



Deposited via The University of York.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/id/eprint/172498/>

Version: Published Version

Article:

Graham, Katherine Elizabeth, Brooks, Jenni, Maddison, Jane Ridley et al. (2021) Two Jobs in One Day: Exploring the Dynamics of Personal Assistance Relationships in the Workplace. *Scandinavian Journal Of Disability Research*. 147–157. ISSN: 1745-3011

<https://doi.org/10.16993/sjdr.761>

Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here:

<https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

RESEARCH

Two Jobs in One Day: Exploring the Dynamics of Personal Assistance Relationships in the Workplace

Katherine Graham¹, Jenni Brooks², Jane Maddison¹ and Yvonne Birks¹¹ University of York, GB² Sheffield Hallam University, GBCorresponding author: Jane Maddison (jane.maddison@york.ac.uk)

Disabled people are under-represented and can experience discrimination in the workplace in the UK and globally. The employment of a Workplace Personal Assistant (WPA) is an option for disabled people who require assistance to undertake their job role. The WPA role is designed to increase the accessibility of the workplace via personalised and self-directed assistance, yet is little known or understood. The dynamics of these assistance relationships are explored from analysis of interviews with disabled people, their WPAs and representatives of the organisations in which they work. Disabled people who use a WPA undertake two jobs in one day: their substantive role and the management of their WPA. Understanding these dual roles, and recognising the subtle skills required and additional labour undertaken, can help to challenge the ableist assumptions that shape the workplace and help open up the workplace for disabled people who require a WPA.

Keywords: personal assistance; disabled people; support relationships; ideal worker; employment

Introduction

Recognition that disabled people have been excluded from the labour market has prompted legislation and initiatives to increase disabled peoples' participation. This trend can be seen internationally, with examples in Australia (Grover and Soldatic 2013), Europe (Scharle and Csillag 2016) and globally in the World Health Organisation's *Disability Action Plan 2014–2021* (World Health Organisation 2015). In the UK context these developments can be seen on the one hand to be focused on a rights agenda (Equality Act 2010) and on the other with increasing conditionality of welfare benefits (Patrick 2011) in a move towards the individualisation of the challenges facing disabled people in predominantly ableist workplaces (Foster 2007). Ableism refers to the 'ideas, practices, institutions and social relations that presume able-bodiedness, and by doing so, construct persons with disabilities as marginalised, oppressed, and largely invisible "others"' (Chouinard 1997: 380).

The Equality Act (2010) is the primary anti-discrimination legislation placing a duty upon UK employers to make 'reasonable adjustments' to the physical environment and to practices, where disabled employees would be placed at 'substantial disadvantage' in the workplace. In addition to these workplace adjustments, the UK Department of Work and Pensions has a funding stream (*Access to Work*) to provide grants for personalised assistance (Department for Work and Pensions 2020). While the opportunity to apply for a grant has existed since 1994, the scheme has been described as the 'government's best kept secret' (Sacre 2011: 14). The scheme funds a range of support, including equipment and/or support from a personal assistant. This role has a range of titles including '(employment) support worker', 'access worker' or, as used throughout this article, 'workplace personal assistant' (WPA).

Regulations and arrangements for workplace personal assistance vary between countries. The Americans with Disabilities Act requirement for employers to make 'reasonable accommodation' only covers support with job-related tasks, not personal care tasks within the workplace, such as eating or using the bathroom (Dowler, Solovieva & Walls 2011). Funding is complex; employees needing assistance with personal care tasks at work are likely to be responsible for funding this themselves (Turner 2003). In Norway, however, the Norwegian Labour and Welfare Administration's functional assistance scheme covers support with both job-related tasks and personal care (Norwegian Labour and Welfare Administration 2021).

Personal assistance has the potential to open up the workplace for disabled people; however, limited research attention has been paid to disabled people's experience of using workplace personal assistance or that of people working in the WPA role. This article draws on empirical data on the experiences of disabled people, their line managers and WPAs to articulate the dynamics of these relationships and explores how an understanding of the WPA role, and complexities

of managing the role within organisational contexts, can help open up the workplace for disabled people who require personal assistance at work.

Disabled people's experiences in the workplace

Research into the experiences of disabled people at work has focused on the impact of workplace policies, organisational culture and the attitudes of colleagues and managers.

Disabled employees are more likely to report ill-treatment than their non-disabled counterparts (Fevre et al. 2013), and while colleagues and clients of organisations were found to be responsible for some of this ill-treatment, managers were seen to be responsible for the largest share. Fevre and colleagues' respondents 'attributed their ill treatment to the nature of their workplace, rather than to stigma or discrimination' (2013: 302), although the authors concluded that 'the survey suggests that the ill-treatment of employees with disabilities is embedded in the social relations of the workplace' (2013: 303).

Even well-intentioned interactions can be problematic. Mik-Meyer's (2016) study of workers with cerebral palsy in Denmark found that they, their colleagues and managers often described relationships resembling those of a 'parent-child, helper-helpless or protector-protected' (2016: 994). Mik-Meyer suggests these acts of caregiving in the workplace, ranging from offers of help with practical tasks to being overprotective, may be interpreted as 'subtle practices of stigmatisation' (2016: 996) and sustain ableist misconceptions that disabled workers are less productive than non-disabled workers (Jammaers, Zanoni & Hardonk 2016).

Research on the role managers play in creating a supportive or unsupportive working environment for their disabled employees also reveals stigmatisation. Foster (2007) reported that a third of disabled participants experienced stress as a result of the reasonable adjustments process. Where managers were able to implement significant adjustments, this was attributed by the researchers to the 'benevolence' of the individual manager, often as part of an individual negotiation with the employee. Such negotiations lack transparency, contributing further to the marginalisation of disability issues within organisations and thereby limiting the possibility for sustainable change.

The concept of the 'ideal worker' has a long history that disadvantages people with impairments (Foster and Wass 2012). Workplaces are often set up for able-bodied people, and adjustments are necessary for disabled people to do their job. These must be negotiated with managers, which can be challenging and automatically mark out a disabled person as different (Fordyce and Riddle 2015; Van Laer, Jammaers & Hoeven 2020). Equipment-based adjustments have been found to be more readily accepted than a workplace personal assistant (Bruyère, Erickson & VanLooy 2004). The emotional labour involved for disabled people in securing adjustments can lead to reluctance to change roles, move jobs or apply for promotion, with individuals fearing the repeated scrutiny this may require and the risk of losing hard-won adjustments (Roulstone and Williams 2014; Wilton 2008).

While UK law requires employers to make 'reasonable adjustments', it does not fully address the ableist organisation of workplaces. For disabled people, who may already feel marginalised or seen as 'less productive' than other workers, bringing a personal assistant into the workplace brings a new dynamic to workplace relationships, requiring attention to manage well.

The personal assistant role: Outside and inside the workplace

The distinctive role of the WPA has been largely ignored in policy and research, both of which focus on the personal assistant (PA) role as part of the social care workforce. However, this broader understanding of personal assistance is a useful context from which to explore the WPA role. The PA workforce has been expanding following the shift towards a 'cash for care' model whereby people entitled to social care can opt to receive money (in the UK in the form of a direct payment) to arrange their own support. Similar schemes have been implemented across Europe (Ungerson and Yeandle 2007) and in other countries, for example Australia (David and West 2017) and the USA (Keigher 2007).

Early research into personal assistance relationships emphasised that while an individual PA's tasks are always specific to the needs of the person they support, fulfilling the role requires a wide-ranging skill-set including '...people skills, common sense, experiential knowledge, and the right disposition' (Flynn 2005: 4). More recent evidence has reinforced the importance of recognising the specificity of individual needs and preferences leading Kelly (2011) to argue that PAs cannot be specialists themselves, rather their expertise lies in supporting the individuals for whom they work. Other research has revealed the complexity of these support relationships. Such complexity includes issues of autonomy and control and day-to-day challenges associated with managing/being a PA. In one study (IFF Research 2008) 12% of PAs reported having disagreements with their employers, of these, 29% disagreeing over the scope of assistance extending to work or education. More generally a disabled person's requirement for flexibility can lead to potentially unstable, insecure employment for PAs or part time hours that do not fit easily with other roles (Guldvik, Christensen & Larsson 2014). An appreciation of workers who 'go the extra mile' (Flynn 2005: 20) can lead to PAs feeling a sense of obligation to their disabled employer, resulting in working more hours than they are paid for (Manthorpe and Martineau 2008: 13).

Other research has revealed the complex dynamics of how disabled people and PAs negotiate their individual assistance relationship. Christensen (2012) identified a variety of relationship styles along a continuum from the hierarchical 'master servant/servant master' approach to 'solidarity' based relationships that reflected a greater degree of symmetry. Christensen's study contrasted the Norwegian system, where an intermediary User-Led Organisation assists with PA

employment, with the UK system, which individualises the process and places employment responsibility with the individual disabled person. She concluded that an intermediary organisation helps to facilitate more professionally based relationships in the centre of the continuum.

In a UK study exploring relationships between disabled people and their PAs, Shakespeare, Stöckl and Porter (2018) used metaphors to describe the different ways in which these relationships were characterised. PA metaphors included: i) an 'extension of self', where the PA is defined by compensatory activities undertaken in place of the disabled person; ii) 'staff', with some participants equating this to a servant relationship; iii) a 'colleague', implying a more mutual relationship; iv) 'professional', where the role is not personal and clearly bounded; v) a 'paid friend', reflecting emotional aspects to the relationship, and vi) 'family', emphasising how PAs can become part of family life. Another study in Japan identified a similar range of relationships with the addition of a view of PAs as a form of 'social asset' whereby PAs work in solidarity with their employer and gained valuable insights into the disabling aspects of society (Yamaki and Yamazaki 2004).

The ableist organisational context of the workplace may have implications for the experience of personal assistance in the workplace and the types of relationship formed. Furthermore, funding for personal assistance is conditional; the roles PAs undertake are broadly defined by the funder, the workplace organisation and colleagues within that organisation. Whilst researching PA roles in disabled peoples' (non-workplace) experience of having a PA, Bonfils and Askheim found

PA support cannot necessarily be used for whatever the user wants and the governance of current schemes mean that the PA has to be employed in an agreed way and disabled people need to fulfil prescribed norms to be considered a suitable user of a PA (2014: 73).

It is not just the 'norms of being a suitable user of a PA' but also a suitable worker/employee that are at stake, and the additional work undertaken by disabled people in the management of their WPA needs to be better understood. Research from the US and Canada has exposed the lack of organisational policies relating to personal assistance within workplace organisations (Dowler, Solovieva & Walls 2011). Existing studies into ableism in the workplace and the separate body of work into PA relationships do not consider how these relationships may be shaped by the workplace; however, the limited available literature does suggest that a workplace setting may impact upon the tasks and nature of the relationship.

Methodology

This article draws on research carried out during 2016 and 2017, funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The aim of the project was to explore the role of WPAs supporting people with physical or sensory impairments through an examination of the relationships between WPAs, disabled people and others in the workplace to understand how the role and associated relationships might be better supported.

The project was conducted primarily in England (two participants were in Scotland) and supported by a project advisory group comprising disabled people, their WPAs, representatives of disabled people's organisations and academics with relevant expertise.

Recruitment

We recruited three types of participant: WPAs ($n = 17$), people with physical or sensory impairments who had a WPA ($n = 15$) and employers of disabled people with WPAs ($n = 4$).

Inclusion criteria focused on the disabled person, who had to

- have a physical and/or sensory (but no cognitive) impairment;
- be in paid employment involving work outside their home; and
- be supported in the workplace by a PA.

Disabled people worked in a diverse range of occupations and with differing contractual arrangements, including self-employment. Employment models of WPA engagement varied, and individual WPAs could be directly employed by the disabled person, by an agency or by the disabled person's employer (in the latter cases, Disabled People's Organisations). There was little consistency around the career background of WPAs, disabled people's recruitment methods or skills requirements. The most common source of funding for WPAs in the project was the Department for Work and Pensions *Access to Work* Scheme.

The approach to recruitment was necessarily broad and pragmatic. There are no organisations of, or for, WPAs in the UK, so our strategy began with Disabled People's Organisations, including Centres for Independent Living, other organisations and networks associated with disability rights and employment support, national charities supporting people with specific impairments and employers with an expressed commitment to inclusive recruitment or who were members of relevant networks. From there, we used snowballing to identify further potential participants by asking participants to distribute project information to their networks.

Data collection and analysis

Semi-structured interviews (typically around 60–90 minutes in length) were conducted with all participants via their choice of telephone, face-to-face or video (in the person's home or workplace). Topic guides were developed in consultation with the project advisory group. The cost of a replacement WPA was offered if the WPA was being interviewed at a time when they were working for the disabled person. Disabled people and WPAs were given a £20 gift token to thank them for their participation.

Interviews were audio-recorded and fully transcribed. Interview data were analysed using the Framework approach (Ritchie, Spencer & Connor 2007), an established and transparent approach well-suited to applied qualitative research and team analysis. The researchers first read the transcripts, noting topics and themes relating either to the predefined research questions or emergent from the data. The thematic framework was refined through team discussion and used to compile a set of thematic charts for data extraction.

Once data extraction was complete, the researchers worked together over several days to examine all the charted material and to compile a central chart for mapping and interpreting the full data set. This iterative process continued until the team was satisfied that a comprehensive account of the data had been produced.

Ethical considerations

Ethical approval was obtained from the Health Research Authority Social Care Research Ethics Committee (SCREC 16/IEC08/0003). All participants were required to give informed consent before the interview and were assured of confidentiality. In cases where a disabled person and their WPA (and/or employer) were taking part, to reassure participants that no information would be passed between them, we proposed that two researchers visit to interview them separately—an offer not taken up by anyone. We also offered to pay for alternative support for the disabled person if the WPA was being interviewed during their working hours—again, no participants took this option. Digital audio files were sent securely to a transcriber working to a signed confidentiality agreement; all data were kept under password protection, and consent forms and paper documentation were kept in locked filing cabinets with restricted access. Participant names have not been used in any dissemination.

Findings: The Dynamics of Personal Assistance in the Workplace

The following sections explore the different dynamics of the relationships between disabled people and their WPAs, with particular attention to how these dynamics are managed by the disabled person. The key themes were the WPA as a practical resource, as a representative of the disabled person and as a colleague. These themes were threaded through the discussions with all three participant groups—WPAs, disabled people and their employers—and were often not mutually exclusive but rather dependent upon the different contexts in which individuals were working. For example, a WPA may be seen and treated primarily as a practical resource during a meeting with external clients, as a representative at an internal meeting and as a colleague when the WPA and disabled person were alone.

WPA as a practical resource: 'Just a pair of hands'

Many of the tasks performed by WPAs were practical, reflecting the requirements of the person they were assisting. Practical support commonly included administrative tasks, such as filing, collecting materials, photocopying, driving, setting up environments to make them suitable for their disabled employer to work in, note-taking at meetings, facilitating travel and interpreting speech for business clients. A minority of WPAs also provided personal care at work, in some cases their only function.

Descriptions of WPA roles were rarely straightforward. Practical descriptions of the role by both disabled people and the WPAs included

'...I'm a bit old school, of the arms and legs philosophy'. [DP 12]

'...[I'm] basically just her arms...' [WPA 1b]

'...[I'm] her hands, feet, and everything.' [WPA 5]

These descriptions of practical support tasks reflect the use of WPAs to counter the ableist workplace environment and emphasise the disabled worker's autonomy, exemplified by one person describing their WPA as '[here] to support me and not get involved in my role' [DP 15].

In the majority of situations WPAs were employed directly by the individual they were supporting, with varying input or interest from their wider organisation. One disabled person commented that their line manager '...did not want any communication about the PA's existence...' [DP6]. In order to maintain distance from the WPA one line manager said:

'...[I] got my head round the fact that they were, you know, an extension of the person that you're employing...

[...]...you just do your job as you would if they weren't there.' [EMP 4]

Line managers tended to perceive the management of WPAs to be the sole domain of their disabled employee(s). This was linked in turn to ideas of control and autonomy:

'...it's really important because the role is there for the individual...[...it's very important that that support is managed directly.' [EMP 15]

The limited organisational involvement with the WPA was a dominant theme. While managers expected that the disabled person would inform their WPA of relevant organisational policies and processes and take responsibility for their WPA adhering to these (for example confidentiality), there was no evidence that organisations had any policies relating to using a WPA. Lack of such policies could be problematic, for example consideration not being given to the need for WPA access to resources needed to fulfil their role, such as permitted entry to parts of buildings and bespoke systems training.

The concept of the WPA as 'an extension' of the person they were assisting could have the effect of making the WPA invisible within the organisation or, at best, an ambivalent presence, which was summed up by one disabled person as 'they exist but they don't exist' [DP3]. A common example was in meetings, in which the WPA was physically present but not taking part. WPAs expressed mixed feelings about this status. One WPA expressed the importance of managing their emotions related to the role in situations where it also resulted in being disregarded as a person:

'Some people completely ignore me. It's horrible, it's weird, it's, it's odd, a really odd feeling ...[... they don't see me as a person ...[...]. But I suppose they think that that's the correct way to deal with a PA but I don't think it is personally.' [WPA 1b]

Another, when discussing working in an open plan office, said:

'...it is a very hidden job. It's like they don't notice me being there, and they'll have conversations that I know they shouldn't be having in front of me...[...it's like kind of, they think I'm some sort of "see no evil, hear no evil, speak no evil", but I hear all sorts.' [WPA 4]

However challenging this may be for WPAs, it was also generally agreed that the ability to be present yet in the background was a core WPA skill, as described here:

'There is a tension...[...if somebody's noticing you you're probably not doing your job right.' [WPA 13]

Managing the WPA's ambivalent status in organisations was a challenge for both WPAs and disabled people. Some disabled people described preparing their WPA for their reported experiences of feeling 'ignored', 'silent', 'hidden', 'invisible' or 'filtered out', for example in meetings:

'I always prep the PAs beforehand and say, there'll be times when this happens, and this is a reflection of the fact that you're actually just an extension of me, you're not going to the meeting on your own individual merit [you're] there for a particular purpose which is for me. And that's reflected sometimes in people's attitudes and behaviours towards a PA.' [DP 11]

The nature of the WPA role involves supporting a disabled person to do their job, not doing that job for them. The characterisation of a WPA as a practical resource ensured the focus remained on the disabled person and their job, rather than on their WPA. However, this had consequences for WPAs, whose lack of recognition within the workplace could mean being ignored by colleagues or denied access to space or resources. Disabled people's time and energy to manage this tension was often not recognised by their line managers.

WPA as a 'representative'

Whilst characterisations of the WPA as a physical 'extension of me' were common across the disabled workers, WPAs and employers in the project, this presents only a partial picture of roles and relationships. Workplace environments include a mix of formal and informal interactions, including small talk in the kitchen or corridor and social events after work. In these less formal interactions WPAs roles shifted from practical to acting as a 'representative' of the person they assisted.

The following example offers reflections upon the practical and emotional labour involved for both a disabled person and a WPA in the latter's shift from practical assistance to acting as a representative. Here, a WPA was unhappy about a situation in the office environment:

'...[and] because of the role they're in they can't challenge that; and 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 about, if you challenge somebody, and it makes them uncomfortable then that will reflect on me...[...]. So that's why I always say if you've got a major problem with something, talk to me first and then we'll try and address it, rather than make a point...[...]. because again it can just really affect the dynamics of my relationship with other people.' [DP 11]

Here, the disabled person is aware of, and actively managing, the potentially negative effect of their WPA on their own professional reputation. This is important given the need for disabled people to maintain their independent 'ideal worker' status.

Disabled people varied in their stance on the circumstances in which they would condone a WPA interacting with colleagues. Only one person was adamant that there should be no interaction, having observed that otherwise things 'can get very messy' [DP 8]. Others were more inclined to think that there was often a fine line to be judged by the WPA. Some people drew this line in terms of formal versus informal encounters, happy for their WPAs to be involved in the latter, for instance small talk in the office kitchen. Another emphasised the importance of recognising that their WPA will have thoughts and feelings in relation to the workplace stating that 'they are not robots' [DP 11]. Less commonly, there was even more flexibility, with some involvement permitted in the more formal context, such as meetings. However, this involved more nuanced, on-the-spot judgement by the WPA, for example:

'A big part of the complexity of the job for my PAs is working out the level of involvement they can and should have in a particular meeting.' [DP 2]

Given the breadth of workplace encounters, WPAs commonly reported lack of clarity about the disabled person's expectations regarding interactions with their colleagues in a given situation. As a result, both disabled people and WPAs noted that, over time, the most successful WPAs developed a 'sixth sense', able to 'read' or 'gauge' their appropriate level of involvement, for example by taking cues from the disabled person's demeanour.

WPA as a 'colleague'

The view that WPAs 'exist' within the workplace as a representative of the person they assist, yet simultaneously 'don't exist', obscures a more collaborative and collegiate dynamic of the relationship between a disabled person and their WPA. Several disabled people defined their relationship with their WPA as that of a colleague, in one case the term being used intentionally to challenge what he observed as the 'slave mentality' concept of the WPA practiced by some disabled people who viewed their WPA as a purely practical resource [DP 3]. Another person emphasised the complexity of managing assistance relationships compared with the assumption that a WPA is simply a type of physical accommodation:

'I think a lot of institutions think, give people support, they'll be fine in the workplace; well it's, it's much, much more complex than that...' [DP 11]

Complexity arose owing to the dynamic and context-dependent character of the relationship. Some disabled people identified the importance of having a WPA with relevant knowledge, experience or skills, either about the nature of the disabled person's job role or the organisation. In this example, a disabled person explained their motivation to employ a WPA already known within the organisation:

'It was almost an implicit job description that [they] would be able to induct [themselves] into it. And [they'd] learn, you know, [they'd] get to know the people [they] needed to know and make the relationships [they] needed to make and [they have] done that very, very effectively.' [DP 17]

Some disabled people saw a more collegiate relationship with their WPA as part of a management and retention strategy, highlighted in this example:

'I think being a PA would be pretty boring, cos they're sitting around until I say "can you do this, can you do that"; so there's whole stretches of time not really doing anything. So I can see that, say, with [WPA 14a] he's sort of itching to do something (laughter). But I mean we, get on really well and I can be clear about what I need and don't need, but I also quite like involving them as well, cos I know if I was being a PA I'd find it very boring just to sit there.' [DP 14]

The importance of this as a retention strategy was described by one WPA for whom the role evolved over time:

'[DP3] is very accepting of the fact that just being a PA in the sense of enabling him to do his job, you would go absolutely bored out of your head...[...].so if you've got any sort of intelligence really you need to be able to be a bit more active in the role...[...].I guess originally I was doing it as a job, I now do it because I actually really enjoy it; it's probably one of the best jobs I've had really. So it's a totally different ballgame from what it was originally.' [WPA 3]

A WPA's presence could also lead them to be misperceived by the disabled person's colleagues as an addition to the workforce. This risk of role drift was reported in office environments, where a WPA might carry out administrative tasks

for the disabled person, such as photocopying, and then be asked to do similar tasks by other staff. Although disabled people using WPAs were not content with these scenarios, on balance some opted not to confront their colleagues so as to avoid straining colleague relationships.

Whereas in most formal settings with colleagues present, disabled people and WPAs thought it critical for the WPA to be discreet and not overstep the remit of their role; more privately disabled people might call upon their WPAs to 'think' as well as 'do', for example by acting as a 'sounding board' [DP 11]. People identified how reflecting with their WPA on events or meetings was helpful, for example their value in making 'good suggestions' and 'spotting things I've not seen' [DP 14]. This required the WPA to pay attention throughout the disabled person's working day, not just in the periods when their practical assistance was required:

'[It's] important that she [WPA] carries a fundamental understanding of what's going on so I can use her as a reflecting point...[...].that's quite a big thing...[...].an important, if unrecognised, part of the role of a PA who supports a disabled person at work is to support the disabled person to manage their workload health-wise.' [DP 2]

However, the more collaborative elements of the collegiate dynamic could create challenges by blurring the boundary between assistance and the substantive job role of the disabled person. This risk was noticed by a line manager:

'The PA needs to be a bit sensitive...[...].because if the PA's sort of bright and really interested in the work, which you hope, they are really, they might want to have a say.' [EMP 5]

Where boundaries were flexible and context dependent, this required specific attention, as described by one disabled person:

'The trouble with this relationship is that [W]PAs can assume extra responsibility...[...].[they] overtook their responsibilities and took on some of [my] responsibility; and they upset another member of staff, caused a bit of a problem.' [DP 3]

One WPA [WPA15] had previously worked as a sign language interpreter and noted that while some elements of the interpreter role were similar to that of WPA—knowing when to stand back, for example—there were several contrasts. In her previous role she had a qualification and strict written codes of conduct, both local and national, as well as access to professional support. This, she noted, made it much easier to maintain workplace boundaries and professional relationships.

The findings in this theme emphasised some of the difficulties faced by disabled people in managing a collegial relationship with their WPA within a workplace setting, simultaneously providing a stimulating environment for the WPA and ensuring the WPA did not take over any aspect of their role.

Discussion

This article has explored the dynamics of the relationships between disabled people, their WPAs and the organisations in which they work. These assistance relationships offer opportunities to open up the workplace for disabled people but remain little understood. The study findings fill a gap in research that focuses on either (a) understanding the processes that enable and maintain ableist workplaces or (b) better understanding assistance relationships within the workplace, which presents some particular challenges and opportunities. The physical presence of the disabled person's accompanying WPA, contrasted with their invisibility in organisational policies, challenges the construction of the 'ideal worker' premised on productivity and autonomy and requires additional labour to manage. This means that disabled people who use workplace personal assistance are required to undertake not only their substantive job role but also another potentially equally challenging but unacknowledged role of managing their WPA(s).

The study identified three distinct and sometimes co-existent ways in which the dynamics of the relationships between disabled people and their WPA were being framed: as a practical resource, as a representative and/or as a colleague. Emphasis was placed on the importance of the disabled person being seen as an independent worker, with the WPA providing practical assistance, and not jeopardising the disabled person's professional standing. On occasions when relationships were more collegial, boundaries needed to be navigated within the complexities of the disabled person's other workplace relationships. These different dynamics offer an insight into the importance of understanding how personal assistance relationships function in different contexts and the skills and labour of disabled people and WPAs involved in managing them.

A better understanding of these dynamics would offer opportunities for organisations to consider the impact of the environment and organisational cultures on employees who may require a WPA. First, considering a WPA as akin to an environmental or technological adjustment ignores the additional labour required by disabled people to manage their assistance on top of their substantive job role so as to conform to an ableist 'ideal worker' status. Secondly, in order to create more enabling and accessible workplaces, it is important to understand how WPA relational dynamics are managed and the workplace factors that impact upon their successful management.

Managing the assistance relationship between formal and informal contexts throughout the day

The context-dependent nature of the assistance relationship means that the three dynamics—practical, representative, colleague—can be present at different times during the working day, with shifts requiring nuanced skills by disabled people and WPAs.

A WPA's practical tasks are the easiest to identify and for others to understand, be they managers, colleagues or clients. This practical dimension is reflected in research exploring home-based personal assistance (Flynn 2005; Shakespeare, Stöckl & Porter 2018; Yamaki and Yamazaki 2004), but drawing solely on this aspect does not recognise the labour involved in managing assistance relationships within an organisational context.

Organisational contexts shape relations in the workplace, creating the need for the WPA to adapt to different behavioural expectations and for disabled people using a WPA to manage these expectations. In formal settings the boundaries may be clearer, with the WPA role more easily defined as 'practical' support. In informal settings, such as small talk in an office kitchen or a work social event, boundaries and behaviour need to be more carefully managed by both disabled people and WPAs. Such work was rarely straightforward and was on-going, owing to the flexibility and unpredictability of encounters in workplace settings.

Collegiate relationships and the construction of the 'ideal worker'

The existence of a WPA draws attention to disabled people as 'other' in organisational contexts and challenges the construction of the independent 'ideal worker'. There are some parallels to the situation faced by Deaf people and sign language interpreters. Where interpreters are viewed by others in the workplace as a colleague, this can facilitate smooth working relationships but risks role boundary tensions (Dickinson and Turner 2014). Acknowledgement of the interpreter's active role in facilitating communication has challenged the traditional model of their invisibility but can also result in attention being drawn to the Deaf person, who may not wish to stand out (Angelelli 2002). The core interpreter role to facilitate communication does create a different workplace dynamic to that of a disabled person and their WPA: if an interpreter is not present, informal interactions between a Deaf person and their colleagues may be missing (Young, Oram & Napier 2019). The focus of the WPA on practical tasks carries the different risk that colleagues will incorrectly perceive that the disabled person is not fully responsible for their own job and therefore not fulfilling the ideal of an independent worker.

These relationships do not exist in a vacuum. Christensen (2012) identified how context can influence the relationships formed between disabled people and their PAs. The workplace setting may also affect these relationships, for example expectations on the disabled person to perform the independent 'ideal worker' role may encourage 'staff'-style assistance relationships with clear boundaries in order to conform to the pressure placed upon disabled people to be 'a suitable user of a PA' (Bonfils and Askheim 2014). In practice, disabled people use a range of WPA management strategies, with those reflecting a more collegiate relationship representing a challenge to the normative construction of the 'ideal worker'. It follows that where these more collegiate relationships are present, there is a risk of others in the workplace framing the disabled person through the lens of deficit and in opposition to the 'ideal worker'—assuming that they require extra help from their WPA—rather than perceiving the disabled person as deploying an active management strategy of their WPA. Our findings suggest that this could be helpfully reframed through a better understanding of the WPA role and recognition of the place WPAs occupy within organisations. Greater awareness of the dynamics of these relationships could create the conditions whereby disabled people can confidently deploy a range of management styles, minimising the potential for othering and comparisons with the 'ideal worker'.

Implications for organisations: Recognition of the WPA in the organisation

Existing research identifies the ableist principles upon which organisations are arranged. This can play out in wider social structures, including transport systems and education (Barnes 2012) and in organisational culture (Foster and Wass 2012), maintained through interactions with colleagues (Mik-Meyer 2016) and organisational spaces (Van Laer, Jammaers & Hoeven 2020). The WPA occupies a physical space yet typically does not formally exist within the organisation, owing to their unique position of being employed directly by the person they assist. The role of workplace organisations in supporting assistance relationships was frequently downplayed by the disabled people involved in this study and by the invisibility of the WPA role at organisation policy level. This meant that the opportunities and challenges of working with a WPA were individualised rather than considered to be organisational responsibility.

Autonomy and independent management of the WPA was a strong theme; however, a balance needs to be struck between the autonomy in assistance relationships and the responsibilities of organisations to create environments in which the existence (and potential future existence) of WPAs can be supported. No managers interviewed for this study had any policies or organisational acknowledgement of the existence of non-staff WPAs. In the majority of cases, the assistance relationship was a private arrangement separate from, but working within, the disabled person's employer organisation. A lack of organisational recognition of WPA existence may arise, on the part of the organisation and/or the disabled person, from the wish to respect the latter's right to manage their own assistance without interference. However, a corollary of this position appears to be a lack of organisational understanding of the nuances of individual WPA relationships, which ignores the complexity and additional burden of managing these in the workplace. In turn, this lack of understanding perpetuates assumptions of the ableist workplace, which limits perception of a disabled person as an independent, 'ideal' worker.

With WPAs deployed by disabled people to suit their individual needs and personal preferences, any organisation-level WPA policies and processes would need to be responsive to individual circumstances. In addition to an organisational policy offering formal recognition that WPAs exist (or are likely to exist at some point in the future), the findings of the current study suggest a starting point for change within an organisation is to initiate early conversations between a disabled person and their line manager when a WPA is starting work. These conversations would seek to clarify expectations of all parties from the start, specifically around key issues such as the WPA's tasks, when and how workplace colleagues should interact with WPAs and how any challenges will be addressed, be they specific to the assistance relationship or the organisation of the workplace. Similar early conversations between disabled people and new WPAs would also serve to clarify role expectations and boundaries for WPAs, given that every PA relationship is unique (Graham and Brooks 2018).

Limitations and Areas for Future Research

This article represents findings on one aspect of a wider, exploratory, qualitative study in an area in which there has been limited research. Overall, we advocate a set of conversations between a disabled employee, their WPA and the line manager within the organisation; however, further studies of how WPA relationships function would build understanding relating to spatial and social relations in the workplace. Creating sustainable changes to the organisation of workplaces cannot be solely reliant on individuals negotiating workplace adjustments; therefore, finding ways in which senior managers in organisations can support these complex relationships is an area for further research. The impact of different models of funding and employment of WPAs might also be usefully explored. In this project, funding sources included the *Access to Work* grant, eligibility for NHS Continuing Care and, for one self-employed person, adding the cost to work tenders. Christensen (2012) suggests that models of PA employment in home settings can affect the types of assistance relationships that develop. While the sample in this study included different WPA employment models (direct employment by the disabled person or by their employer or use of an agency), the numbers are too small to draw firm conclusions about their impact.

Conclusion

Workplaces in the UK and internationally are commonly ableist places, arranged in ways that at an institutional level marginalise disabled people. The lack of acknowledgement of the WPA role maintains rather than challenges the ableist organisation of the workplace. The relationships explored in this article highlight the importance of understanding the WPA role itself, together with the additional labour required from a person who uses a WPA to fulfil their job role and the dynamics of workplace personal assistance, with a WPA potentially moving between practical tasks, acting as a representative of the person they assist and holding collegiate aspects of the relationship. A lack of organisational recognition of the existence of a WPA, however benign in intention, leaves challenges of managing a WPA unacknowledged, which in turn serves to sustain ableist cultures and social relations. It follows that recognising that WPAs exist (or are likely to exist in the future) raises issues for disabled people and managers to address jointly at the wider organisational level.

Acknowledgements

The authors thank all the study participants and the project advisory group for their support with the research. They are also grateful to two anonymous reviewers for their constructive comments.

Funding Information

This article reports on independent research funded by the NIHR School for Social Care Research. The views expressed are those of the authors and not necessarily those of the NIHR, the National Institute for Health Research or the Department of Health and Social Care.

Competing Interests

The authors have no competing interests to declare.

References

- Angelelli, Claudia V. 2002. "Deconstructing the invisible interpreter: A critical study of the interpersonal role of the interpreter in a cross-cultural/linguistic communicative event." Paper presented at XVI World Congress of the Fédération Internationale des Traducteurs, Vancouver, August 3–10.
- Bonfils, Inge S., and Ole P. Askheim. 2014. "Empowerment and personal assistance – resistance, consumer choice, partnership or discipline?" *Scandinavian Journal of Disability Research* 16(1): 62–78. Accessed July 21, 2020. DOI: <https://doi.org/10.1080/15017419.2014.895414>
- Bruyère, Susanne M., William A. Erickson, and Sara VanLooy. 2004. "Comparative Study of Workplace Policy and Practices Contributing to Disability Nondiscrimination." *Rehabilitation Psychology* 49(1), 28–38. DOI: <https://doi.org/10.1037/0090-5550.49.1.28>
- Chouinard, V. 1997. "Making space for disabling differences: Challenging ableist geographies. Environment and Planning D." *Society and Space* 15: 379–387. DOI: <https://doi.org/10.1068/d150379>

- Christensen, Karen. 2012. "Towards sustainable hybrid relationships in cash-for-care systems." *Disability and Society* 27(3): 399–412. Accessed July 21, 2020. DOI: <https://doi.org/10.1080/09687599.2012.654990>
- David, Christina, and Raelene West. 2017. "NDIS Self-Management Approaches: Opportunities for choice and control or an Uber-style wild west?" *Australian Journal of Social Issues* 52(4): 331–346. Accessed July 21, 2020. DOI: <https://doi.org/10.1002/ajs4.23>
- Department for Work and Pensions (UK). 2020. "Access to Work." Accessed July 21, 2020. <https://www.gov.uk/access-to-work>.
- Dickinson, Julie, and Graham Turner. 2014. "One job too many? The challenges facing the workplace interpreter." In *Interpreting in a Changing Landscape: Selected Papers from Critical Link 6*, edited by Yvonne Fowler, Krzysztof Kredens and Christina Schäffner, 133–148. Amsterdam: John Benjamins Publishing Company. DOI: <https://doi.org/10.1075/btl.109.12dic>
- Dowler, Denetta, Tatiana Solovieva, and Richard Walls. 2011. "Personal assistance services in the workplace: A literature review." *Disability and Health Journal* 4(4): 201–8. Accessed July 21, 2020. DOI: <https://doi.org/10.1016/j.dhjo.2011.04.003>
- Equality Act. 2010*. London: The Stationery Office. Online. Accessed July 21 July, 2020. <https://www.legislation.gov.uk/ukpga/2010/15/contents>.
- Fevre, Ralph, Amanda Robinson, Duncan Lewis, and Trevor Jones. 2013. "The ill-treatment of employees with disabilities in British workplaces." *Work, Employment and Society* 27(2): 288–307. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0950017012460311>
- Flynn, Margaret. 2005. *Developing the Role of Personal Assistants*. London: Skills for Care.
- Fordyce, Mariela, and Sheila Riddell. 2015. "Employment experiences and outcomes of young people in Scotland who are deaf or hard of hearing: Intersections of deafness and social class." In *Disabled people, work and welfare: Is employment really the answer?*, edited by Chris Grover and Linda Piggott, 163–180. Bristol: Policy Press. DOI: <https://doi.org/10.1332/policypress/9781447318323.003.0009>
- Foster, Deborah. 2007. "Legal obligation or personal lottery? Employee experiences of disability and the negotiation of adjustments in the public sector workplace." *Work, Employment and Society* 21(1): 67–84. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0950017007073616>
- Foster, Deborah, and Victoria Wass. 2012. "Disability in the Labour Market: An Exploration of Concepts of the Ideal Worker and Organisational Fit that Disadvantage Employees with Impairments." *Sociology* 47(4): 705–721. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0038038512454245>
- Graham, Katie, and Jenni Brooks. 2018. "Taking on a personal assistant to support you at work: a guide for people with physical or sensory impairments." Accessed June 1 2021. <https://workplacepersonalassistant.org/wp-content/uploads/2018/10/Workplace-PA-booklet.pdf>.
- Grover, Chris, and Karen Soldatic. 2013. "Neoliberal restructuring, disabled people and social (in)security in Australia and Britain." *Scandinavian Journal of Disability Research* 15(3): 216–232. DOI: <https://doi.org/10.1080/15017419.2012.724446>
- Guldvik, Ingrid, Karen Christensen, and Monica Larsson. 2014. "Towards solidarity: Working relations in personal assistance." *Scandinavian Journal of Disability Research* 16(1): 48–61. Accessed July 21, 2020. DOI: <https://doi.org/10.1080/15017419.2014.897644>
- IFF Research. 2008. "Employment aspects and workforce implications of direct payment." Leeds: Skills for Care. Retrieved from Social Care Online <https://www.scie-socialcareonline.org.uk/employment-aspects-and-workforce-implications-of-direct-payment/r/a11G0000001831bIAA>.
- Jammaers, Eline, Patrizia Zanoni, and Stefan Hardonk. 2016. "Constructing positive identities in ableist workplaces: Disabled employees' discursive practices engaging with the discourse of lower productivity." *Human Relations* 69(6): 1365–1386. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0018726715612901>
- Keigher, Sharon M. 2007. "Consumer-direction in an 'Ownership Society': An Emerging Paradigm for Home and Community Care in the United States." In *Cash for care in developed welfare states*, edited by Claire Ungerson and Sue Yeandle, 166–186 Basingstoke: Palgrave Macmillan.
- Kelly, Christine. 2011. "Making 'care' accessible: Personal assistance for disabled people and the politics of language." *Critical Social Policy* 31(4): 1–21. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0261018311410529>
- Manthorpe, Jill, and Stephen Martineau. 2008. *Support workers: Their role and tasks: A scoping review*. London: King's College London. Accessed July 21, 2020. www.kcl.ac.uk/sspp/policy-institute/scwru/res/roles/support.aspx.
- Mik-Meyer, Nanna. 2016. "Disability and 'care': Managers, employees and colleagues with impairments negotiating the social order of disability." *Work, Employment and Society* 30(6): 984–999. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/0950017015617677>
- Norwegian Labour and Welfare Administration. 2021. "Functional assistance in working life." <https://www.nav.no/no/Bedrift/Hjelpemidler/Funksjonsassistanse>. Accessed 27th January 2021.
- Patrick, Ruth. 2011. "Disabling or Enabling: The Extension of Work-Related Conditionality to Disabled People." *Social Policy & Society* 10(3): 309–320. Accessed July 27, 2020. DOI: <https://doi.org/10.1017/S1474746411000042>

- Ritchie, Jane, Liz Spencer, and William Connor. 2007. "Carrying out qualitative analysis." In *Qualitative research practice: A guide for social science students and researchers*, edited by Jane Ritchie and Jane Lewis, 219–262. London: Sage.
- Roulstone, Alan, and Jannine Williams. 2014. "Being disabled, being a manager: 'Glass partitions' and conditional identities in the contemporary workplace." *Disability & Society* 29(1): 16–29. Accessed July 27, 2020. DOI: <https://doi.org/10.1080/09687599.2013.764280>
- Sacre, Liz. 2011. "Getting in, staying in and getting on in work. Disability employment support fit for the future." A review to Government. Department of Work and Pensions UK. Accessed July 21, 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/49779/sayce-report.pdf.
- Scharle, Ágota, and Máton Csillag. 2016. *Disability and Labour Market Integration*. Luxembourg: Publications Office of the European Union. Accessed July 21, 2020. DOI: <https://doi.org/10.2767/26386>
- Shakespeare, Tom, Andrea Stöckl, and Tom Porter. 2018. "Metaphors to work by: The meaning of personal assistance in England." *International Journal of Care and Caring* 2(2): 165–179 Accessed July 21, 2020. DOI: <https://doi.org/10.1332/239788218X15187915600658>
- Turner, Ed. 2003. "Using a personal assistant in the workplace." *Journal of Vocational Rehabilitation* 18(2): 81–85.
- Van Laer, Koen, Eline Jammaers, and Wendy Hoeven. 2020. "Disabling organizational spaces: Exploring the processes through which spatial environments disable employees with impairments." *Organization Online First* 1–18. Accessed July 21, 2020. DOI: <https://doi.org/10.1177/1350508419894698>
- Wilton, Robert D. 2008. "Workers with disabilities and the challenges of emotional labour." *Disability & Society* 23(4): 361–373. Accessed July 21, 2020. DOI: <https://doi.org/10.1080/09687590802038878>
- World Health Organisation. 2015. "WHO global disability action plan 2014–2021: Better health for all people with disability." Accessed July 21, 2020. https://apps.who.int/iris/bitstream/handle/10665/199544/9789241509619_eng.pdf
- Yamaki, Chikako Kimura, and Yoshihiko Yamazaki. 2004. "'Instruments', 'employees', 'companions', 'social assets': Understanding relationships between persons with disabilities and their assistants in Japan." *Disability & Society* 19(1): 31–46. Accessed July 21, 2020. DOI: <https://doi.org/10.1080/0968759032000155613>
- Young, Alys, Rosemary Oram, and Jemina Napier. 2019. "Hearing people perceiving deaf people through sign language interpreters at work: On the loss of self through interpreted communication." *Journal of Applied Communication Research* 47(1): 90–110. DOI: <https://doi.org/10.1080/00909882.2019.1574018>

How to cite this article: Graham, Katherine, Jenni Brooks, Jane Maddison and Yvonne Birks. (2021). Two Jobs in One Day: Exploring the Dynamics of Personal Assistance Relationships in the Workplace. *Scandinavian Journal of Disability Research*, 23(1), 147–157. DOI: <https://doi.org/10.16993/sjdr.761>

Submitted: 25 August 2020

Accepted: 11 March 2021

Published: 08 June 2021

Copyright: © 2021 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.



Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

OPEN ACCESS