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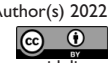

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‘They Exist but They Don’t Exist’: Personal Assistants Supporting Physically Disabled People in the Workplace

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Abstract

Employment rates in England for disabled people are persistently lower than for non-disabled people. Support from a Workplace Personal Assistant is one way of narrowing this gap. Personal assistance is an empowerment-driven model in which the disabled person controls their support: who provides it, when, how and where. Previous research has focused on the personal assistant role in the home setting. This article draws on data from 32 qualitative interviews in the first UK study to explore personal assistance in the workplace for people with physical and/or sensory impairments. To maintain their enabling role in this external setting, Workplace Personal Assistants needed to strive for occupational invisibility when among the disabled workers’ colleagues: to ‘exist but not exist’. This article examines the Workplace Personal Assistant role as invisible work, applying Hatton’s conceptual framework. The analysis contributes to understanding of workplace personal assistance and ways in which mechanisms can intersect to produce multiple invisibility.

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Introduction

Background

Employment rates in England for disabled people are persistently lower than those for non-disabled people. Latest Office for National Statistics estimates show rates of 52.3% and 81.1% respectively, representing a 'disability employment gap' of 28.8% (Powell, 2021). For some disabled people, participation in paid employment can, and has been, enabled through personal assistance, an empowerment-based model of support stemming from disability rights campaigning for independent living (European Network on Independent Living (ENIL), 2013; Evans, 2003). Personal assistance represents a shift from traditional state-directed provision of 'care' to a disabled person being in control of their bespoke support: who provides it, when, how and where. State funds for purchasing support from Personal Assistants (PAs) are via Local Authority (LA) and National Health Service (NHS) personal budget direct payments. An additional, workplace-specific source of funding is *Access to Work*, a Government grant scheme covering various types of practical assistance for disabled workers, including a Support Worker (Department for Work and Pensions (DWP), 2020a).

Limited research available on workplace personal assistance, from schemes in the USA and Norway, suggests that it is required for, and can result in, successful employment for disabled people (Dowler et al., 2011; Helle and Widding, 2000). However, little is known about the Workplace Personal Assistant (WPA) role. PA research has focused on the domestic setting, where setting-specific factors of informality and privacy, along with the intimate nature of personal care tasks, have shaped current understanding, for instance a blurring of work/personal relationship boundaries leading to positive and/or negative outcomes for disabled people and PAs (see for example Glendinning et al., 2000; Porter et al., 2021; Ungerson, 1999).

By contrast, the WPA role is situated in an external normative setting in which the disabled person is in a paid work role, accompanied by their WPA to assist with work-related tasks and/or personal care. A unique feature of workplace personal assistance is that the WPA enabling role is wholly bound within the formal job role of the disabled worker. Little is known about how the WPA role is operated in order to be understood by a disabled worker's colleagues as a 'tool which allows for independent living' (ENIL, 2013: 1). A clue is offered in Barrett's (2001) personal reflections on his (USA) experience as a PA for the same person at home and in the workplace. Flagging up as 'tremendous' (Barrett, 2001: 51) the differences between the two settings in terms of PA tasks, behaviour and relationships, he saw remaining 'unobtrusive' as key to WPA role effectiveness as a tool of empowerment, through avoiding misunderstandings by other workers as to who is 'getting the job done' (p. 57).

This article explores workplace personal assistance as invisible work. Drawing on empirical data from the first UK study of this type of assistance used by people with

physical or sensory impairments, it applies Hatton's (2017) conceptual framework of invisible work to the WPA's unique empowerment-driven role.

Workplace personal assistance as invisible work

The term 'invisible work' was first used by Daniels (1987) to highlight women's unpaid domestic labour and voluntary work as culturally and economically devalued. Since then its scope has spread via largely descriptive analyses of many types of work, whether paid or unpaid, formal or informal, undertaken in or out of physical sight, actively hidden by the worker or visible but ignored by others (for example Crain et al., 2016; Leonard, 1998; Nardi and Engeström, 1999; Whiting and Symon, 2020). In the context of formal, paid employment, Poster et al. (2016) define invisible work as activities performed in response to employer requirements (explicit or implicit) which are crucial for workers to obtain or retain their jobs yet are overlooked, ignored and/or devalued by employers and others.

Such requirements can render the work/worker invisible, depending on the social context. Star and Strauss (1999) portray this variation on a continuum. At one end lie highly socially visible workers who undertake invisible work. An example is nursing, with nurses performing overt/planned routine tasks but also invisible work alongside to create a therapeutic relationship (Lydahl, 2017). At the other end of the continuum lie workers deemed socially invisible despite the act or product of their work being visible. Labelled by Star and Strauss as 'non-persons' (1999: 14), examples include domestic and service workers. Barrett's (2001) stress on the need for WPAs to remain unobtrusive suggests they fall into this non-person group. However, the WPA role being bound within that of the disabled worker raises questions about how the two roles are performed in tandem in the social setting of the disabled person's workplace and where the boundaries of (in)visibility lie for the WPA, both as a worker and with regard to their work.

Mechanisms producing invisible work. Hatton (2017) has sought to develop the concept of invisible work as more analytically robust by proposing a framework defining invisible work as 'labour which is economically devalued through three intersecting sociological mechanisms of invisibility' (p. 337). These mechanisms – sociocultural, sociospatial and sociolegal – are considered here, to contextualise the WPA's enabling role as invisible work.

Sociocultural mechanisms. Some types of labour are hidden, and therefore devalued, by cultural ideologies and assumptions about what counts as 'work'. Such sociocultural mechanisms act both on workers' bodies and occupational skills, so that 'the product of such labour is expected and normalised. . . while the skills and labour involved are minimised or disregarded' (Hatton, 2017: 341). Mechanisms operating on workers' bodies require hidden bodily effort to conform to employer expectations and fall into three overlapping categories: aesthetic labour, for instance adopting a particular appearance (Warhurst and Nickson, 2007), emotional labour, such as being required to serve with a smile even when customers are rude (Hochschild, 1983) and/or identity work to navigate tensions between personal and occupational identities, for instance as explored by Kreiner et al. (2006) with regard to priests.

With the antecedents of personal assistance in care work, evidence suggests that the required bodily labour and occupational skills have been similarly rendered invisible by the sociocultural mechanism of gendered work. For example, PAs consistently report being in a support relationship as involving a good deal of emotion work. This is not necessarily in the sense of Hochschild's (1983) requirement to *perform* emotion, but the broader emotion work associated with the relationship, including maintaining a work/personal boundary and managing felt obligation to agree to assistance requests beyond contracted hours (Manthorpe and Martineau, 2008; Porter et al., 2020; Ungerson, 1999). Occupational skills required by PAs to support another person are similarly naturalised and devalued as gendered work: '. . .people skills, common sense, experiential knowledge, and the right disposition' (Flynn, 2005: 4). In practice PAs require expertise to recognise and respond to an individual's bespoke needs and personal preferences (Kelly, 2011). In the case of workplace personal assistance, for which some disabled workers may recruit PAs wholly or in part for skills relevant to their own job role, additional questions arise regarding how WPAs deploy these skills while ensuring the disabled worker is always seen by their colleagues as the person 'getting the job done' (Barrett, 2001: 57).

Also important for contextualising workplace personal assistance is evidence from disabled people's experiences of the workplace as socioculturally ableist. Predicated on employers' expectations of the 'ideal worker' (Foster and Wass, 2012), disabled people have reported a wide variety of disregarded tasks and skills required to obtain and retain paid job roles, including disclosing impairment, dealing with ableist attitudes, disabling systems and environments, and securing workplace adjustments (Inckle, 2018; Mik-Meyer, 2016; Prideaux et al., 2009; Roulstone and Williams, 2014; Wilton, 2008). The unacknowledged tasks of recruiting and managing WPAs have also been likened by disabled workers to 'having another job' (Graham et al., 2021; Katzman and Kinsella, 2018). This ableism, and its accompanying expectation of the 'ideal worker', may render the WPA role invisible from the perspective of the disabled worker's employer since, despite a WPA's physical presence, the role is bound within that of their employee, with responsibility for WPA management lying within a disregarded zone of their labour.

Sociospatial mechanisms. Hatton defines these mechanisms as occurring when work is devalued through physical segregation from the socially-constructed workplace, either in the domestic sphere or in non-traditional worksites such as prisons. Evidence on personal assistance in the home setting is consistent with this definition, intersecting with the sociocultural mechanism of gender which devalues 'care' work. By contrast WPAs are physically located within the disabled person's workplace. Conceptually, their enabling role being bound with the disabled worker's job role creates the potential for two co-existing socially-constructed workplaces, one comprising the WPA/disabled worker which operates within the latter's wider workplace. This scenario raises empirical questions such as how WPA (in)visibility requirements may differ between the two workplaces and how boundaries between them are demarcated and maintained.

Sociolegal mechanisms. Hatton defines three types of work as invisible, owing to their exclusion from legal definitions of employment: work which is non-economic (unpaid), illegal, or informal ('off the books') (Hatton, 2017: 342). For Hatton the significance of

illegality is the corollary of lack of state regulation, meaning there is little systematic knowledge about these types of labour. While PAs are legally employed, Porter et al. (2020) note the UK organisation of personal assistance via private contracts as a 'striking feature' (p. 192) in giving disabled people a level of control largely free from state oversight. By contrast, for example in the Norwegian model, PAs are employed by an intermediary User-Led Organisation which brokers the disabled person/PA relationship (Christensen, 2012). It has been argued that the UK model obscures personal assistance at macro workforce level, where as an occupation it manifests as unorganised and precarious, carrying associated risks for the isolation and exploitation of individual PAs owing to weakly-formalised working conditions and lack of registration, collective representation and support networks (Guldvik et al., 2014; Leece, 2010; Woolham et al., 2019). Within the PA workforce, WPAs constitute a particularly hidden group owing to operating outside the conventional domestic setting. Latest estimates indicate that around 70,000 people are using LA direct payments to fund PAs (Skills for Care, 2021), but no breakdown is available on the settings in which their PAs are being deployed. While the *Access to Work* grant scheme is clearly workplace-focused, relevant information is scant, limited to the number of people in receipt of a Support Worker grant payment (10,720 during 2019–2020) with no detail such as the number of award-holders with physical and/or sensory impairments, or types of support being provided (DWP, 2020b).

This article applies Hatton's conceptual framework to data analysis from the first UK empirical study on the experiences of WPAs and workers with physical and/or sensory impairments who deploy them. Of particular interest is understanding how the mechanisms of invisibility operate given the WPA's unique empowerment-driven role as a disabled worker's enabling tool.

The empirical study

Aim, design and methodology

The data analysed here are from a study (carried out over 18 months during 2016–2017) which aimed to explore (a) the role of WPAs who support people with physical disabilities or sensory impairments and (b) WPA relationships in the workplace, both with the disabled worker and other social actors. Given the exploratory nature of the research, the design was qualitative, using semi-structured interviews with WPAs, disabled workers and their managers. The number of managers recruited was low (n=4) and, since less relevant to the focus of the current article, the manager perspective is excluded. The project was carried out primarily in England (two participants were in Scotland) and supported by an Advisory Group comprising disabled workers, their WPAs and academics.

Participant recruitment

Owing to the hidden nature of the WPA workforce, the approach to recruiting WPAs and disabled workers was broad-based and pragmatic. Recruitment routes included: organisations and networks associated with disability rights, employment support and specific impairments; employers with an expressed commitment to inclusive recruitment, for

example those self-identified as Disability Confident (DWP, 2014); snowballing; and Twitter. Eligibility criteria focused on the disabled worker, who should (i) have a physical and/or sensory (but no cognitive) impairment, (ii) be in paid employment, including self-employment where this involved time in workplace settings outside the home and (iii) be supported by a PA in the workplace. Fifteen disabled workers and 17 WPAs were recruited with connections as follows:

- 13 disabled worker/WPA dyads (n=28): in two cases, a disabled worker had 2 WPAs;
- 4 single participants: comprising 2 disabled workers who used WPAs ad-hoc; and 2 WPAs not currently active in the role.

Data collection and analysis

Interviews were semi-structured, typically around an hour in length and carried out individually, either face-to-face (in person or via Skype, at the participant's home or workplace) or by telephone, according to their preference. Interview*s* were audio-recorded and transcribed. The data were analysed thematically using *Framework*, a staged and iterative process (Spencer et al., 2014) involving all the researchers. Following immersion in the transcripts to identify preliminary issues, concepts and themes, the researchers constructed a thematic framework to manage and organise the data. In a pilot stage all the researchers applied the framework by using it to label ('index') the data in a small number of transcripts, then met to check interpretation and refine the framework. Three researchers (JB, KG, JM) then indexed all the transcripts and carried out the remainder of the analysis.

Indexed data were summarised for display using thematic charts. Each chart row displayed one participant's data, with columns used for sub-themes. Reading along a chart row therefore provided an overview of an individual's data on a theme, reading down the columns enabling comparison between participants. Dyad members were displayed in adjacent rows to facilitate comparison of their accounts. After sharing analytical notes to reflect on emerging issues, to facilitate deeper comparison between the perspectives of WPAs and disabled workers the researchers displayed the data in a second set of charts. Here the rows represented sub-themes, two columns displaying data from WPAs and disabled workers. The researchers then worked together in the continued gradual and iterative process of interpreting the data through identifying characteristics and differences, defining and interrogating concepts and seeking explanations within the data for connections and patterns observed.

Participant characteristics

Disabled workers. Most disabled workers were female (11/15). Eleven people had a physical disability, the other four a visual impairment. Participants included those working full and part-time and in a range of sectors: academia, law, IT support, performing arts, training, consultancy, primary education and disability advice. A third were self-employed. *Access to Work* was the most common WPA funding stream (9/15), others

were NHS Continuing Care, LA direct payments and (in the case of one self-employed person) costing a WPA into tenders. In most cases (11/15), the disabled worker employed their WPA directly; another two disabled workers used an agency and in the remaining two cases the disabled worker's employer also employed the WPA. In one of these cases (a User-Led Organisation) the arrangement was at the disabled worker's request; in the other the disabled worker drew on the organisation's pool of WPAs.

Workplace Personal Assistants. Most WPAs were female (13/17). Professional backgrounds varied widely: care, pastoral work, social work, youth work and other types of person-centred roles (classroom assistant; communications support for D/deaf people), retail, performing arts, further and higher education, research and other office-based roles, such as administration (including office PA), management and training. Job titles varied; aside from Workplace PA (the term settled on by the research team) other terms used were Personal Assistant, Support Worker, Employment Support Worker, Access Worker, Disability Aide and (in the performing arts) Creative Enabler. The most common route into PA work had been through a job advert (10/17), most often when looking for a change or something interesting to do, for example in early retirement. Word of mouth was the other main route used, five WPAs already knowing either the disabled person (in one case a family member) or a PA working for them.

In the majority of cases (11/17) the WPA had been recruited for workplace support only and, in all but one of these cases, solely for work-related tasks. The exception was a disabled person who required personal care during working hours and preferred to keep separate their work and home-based assistance personnel. The role of the other six WPAs was generic: to assist the disabled person in any setting with personal care plus any other tasks required.

This article uses pseudonyms for direct quotations and, unless apparent from the preceding text, an indication as to whether the person is a disabled worker or WPA. Quotations also show the page number of the interview transcript.

Study challenges/limitations

While the number of participants and spread of characteristics achieved was satisfactory, recruitment was challenging owing to WPAs being a hidden workforce. No data were available on WPA numbers and there were no bespoke training courses or active peer networks. There were also no clear routes to find disabled workers, other than in disability-focused organisations.

Findings: Implementing the enabling WPA role

WPAs' and disabled workers' accounts revealed that together their work took place in two separate, but inter-connected, sociospatial worlds: public and private. The public world was where the disabled worker and WPA performed their respective roles in front of the former's colleagues, seeking to foreground the disabled worker's role with the WPA role intentionally invisibly bound within it. Away from the gaze of colleagues, the disabled worker and their WPA occupied a private 'workplace-within-the-workplace'.

This site was used for the hidden practical and emotion work required by both parties to construct and maintain the public performance of the WPA's role identity, along with the expression of other aspects of their relationship withheld from the public sphere. This findings section is organised around how the WPA role operates within and in transition between these two sociospatial worlds.

The public world of the disabled person's workplace

While the notion of a WPA role to assist a disabled worker was not difficult for others in the workplace to grasp, its practical implementation could be problematic. As an enabling tool wholly bound within the formal job role of the disabled worker, WPA role identity was a poor fit within the normative social structure of workplace organisations. This was especially so where the disabled worker employed their WPA directly (most cases in the sample), since neither the WPA role nor post-holder was visible at organisational level in terms of conventional means for acknowledging and understanding job roles, such as featuring in the staffing structure, list of employees, or payroll system. This invisibility led to difficulties in operating the role, owing both to oversight at organisational policy level and day-to-day uncertainties among WPAs and other workplace social actors on the scope of the role and its intended degree of invisibility.

Disregard for the WPA role at organisational level left some WPAs denied the access rights available to the disabled worker, which compromised the assistance they could provide. Examples included not being issued with swipe cards to enter certain parts of buildings, not being offered training on bespoke computer systems and being denied permission to accompany the disabled worker to confidential meetings. These were usually teething problems each disabled worker managed to resolve over time, however in one case Jessamine's working arrangements with her WPA were permanently complicated by her organisation's confidentiality policy meaning her WPA had to be based on a different floor.

At the level of day-to-day colleague understanding, when attempting to convey the unconventional WPA role to others in terms of empowerment, both disabled workers and WPAs commonly portrayed the WPA as a depersonalised assistance device:

> an extension of me. . . a tool that I use in order to function on a daily basis. (Joel, disabled worker: 6)

> I'm her hands, her feet. (Kate, WPA: 1)

However the requirement to carry out an invisible role while being physically present in the workplace created an ambiguous identity for WPAs summed up by one disabled worker as 'they exist but they don't exist' (Phil: 2). WPAs reported their own and others' uncertainty about the boundaries of both their occupational and personal identity: under what circumstances could a WPA interact with others and thereby become visible? Responsibility for guidance lay with the individual disabled worker, whose freedom to scope their personal assistance meant that they shaped an individual WPA's identity:

> Every disabled person does it differently. . .there's no standard etiquette. (Joel, disabled worker: 4)

However clear guidance from disabled workers was often not forthcoming, fuelling lack of others' understanding. Rhys held the most clear-cut stance, arguing from an empowerment perspective that his WPA should be regarded by others as invisible:

> People have said to me, 'who's this person working for you, you've never introduced them' and I said, 'they're my support worker, I don't need to introduce them' (laughs). They find that very strange, but that's my approach to it . . . otherwise it makes things very messy. (Rhys: 8)

Messiness arose owing to lack of clarity about the enabling function of the WPA role, meaning colleagues might approach the WPA instead of the disabled worker directly:

> In circumstances like that I tell [the WPA] to just turn away, walk away, don't say anything at all, right, blank them; you may feel you're being extremely rude but that's the only way, because then that person will direct their conversation to [me] where it should be in the first place. The moment you start to make excuses and things like that it's wrong, because it's then making the disabled person feel uncomfortable. (Rhys: 21)

Guidance from other disabled workers was more equivocal, reflecting unease about portraying their WPA as a depersonalised 'tool' in case colleagues should think they viewed their WPA as a 'slave' or 'robot'. Instead they sought to describe the WPA as both an extension of themselves *and* having a separate identity:

> They're an extension of me but they're also their own person, they aren't just my slaves. (Taylor: 12)

However when describing how this dual identity might work in practice, accounts could become conflicted. For example, while Joel wanted his WPAs to engage with his colleagues, their self-expression was limited owing to requiring his WPAs to represent him:

> I don't like to think that my PAs are just robots that don't have any engagement at all [with my colleagues]. So when, in certain circumstances they'll know that they can be part of the conversation as well, they can throw out observations and ideas as much as I will; ultimately my decision is final, but I want them to be involved . . .
>
> You can get times when . . . you can see the PA's uncomfortable with what the person's talking about and you can tell that maybe outside they would have challenged that, but because of the role they're in they can't . . .. I always say to them you've got to remember you are an extension of me, not just in terms of a tool that I have to use in order to function on a daily basis, but you also represent me as well, so you need to be very careful. If you challenge somebody and it makes them uncomfortable then that will reflect on me. (Joel: 4 & 6)

In turn, lack of clarity created uncertainty about WPA role boundaries, both for WPAs and the disabled worker's colleagues. WPAs whose work included common office tasks

such as photocopying could be asked by others to do these tasks and feel too uncomfortable to refuse, risking role drift into a general office resource. Conversely, a WPA might exploit their ambiguous status by attempting to use the role instrumentally as a way into the disabled worker's job sector. Sharon, who worked in performing arts, had experienced several WPAs wanting to be overly involved: 'like they want to take part, they want to get to know people, and that's not what I want . . . I've had to tell [WPAs] to back off a bit' (Sharon: 12).

More generally, given the myriad types of social interaction in the workplace, it was tricky for disabled workers to guide their WPAs in advance for all scenarios, which fuelled uncertainty. In practice, WPAs typically took day-to-day responsibility for managing their boundary of their invisibility, learning to judge where their employer would place it in any given encounter. WPAs used feedback from their mistakes, over time developing nuanced social skills to identify subtle cues from the disabled worker, such as their demeanour:

> It's hard to describe what you do. . .it's something in the air, something you absorb, something that you get a sense for, how to gauge a situation . . . you become quite good at gauging when to interact and when not to. (Ramona, WPA: 6)

> All my PAs have sixth senses. (Taylor, disabled worker: 10)

WPAs used the level of formality of the encounter and its degree of work-related content to guide their general approach and behaviour. This meant that while informal social chat with the disabled worker's colleagues was often permitted, the WPA speaking in a formal meeting was generally taboo. WPA used various bodily strategies to reinforce their invisible status in meetings, for example not taking part in round-table introductions, sitting slightly away from the table behind the disabled worker and being more casually dressed.

Given the focus of the WPA role on disabled worker empowerment, WPAs whose previous employment had afforded them higher workplace role status could feel a keen sense of their own disempowerment, at least at the start. Dawn contrasted her experience in meetings as a WPA with her previous conventional 'office PA' role:

> It's a very disempowering position to be in . . .The [office PA] role that I had before . . . you were classed as somebody's relatively high-up, as their second in command, [now] it's quite disempowering when you're almost told that you need to sit down, be quiet and not exist. (Dawn: 5–6)

Not all new WPAs had initially understood their role as empowerment-based. An example was Eleanor, who felt frustrated in the role, feeling it had been mis-sold at interview as a 'step on the ladder' (Eleanor: 1) to a career in the disabled worker's job sector. By contrast, WPAs who talked about using the concept of empowerment to guide their role behaviour framed evidence of their invisibility as a positive marker of being a successful enabler:

> You almost have to disappear, it's like you don't want the access tool to stand out. If somebody's noticing you you're probably not doing your job right. (Matt: 17)

Similarly, Clare likened her role to being a 'waiter in a high-class restaurant':

> Yes, you're there, you've got a job, but your job should be so unintrusive that you can do your job without actually affecting proceedings. . .filtered into the background. (Clare: 4–5 & 7)

Social interaction scenarios which blurred work/personal identities were more problematic for WPAs to judge the boundary of their invisibility, for instance when office kitchen chat turned to work matters, or the WPA accompanied the disabled worker to a work-related social event. Having accompanied Joel to a conference dinner, WPA Ramona reflected on her decision-making about participating in the conversation:

> I guess I contributed more than I would in a normal work situation because it's a little bit more relaxed. So you're talking, trying to gauge the line between enough and not wanting people to think you're being rude either, cos sometimes you think 'I stick out like a sore thumb here', you know. Not that I wouldn't be able to contribute anything but it's not my environment and it's not my dinner. (Ramona: 6)

Their role identity being presented as invisible meant that some WPAs also found their personal identity routinely unacknowledged by the disabled worker's colleagues. Working in an open-plan office, Eleanor felt invisible both as a worker and a person:

> It is a very hidden job. Some people, it's like they don't notice me being there, they'll have conversations that I know they shouldn't be having in front of me . . . there's only two or three that would actually have a conversation with me, or say 'hi Eleanor'. It's like working here but not working here, it's very odd, it's the strangest job I've ever had. (Eleanor: 11–12)

Jody summed up how being treated as personally invisible could make her feel:

> Some people completely wipe me out as if I'm not a human being. It's horrible, it's weird, it's odd, a really odd feeling. . . cos they don't want to talk to me, they don't see me as a person, whereas I am a person and I'm doing a good job. I suppose they think that that's the correct way to deal with a PA but I don't think it is personally. (Jody: 12)

WPAs who supported the disabled person both in their home and the workplace contrasted the two settings in terms of capacity to express their personal identity. Doing so was much easier in the private home setting, where the disabled person was not in their work role and the WPA relationship was styled more informally:

> I try and be more professional obviously at work. I prefer the other side of it, the home, it's more informal. You've got to be sort of more discreet at work, I mean I'm there but I'm sort of trying to be sort of in the background. (Christine: 11–12)

> I've just known how to like be a silent carer when she's at work. (Florence: 4)

The private world of the workplace-within-the-workplace

In addition to performing their public roles in the workplace, disabled workers and their WPAs occupied a private workplace-within-the-workplace. This parallel social world

was the site for various types of private practical and emotion work. Such work included disabled worker feedback on WPA performance at role boundaries, for example reminding a WPA not to speak in meetings. This was also a space in which to let off steam about other social actors' misunderstanding of the WPA role. For example, after occasions when Taylor's colleagues expected her WPA Florence to do similar tasks for them: 'we'll have a good old bitch about whoever's done it (laughter)' (Taylor: 11).

In the private workplace, a WPA's role could also shift beyond enabling. An example was given by Matt, both an experienced part-time WPA and more experienced in their shared creative arts field than the disabled worker he was assisting. For Matt, this created an especially 'blurry' role boundary (Matt: 9). His strategy while under the gaze of others was to stay focused on the empowerment purpose of his role, concealing these valuable attributes, but in private offering to shift his role to colleague/mentor:

> [The WPA has] to hold back, not give their opinions . . . there is a discipline to it, to not intervene. . .. Afterwards [you can] ask them 'would you like to have some feedback on a peer-to-peer basis?', that's fine. But I think in the situation when the WPA starts to input, it can really undermine the disabled person. (Matt: 9)

In private, some disabled workers invited their WPAs to transgress the enabling boundary by acting as a work-related reflecting point. While disabled workers appreciated this added value from having a WPA, it could place a burden on the WPA themselves. For example, Clare spoke about having to pay attention throughout meetings in which she had neither a role nor personal interest, just in case Nicola, the disabled worker, wanted to discuss anything afterwards.

WPAs found that the nature of their enabling role blurred conventional boundaries between a work/personal relationship, demonstrated in this example from WPA Dawn:

> It's a very unique job . . . you've got to get on with the person that you're working for . . . build a friendship . . . and that's a very difficult one . . .We don't socialise out of work, but you have to be a friend, it's more than being a colleague because there's certain things that you have to know about that person that you wouldn't know in an ordinary business relationship. For example Phil can't operate a cash point so I know his PIN numbers for his bank accounts; you've got to have a great element of trust. (Dawn: 7–8)

Blurred boundaries could lead to WPAs being engulfed by feelings of obligation. WPAs Clare and Jackie both worked for self-employed people whose requests for assistance were unpredictable and could involve long hours, including distant travel and overnight stays. Both reported struggling to balance the desire to meet their personal commitments with the knowledge that, without their support, the disabled worker would be unable to accept the job contracts they were offered.

Discussion

Applying Hatton's (2017) conceptual framework to the WPA role extends understanding both of personal assistance and the operation of mechanisms of invisible work. Away from the home setting, the unconventional enabling function of the WPA role was less

clearly understood within a disabled person's workplace, where all three mechanisms of invisibility – sociocultural, sociolegal and sociospatial – contributed both separately and in combination to render WPAs 'multiply invisible' (Hatton, 2017: 345).

Sociospatial mechanisms of invisible work

Hatton argued that work can be devalued when physically segregated from a socially-constructed traditional workplace, for example domestic labour. The current analysis found this concept also helpful for exposing a sociospatially unacknowledged worksite physically located *within* the socially-recognised workplace. This private 'workplace-within-the-workplace', comprising the WPA and disabled worker, was used for a variety of backroom functions, such as reflection on the WPA's public role performance and to allow for a WPA to step beyond their enabling role, for example to share their expertise in the field of the disabled worker's job role. The existence of co-located public and private sociospatial zones has parallels with Goffman's (1959) use of theatre as metaphor for social interaction, in particular its front and back stage areas. Following Goffman's scheme the disabled worker and WPA comprise a team, whose respective front stage roles of 'ideal worker' and 'enabling tool' are performed with the goal of being believed by the audience of the disabled worker's colleagues. The private back stage zone is used to craft these performances and to allow other behaviour which would be inappropriate in their audience-facing roles. In workplace personal assistance the existence of these two zones, physically co-located but sociospatially separate, intersects strongly with sociocultural mechanisms relating to disabled people's empowerment and workplace ableism.

Sociocultural mechanisms of invisible work

In Hatton's framework, intentional invisibility is associated with illegal work. However, the study reveals two powerful sociocultural mechanisms which, operating together on WPAs, require them to strive for invisibility: the empowerment ethos underpinning the WPA role and the workplace ableism requiring disabled people to present to their employers as 'ideal workers'.

Being physically present yet striving for invisibility, WPAs occupied the ambiguous position of 'existing but not existing' in the disabled person's workplace. Since disabled workers constructed their WPA role identity according to personal preference, alternative framings for the role were applied, such as a 'tool' or 'representative', in turn affecting the degree of invisibility experienced by individual WPAs with regard to both their occupational and personal identity, along with the invisible labour required, including at role boundaries, to maintain the desired status. Such labour included a variety of body and skills work. Body work included appearance, for instance dressing more casually than the disabled worker, and emotion work of different kinds. This included, in Hochschild's (1983) sense, WPAs' management of their own emotions when acting as their employer's representative. WPAs also experienced emotional impacts of striving for an invisible identity among other workplace social actors which, for some, included distress arising from occupational and/or personal disregard. In common with PAs working in home settings, WPAs also experienced the broader emotion work involved in a support relationship, such as

maintaining work/personal boundaries and felt obligation to respond to requests for additional assistance. An added factor for WPAs was awareness that declining requests would mean the disabled person being unable to take up their paid work offers.

WPAs' day-to-day judgements in gauging and managing the (in)visibility of their occupational and personal identity within and across the public and private sociospatial zones of the workplace demonstrated the high level of nuanced interpersonal skill required in their enabling role. For PAs supporting the same person both at home and work, the study also demonstrated the skills required to tailor role performance to each setting. Seeking to be more discreet in the work setting echoed Barrett's (2001) identification of striving to remain unobtrusive as a distinctive characteristic of the WPA role.

Like Barrett, some WPAs in the current study used the concept of empowerment to frame positively their public experience of invisibility, enhancing resilience and job satisfaction. For others however, fulfilling an empowerment-based role felt disempowering, for instance owing to loss of status and agency compared with previous work roles, or the requirement to conceal relevant expertise from wider organisation, for which they would conventionally have been valued. The notion of disabled people's empowerment being achieved at the expense of PA invisibility is ethically problematic and subject to debates around ignoring collaboration in assistance relationships (Christensen, 2012; Neumann and Gunderson, 2019; Shakespeare, 2013). The current study's illumination of the invisible PA/disabled worker 'workplace-within-the-workplace' adds to existing awareness of such collaborative work and the mechanisms which render it invisible.

Sociolegal mechanisms of invisible work

Hatton defined sociolegal invisible labour as legally-excluded (unwaged, illegal or off-the-books) meaning 'there is little systematic knowledge of these types of labour' (Hatton, 2017: 342). They did, however, note exceptions, for example the exemption of legally-employed US corporate executives from federal wage law scrutiny owing to being legally construed as not requiring such protection. Workplace personal assistance presents another case in which workers can be positioned beyond detailed state scrutiny *despite* being legally employed. For WPAs, this sociolegal outcome is produced via intersection with the sociocultural mechanism of empowerment which underpins the UK model of disabled people's direct employment of PAs. At macro level, this means PAs are an occupational group about which little systemic information is gathered. In the study, WPA direct employment contributed to their invisibility owing to lack of employee status in the disabled worker's employing organisation. Such invisibility manifested both in WPA disregard at workplace policy level (for example, inattention to the need for WPA access to permissions and training) and in day-to-day uncertainty among the disabled worker's colleagues around WPA role boundaries, risking role drift and potential undermining of the disabled worker's role status.

Conclusion

Hatton (2017) saw their conceptual framework as providing the foundation for further research to 'untangle' the complex systems producing invisible work. Applying the framework to the case of workplace personal assistance contributes to such untangling

by showing how Hatton's three mechanisms operate and intersect to render a group of workers and their work 'multiply invisible' (2017: 345). The findings contribute to avenues Hatton identified for further research, in particular in exploring how and where analytical boundaries are drawn and the relevance of a particular sociolegal context.

The WPA's unique enabling role emerges as key to invisibility, being wholly bound within that of the disabled worker. Socioculturally, WPAs are subject to layered invisibility, owing to the dual mechanisms of empowerment and workplace ableism operating on the disabled worker. These mechanisms intersect, rendering the WPA role invisible as a tool of a disabled person's empowerment which is located in a disregarded zone of a disabled worker's labour. In the UK context, empowerment also strongly underpins WPA's sociolegal invisibility since, although legally employed, the PA employment model of private contracting gives disabled people a level of control largely free from state oversight. Impacts for WPA invisibility arise from lack of employee status in the disabled person's workplace, together with the disabled worker's personal framing of the WPA role (for example as a depersonalised tool, or a representative) which shapes the contours of individual WPA invisibility both as a worker and in terms of their work.

The study evidence on sociospatial invisibility widens Hatton's initial focus on physically-segregated worksites to expose a private disabled worker/WPA 'workplace-within-the-workplace', physically co-located but sociospatially unacknowledged within the disabled person's wider workplace. Concealment of this worksite is strongly associated with sociocultural mechanisms of empowerment and workplace ableism, since private site activity (such as the WPA and disabled person working collegially) disrupts the public presentation of the disabled person as an ideal worker and their WPA as an enabling tool.

Further research might usefully compare different WPA employment models: while most disabled workers in the current study followed the conventional UK PA model of employing their WPAs directly, a small number did not, using an agency or a PA employed by their own employer. Such comparative research would deepen understanding of the interplay between sociolegal and other mechanisms acting on WPA invisibility. Research might also helpfully explore why some WPAs can draw on disabled people's empowerment as positive frame for their own invisibility, while others experience role invisibility as fundamentally disempowering. Investigating the perspectives of disabled workers' managers and colleagues would round out empirical understandings of the WPA role and how implementation challenges might be ameliorated. At workforce level, research to improve information on the hidden WPA workforce, and to understand facilitators and barriers to its growth, would inform the workforce development needed to help close the disability employment gap.

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