social care, direct payments	High
Wilcock et al	2021	UK	Qualitative interviews: 30 directly employed care workers in England	Directly employed care workers, healthcare communication, well-being	High
Woolham et al	2019a	UK	Qualitative interviews: 105 PAs in England	Employment conditions, job satisfaction, exploitation, regulations	Medium
Woolham et al	2019b	UK	Telephone interviews: 115 PAs	PA demographics, employment conditions, job satisfaction	High

(*Continued*)

Table 1: Continued

Author(s)	Year	Country	Method	Themes	Rating
Woolham et al	2020	UK	Qualitative interviews: 37 PAs	COVID-19 impact, PA responsibilities, employer relationships	High
Zaviršek and Fischbach	2023	Central and Eastern Europe	Policy/country analysis: multiple Central and Eastern European countries	Independent living, familialism, paternalism, disability rights	Low

section follows the reviewed literature, which focused on the importance of being attentive to the needs of PAs, it situates this in the context of employers' need for autonomy and access to training and support. The literature recommends training for both PAs and PA employers (Ridley and Jones, 2002; National Development Team for Inclusion, 2010; Manthorpe et al, 2011; Cairncross and Crick, 2014; Graby, 2018; Theakstone et al, 2022; TLAP, 2022; Skills for Care, 2023). A consistent finding is that PAs often lack access to training and support (Ahlström and Wadensten, 2012; Unison, 2012; Hamilton et al, 2015; Norrie et al, 2019; 2023; Woolham et al, 2019b; 2020; Theakstone et al, 2022; Lawrence et al, 2024). PAs report insufficient training on how best to support their employers, which can be detrimental to confidence in performing the role (Ahlström and Wadensten, 2012). However, employers may want to direct how support is provided, with perceptions that formal training may undermine their autonomy (Norrie et al, 2019). Glendinning et al (2000) highlight tensions regarding disabled people's desire for PAs to have sufficient training to undertake the role but not so much that it erodes employer choice and control.

However, employers may also have training and support needs. With responsibility for supporting the well-being of PAs through the administration of recruitment, payroll and tax (Cairncross and Crick, 2014; Graby, 2018; SDSS and The Alliance, 2020), employers need to be confident that they are acting within employment law (Leverton et al, 2022a). Ridley and Jones (2002) foreground the need for training/support to enable diverse disabled employers to meet their obligations, including employers with fluctuating mental health. Woolham et al (2019b) highlight the incidence of inadvertent employment law breaches, reinforcing the need for training to protect PA employers and PAs.

PAs often work alone, and isolated working can affect well-being (Ahlström and Wadensten, 2012). Lone working restricts access to peer support (Wallace et al, 2022); a lack of peer support was exacerbated by lockdowns during the COVID-19 pandemic (Woolham et al, 2020; Norrie et al, 2021). Studies highlight an absence of emotional support for PAs (Manthorpe et al, 2011). Risks associated with lone working can erode protections in the event of abuse or violence (Cairncross and Crick, 2014). Woolham et al (2019b: 141) recommend that PAs form networks to enable them to discuss their role in a 'moderated, but protected environment'. The spatial aspect of PA work also has consequences for well-being: the employer's home becomes a workplace, with potential vulnerabilities absent in more traditional workspaces (Cairncross and Crick, 2014). There is also a need for support to broker conversations between PAs and employers on sensitive topic areas (Wallace et al, 2022).

In terms of the nature of PA work, aspects of the PA role are often highly skilled and complex (Thompson and Pickering, 2021), involving a range of assistance, including with activities of daily living and intimate personal care (Ahlström and Wadensten, 2012; Graby, 2018; Wilcock et al, 2021). PAs may also conduct health-related activities, such as administering medication and assisting with catheter care (Wilcock et al, 2021). Studies show that working with employers whose health is deteriorating or fluctuating can be challenging (Wilcock et al, 2021), physically taxing (Ahlström and Wadensten, 2012), and emotionally demanding (Andersson et al, 2022).

There is evidence that PAs benefit from stress management skills to prevent their stress from having a detrimental impact on their employer (Andersson et al, 2022). During the COVID-19 pandemic, PAs provided significantly more emotional support, and infection control also became more important, increasing stress and anxiety (Woolham et al, 2020; Norrie et al, 2023). These stresses were accompanied by a lack of resources to support PA well-being during the pandemic (Norrie et al, 2023). Thus, changing demands in response to the pandemic and a lack of adequate support created specific stresses within the caring nexus.

Relationality

An ethics of care is relational, foregrounding issues of trust and power while making visible the wider material structures that mediate relationships. While the PA–employer relationship is a source of job satisfaction, this can lead to blurred boundaries that affect PA well-being. Two themes from the literature reviewed engage with this: relationships and blurred boundaries, and employment conditions and insecurity, which highlights the structural factors that impact wellbeing.

Wider systems create structural barriers to PA well-being, with poor employment conditions being detrimental (Roland et al, 2022). PAs often receive low pay (Leece, 2006; 2010; Unison, 2012; Figgett, 2017; Graby, 2018; Wallace et al, 2022; Norrie et al, 2023) and lack opportunity for progression (TLAP, 2022). PAs are often precarious workers (Woolham et al, 2020; Wilcock et al, 2021; Leverton et al, 2022a), with some having no contracts and poor employment terms and conditions (Leece, 2006; Manthorpe et al, 2010; Beer et al, 2013; Figgett, 2017; Woolham et al, 2019a; 2020; Wilcock et al, 2021; Leverton et al, 2022a; Roland et al, 2022; Theakston et al, 2022; Wallace et al, 2022; Norrie et al, 2023). PAs sometimes have unclear job descriptions and are regularly excluded from employee benefits, including pensions, sickness, maternity, holiday and redundancy pay (Woolham et al, 2019a). Poor employment conditions can also affect health-related behaviour among PAs, with Wilcock et al (2021) demonstrating how a lack of sick pay affects decisions about whether to work during periods of illness. Improved pay and conditions are required to promote security and stability for PAs and thereby improve their well-being outcomes. However, poor pay and conditions are shaped by the wider macro context, outside the power of PA employers, creating tension within the relationship (Graby, 2018). Hence, it is recommended that PA employment conditions be improved, including through fair compensation, enhanced contractual terms and increased stability (Unison, 2012; Cairncross and Crick, 2014; Woolham et al, 2019b; Roland et al, 2022).

The literature highlights the need for support to enable employers and PAs to agree on the boundaries of their relationship (Bahner, 2012; Woolham et al, 2019b;

Porter et al, 2020). The evidence shows that PA–employer relationships rarely reflect a traditional employer–employee dyad (Leverton et al, 2022a; Hultman et al, 2023), sometimes likened to friendships or familial relationships due to the proximity and embedded nature of the work (Wadensten and Ahlström, 2009; Leece, 2010; Manthorpe et al, 2010; Arksey and Baxter, 2012; Shakespeare et al, 2017; Porter et al, 2022; TLAP, 2022). This closeness can foster intimacy and trust, mutuality and reciprocity, with employers also supporting PAs (Figgett, 2017; Shakespeare et al, 2017; Graby, 2018; Rodrigues, 2020; Manthorpe et al, 2021; TLAP, 2022). These relational dynamics are often valued (Reid Howie Associates, 2010; Porter et al, 2020; Wallace et al, 2022; Lawrence et al, 2024) and so have the potential to support PA well-being.

Some employers maintain professional boundaries (Figgett, 2017; Graby, 2018), and some PAs keep their private life personal (Glendinning et al, 2000; Shakespeare et al, 2017). However, the more typical blurring of professional and personal boundaries can negatively affect PA well-being (Shakespeare et al, 2017; Graby, 2018; Woolham et al, 2019a; Leverton et al, 2022a; Porter et al, 2022) and can lead to PAs working unpaid hours or feeling a duty 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 study demonstrated how PA–employer relationships are often bound with emotion work, involving conflict or 'troubles': personal troubles resulting from clashes in personalities and values; practical troubles related to PA performance, management style and working conditions; and proximal troubles emanating from close working conditions (Shakespeare et al, 2017; Porter et al, 2022). While PA–employer relationships are often shaped by mutuality and reciprocity, issues of frustration and dissatisfaction, as well as control and abuse, can also be experienced by both parties (Graby, 2018; Zaviršek and Fischbach, 2023).

The negotiation of power within relationships also affects PA well-being: PAs are reliant on their employers for income, but PAs can also hold power over their employers (Graby, 2018). Nordic studies have highlighted issues with PAs being in a subordinate position and lacking control (Ahlström and Wadensten, 2012). The PA–employer relationship has been described as encompassing 'incomplete mutuality' due to the ways in which PAs and PA employers depend on each other (Ahlström and Wadensten, 2010).

Care as a valuable social good

An ethics of care is premised on care being a social good and a fundamental component of what makes us human. Care is situated as a shared responsibility rather than an individual endeavour; how societies are organised and the extent to which caring needs are met is indicative of levels of social justice (Tronto, 2013). One theme from the reviewed literature engaged with this: job satisfaction and perceptions of PA work. This theme represents one example of care being a valuable social good, though the reviewed literature does not reflect the breadth of this underpinning principle.

PAs often report high job satisfaction (Leece, 2006; Reid Howie Associates, 2010; Scottish Centre for Employment Research, 2018; Manthorpe et al, 2021; Lawrence et al, 2024), indicating that the work has the potential to positively influence well-being. This strong sense of fulfilment and purpose comes from building quality relationships, developing an understanding of their employers' needs and preferences, and supporting employers to achieve personal outcomes (Wallace et al, 2022).

Flexibility and autonomy are often valued by PAs, as they can fit their role around personal circumstances, including family responsibilities (Reid Howie Associates, 2010; Shakespeare et al, 2017; Theakstone et al, 2022; Wallace et al, 2022; Cominetti, 2023; Skills for Care, 2023; Lawrence et al, 2024). Having autonomy and control at work is associated with work-related quality of life (Silarova et al, 2022), factors that also apply to PAs.

Yet, there is a paradox between the rewarding nature of the work and the low public and professional status accorded to PAs (TLAP, 2022; Norrie et al, 2023). The material and cultural devaluation of PA work affects levels of pay that employers can offer PAs; disablism and the cultural conflation of disability with dependency also have negative consequences for the recognition of PA work (Graby, 2018). During COVID-19, inadequate access to personal protective equipment (PPE) for PAs was symbolic in reinforcing low status (Woolham et al, 2020; Leverton et al, 2022b).

Discussion

The themes discussed illuminate some of the synergies and contradictions regarding PA and employer well-being. Tronto's (1993; 2013) phases of caring and principles are employed to surface the nuance and complexity in PA–employer relationships.

Tronto's (1993) first phase of care is 'caring about with attentiveness'. Although this involves recognising the needs of others, one's own needs must be met to facilitate this (Tronto, 1993; Ward, 2016; Kittay, 2021). This systematic review has reinforced the need to view employers and PAs as interconnected, with the close spatial and temporal proximities creating a complex and often intimate relationship that can support and hamper well-being for both parties. The close nature of PA–employer relationships and the flexibility of the role can enable PAs to fit the work around their personal circumstances, which could support PA well-being.

However, PAs may lack confidence, an issue exacerbated by lone working, while employers may require help to be a good employer (Priestley et al, 2010). Focusing on employer needs at the expense of PA well-being will negatively impact both groups, with potential to increase turnover in a sector struggling with acute recruitment/retention challenges (Gousia and Allan, 2024). Woolham et al (2019b) reported PAs being confident in finding alternative forms of employment if needed, underpinning the precarity of support for disabled people. Hence, there is a need to be attentive to the needs of all people in the caring nexus to provide the foundation for needs to be met.

Tronto's (1993) second phase of care is 'caring for with responsibility'. Once needs have been recognised, responsibility needs to be assumed to meet these. Responsibility is not just about obligation; it is often bound with trust and reciprocity (Tronto, 1993; Sevenhuijsen, 2003), which characterise the best PA–employer relationships. However, personal–professional blurring can result in PAs assuming too much responsibility, with potentially negative consequences for PA well-being through the provision of paid or unpaid overtime linked to a sense of duty (Leece, 2010; Ahlström and Wadensten, 2012; Woolham et al, 2019a; Porter et al, 2020; Theakston et al, 2022). This will likely continue in the absence of adequate material and symbolic recognition of

PA work. The evidence suggests that the state drives 'over-responsibility' by PAs due to inadequate support structures to facilitate clear boundaries, exploiting the strong reciprocal relationships between PAs and employers. Further, employer responsibility to improve wages and terms and conditions is structurally constrained by insufficient budgets and restrictive and inconsistent practice around how budgets can be spent (Social Work Scotland, 2024).

Tronto's (1993) third phase is 'care giving with competence' and constitutes caring activities, or the practical 'doing' of care. This raises the question of what comprises competence in the PA–employer nexus, which will vary according to the relationship and context. The evidence reinforces tensions between PAs' need for training for skill development and confidence to meet employer needs and the rights of employers to direct their support, including through the provision (or withholding) of training. Reformulating the PA–employer nexus in terms of interdependence requires examining outcomes for both parties, constituting a form of mutual competence. This aligns with Ward's (2016: 174) calls for competence to be understood as 'embedded in relational mutuality'.

PA well-being could suffer due to insufficient confidence and access to training and support, which could affect care quality; yet, training that contradicts the wishes of an employer could negatively impact care experience and agency. Hence, competence is bound by issues of power and interdependence, reinforcing the need for support to broker conversations between PAs and employers on sensitive topic areas; this form of dialogical care may help to address communication difficulties and enable clearer boundary maintenance.

The fourth stage is 'care receiving with responsiveness' and is focused on the voice of the person receiving care (Tronto, 1993). PAs were introduced to promote autonomy; directly employing a PA ostensibly enables employers to have choice over their support. Yet, poor employment conditions and insecurity are endemic in adult social care (Hemmings et al, 2024), and people often experience challenges in the recruitment and retention of PAs due to the level of care need, complexity of support provision and wider labour market context (Gousia and Allan, 2024). Fair wages are needed to encourage a sufficient workforce to support disabled people while also promoting the well-being needs of PAs. To be possible, employers must have adequate budgets to pay a fair wage, which requires wider structural change.

The final stage is 'caring with solidarity' (Tronto, 2013). Care provision should support 'justice, equality, and freedom for all' (Tronto, 2013: 23). The isolated nature of PA work highlights the struggle for solidarity among PAs, particularly in the current context of cuts. There was little evidence of solidarity between employers and PAs beyond their individual relationships; while both want better 'terms and conditions' for the other, the levers are limited, and there is a risk of individualism and marketisation damaging these relationships. An ethics of care provides a counter-narrative to neoliberalism's entrenchment of individualism (Casalini, 2020), where people who require care and support are 'denigrated as dependents' (Kittay, 2021: 19). Although personal assistance emanates from the independent living movement, the cost-cutting agenda represents a co-option of its founding principles through reinforcing market logic. This substantiates findings from the early implementation of self-directed support in Scotland, where austerity was found to be eroding the progress made by disabled people (Manji, 2018).

Although PAs are intended to support greater autonomy and independent living, there is a risk that employer emancipation may be at the expense of PA well-being in the current climate (Graby, 2018). Good care outcomes cannot be achieved through the domination and exploitation of people providing care (Kittay, 2021). Although symptomatic of structural inequality, low pay and precarity (Kittay, 2021), both PAs and their employers will likely suffer should this unmet need continue.

Strengths, limitations and gaps

This systematic review has generated novel understandings about what works to support PA well-being, representing the first systematic review that focuses on well-being needs. The application of ethics of care theory has elevated the empirical findings by weaving together micro caring relationships and their entanglements in wider, complex social and political systems that shape the possibilities of personal assistance. Examining the PA–employer nexus has also reinforced the importance of mutual competence and the risk of 'over-responsibility' by PAs, driven by the structural exploitation of unique PA–employer relationships, so often bound with reciprocity, mutuality and trust. Finally, using expert groups to ground the empirical findings created space for more formal academic collaborative research to further explore the key themes identified in this review.

This review is limited by the lack of tested interventions about what works to support PA well-being. Recommendations in the literature are predominantly based on the findings of research and the suggestions that are made on the basis of this. There is also poor data on the composition of the PA workforce, which limits the ability to examine if study samples are representative of the wider population, and there is a gap in knowledge about how PA well-being intersects with equalities issues, particularly with regard to gender and unpaid caring.

Notes

[1] Eligibility criteria are set by local authorities and therefore vary, though they often centre on critical risk or urgent need or on substantial risk or high levels of need (SDSS, 2025).

[2] This proforma was created for IMPACT's evidence review process.

[3] For an evaluation of the expert groups, see Brunner and McLean (2024).

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Research ethics statement

The authors of this article have declared that research ethics approval was not required because the article does not present or draw directly on data/findings from empirical research.

Contributor statement

AM and OT conducted the systematic review of the literature, including screening, data extraction, data analysis and interpretation, and write-up. AM, OT, RB and RM designed and conceptualised the study and wrote the first and subsequent drafts of this manuscript.

Conflict of interest

The authors declare that there is no conflict of interest.

References

Ahlström, G. and Wadensten, B. (2010) Encounters in close care relations from the perspective of personal assistants working with persons with severe disability, *Health & Social Care in the Community*, 18(2): 180–8, doi: 10.1111/j.1365-2524.2009.00887.x

Ahlström, G. and Wadensten, B. (2012) Enjoying work or burdened by it? How personal assistants experience and handle stress at work, *Journal of Social Work in Disability & Rehabilitation*, 11(2): 112–27, doi: 10.1080/1536710X.2012.677648

Andersson, K., Lövgren, V., Ahnlund, P. and Kalman, H. (2022) Empathetic attuning: 'How would I feel if I had to expose myself all the time?' – strategies for managing personal and intimate care in Swedish formal home care, *British Journal of Social Work*, 53(2): 921–38, doi: 10.1093/bjsw/bcac164

Angelova-Mladenova, L. and Crespo Fernandez, R. (2024) *Towards Dignity and Autonomy: A Comprehensive Look at Personal Assistance Policies for Persons with Disabilities Worldwide*, www.ilo.org/wcmsp5/groups/public/---ed_emp/---ifp_skills/documents/publication/wcms_915795.pdf.

Arksey, H. and Baxter, K. (2012) Exploring the temporal aspects of direct payments, *British Journal of Social Work*, 42(1): 147–64, doi: 10.1093/bjsw/bcr039

Aromataris, E. and Munn, Z. (2020) *JBI Manual for Evidence Synthesis*, JBI, https://synthesismanual.jbi.global.

Bahner, J. (2012) Legal rights or simply wishes? The struggle for sexual recognition of people with physical disabilities using personal assistance in Sweden, *Sexuality and Disability*, 30(3): 337–56, doi: 10.1007/s11195-012-9268-2

Barnes, M. (2016) Beyond the dyad: exploring the multidimensionality of care, in M. Barnes, T. Brannelly, L. Ward and N. Ward (eds) *Ethics of Care: Critical Advances in International Perspective*, Policy Press Scholarship Online, pp 31–44, doi: 10.1332/policypress/9781447316510.003.0003

Beer, G., Paxman, J. and Morris, C. (2013) *Personal Health Budgets: a Revolution in Personalisation*, Denplan, https://2020health.org/publication/personal-health-budgets-a-revolution-in-personalisation/.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2): 77–101, doi: 10.1191/1478088706qp063oa

Bregaglio Lazarte, R. (2021) *Marco legal de los derechos de las personas con discapacidad: América Latina y el Caribe*, BID, doi: 10.18235/0003816

Brunner, R. and McLean, R. (2024) *PA Wellbeing Demonstrator Project 2023–24 Evaluation Report*, https://impact.bham.ac.uk/wp-content/uploads/2024/08/PA-wellbeing-evaluation-report-word.docx

Cairncross, L. and Crick, A. (2014) *Research on Abuse and Violence Against the Social Care Workforce: Focus on Personal Assistants*, Skills for Care, https://ipc.brookes.ac.uk/publications/research-on-abuse-and-violence-against-the-social-care-workforce-focus-on-personal-assistants/.

Casalini, B. (2020) The nurturing language of care ethics and of other related feminist approaches: opposing contemporary neoliberal politics, in P. Urban and L. Ward (eds) *Care Ethics, Democratic Citizenship and the State*, Springer International Publishing, pp 117–36.

Chou, Y.C., Chen, B.W. and Kröger, T. (2021) Lost in translation: implementing personal assistance in an East Asian context, *Disability & Society*, 38(4): 587–609, doi: 10.1080/09687599.2021.1930517

Cominetti, N. (2023) *Who Cares? The Experience of Social Care Workers, and the Enforcement of Employment Rights in the Sector*, Resolution Foundation, www.resolutionfoundation.org/app/uploads/2023/01/Who-cares.pdf.

European Commission (2010) European Disability Strategy 2010–2020: A renewed commitment to a barrier-free Europe, https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=URISERV:em0047.

Ferguson, I. (2012) Personalisation, social justice and social work: a reply to Simon Duffy, *Journal of Social Work*, 26(1): 55–73, doi: 10.1080/02650533.2011.623771

Figgett, D. (2017) *Recruitment and Retention in Adult Social Care: Secrets of Success*, Skills for Care, www.skillsforcare.org.uk/resources/documents/Recruitment-support/Retaining-your-staff/Secrets-of-Success/Recruitment-and-retention-secrets-of-success-report.pdf.

Fisher, B. and Tronto, J. (1990) Toward a feminist theory of caring, in E.K. Abel and M.K. Nelson (eds) *Circles of Care*, SUNY Press, pp 35–62.

Flower, M. and Hamington, M. (2022) Care ethics, Bruno Latour, and the Anthropocene, *Philosophies*, 7(2): art 31, doi: 10.3390/philosophies7020031

Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K. and Tyrer, J. (2000) New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance, *Health & Social Care in the Community*, 8(3): 201–11, doi: 10.1046/j.1365-2524.2000.00242.x

Goodley, D. and Swartz, L. (2016) The place of disability in Grech, in S. Grech and K. Soldatic (eds) *Disability in the Global South*, Springer International Publishing, pp 69–83.

Gousia, K. and Allan, S. (2024) Factors affecting recruitment and retention of personal assistants in England: a quantitative analysis, *International Journal of Care and Caring*, 9(4): 770–91, doi: 10.1332/23978821y2024d000000072

Graby, S.D. (2018) Personal Assistance: The Challenge of Autonomy, PhD thesis, University of Leeds, https://etheses.whiterose.ac.uk/23231/2/Graby_SD_SociologyandSocialPolicy_PhD_2018.pdf.

Grech, S., Weber, J. and Rule, S. (2023) Intersecting disability and poverty in the Global South: barriers to the localization of the UNCRPD, *Social Inclusion*, 11(4): 326–37, doi: 10.17645/si.v11i4.7246

Groot, B.C., Vink, M., Haveman, A., Huberts, M., Schout, G. and Abma, T.A. (2018) Ethics of care in participatory health research: mutual responsibility in collaboration with co-researchers, *Educational Action Research*, 27(2): 286–302, doi: 10.1080/09650792.2018.1450771

Hamilton, S., Szymczynska, P., Clewett, N., Manthorpe, J., Tew, J., Larsen, J., et al (2015) The role of family carers in the use of personal budgets by people with mental health problems, *Health & Social Care in the Community*, 25(1): 158–66, doi: 10.1111/hsc.12286

Hemmings, N., Allen, L., Lobont, C., Burale, H., Thorlby, R., Alderwick, H., et al (2024) *From Ambition to Reality: National Policy Options to Improve Care Worker Pay in England*, https://www.health.org.uk/reports-and-analysis/reports/from-ambition-to-reality-national-policy-options-to-improve-care.

Hughes, B., McKie, L., Hopkins, D. and Watson, N. (2005) Love's labours lost? Feminism, the disabled people's movement and an ethic of care, *Sociology*, 39(2): 259–75, doi: 10.1177/0038038505050538

Hultman, L., Rosqvist, H.B., Elmersjö, M. and Koziel, S. (2023) Making me with others-gendered meanings of youth and youthfulness among young female disabled assistance users, *Disability & Society*, 38(9): 1626–46, doi: 10.1080/09687599.2021.2007360

JBI (nd) Critical appraisal tools, https://jbi.global/critical-appraisal-tools.

Katzman, E.R., Kinsella, E.A. and Polzer, J. (2019) 'Everything is down to the minute': clock time, crip time, and the relational work of self-managing attendant services, *Disability & Society*, 35(4): 517–41, doi: 10.1080/09687599.2019.1649126

Kittay, E.F. (2021) Precarity, precariousness, and disability, *Journal of Social Philosophy*, 52: 292–309, doi: 10.1111/josp.12391

Lawrence, J., Adderley, J. and Hirst, K. (2024) *The Personal Assistant Workforce Survey: Annual Survey 2023 Report*, Self Directed Support Scotland.

Leece, J. (2006) 'It's not like being at work': a study to investigate stress and job satisfaction in employees of direct payment users, in J. Leece and J. Bornat (eds) *Developments in Direct Payments*, Policy Press, pp 189–205.

Leece, J. (2010) Paying the piper and calling the tune: power and the direct payment relationship, *British Journal of Social Work*, 40(1): 188–206, doi: 10.1093/bjsw/bcn085

Leverton, M., Samsi, K., Woolham, J. and Manthorpe, J. (2022a) 'I have enough pressure as it is, without the worry of doing something wrong because of ignorance': the impact of Covid-19 on people who employ social care personal assistants, *The British Journal of Social Work*, 53(2): 1243–62, doi: 10.1093/bjsw/bcac228

Leverton, M., Samsi, K., Woolham, J. and Manthorpe, J. (2022b) Lessons learned from the impact of Covid-19 on the work of disability support organisations that support employers of social care personal assistants in England, *Health & Social Care in the Community*, 30(6): e6708–18, doi: 10.1111/hsc.14098

Lynch, K., Lyons, M. and Cantillon, S. (2009) Love labouring: power and mutuality, in K. Lynch, J. Baker and M. Lyons (eds) *Affective Equality: Love, Care and Injustice*, Palgrave Macmillan, pp 114–31.

Macgregor, A., Tawodzera, O., Brunner, R. and McLean, R. (2024) *What Works in Wellbeing for Personal Assistants (PAs) to Disabled People? A Systematic Review*, IMPACT, https://impact.bham.ac.uk/wp-content/uploads/2024/08/Systematic-review-pdf.pdf.

Manji, K. (2018) 'It was clear from the start that [SDS] was about a cost cutting agenda.' Exploring disabled people's early experiences of the introduction of Self-Directed Support in Scotland, *Disability & Society*, 33(9): 1391–411, doi: 10.1080/09687599.2018.1498767

Manthorpe, J., Martineau, S., Moriarty, J., Hussein, S. and Stevens, M. (2010) Support workers in social care in England: a scoping study, *Health & Social Care in the Community*, 18(3): 316–24, doi: 10.1111/j.1365-2524.2010.00910.x

Manthorpe, J., Moriarty, J. and Cornes, M. (2011) Keeping it in the family? People with learning disabilities and families employing their own care and support workers: findings from a scoping review of the literature, *Journal of Intellectual Disabilities*, 15(3): 195–207, doi: 10.1177/1744629511419615

Manthorpe, J., Samsi, K., Norrie, C. and Woolham, J. (2021) Caring in Covid-19: personal assistants' changing relationships with their clients' family members, *Journal of Long Term Care*, 2021: 256–63, doi: 10.31389/jltc.77

Mladenov, T. (2019) What is good personal assistance made of? Results of a European survey, *Disability & Society*, 35(1): 1–24, doi: 10.1080/09687599.2019.1621740

Moher, D., Liberati, A., Tetzlaff, J. and Altman, D. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, *PLoS Medicine*, 6(7): art e1000097. doi: 10.1016/j.ijsu.2010.02.007

Morris, J. (1998) Feminism, gender and disability, https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/morris-gender-and-disability.pdf.

Morris, J. (2001) Impairment and disability: constructing an ethics of care that promotes human rights, *Hypatia*, 16(4): 1–16, doi: 10.1111/j.1527-2001.2001.tb00750.x

Nally, D., Moore, S.S. and Gowran, R.J. (2021) How governments manage personal assistance schemes in response to the United Nations Convention on the Rights of Persons with Disabilities: a scoping review, *Disability & Society*, 37(10): 1728–51, doi: 10.1080/09687599.2021.1877114

National Development Team for Inclusion (2010) Paths to personalisation in mental health, https://themhs.wordpress.com/wp-content/uploads/2011/12/paths-to-personalisation1-1.pdf.

Neumann, C.E.B. and Gundersen, T. (2019) Care parading as service: negotiating recognition and equality in user-controlled personal assistance, *Gender, Work & Organization*, 26(7): 948–61, doi: 10.1111/gwao.12297

Norrie, C., Woolham, J., Samsi, K. and Manthorpe, J. (2019) Skill mix: the potential for personal assistants to undertake health-related tasks for people with personal health budgets, *Health & Social Care in the Community*, 28(3): 922–31, doi: 10.1111/hsc.12923

Norrie, C., Woolham, J., Samsi, K. and Manthorpe, J. (2021) Personal assistants' role in infection prevention and control: their experiences during the Covid-19 pandemic, *Health & Social Care in the Community*, 30: e1926–34, doi: 10.1111/hsc.13624

Norrie, C., Luijnenburg, O., Moriarty, J., Samsi, K. and Manthorpe, J. (2023) 'You're out on a limb, on your own': social care personal assistants' reflections on working in the Covid-19 pandemic – implications for wider health and care services, *PLoS One*, 18(12): art e0295385. doi: 10.1371/journal.pone.0295385

Nutley, S., Powell, A. and Davies, H. (2013) *What Counts as Good Evidence? Provocation Paper for the Alliance for Useful Evidence*, Alliance for Useful Evidence/University of St Andrews.

Porter, T., Shakespeare, T. and Stöckl, A. (2020) Performance management: a qualitative study of relational boundaries in personal assistance, *Sociology of Health & Illness*, 42(1): 191–206, doi: 10.1111/1467-9566.12996

Porter, T., Shakespeare, T. and Stöckl, A. (2022) Trouble in direct payment personal assistance relationships, *Work, Employment and Society*, 36(4): 630–47, doi: 10.1177/09500170211016972

Priestley, M., Riddell, S., Jolly, D., Pearson, C., Williams, V., Barnes, C., et al (2010) Cultures of welfare at the front line: implementing direct payments for disabled people in the UK, *Policy & Politics*, 38(2): 307–24, doi: 10.1332/030557309x477956

Reid Howie Associates (2010) *Study of the Workforce and Employment Issues Surrounding Self-Directed SUPPORT*, Scottish Government Social Research, https://lx.iriss.org.uk/sites/default/files/resources/LX%20-SDS-Workforce%20Issues.pdf.

Ridley, J. and Jones, L. (2002) *Direct What? – A Study of Direct Payments to Mental Health Service Users*, Scottish Executive, https://knowledge.lancashire.ac.uk/id/eprint/7039/1/0042103.pdf.

Rodrigues, R. (2020) Caring relationships and their role in users' choices: a study of users of Direct Payments in England, *Ageing and Society*, 40(7): 1469–89, doi: 10.1017/s0144686x19000035

Roland, D., Allan, S., Chambers, E., Smith, D. and Gousia, K. (2022) Personal assistants in England and the factors associated with absenteeism, *Frontiers in Public Health*, 10: art 970370. doi: 10.3389/fpubh.2022.970370

Scottish Centre for Employment Research (2018) *Personal Assistants Working Under SDS Options One: Experiences of Fair Work*, University of Strathclyde, www.fairworkconvention.scot/wp-content/uploads/2018/11/Personal-Assistants-working-under-SDS-Option-One-experiences-of-fair-work.pdf.

SDSS (Self Directed Support Scotland) (2025) SDS handbook, https://handbook.scot/sds-handbook/.

SDSS and The Alliance (2020) People's experiences of self-directed support and social care in Scotland, www.sdsscotland.org.uk/wp-content/uploads/2020/10/MSMC-Scotland-Report-2020.pdf.

Sevenhuijsen, S. (1998) *Citizenship and the Ethics of Care*, Routledge.

Sevenhuijsen, S. (2003) The place of care: the relevance of the feminist ethic of care for social policy, *Feminist Theory*, 4(2): 179–97, doi: 10.1177/14647001030042006

Shakespeare, T. (2006) *Disability Rights and Wrongs*, Routledge.

Shakespeare, T. (2014) *Disability Rights and Wrongs Revisited*, 2nd edn, Routledge.

Shakespeare, T., Porter, T. and Stöckl, A. (2017) *Personal Assistance Relationships: Power, Ethics, and Emotions*, ESRC Project ES/L007894/1, University of East Anglia, www.sdsscotland.org.uk/wp-content/uploads/2017/07/PA-Relatiionship-Power-Ethics-EmotionsUAEJune-2017.pdf.

Silarova, B., Brookes, N., Palmer, S., Towers, A. and Hussein, S. (2022) Understanding and measuring the work-related quality of life among those working in adult social care: a scoping review, *Health and Social Care in the Community*, 30(5): 1637–64, doi: 10.1111/hsc.13718

Skills for Care (2023) Individual employers and the personal assistance workforce, www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/Individual-employers-and-the-PA-workforce/IE-and-PA-survey-2023.pdf.

Social Work Scotland (2024) Reflections on practice – self-directed support across Scotland, https://socialworkscotland.org/wp-content/uploads/2024/05/Flexible-Use-of-Direct-Payments-FINAL.pdf.

Tawodzera, O. and Glasby, J. (2025) Who decides 'what works', and how does it get implemented? Insights from the UK's new centre for implementing evidence in adult social care, *International Journal of Care and Caring*, 9(1): 40–59, doi: 10.1332/23978821y2024d000000034

Theakstone, D., Lawrence, J. and Adderley, J. (2022) *The Personal Assistant Workforce Survey: Annual Survey 2022 Report*, Self Directed Support Scotland, www.sdsscotland.org.uk/wp-content/uploads/2024/03/Annual-PA-Workforce-Survey-2022-Report.pdf.

Thompson, J. and Pickering, S. (2021) *Individual Employer Pay Scale Report: Survey & Interview Findings*, Sheffield City Council, www.sdsscotland.org.uk/wp-content/uploads/2022/05/SHEFIELD-PA-ANALYSIS-REPORT-Individual_Employer_Pay_Scale_Report_Survey_Interview_Findings_Abridged_-002.pdf.

TLAP (Think Local Act Personal) (2022) The forgotten workforce: recruiting and retaining personal assistants – a survey of people supported by personal assistants, www.thinklocalactpersonal.org.uk/_assets/Reports/Personal-Assistant-Survey-The-Forgotten-Workforce.pdf.

Tronto, J. (1993) *Moral Boundaries: A Political Argument for an Ethic of Care*, Routledge.

Tronto, J. (2013) *Caring Democracy: Markets, Equality, and Justice*, New York University Press.

Unison (2012) Getting personal: rights at work for personal assistants, www.unison.org.uk/content/uploads/2013/06/On-line-Catalogue206693.pdf.

Urban, P. and Ward, L. (2020) Introducing the contexts of a moral and political theory of care, in P. Urban and L. Ward (eds) *Care Ethics, Democratic Citizenship and the State*, Palgrave Macmillan.

Wadensten, B. and Ahlström, G. (2009) Ethical values in personal assistance: narratives of people with disabilities, *Nursing Ethics*, 16(6): 759–74, doi: 10.1177/0969733009341913

Wallace, S., Llewellyn, M., Garthwaite, T., Randall, H. and Sullivan, S. (2022) *Research on the Employment of Personal Assistants in Social Care*, Welsh Government, https://www.gov.wales/sites/default/files/publications/2022-09/research-on-the-employment-of-personal-assistants-in-social-care_0.pdf.

Ward, N. (2016) Reciprocity and mutuality: people with learning disabilities as carers, in M. Barnes, T. Brannelly, L. Ward and N. Ward (eds) *Ethics of Care: Critical Advances in International Perspective*, Policy Press, pp 165–78.

Watson, N., McKie, L., Hughes, B., Hopkins, D. and Gregory, S. (2004) (Inter) Dependence, needs and care: the potential for disability and feminist theorists to develop an emancipatory model, *Sociology*, 38(2): 331–50, doi: 10.1177/0038038504040867

Wilcock, J., Manthorpe, J., Moriarty, J. and Iliffe, S. (2021) 'It's a real fine balancing act': directly employed care workers' experiences of engaging with health services, *International Journal of Care and Caring*, 5(3): 415–32, doi: 10.1332/239788221x16099486601224

Woolham, J., Norrie, C., Samsi, K. and Manthorpe, J. (2019a) The employment conditions of social care personal assistants in England, *The Journal of Adult Protection*, 21(6): 296–306, doi: 10.1108/jap-06-2019-0017

Woolham, J., Norrie, C.M., Samsi, K. and Manthorpe, J. (2019b) *Roles, Responsibilities, and Relationships: Hearing the Voices of Personal Assistants and Directly Employed Care Workers*, NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London, doi: 10.18742/pub01-005

Woolham, J., Samsi, K., Norrie, C. and Manthorpe, J. (2020) *The Impact of the Coronavirus (Covid-19) on People Who Work as Social Care Personal Assistants*, NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London.

Zaviršek, D. and Fischbach, S. (2023) Independent living in post-socialist countries, *International Journal of Disability and Social Justice*, 3(1): 96–113, doi: 10.13169/intljofdissocjus.3.1.0096