



University of East Anglia research study

Personal Assistance Relationships

Power, ethics and emotions

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June 2017

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Report on ESRC Project ES/L007894/1.

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Introduction

Personal assistance (PA) refers to new ways of delivering personal support which were pioneered by the Independent Living (IL) movement from the 1970s onwards. Rather than care workers being supplied by the state, or by voluntary organizations, disabled people living in the community received direct payments to become employers of their own support staff. The IL pioneers rejected the word 'care' and wanted to separate tasks from emotions (Shakespeare 2014; Watson et al. 2004). For them, the PA model meant a cash service, controlled by the disabled person, in which workers performed the tasks which the disabled person could not do – self-care, domestic tasks, driving – with no need for emotions such as gratitude. In this way, disabled people could become socially independent and regain control of their lives (Morris 1993).

In Norfolk, where the current research project was based, Independent Living began in 1993, when the Independent Living Project (Norfolk) began supporting 60 employers to live independently paying their own assistants (Joseph Rowntree Foundation 1995). Today, several thousand disabled people receive direct payments to employ their own personal assistants in Norfolk.

The PA model later spread beyond the core constituency of adults with physical impairments to people with intellectual impairments and to children (Pearson et al. 2005). PA is now a mainstream option, not a radical alternative, for example with the roll-out of personal budgets (Duffy 2011). In England, an estimated 65,000 disabled people are directly employing 145,000 personal assistants in 2015 (Skills for Care 2016). Only 28% of those receiving Local Authority direct payments employ their own staff, making up about 9% of the adult social care jobs in England. In 2008, 49% of direct payment recipients employed their own staff, showing that there has been a transition to using agency and other staff, rather than direct employment. Several hundred disabled people have self-employed personal assistants supporting them and an unknown number are self-funding their personal assistance (Skills for Care 2016). Further afield, all the Nordic countries, Netherlands, Switzerland and other European countries, US, Canada and Australia are using the personal assistance approach, which indicates the international relevance of this study.

Aims and objectives of the research project

This study aimed to understand the relationships of power, ethics and emotions which underlie the PA model, by gathering and analysing qualitative data. The project will improve understandings of what makes a good PA relationship, and how it can go wrong, and will thus contribute to maximizing good employment relationships. Most importantly, the research addresses the key question of how disabled people can be empowered without disempowering workers.

Aim 1: To understand the diversity and complexity of the personal relationships involved in PA. This is particularly important now that PA has been mainstreamed, and it is not just the 'core' disability rights movement activists who use the service.

Objective one: to explore how PA differs from homecare and from informal care.

Objective two: to see how users/workers understand and describe the PA relationship themselves/to others.

Objective three: to explore the differences between IL philosophy and the practice of PA.

Aim 2: To explore the nature of the role of personal assistant and how it is experienced. *Objective one:* uncover why people want to work as personal assistants, what training they have had, and how this fits into their career plans.

Objective two: to explore the status of the PA worker and the potential tensions when one person's home is another person's workplace.

Objective three: to explore job satisfaction and emotional bonds between worker and employer.

Aim 3: To understand power dynamics in personal assistance relationships, and how conflict or other difficulties are negotiated/avoided.

Objective one: to uncover who is in control of the PA relationship, and the extent to which there is a risk of exploitation of either party.

Objective two: to map the typical patterns of duty, obligation, gratitude, respect and affection which flow between different PA users and workers.

Objective three: to look at how boundaries are maintained, and what happens when boundaries are crossed and PA workers become friends or even sexual partners of PA users.

Objective four: to explore how conflicts develop and how they are resolved.

Aim 4: To explore the potential contribution of psychosocial approaches to the study of caring relationships and in disability studies.

Objective one: to understand how we can research the role of support arrangements in contributing to or undermining self-esteem, and the role of psychosocial investments in the IL model of support.

Objective two: to investigate what approaches are fruitful in investigating support workers' motivations and investments in care work.

Objective three: to explore how interpretative approaches can be balanced with a commitment to making space for disabled voices.

As well as gratefully acknowledging the support of the Economic and Social Research Council, the team would like to acknowledge the support of the following individuals with this research project:

Bill Albert, Veronica Bion, Sue Bott, Stuart Bracking, Jane Campbell, Karen Christensen, Agnes Fletcher, Mel Halacre, Mark Harrison, Wendy Hollway, Tracey Jannaway, Nicola Jones, Eva Feder Kittay, Jenny Morris, Alicia McConnell, Ben Reed, Jackie Leach Scully, David Shenton, Sian Vasey, Nick Watson, Fiona Williams, Fiona Wright, Paul Wright.

Above all, we are grateful to the individual disabled people and personal assistants who shared their lives with us during the research.

Background

The experiences of disabled employers and PAs have been the subject of academic research for over a decade. This literature has begun to detail the ways in which personal assistance is experienced as a 'hybrid' form of relationship (Ungerson 1999; Christensen 2012) combining spheres of experience normally thought of as distinct and separate: professional and personal relationships; public and private domains; instrumental and emotional actions.

A core principle of personal assistance relationships, particularly in the UK, is that because they are based on a financial transaction, the role of emotions and power are minimised (Shakespeare 2014). Independent Living philosophy has played a key role in the development of personal assistance, and it continues to inform how personal assistance relationships, emotions, and power are understood. However, recent literature has begun to question whether the assistive relationships can ever be as pragmatic or professional as Independent Living philosophy would proclaim.

This literature review will present, critique and synthesis literature on personal assistance. Several key issues will be outlined, particularly discussions of power, ethics and emotions. The historical background of personal assistance will not be covered, neither will debates concerning personalisation or Independent Living (see Clevnert and Johansson 2007; Guldvik, Christensen and Larsson 2014; Morris 1993, 1997; Shakespeare 2014).

Personal assistance as blurred boundaries

Shakespeare (2014) argues that the actuality of personal assistance involves two characteristic features. First, support and assistance are always more complex than is portrayed by Independent Living philosophy; second, personal assistance *always* entails relational dynamics beyond simply the delivery of tasks. Indeed, a large body of literature confirms these claims and demonstrates that from being singularly professional or instrumental, personal assistance relationships involve the confluence of various roles and relationships (Ungerson 1999; Christensen 2012).

Personal assistance involves a dynamic blend of social and professional roles, with fluid relational and procedural boundaries. This complexity is said to involve the 'blurring of boundaries' (Guldvik, Christensen and Larsson, 2014; Williams, Ponting and Ford 2009). Here, boundaries refer to the social and professional rules or norms that guide behaviour and emotions through tacit obligations upon the self and concomitant expectations upon others. In the context of personal assistance, these norms include the way that disabled employers and PAs feel about one another, how and where they interact, and the type of tasks which are carried out.

Without any clear model, personal assistance relationships often resemble a blend of other roles, involving feelings and actions that cut across otherwise distinct social roles. Schelly's (2008) reflexive ethnography demonstrates how PA relationships develop over time through shared experiences and common interests. After 12 months of ethnographic study, Schelly reported in close detail just how his relationships with his disabled employer had evolved:

'What began as a pragmatically motivated job was inevitably and unexpectedly replaced by the lifestyle accompanied with being a live-in personal assistant. Indeed, SW's life quickly merged with my own so that our emotions were often reflective; days when he was happy were mirrored by my happiness. When I noticed that services provided by the state were a

source of frustration for SW I shared his frustration and gained a sense of pride about my role as a personal assistant' (Schelly 2008:728).

Other studies suggest that the nature of personal assistance work shapes the relationships that ensue between employers and workers. Work that requires intimacy, trust, and which occurs over a prolonged period of time is likely break down personal, social and professional barriers. Assistance work involves physical touch, shared activities, and prolonged periods of time spent with another person; further the workplace of one party is the home space of the other (Ungerson 1999; Glendenning et al. 2000). For Woodin (2006) personal assistance work – involving physical proximity, intimate assistance, and tasks requiring trust – will often result relationships that resemble friendships. Yet whilst PA relationships involve characteristics features of friendship (such as emotional attachment and shared interests) they also retain fundamental qualities of the employer-employee relationship. Accordingly, Woodin (2006) terms the PA relationship 'paid friendship'.

In hybrid relationships such as 'paid friends' it can be difficult to know how to feel or act towards the other person. Every PA participant in Ungerson's (1999) study described the relationship as that of employer-employee, but other relational constructs (such as friendship) were also important. This picture is complicated yet further where disabled employers hire existing friends or neighbours; a situation which may result in rewarding relationships, but can equally be emotionally fraught and painful. PAs often lack clear job descriptions, specified working hours, or clearly defined entitlements. Indeed, PAs often do not recognise their duties as 'work', per se, because of the close connection they feel towards their employer, and because many of their tasks are social in nature. Glendenning et al. (2000) report that PAs are often face confusion over their duties and their feelings towards their employers. In Sweden, Ahlström and Wadensten (2010) report that PAs express solidarity towards their employers; yet with this solidarity comes uncertainty:

'[T]here was no clear differentiation between the professional, instrumental tasks and what could be considered social interaction. The interviewees also felt a lack of differentiation between their own professional arena and the private arena of the disabled person' (Ahlström and Wadensten 2010:185).

As these observations suggest, the 'blurring of boundaries' is a complex process, connected to the meaning of relationships, their emotional entailments, and appropriateness of feelings and actions therein.

Boundary work

Boundaries act as the mould into which we pour our behaviours, tacitly guiding our feelings, gestures, and actions in ways deemed appropriate to particular relationships. Yet unlike physical boundaries, relationship boundaries involve issues of power, influence and control (Austin et al. 2006). Boundaries are double edged, they help us to understand what feels right, but their transgression may result in criticism or censure, and prompt feelings of shame, anger, even disgust.

Ungerson (1999) describes numerous examples of 'boundary maintenance' in the PA relationship where relational and procedural boundaries are considered, negotiated, and practiced in ways which affirm or reshape the relationships. For instance, PAs described their attempts to understand the timing and meaningful physical touch (such as a 'friendly' kiss), or working out who should be present during personal care. Boundary maintenance involves attempts to define what is acceptable so that transgression does not occur; as Ungerson states 'the intimacy of paid care relationships is...

not so great that it allows for the total breakdown of barriers' (Ungerson 1999:597). In a similar fashion, Ahlström and Wadensten (2010) talk of PAs 'handling the relationship'. The authors describe this kind of boundary work as setting limits between private and professional spheres; striving for equilibrium of closeness and distance; and establishing the borderline between friendship and professional relationship. In Japan, Yamaki and Yamazaki (2004) found that disabled employers actively work to build mutually supportive relationships. The authors describe this work as everyday gestures and verbal expressions intended to make PAs feel comfortable, and creating opportunities to have fun with PAs – sharing social occasions, holidays, and hobbies. However, all participants in this study also expressed a desire to 'keep their relationships in check', as well as voicing concerns about 'overfamiliar' relationships (Yamaki and Yamazaki 2004; 39).

Others have emphasised the role of discursive interactions in shaping assistance relationships (Williams et al. 2009; Williams, Ponting, Ford and Rudge 2009b). Williams et al. (2009b) report that disabled employers with learning disabilities prefer relaxed and friendly dealings with their PAs. Yet personal assistance continues to involve 'shifting tensions between the professional and personal identities of both participants' (Williams et al. 2009:621). Discursive exchanges are central to what the authors term the 'work' of 'doing ordinary'. Exchanges between disabled employers and PAs involve references to shared knowledge, joint experiences, and personal information – all of which helps to build less institutional, more equitable, relationships that retain basic features of the employer-employee relationship. O'Brien (2013) depicts similar relationship work, and claims that PAs often develop what is termed a 'wider zone of indifference', meaning they 'gracefully avoid some things that might be acceptable or at least tolerable in other adult relationships' (O'Brien 2013:196). Accordingly, good PAs are those who;

'actively support a person's pursuit of interests they may not share, look for ways to discover and honour a person's preferences even when that calls on them to change, implement accommodations that may be demanding; and sometimes absorb or forgive a level of mistreatment that they would not usually tolerate from another person' (O'Brien 2013:197).

Such relationship work requires resilience and the capacity to prioritise the preferences of others over one's own. Just as in Woodin's (2006) analytic category of 'paid friendship', whilst assistance relationships resemble friendships, they should not be mistaken friendships alone.

Less formal relationships may be beneficial and desirable for a number of reasons. Relationships involving emotional attachment are more likely to encourage sensitivity towards the other person's emotions and close communication, whilst some employers say that they actively seek PAs who demonstrate compassion or the potential for friendship (Matsuda et al. 2005). PAs may find their work more satisfying when they feel a bond of friendship with their employer (Matsuda et al. 2005:70). Less formal relationships result in everyday tasks being less regimented, and the work of a PA will often include activities unheard of in other caring roles: holidaying with their employer; overlapping social networks; taking one's children to work; completing one's own personal tasks whilst on 'work time' (Leece 2010; Leece and Peace 2010). These factors lead Leece (2010) to argue that PAs find satisfaction in their work, despite the challenges of insecure employment, low wages, and poor terms of employment.

However, friendship is no panacea, and several authors illustrate the negative consequences of closer relationships. Informal PA relationships may allow PAs to act unprofessionally or fail to

prioritise the needs of their employers (Ahlström and Wadensten 2010). When emotionally close PA relationships come to an end, this may be difficult to come to terms with (Woodin 2006). PAs may find it difficult to work in relationships and environments where guidelines concerning feelings and actions remain ambiguous. Indeed, moral and emotional dilemmas may be commonplace as PAs seek to define the personal and professional parameters of PA relationships (Ahlström and Wadensten 2011). For some, this interweaving of personal and professional spheres can be profoundly difficult (Glendenning et al. 2000).

Power and personal assistance relationships

Power (and related themes of empowerment, self-determination and control) is a central ideological impetus behind personal assistance (Clevnert and Johansson 2007; Guldvik, Christensen and Larsson 2014; Morris 1993, 1997). Personal assistance is a vital tool of independent living, but empowering disabled people to take control over their own support arrangements also has practical benefits. Where disabled people are able to employ their own staff, they are more likely to recruit someone whose personality matches their own. Further, being able to recruit, train, and decide terms of employment may raise the status of disabled employers in the eyes of their workers (Glendenning et al. 2000). Power is fundamental to understanding direct employment relationships and is expressed in several ways: the ability to choose workers and shape the relationship; the power to determine the boundaries of the relationship; being able to 'set the agenda' within the relationship; controlling terms of employment; and the power to make one's interests take precedence (Leece 2010).

The home is also likely to play role in shaping power relationships. Writing about homecare, Twigg (1999, 2000) has shown that the home acts as a power base for disabled people, containing as it does 'both ideological and material resources that can underpin their independence and power of determination' (Twigg 1999:391). The home's association with an ethic of privacy, the power to exclude, and embodied identity enables disabled people to resist professional domination (Twigg 1999). Those who enter the home have the status of a 'guest', and must adjust their dispositions and actions accordingly. Being a guest means having to ask permission to do certain things, as well as observing norms around the inhabitant's private space. Writing from a socio-geographical perspective, Milligan (2003) argues that the home empowers those who rely on support through material resources, through its ideological associations, and by affirming one's attachment to place. The home serves as a point of emotional anchorage, reinforcing ones connection with past identity and relationships (Milligan 2003). These factors establish the home as a site of 'ontological security' that helps those in receipt of assistance feel physically safer, whilst also reinforcing their sense of self. However, the meaning of the home may be subverted, particularly where the apparatuses of care proliferate. Milligan (2003) cautions against the 'dis-location from home space' whereby;

'the home-space becomes a place of work as living rooms take on features of the hospital ward and health professionals and care-workers move in and out, governed by time constraints and a lack of shared identity (thus understanding) with the cared-for' (Milligan 2003: 462).

Similarly, Hall et al. (2011) claims that that care introduces new people, techniques and financial arrangements into the home-space, the result of which may be 'a new "vulnerable" space weighted with complex and embodied familial relations and meanings' (Hall et al 2011:592). Under such conditions, the home may come to resemble a 'new institutional form', with the meaning of home redefined according to an ideology of care.

Research has also begun to highlight unequal relationships between disabled employers and their PAs. Christensen (2012) argues that the UK model of personal assistance gives rise to two types of relationship; a master-servant style relationship, or relationships based upon solidarity. In master-servant style relationships, traditional hierarchies of care are challenged, only to be replaced relationships 'where the master (user) has unlimited power to get things done in the way she/he wants to' (Christensen 2012: 405). In these circumstances, PAs are clearly vulnerable to abuses of power – being disrespected, subject to verbal abuse, or having their terms of employment disregarded. In contrast Leece (2006) claims that PAs are *less* likely to feel like 'servants' than homecare workers. Christensen (2012) adds that certain PAs are more likely to experience unequal relationships than others, with migrant workers, workers who lack educational and professional qualifications, and those lacking social networks and language skills being at particular risk. Similar concerns about the vulnerability of low-paid, transient and migrant workforce have been voiced by Ungerson (1997), whilst in Norway, Falch (2010) also points to the role of wider social forces in shaping relational dynamics and posits that a PA's wider status often determines whether or not they are subordinate to their employer. Ahlström and Wadensten (2010) describe the PA relationship as one of 'incomplete mutuality' and claim that PAs often feel as though they are little more than the 'tool' of their disabled employers. In another study, the same authors report that some PAs struggle with feelings of subordination (Ahlström and Wadensten 2012). This is perhaps understandable, given that many PAs have little control over their working environment or practices. Further, where PA relationships develop into friendships, PAs may find it difficult to leave work on time, or feel an implicit obligation to work outside their paid hours (Ahlström and Wadensten 2012). In a Nordic review of personal assistance literature, Guldvik, Christensen and Larsson (2014) caution that existing models of personal assistance may be at odds with the principle of co-determination; echoing earlier studies, the authors point to the role of labour market forces in shaping unequal relationships and precarious employment.

Emotions and personal assistance

The separation of tasks from emotion is a fundamental precept of personal assistance (Shakespeare 2013). Yet as outlined above, PA relationships often resemble friendships, even family-like bonds. Such relationships clearly involve greater emotional attachment than would be expected in most employer-employee relationships. Indeed, research has shown that disabled employers and PAs are often more satisfied in relationships involving mutual attachment (Matsuda et al. 2005); whilst close relationships also hold instrumental benefits for those involved (Leece 2006). However, this picture is complicated by the connections between emotions and power. Ungerson (1999) warns that where the PA relationships involve friendship, emotional pain is more likely: 'once feelings of affection arise, then the consequences of crossing boundaries can range from the minor pain of social embarrassment to the personal risk of a broken heart' (Ungerson 1999:597). Further, when close relationships come to an end this may be emotionally damaging for both employers and workers (Woodin 2006).

Personal assistance involves emotional work – a term coined by Hochschild (1979, 1983) in reference to the work involved in managing feelings and emotions according to workplace conventions. *Cognitive* emotion work involves 'the attempt to change images, ideas, or thoughts in the service of changing the feelings associated with them' (Hochschild 1979: 562); *bodily* emotion work involves 'the attempt to change somatic or other physical symptoms of emotion (e.g., trying to breathe slower, trying not to shake)' (Hochschild 1979: 562); whilst *expressive* emotion work involves 'trying

to change expressive gestures in the service of changing inner feeling (e.g., trying to smile, or to cry)' (Hochschild 1979: 562). Ahlström and Wadensten (2010) report that PAs routinely undertake this kind of emotion work –repressing feelings such as fear and anger – and many find this to be the most difficult aspect of their work. Falch (2010) also outlines emotional work of PAs, and reports female PAs who described 'wearing a mask' at work, whilst male PAs spoke about 'leaving themselves at home and becoming a different person' (Falch 2010:135). This kind of emotion work requires significant time and energy and can be onerous, particularly the 'spill-over effects' –mental fatigue and strained social relationships outside of work (Falch 2010). What is less clear is whether or not personal assistance involves more or less emotion work than other caring professions. Some have argued that PAs lack peer support common to other professions (Christensen 2012; Glendenning et al. 2000), whilst others suggest that the informal 'friendly' PA relationships enable workers to discuss their personal worries with employers (Leece 2006).

Ethics and personal assistance

Few studies consider the ethical dimensions of personal assistance directly; however, much that has been written about personal assistance concerns how employers and PAs ought to feel and behave towards one another. These are implicitly ethical concerns. Romer and Walker (2013) contrast personal assistance with other care roles (such as domiciliary or medical roles), arguing that the latter stress professional rules about to *what not to do*:

'do not be a friend, friends are not paid; maintain a professional distance; keep strict boundaries between work and your personal life; do not invite people being supported into your circles of relationship; do not become involved in the family life of the person you are supporting; be present only on your work shift; and leave promptly when your shift is over' (Romer and Walker 2013:188).

In contrast, personal assistance routinely requires employers and PAs to confront and transgress these boundaries. Much that is considered 'boundary work' might also be considered ethical work. As Ahlström and Wadensten (2010) point out, boundary work concerns the everyday moral dilemmas faced by employers and workers.

PA work may also involve explicit ethical dimensions, particularly where tasks are of questionable moral status. Earle's (1999) study of sexual facilitation revealed the moral complexities involved in this kind of work. Several PAs in this study refused to engage in sexual facilitation, citing the 'morally reprehensible' nature of sexuality, concerns over privacy, and personal sexual preference. Similar issues have been considered by Bahner (2013), who reports that PAs make ethical decisions based upon personal moral standpoints rather received ethical frameworks.

Ethical decisions may also impinge upon the autonomy of disabled employers, particularly where PAs assume control and act in the 'best interests' of their employer. Nearly half of the PAs interviewed in Clark, Hagglund and Stout's (2004) study said that they had to 'ignore what the consumer wants for his or her own good' (Clark, Hagglund and Stout 2004:176). The authors of this study highlight competing ethical frameworks at play in these narratives:

'conflict between the ethical models of beneficence and autonomy in health care... There is little consensus about which model assistants should emphasize in their work with consumers, though most consumer-driven PAS models emphasize the autonomy model (Clark, Hagglund and Stout 2004:178)'.

Ethical issues become yet more complex where assistive relationships involve close emotional attachment. Where PA relationships develop, subtle shifts in power will likely occur. In close personal relationships, the ethical actions of one person – ‘doing the right thing’ – may result in the exploitation of self or other. Disabled employers may feel a sense of obligation towards their workers (Glendenning et al. 2000; Ungerson 1999), whilst PAs may find it difficult to refuse unpaid work or terminate long-standing roles (Leece 2010).

Findings

In titling the project 'power, ethics and emotions' we made a working assumption, based on our knowledge of the literature. As social scientists, it was our expectation that the lived experience and social practice of personal assistance was likely to involve a dynamic interplay of emotions ethics and power. Throughout our data collection it rapidly became evident that our assumption was justified, and although these terms were not necessarily explicit in the data, much of the discussion did revolve around these concepts.

Restoring power to the disabled person was the explicit goal of the personal assistance innovation. As Dave Morris says: 'I have always believed that living is about independence, control, spontaneity, personal development, responsibility' (Vasey 2000). Rather than being dependent on family, friends, council staff or a voluntary organisation, disabled people would be given the money to employ support workers, thus becoming empowered. The disabled person who can employ his or her personal assistant can take control of life and dictate exactly when, how and who support is provided – with no need for gratitude or dependence. This is why power relations are central to personal assistance (Leece 2010).

It's slightly less obvious that ethics are involved. However, intimate care from doctors and nurses is certainly governed by ethical codes, and the assumption is that care workers of all kinds should also consider ethics (Banks 2008). Disabled people themselves encounter ethical issues as employers – how to recruit, manage and sometimes fire their workers, who are often migrants, women or otherwise socially disadvantaged – another reason why power is relevant. More deeply, the feminist ethic of care offers an alternative way of thinking about personal assistance to the dominant independent living narrative (Tronto 1993).

Emotions arise because the connections between the disabled person and his or her personal assistant(s) are often long-term, intimate working relationships. Moreover, some disabled people, but not all, are isolated and have difficulties in their lives. Not surprisingly, some turn to their personal assistant to vent these feelings:

'So, which is also part of a PA's job I think, in being there psychologically, that you can talk to them about what's worrying you and things like that. Not the deep stuff, but it could just be something to do with the illness that you want to unload' (#103).

This respondent stated that she would do the same, if her assistant needed to 'unload'. Alternatively, more positive emotions can develop through closeness, but this can be equally risky, as in the young man who found he had fallen in love with his personal assistant, who then left the job to return to her home country. So emotions such as gratitude, affection, concern, resentment, frustration can play their part in the personal assistance relationship.

Personal assistance can only be understood by thinking psychologically and ethically, as well as in terms of sociological concepts such as meanings, roles, boundaries and power. Our presentation of findings will first consider the metaphors that disabled people and personal assistants draw on; the issue of maintaining boundaries; and finally the problem of conflict. Throughout, we will try to consider social, psychological and ethical dimensions at all times.

Metaphors to work by

Data confirms that there is no one kind of personal assistance relationship. Disability is very diverse, and we found that different disabled people had different ways of approaching employment and management of their workers. This reflects personality characteristics, and what life goals the individual was employing a personal assistant to enable them to achieve. There was a particular difference between those people who had been active in the disability rights community, and those people who were coming to personal assistance from other forms of social care, but without an ideological commitment to independent living. There were also differences between people who employed personal assistants to support their disabled children, and those who employed assistants directly on their own behalf.

Differences also reflected known differences in the backgrounds and motivations of personal assistants, who were themselves very diverse. Some people came to personal assistance with training in social care or other sectors, and so had various preconceptions of their own. Others were new to social care. Some people were looking for convenient, flexible work, and others were looking for a meaningful long term career. All of these personal characteristics influence the personal assistance relationship.

In thinking about these different kinds of personal assistance relationship, we initially considered that we could develop a classification of 'ideal types' of relationship. This could also be conceptualised in terms of 'models'. But this suggests an intentionality and complexity to people's thinking which appears lacking. We also thought we could talk in terms of competing discourses of personal assistance. Yet, partly because there was a lack of consistency and coherence in the way that people talked, we came to think in terms of metaphors.

Lakoff and Johnson (1980) have described the ways in which metaphors our everyday lives and our everyday functioning, down to the most mundane of details:

'Our ordinary conceptual system, in terms of which we both think and act, is fundamentally metaphorical in nature' (Lakoff and Johnson 1980:3).

Metaphors both highlight and hide aspects of our experience. We are not always aware that we are using them, and they reflect the society and culture we live in. Because we create metaphors from thinking patterns that are already familiar to us, they allow us to deal with situations that are new to us, they allow us to communicate situations that are new to others. We simply use the 'as if' character of a metaphor to integrate new experiences into our already existing cognitive system. Yet, importantly, metaphors have entailments. When we describe our reality in a particular way, then the words and phrases we use come with a cultural baggage.

As established, personal assistant is a new role and generates a new relationship. In academia, we might use technical descriptions such as 'commodified support relationship', but these are not necessarily meaningful to people in their lives, let alone easy to incorporate into everyday discourse. Importantly, the phrase 'personal assistant' is itself a metaphor, drawn from the business world of a professional assistant who supports an executive or celebrity. We lack an established social and cultural understanding of the nature and meaning of personal assistance. So it is not surprising that people reach for metaphors to clarify these roles and situations.

Extension of self

One set of metaphors clustered around the idea of the personal assistant as compensating for what the disabled person physically could not do for themselves. So one person said:

‘I will always say “you are an extension of my hands, you have to do what I can’t do”... I can’t open packets, I can’t open the fridge or freezer, and that’s what she’s there for’ (#116).

Others also used this notion of extension as a compromise, something that appeared neutral:

‘I would tend not to use the phrase “friend”, I guess I don’t like “servant” either, really... “extension” I would say’ (#127).

Nobody in our study used the phrase ‘robot’ which is sometimes found in the personal assistance literature. But as expressed by respondent #129, there was a tendency to highlight the basic character of assistance:

‘I need physical help at some times, there’s no negotiation on that, you know, I have to get to bed, I need someone to lift and get me out, how else can you describe that? It’s just, it’s physical, mechanical thing you know...’ (#129).

Perhaps reflecting this utilitarian emphasis, and drawing on explicit disability rights movement thinking, another disabled person said:

‘I would describe them as a “worker” and “arms and legs”’ (#136).

However, this latter approach was felt to be alienating by one respondent:

‘He’s a human being, he needs to be treated respectfully, etc. I can’t see him being my arms and legs, in that sense’ (#132).

This respondent is picking up on the implication in this usage that the personal assistant has no agency or personhood of their own, but must always simply execute the given orders. This may suit some personalities, but many individuals may feel alienated and end up giving perfunctory service, because they do not feel fully respected.

Staff

Other people used the term ‘staff’ and cognate terms such as ‘servant’, so for example respondent #207 said:

‘I quite like to see myself as a servant really. I don’t feel at all uncomfortable with that term. I am a worker or a servant, but a friendly one’.

One mother, who employed a number of personal assistants to support her two children with disabilities, talked throughout her interview in terms of staff, referring to staff meetings, and seeing herself as manager of a team of staff.

Terms like staff and servant, in the British context, could be interpreted either as connecting to a local authority or private care home context, as with the mother mentioned, or as relating to the *Upstairs, Downstairs* or *Downton Abbey* stereotype of wealthy elites with their subordinates. The entailments here are that the worker is seen but not heard; not participant in conversations; leading a separate existence to the disabled person.

Another personal assistant, who himself had had some training in the social work field in his own native country, resented that he was now being treated as a simple employee:

‘I didn’t realise from the beginning, because of my little knowledge of English...and then with time I noticed that sometimes she was treating me like a servant – ‘you haven’t done this’... If you want me to be a servant, I can be a servant and only do things that you want me to do, and nothing more...’ (#223)

In other words, there is a risk that when someone is treated as a servant, they will act like a servant, keeping distance and potentially ending up alienated and discouraged.

Colleague

The colleague metaphor is potentially more mutual, and more empowering for the employee. The implication of the metaphor is that people are convivial and equal, but that the private realm remains somewhat separate. People may socialise occasionally, but they would not share emotional confidences. They are friendly in the work context, but not more. So respondent #136 said:

‘They are friends in the same way a work colleague might be a friend. We can be on friendly terms with each other, I believe this helps the relationship, but they are doing a job and both parties shouldn’t forget this’.

However, not everyone found this a useful approach. A personal assistant respondent disagreed with the colleague analogy:

‘it’s different from professional relationships because you are in the person’s house and into their lives completely. It’s not as if you are relating to your colleague at work or your boss at work, you are part of their daily routine and you get to know their most personal needs.’ (#206)

Professional

When people, particularly personal assistants, resorted to the metaphor of professionalism, it seemed to be about asserting separateness. This was a job, and it was not personal. There were clear boundaries – to behaviour, to intimacy, to the working day – and these should not be violated. The professionalism metaphor was also about the implication of a code of conduct, a quality of

service in which people could take pride. So for example, this respondent also said of one disabled employer:

'I felt that he was feeling things towards me that I was not... I was living more a professional kind of relationship..., So when it got so personal, I realised that I had to tell him...' (#206).

Paid friends

Many people spontaneously came up with the concept of 'paid friends'. This was sometimes because the disabled person had literally recruited a friend to support them. For example, respondent #103 said:

'we'd been friends for twenty years as being neighbours and became very friendly and she knew my MS and knew I needed help occasionally... So I thought, well, if she's doing things for me already, why can't I pay her' (#103).

The same woman thought of it in terms of 'doing a favour for a friend even though they're being paid for it'. The added advantage, according to respondent #133, was 'I found it easier to talk to somebody that I knew as well'.

Alternatively, a stranger had come to work for them, and over time had turned into a friend, as respondent #103 says:

'I employed people who became friends and still are friends' (#103).

Sometimes, disabled people were explicit about wanting a friend as much as a worker:

'I just very much wanted someone who would be my friend really and take me out and do nice things... So with L, because I am paying her to be my friend – sounds awful – but I say what I would like to do and she fits in with me, as opposed to the other way round. [...] she is my friend but she's not my friend' (#119).

This way of thinking about paid friends seems reminiscent of the wealthy lady's companion in the pre-war period.

Personal assistants sometimes found that this made the job more satisfying than usual care work:

'She would ask me to do a job, then we would have a coffee or a chat... so it split up the time a bit more, and it invigorated that, having someone to talk to like you would in a normal job- that's what made it enjoyable' (#208).

The implications of a 'paid friend' are that the transaction is not solely a commercial arrangement, that there is a relationship based on trust and emotional connection. But 'paid friend' is obviously an ambiguous concept which people sometimes struggled to define:

'perhaps I should say more 'friendly-like', but it does feel that we have got more of a friendship basis...obviously we're not friends like I am with other friends...' (#205).

Some disabled people warned against the assumption that the relationship would become a friendship:

'I've got friends already. I see my friends, so why do they have to be friends? There's an element of friendship there, but it's not social, you don't have to like someone to do a good job, although it helps' (#106).

This relates to the disability rights origins of the personal assistance relationship, which was very much based on separating tasks from emotions, and keeping boundaries between the private and the public. A similar thought was voiced by a personal assistant:

'I give my time and I try to the best as I can to give you a good service, but I am getting money, so it's not like a friendship, it's very different' (#201).

Moreover, there could be risks and costs consequent on the emotional connection associated with friendship:

'when you are invested personally, you can easily get hurt' (#206).

Family

Some disabled people went beyond the notion of friendship, to draw on metaphors of relatedness. So one disabled woman had different personal assistants for each day of the week, who she tended to see like surrogate daughters:

'I just get really mother hen in my old age... it's like I see them all as naughty children, it's quite interesting... They are all female, they're all young women a long way from home because they're Eastern Europeans or whatever, and I admire them greatly' (#111).

Another disabled woman talks about the complexity of the relationship:

'She is part of the household, really, because my daughters all love her... I would say it is almost like a family friend – not quite a personal friend.... It's like a forced relationship through what you need...it is a very unusual relationship, it is not a mother-child, it's not a parenting, but it has got all those elements' (#120).

Family type relationships seem to depend on the age of the participants. For example, this personal assistant was a similar age to the young woman she had supported for several years. She felt she would be involved in this disabled woman's life in years to come:

'I know her so much more than anyone could, because of our relationship. It's more than that, because people can know each other when they're best friends, but with her, it's more, a connection that other people don't know that stuff. Like, maybe a sister' (#211).

The implication of the family metaphor is that tasks are performed either out of love and/or a sense of duty. The exchange is not solely financial. Family relationships offer rewards of deep trust and shared emotional confidence. But they leave both parties vulnerable, for example if they end because of the departure of one party, or if they break down.

Implications of metaphors

We have found that metaphors were often used when we asked disabled people and personal assistants to talk about roles. Our data echoes the findings of the Japanese study of Yamaki and Yamazaki (2004), which found that assistants were characterized as ‘instruments’ (functional); ‘employees’, ‘companions’ and also ‘social assets’. In other words, there is no one model for personal assistance. Moreover, everyone is different, and each relationship is unique. Personal assistance is multi-faceted: a disabled person may have different relationships with different personal assistants. Personal assistants too have different expectations and may prefer different ways of relating:

‘When it comes to being a PA, it depends a lot on variables such as chemistry with the person, boundaries, experience on the part of the user and the PA’ (#206).

The ‘paid friendship’ idea, which is found in the work of Woodin (2006) and Christensen (2012) is paradoxical, but still helpful. Friendship does not involve financial exchange. But it does entail reciprocity when it comes to help. Friendship normally involves a give and take, a balance. Disabled people often cannot reciprocate practical assistance that friends give them. This is why personal assistance, cash for care, is such an important and empowering solution, creating reciprocity and removing the potential for dependency. But friends are also emotionally reciprocal – they care about each other equally – which of course disabled people are very capable of doing with their personal assistants.

In general, we found that disabled people stressed friendship with their assistants, while personal assistants were more likely to talk in terms of friendliness. We interpret this as signalling that workers want to preserve their own privacy and autonomy. Friendship has benefits, but also carries risks, because personal assistants may leave the employer and go on to other jobs, which may mean the end of the friendship:

‘Sometimes it’s sad to let go, not let go but... to realise that no one lasts forever and everyone has got their own lives to lead and you can’t stick to the same person all the time’ (#101).

We found examples of each of the different PA metaphors running smoothly as inter-personal relationship, so we cannot recommend one approach. However, we felt from our data as if the simple staff or extension metaphor carried with it potential risks for some personal assistants, who might feel alienated or even exploited. Conversely, the family metaphor entailed risks for both parties because it could be intense and emotionally fraught. Neither of these options appeared to us as sustainable as the other alternative metaphors.

In particular, problems in PA relationships may arise if there is a lack of clarity. If people are unclear about the metaphor they are thinking in terms of, or the roles they are expecting each other to fulfil, confusion or tension may result. Conflict can emerge from crossing boundaries, which may be implicit and hidden. Both parties in the PA relationship, we suggest, need to be clear about their

expectations. Of course, relationships can and do change. For example, friendship may grow between strangers. So the metaphors and roles are not static:

‘Disabled people and their attendants are left to grapple with the nature of their relationship privately, away from public conversations about personal assistance’ (Kelly 2011:5).

We conclude, along with Yamaki and Yamazaki (2004), that there is a need for training and support for disabled people, as well as for personal assistants, to ensure that the relationship goes smoothly.

Boundaries

The ‘nature of the job’ and advantages of informality

Many disabled informants said that formal PA relationships were neither possible nor desirable, as the PA work fostered informality and emotional attachment. Informant #103 said that it was ‘the nature of the job’ for personal assistance to involve friendship, adding that intimate tasks, and the trust needed to complete these tasks, precipitated informality:

‘they’re doing quite personal things like showering you. They’ve got to be people you trust intimately and people that you know, very, very well, and because of that you’ve got that relationship going... I don’t differentiate between the friendship side of it and the work side of it. The two go together as far as I’m concerned’.

Informant #121 explained relying upon other people for help involved disclosing personal information to her PAs: ‘I literally can’t do things, and you have to tell them things because that’s what happens to your body’. This disclosure of personal information meant that for this informant, the distinction between personal and professional realms felt artificial and unrealistic; ‘people know things about me that they wouldn’t know in any other circumstance’. Similar sentiments were expressed by informant #130, who stated in clear terms that PAs become ‘involved in every aspect of your life’, and that there was ‘no privacy from them whatsoever’.

Other factors conducive to close relationships were working towards shared goals – the independence of the employer – and spending long periods of time together. Informant #107 said it was ‘natural’ to become close to PAs, adding that ‘you’re always going to become some kind of friend ... because you’re working so closely... you’re spending up to 72 hours in each other pockets’. PA informant #216 said ‘if you are with somebody so much, it is very easy to drift into friendship’, whilst another PA, #206, said ‘you’re there with them twelve hours a day’. This informant also spoke about the significance of the home space, saying that working relationships felt more relaxed and less formal; ‘It’s not as if you are relating to your colleague at work or your boss at work, you are part of their daily routine and you get to know their most personal needs... you are in the person’s house and into their lives completely’.

Many informants said that closer PA relationships held instrumental benefits, as friendly PAs were more likely to go ‘over and above’ their stated duties. Informant #103 felt regarded her PAs close friends, and illustrated this by their willingness to help without being paid;

‘This is where the friendship comes in, because she’s a friend and she wants to do something for me and she wants to help me and being friends they want to help you. Not being told to do something because they’re working for me, but because they’re friends, you want to help a friend’.

Disabled informants also said that informal relationships felt more relaxed, easier to manage and were less disruptive to their home space. Informant #110 said that maintaining formal relationships with PAs was impractical; ‘I’m a human being and I can’t act like I am an employer all the time’. This informant suggested that informal relationships were key managing the stresses of being an employer; ‘you have to de-formalise somehow, otherwise you would go bonkers!’, adding ‘at the end of the day, I can’t live in a school atmosphere. This is my house, I have to be able to relax in my own home’. Informant #135, who manages PAs on behalf of her son, suggested that informality and rapport were key to sustainable PA relationships; ‘you can’t run it rigidly’ she said, ‘it just doesn’t work’. This informant explained that rigid working practices were ill suited to the unpredictable pattern of PA work; ‘the problem is when you’ve got personalities, and it’s human beings, it just doesn’t work’.

A small number of disabled informants drew connections between closer PA relationships and personal safety. Informant #110 said that knowing her PAs on a personal basis made her feel safer; ‘there is always that worry’ she said, ‘that you could have a complete weirdo, a lunatic’. This informant continued to explain how at the beginning of PA relationships, PAs would ‘only show you what they think you want to see’, and it was only by developing a closer relationships that she felt safe; ‘I do get to know quite a lot about the people’ she said, ‘but that’s the only way I feel happy. If I’m not happy, I don’t feel safe’.

In rare cases, informants described intensely close PA relationships marked by strong emotional connections. Informant #221 enjoyed one such relationship with the child she supported, and she described the intimacy they shared; ‘if she wants to take a nap in bed, I will snuggle up beside her and look after her’. This informant said that the child’s parents, her employers, also took a close interest in her life and wellbeing – something she valued;

‘From a selfish point of view, they appreciate me and are interested in what I’m doing and what me and XX (child) are doing and how we’re getting on’.

Here the personal and professional realms overlap, and the emotional connection is valued by this informant. Reflecting on this relationship, informant #221 said ‘we come along as a bit of a couple really [laughs], you don’t get one without the other’.

The risks of informality

Despite the benefits of informal relationships, nearly all informants spoke about problems they had encountered. Disabled informants’ concerns related both to practical problems and emotional entanglements, whilst PA informants spoke of ethico-legal dilemmas and the prospect of giving too much of themselves – both physically and emotionally – in closer PA relationships. These issues are outlined in the sections that follow.

Practical problems

Many disabled informants recounted experiences of unsatisfactory support within informal PA relationships and many stated a preference for formal relationships. Informant #110 had convivial dealings with her PAs, but said that she took care not to 'fall into the trap of being a bit easy on people'. This informant explained that when PAs became 'a little bit comfortable', their standards would slip; 'when they feel they've got their feet under the table... they don't do as much or do things correctly, they try to cut corners'. Similarly Informant #111 said she was wary of being 'too informal' with her PAs, and reasoned that 'at the end of the day the PA is there to be a PA... you don't want it to be forever'. This informant was clear that she prioritised professionalism over friendship; 'you want consistency, I don't want someone there forever because they run out of steam'.

Many disabled informants said it was more difficult to act assertively towards PAs within informal relationships. When asked whether it was important to be friends with a PA, informant #127 said 'it's important, but it's not the be all and end all'. This informant recognised the benefits of friendly working relationships, but cautioned 'there has to be boundaries' adding that friendship could easily lead to situations in which PAs could 'get away with stuff'. This informant said that PA relationships as a 'balancing act' between formality and informality, and said 'I'm not saying be rude to them, but you can't be their best mate either'. This informant also said that giving close instructions became 'awkward' within friendly PA relationships; 'you have to ask them to do things, but if they don't want to do it, or if they've done something wrong, you have to say to them "no I don't want it done like that"'. Similarly, informant #108 expressed unease at the prospect of acting authoritatively towards PAs; 'I am not a massive fan of confrontation'. This informant explained that whilst friendship made it difficult to discipline PAs, it also held implications for her independence. She described one relationship with a PA, whom she regarded as a friend, who tended to make decisions on her behalf; 'I sometimes find that really difficult because there is very limited lines between friend and carer, and the roles tend to merge a lot... which then does create problems... she will try and make decisions for me'.

Some informants had experience of employed existing friends of family members to become PAs, but most felt this was unfeasible. Informant #136 said 'it just didn't work', adding 'it's just not feasible... they take the piss'. As with other PA users, this informant suggested that informality and conviviality could easily lead PAs to lower their standards, whilst also making it more difficult to enact authority. This informant stated a clear preference employing strangers rather than friends, saying of strangers 'it's a lot easier to assert professional control over them'. Informant #107 said that clear role expectations were important for sustainable PA relationships, and contrasted other professional roles with friendship: 'you go to see your doctor, your doctor isn't going to be your PA; your teacher at school, they're not going to become your PA. I find that if a friend becomes your PA it makes it messy'. When asked what it meant for a PA relationship to become 'messy', participant #107 replied; 'It's hard to dismiss someone because you have an emotional attachment as well as the professional side. Also, you've got the fear of losing a friend'. Informant #121 recalled her first experience of employing PAs after being diagnosis with MS; 'I knew my sister-in-law did that sort of work, so I asked her if she'd do it... I needed somebody there and then'. After a short time, #121 became unhappy with the support provided by her sister-in-law and decided the PA relationship should end. However, their familial ties meant that ending the relationship was complicated; 'she had her problems... I had to get rid of her, which put my brother in a very awkward position... it was horrible, it was really horrible'. This informant described her subsequent decision to employ 'somebody completely separate' which, she said, 'was the best thing I ever did... much better than family, much better'. When asked why familial relationships made for poor PA relationships, #121 replied; 'because they're your family ... it didn't work at all, it made it terribly uncomfortable'.

In a small number of cases, PA users indicated that informality and friendship allowed unscrupulous PAs to take advantage of their employers. Informant #129 recalled one such occasion; ‘a couple of PA’s... they were American, they were making transatlantic phone calls... I got a phone bill, which was like £300.00!’. This informant said he had been unable to recover the costs incurred by these PAs, and that their actions left him feeling demeaned and disrespected;

‘I tried to make them pay me back, and they paid a little bit back, but that kind of casual disrespect of someone else’s money’. Reflecting on the actions of his PAs, this informant said ‘those kind of things are where the boundary is not really there’.

Emotional entanglements

Both disabled and PA informants spoke of close PA relationships involving emotional entanglements, and many told of anger, frustration and pain they had experienced whilst caring about the person they worked with. The clearest example of this was provided by informant #107, who had fallen in love with his PA. This informant described the circumstances which led to this deep attachment, and the resulting difficulties he had experienced after his affections were not reciprocated.

‘The relationship became a bit messy in terms of attachment. They weren’t clear boundaries, which neither of us set. There were times when it got very confusing for both parties. It ended mostly because the person was leaving, they were only in the country for six months’

This informant continued to describe the impact of this experience:

‘It was quite traumatic... there were tears, letters and emails, and trips to the airport. It was quite messy. Looking back on it now, I feel stupid, because I don’t know how it happened... but that’s the thing, when you’re in love with someone it’s just so weird, you just don’t think.

Despite this being a painful experience, informant #107 remained sanguine, saying ‘it made me realise how important it is to have boundaries and to understand the relationship between the PA and a PA user’. In summary, this informant said ‘I see it completely differently now. I employ female PAs and male PAs and there are no issues of that kind of attachment. You can have friends, but that’s it’.

A small number of disabled informants detailed the emotional work they undertook whilst supporting their PAs. Informant #110 said that she had previously ‘fell into being a little bit too caring’, meaning that her emotional investment in the lives of her PAs had become too onerous. This informant said that she had allowed her PAs to discuss their personal troubles and seek her advice, but they come to rely on her for emotional support; ‘I had people texting me all hours of the day and night, which was a bit ridiculous’. Now a more experienced employer, this informant said that she had learned to support her PAs whilst also ensuring this was on terms which suited her; ‘if you are aware that somebody might be struggling with whatever, you have to let people say something about it, [but] they have to know that they can’t do it all the time. You have to make space for them to do that’.

PA informants also reported widespread emotion work. In one clear example, informant #201 said; ‘you don’t really finish your shift and finish your work’. This informant said that she tried to separate her work and home life; ‘I finish my shift and I think “oh I won’t think about it”, but this was often impossible, ‘I go home and think ‘oh, she said this today’ – I wonder what she meant with that?’.

This informant appeared ambivalent about this emotion work, saying 'I like that and I don't like that', and suggested that this work involved professional benefits and personal costs;

'I like it because it makes me think of the way I can relate and communicate the next time, and to think if I did do a good job or not. So it's kind of evaluation time. And I don't like it because I think 'Okay my shift is finished, I have to do something for me now and not constantly for someone else''.

Other PAs indicated that emotional pain was more likely. Informant #213 spoke warmly about the 'lovely relationship' she shared with the older woman she supported, describing her as 'like a mum, she really is, she's lovely'. As she spoke about this relationship, this informant explained that her employer's health had deteriorated in recent months. When asked how she felt about this, #213 replied;

'It feels like it is my mum having a bad turn... I will feel awful when she dies, or if she has to go into a home. We talk about this, she definitely doesn't want to go into a home, and I will feel really bad, but I can put my other hat on and say 'this is what will happen', and it's not quite as bad then'.

Another PA informant, #222, recalled feeling 'injured' after being admonished by her employer. This informant detailed an argument between her employer and her employer's daughter, after which her employer scolded her for venturing an opinion on the daughter's behaviour – 'I spoke to XX my client the next morning, and explained how I felt about what had gone on...she turned to me and harshly said 'she doesn't need you parenting her''. This informant described her response, saying 'I felt really injured by that'. When asked why this was the case, #222 pointed to the close relationship she held with her employer; 'because I care passionately about how my client, because that matters to me, it so matters... therefore it is important to me'.

Ethico-legal considerations

Several PAs drew upon discourses of legal and professional ethics when making sense of complex dilemmas around boundaries. The logic of safeguarding was identified by a small number of PAs, particularly those with a background in formal care roles such as domiciliary care. These informants were more likely to maintain emotional distance and eschew other social aspects of PA relationships.

When asked whether it was possible to separate tasks from emotions, informant #207 said 'yes, definitely. They have to be'. This PA explained that emotional distance was vital for her to meet what she deemed to be her legal duties; 'I am bound by legislation that would require me to make a report to someone if I felt something wasn't right'. This informant, who had previously worked for a care agency said 'I can't get emotionally involved in the tasks, because then my objectivity would be clouded'. Similarly, informant #217, who had also worked as domiciliary carer, said that she would not complete tasks without having received formal training: 'there are certain things I won't do. I go to one lady and she needs a suppository for her medication, and I won't do that because I am not trained'. This PA explained that her standpoint had caused tensions with other PAs, who she felt were unprofessional in their conduct towards their employers; 'I think you can be seen as a bad person, but actually you are doing things by the book'. When asked why it was important to 'do things by the book', informant #217 replied; 'well something could become a safeguarding issue, and if there was an enquiry... it's about covering you back at the end of the day'.

PA informant #206 said that the 'finding' the boundary between 'personal and the professional' was the 'biggest challenge that I found'. This informant spoke in depth about one PA relationship, in which he had supported a young man who lived with his mother. He felt that the young man in question was constrained by his mother, who #206 said was controlling and overprotective. This informant experienced this as a dilemma, because he harboured aspirations on behalf of his employer;

'I felt he should somehow make himself heard with mother, that he was capable of things... I really wanted to help him in this fight, I felt that he was feeling the same things that I felt but he couldn't actually externalise them to the mother'.

At the same time, however, #206 explained that any intervention would be inappropriate; 'I realised that it wasn't my place to be doing this, it wasn't part of my job'. For informant #206, this decision was a question of professional ethics:

'it wasn't ethical to become the intruder in that situation. So I stepped back and I refrained from saying anything. But in me, in myself, I felt that difficulty in keeping my mouth shut and finding the balance'.

Summarised his emotional and moral ambivalence, informant #206 said this was a struggle between 'being genuine as a person' whilst also 'being professional in what you're doing'.

PAs 'giving too much'

Nearly all PAs spoke about boundaries when discussing the appropriateness of tasks, and here a major concern was that work would impinge upon their private lives. Informant #203 outlined the risks of becoming too involved in her employer's life, saying 'it's easy to get sucked in and over commit yourself', adding this was 'at the detriment to yourself if you're not careful'. This informant described this as 'giving 120 per cent, rather than 100 per cent' and when asked what it meant to become overcommitted, she replied;

'you can become totally overwhelmed by the whole situation, if you are being called on too much and you've allowed yourself to be pulled into a situation where you are doing more and more hours... you can be overwhelmed'.

Similar concerns were expressed by informant #208, who said 'you have to create a boundary between the friendship role and the professional role... being able to be clear about how much you can physically do because someone can just push you and push you'. This informant explained that being 'pushed' by an employer involved emotional as well as physical work, saying; 'often people are quite lonely, they don't interact much, and they don't work... you can become on the receiving end of a lot of emotional stuff, which I find can be very exhausting'.

Describing her work as 'such an essential thing', informant #219 explained that she was unable to remain disinterested in the wellbeing of her employers. One consequence of this was that this informant regularly committed more time and energy than was feasible. Describing a recent working week, informant #219 said 'I was supposed to work one 12 hour shift, I ended up working four'. Recognising that this degree of commitment was not sustainable, #219 questioned whether it was possible for her to continue in personal assistance work; 'I don't really see myself doing it, because you get committed and there are always crises, crises always occur and you really want to help'.

In rare cases, informants described intensely close PA relationships in which the wellbeing of their employers appeared to dominate their own lives. In one case, the bond between informant #221

and the child (Chris) she supported was such that she dedicated considerable time and energy to his support without pay. Describing events after the child was withdrawn from mainstream school, informant #221 said she had taken on extra duties to meet this child's educational needs;

'I was teacher, PA, everything... officially I was teaching him 15 hours a week, three hours every morning, but then I was doing other activities, so I had him six days a week. A lot of hours'.

This informant said that she was paid for approximately 24 hours per week, but when asked how many hours she actually worked, #221 replied 'at least double that'. Explaining why she committed so much of her free time to this relationship, #221 said:

'I suppose I worked with him for so long, invested everything... it has gone further than just a PA job. I knew I could help him, so I had to. I couldn't watch him carrying on down the path, I knew where that would end up. I had to do something'.

As this case illustrates, without clear boundaries between personal and professional realms, emotional attachment can precipitate a personal dedication which far exceeds what might reasonably be expected. For informant #221, this commitment was a natural and rewarding feature of a deeply committed personal relationship. Yet thinking dispassionately, this example also illustrates ethical dilemmas concerning both the appropriateness affective relationships, and whether or not PAs receive adequate reimbursement for their work.

In another example, PA #219 reflected on a relationship marked by mutual attachment. Over the course of this relationship, informant #219 found herself taking on more hours until she became over-committed;

'I was her sole employee, and everything rested on me and that wasn't a good feeling. I just got way too involved with her. I feel like I would do lots of things differently now'.

As a consequence of these pressures, the relationship broke down. Reflecting on where things had gone wrong, informant #219 explained how she would act if she were in a similar situation again;

'try and maintain those more professional boundaries, and maybe hold back a bit... just because we're getting on so well, she is still my employer. And maybe when she offers the hours, instead of 'oh yes that'll be nice', maybe think more about the impact of that, that actually it would be really good if she had someone else on her books, so maybe give that to someone else and then there's someone there. That woman dropped away and I was left the sole person and I don't think that helped, it wasn't good for her, it wasn't good for me, it wasn't good for us, ultimately.

PAs protecting their private realm

A primary concern for many PAs was the preservation of their private realm and distancing their personal life and relationships from work. For many PAs this meant withholding personal information and maintaining clear boundaries in terms of space and place – where they spent time with their employer and limiting interactions with their employers to those within paid hours. Consequently, many PAs said they were privy to employer's deeply personal information, spaces and activities, whilst simultaneously controlling their own personal information limiting access to their own private time and spaces.

One PA informant, #207, articulated these issues clearly when discussing her relationship with her employer, saying ‘her life is my life, I don’t want my life to be hers’. This informant did not want to share her personal life with her employer; ‘she is not sharing a part of me, she is sharing herself. I don’t want to share myself with her, I don’t want to share myself with anybody if I don’t have to, when you are disabled you have to’. Another informant, #217, said that she preferred not to discuss her family life with the people she supported;

‘I don’t say much... you have polite banter, but I think you still have to be careful what you say. They talk about your family. I talk about my family in general, but you don’t burden them with all the woes and the traumas in your life’.

When asked to explain why she preferred only superficial conversation, this informant replied ‘protecting my own family, because you don’t know what they will say to someone else’. Similar concerns were expressed by informant #223, who recalled having worked for a woman who ‘wanted to lead my life, live my family life with my problems, and even to have control over it’. This informant explained that her employer ‘was trying to take as much as she can from my life’, by directing her leisure time. #223 managed this situation by limiting the opportunities her employer had to become involved in her personal life;

‘I would lie to her ... it was little white lies, it doesn’t hurt anybody, but I didn’t tell her everything. And gradually I also started to tell her less about my life, it was more my life. [At] the beginning I thought we could be friends and share many things. No we can’t, you have to keep this line. It is like marriage, you have to keep a little bit for yourself if you want still to be yourself’.

Informant #218 spoke about the asymmetry of information between her and her employers, saying ‘They want you to be part of their family, because you know so much about them, they want to know more about you’. This informant said that it was difficult to maintain a distinct private realm because her employers would frequently enquire about her family life; ‘I’m sorry but they like to know everything, what’s going on and you personally’, adding ‘this is my work situation and this is my home situation’. Asked why she wanted to maintain a clear and distinct public and private domains, informant #218 said;

‘I do know people who have got involved in family life, and if things do go wrong... no, not for me...they know my address, they know my name, and geographically we’re very close... I don’t want them to get the feeling that they can just pop around’.

Conflict

Our data show that conflict is common in personal assistance relationships. In the sections that follow, we illustrate the consequences of conflict using the metaphors of wounded and ruptured. We identify three ideal types of conflict – practical, personal and proximal conflict – and outline these in turn. Finally, in the context of these findings we identify several strategies intended to prevent conflict, or to limit the damage caused by conflict where it does occur.

Degrees of conflict

The course of few relationships is entirely smooth and all relationships require some degree of care if they are to sustain. All informants in this study, both employers and workers, reported feeling

dissatisfied or disaffected at some time, but the significance of this conflict varied widely. At worst, informants spoke about intractable problems or irreconcilable differences which caused relationships to **rupture** beyond repair. Less significant insults were more common, and informants spoke frequently of **wounded** relationships, injured by less significant problems. If cared for, these wounded relationships may heal and grow, but if left unattended relational problems are likely to deepen and cause ruptures.

Wounded relationships are marked by low-level dissatisfaction, often concerning practical issues rather than personal problems.

Many disabled informants criticised PAs over their performance, but these issues were often tolerated by informants who said that, on balance, their PAs met their needs. Informant #132 provided a clear example of this as he expressed mild annoyance when discussing his PA's attitude, saying 'he's a bit lazy, not in the personal task stuff but in other stuff. If I say 'can we fix this?' he'll say "maybe we can do it tomorrow". Later in his interview this informant reiterated the same concerns, but stated clearly that these problems were not important enough for him to question this PA's position; 'he's a procrastinator, in a way, but it's never bothered me too much because as long as he does his main job'. In another example, informant #135, who managed several PAs on behalf of her son, spoke about a PA whose mother exerted undue influence over her work. This informant explained that the PA in question lacked experience, and reasoned that she relied upon her mother's advice because she felt unable to make independent decisions. This situation developed to the point where the PA's mother was 'dictating what her daughter should and shouldn't be doing', which in turn caused discontent among other PAs – 'it got the other staffs backs up'. Rather than ignoring these problems, #135 took care to support her PA to become more confident and independent of her mother. In time, the PA gained experience and knowledge, and remains a valued member of #135's team of PAs today.

Several disabled informants reported that their PAs had curtailed their autonomy, and whilst many found this to be infuriating, most indicated it did not warrant further action. Informant #107 provided one example, detailing a visit to the cinema;

'A PA of mine said "can we go to the cinema?", and I said "we can either watch 50 Shades of Grey or we can watch Birdman" and she went "oh I'm not watching 50 Shades of Grey"'.

This informant accepted his PA's preference, but quickly began to question whether or not this had been appropriate;

'At the time I said "oh don't worry about it we'll watch Birdman", but the next day and a few days after I sat there and thought "should I be letting my PA dictate and choose what I watch?"'.

This informant chose not to confront his PA, despite resenting his actions;

'I should have said "I am going to watch this film, we're going to watch this"... [but] I can't do that. I don't have the balls to do it. I would feel really uncomfortable. So we just watched Birdman. Birdman was awful'.

Whilst this episode did not cause an immediate or open dispute, it did harm the relationship. #107 continued to harbour resentment towards this PA long after the event. In another example informant #108 said that her PA tended to make choices on her behalf. This informant explained that she frequently had to challenge, or 'remind', her PA that her role was to facilitate choice, rather than actively making choices. Whilst this irritated #108, it did not result in overt disagreement.

However, #108 suggested that having to admonish her PA was tiresome and a point of frustration in itself; 'I have to put my foot down', adding 'I hate doing that'.

PA informants spoke in similar terms, and many identified frustrating aspects of their work. Informant #219 said that her employer frequently made payroll errors, but her frustration centred on the fact that her employer refused to take reasonable steps avoid these errors; 'I suggested to her that we keep timesheets, and keep track of when I was there, and she was really against it'. A more extreme example was presented by informant #201, who said that her employer insisted that she remain silent unless spoken to. This informant said her employer 'blocks me completely', and told her to sit in another room, saying 'that's really frustrating'. When asked how this made her feel, informant #201 said;

'very mechanic, and very subordinated. So you have to wait their time, of course you are there to work for these people but to not give you the possibility to talk, is not very human. That is very hard'.

Several PAs said they were unable to influence their working routine, and some indicated their work was unfulfilled. Informant #220 provided one clear example, saying 'I feel like our professional judgement isn't taken into account a lot of the time'. Asked how this made him feel, informant #220 said 'it's very annoying to be honest, and sometimes I get so frustrated... sometimes I just think I should leave'. In another example, informant #208 expressed frustration because she lacked autonomy, adding that working alongside a single person led to feelings of frustration in both parties;

'there can be frustrations because the PA user doesn't have enough time to themselves to just be themselves, because it's not like you're choosing to hang out with someone for the whole day, it's a necessity. And then for the PA it is also a similar thing, I find that I lose a bit of my autonomy'.

Ruptured relationships occur where wounded relationships are not cared for, or where acute problems or crises lead to irreconcilable problems.

Safety was a common theme among workers and employers, and several informants told of PA relationships that had ended following safety concerns. Informant #117 recalled dismissing a PA after his safety was compromised; 'he didn't know how to hoist me! He very nearly dropped me on the floor'. This informant explained that he felt unable to continue working with this PA once his safety had been compromised; 'he failed twice... just too dangerous'. In another example, informant #121 said that her PA had 'gone berserk' and stormed out of her home in a fit of anger – 'he just went off on one'. This experience left informant #121 feeling vulnerable and isolated; 'it was horrible' she said, adding 'he just went and I was left again with no help'. Once informant #121 felt unsafe, she explained that the relationship was damaged beyond repair; asked whether or not this problem could have been resolved, she replied 'not after that'.

PA informants also spoke about relationships that had ruptured following safety concerns. Informant #221 spoke of a role that had 'fizzled out' because she felt unable to support the child in her care;

'his behaviour was quite challenging, and because I didn't see him very often I didn't feel very able to look after him safely... He's quite big and his behaviour is quite challenging'.

This informant raised her concerns with the child's parents, but they disagreed and refused to adapt their support arrangements. With her concerns dismissed and with no additional support in place,

#221 explained how both parties allowed the relationship dwindle and fade; 'I kept mentioning that I didn't feel safe. Then I got called less and less, to have him'.

Breaches of trust were another point of rupture, and several disabled informants said that PA relationships were unfeasible once trust had been lost. Informant #120 provided a clear example, and speaking about deceitful actions of her PA she said 'she turned out to be absolutely awful, she stole from me and my children, told lies, and in the end we had to get the police involved'. Another example was provided by informant #118, who dismissed her PA after discovering her manipulative behaviour;

'I actually got a recording of her... just being the nastiest person I ever heard in my life, completely fabricating things and saying that I was embezzling money'.

Understandably, upon hearing this recording and discovering the actions of her PA, #118 said that she 'got rid of her' immediately, but added that this experience had been 'very, very intimidating'.

Forms of conflict

Our analysis reveal three distinct but related forms of conflict, each of which requires different approaches to prevention and resolution. In the sections that follow we present three forms of conflict in turn: practical, procedural, and proximal.

Practical conflict involves dissatisfaction with practical processes or outcomes. Disabled informants and PAs spoke of different practical concerns, and whilst employers focused upon the performance of their workers, PAs emphasised concerns over working conditions.

Some disabled informants suggested that practical problems were more likely to occur when workers had experience of traditional care roles, such as domiciliary or residential care. Informant #110 said that PAs with this kind of experience were less willing to take instruction; 'they seem to think they know it all already, because they've had training'. Illustrating this point, informant #110 spoke about a PA who had struggled to make the transition from residential care to personal assistance;

'She was quite challenging to work with. She got very upset because in her experience working in a care home she was used to having bleach and certain materials locked away in a cupboard, and of course this being a private house I just had my bleach under the sink not locked away or anything like that'.

#110 explained that these issues reflected a broader problem in support and assistance, in which outdated and paternalistic notions of care prevailed;

'the way she did things, the way she spoke to me, I thought was appalling. Her whole attitude was very much that she knew what she was doing and I didn't know what I was doing, she was difficult'.

As a consequence of this, informant #110 avoided PAs with experience of formal care work, saying 'maybe it's a bit prejudiced... but I would struggle with somebody with that sort of background... they seem to think they know it all already, because they've been training'.

Another example was given by Informant #106, who said that her direct style of management caused disagreements – 'I have a particular order, and that doesn't always go down well'. This

informant explained that it was vital for her PAs to follow close instruction, otherwise it was not possible to complete important tasks within her funded hours. But some PAs, especially those with experience in formal care roles, struggled to take directions from her because she was a disabled employer; 'In their head I shouldn't be telling them what to do, they say "well we've been trained", I say "I don't care, you've been trained wrong". As with other disabled employers, this informant said that where possible she avoided PAs with experience of formal care, reasoning 'it comes up again and again... it's got to be something endemic in their training'.

PA informants also spoke about practical problems, particularly the appropriateness of tasks. Informant #201 provided one example, saying that her employer asked her to complete tasks she deemed inappropriate;

'I shouldn't be doing... mending a wheelchair or mending electricity, I don't have a clue. So I say to this person "you have to call electrician, you have to call the doctor, you have to call the gardener", because it's something I don't know how to do'.

This informant continued to detail the most infuriating instance of this problem; having to tend to her employer's pets;

'this lady has six birds, I hate birds, I don't like them, I feel they're dirty so I don't feel comfortable with it, but I have to do it because I am doing it for her. In that way it is more acceptable, but I don't really think that is in the role of the personal assistant'.

Asked whether she felt able to discuss this issue with her employer, informant #210 said 'no, she will say "the other PA user does this, so why are you complaining about it?". Questioned about how this made her feel, #201 replied in clear terms; 'It's nasty, you think you are being a bit horrible to them... maybe she just thinks I am posh that I don't want to do this'.

Other PAs revealed frustrations over their employer's style of management, or the fact that other people – such as employer's partners, parents or children – were involved in their day-to-day supervision. Informant #206 described being micromanaged by his employer's mother, a situation he found both unnecessary and dispiriting:

'She wanted me to arrange the food that is her son is eating. We would go to the office, me and the user, and she would remain at home. At a certain time, at lunchtime, she would call to make sure that I had arranged things in plate! It's absurd to me'.

The actions of his employer's mother left informant #206 feeling ambivalent – at once 'frustrated' but also feeling 'some attrition with the user because it was in the middle of the relationships'. This example shows that practical problems – such as an employer's style of management – are connected to, and feed into, interpersonal psycho-social dynamics. The frustration felt by this informant stemmed from a practical concern, but also the micro-politics of his employer's filial relationship.

A small number of PAs expressed dissatisfaction over their working practices or routine, particularly their inability to affect their work. Informant #220, who assists a child, said that his opinions were ignored by the child's mother and innovations were dismissed without consideration; 'I get so frustrated with her that I think I should leave'. This informant's frustrations were emphasised yet further by his belief that he could improve the child's supportive arrangements;

'last week, we took XX [child] swimming because that's the routine, but he had a bad cold, and I think he'd had a seizure as well so he was very sick, doubled over in his wheelchair'.

This informant continued to explain that he felt unable to challenge the mother's authority, despite the fact he felt to do so would be in the best interest of the child's wellbeing;

'I would have loved to have felt confident enough to make the call that actually he isn't up for swimming, if he could speak he would tell us that... but I didn't feel that I was in the position to make that decision, and so he did go swimming against my better judgement because if he hadn't, then his mum wouldn't have been very happy'.

Personal conflict involves antagonistic personalities or values. The distinction between practical and personal conflict was illustrated by informant #129, who said 'it goes wrong one of two ways', adding 'either just mismatch personalities or they're just not very good PAs'.

Employers and PAs spoke about personal conflict in comparable ways, both identifying similar inter-personal problems. Informant #205 recalled a brief but 'damaging' period working for an employer she described as 'really mean' and 'angry a lot of the time'. This informant spoke about the atmosphere of her employer's home, saying 'it was just horrible, traumatic', adding that 'if you did something wrong she would just shout and scream'. Seeking to resolve these issues, this informant confronted her employer, who explained that her anger was due to anxiety. Despite this dialogue, informant #205 felt unable to continue working in what she described as a 'brutal' PA relationship. In another example, PA Informant #223 struggled to work with an employer she described as immature – 'she is a very intelligent person, but emotionally, as a child'. This informant explained that this relationship was 'very difficult', adding;

'because of my knowledge – I was mother, twice divorced, had a company – my experience was much bigger than most women my age. She was like a child, but she was my boss and I was working for her, and that was a very difficult part'.

Values were also at the heart of conflict, and many disabled employers reported clashing with PAs over religion, culture and other lifestyle choices. The clearest example of this was given by informant #107, whose use of sex workers led to a ruptured PA relationship. This informant had agonised over whether or not to tell his PA about his use of sex workers, and described her response to his disclosure as 'really upset' and 'really angry'. #107 felt that his PA's faith had played a role in her response, saying 'she was very strong catholic and very religious and we had this chat in the car and she said "this is really difficult, I can't do this"'. This relationship deteriorated and their disagreements 'became personal'; quoting his PA, #107 said 'you use the escorts so that means you're a pervert'. Reflecting on this episode and the response of his PA, #107 said 'that's part of my life that I have struggled with for many, many years to feel comfortable with... [and] by attacking my values... I had to let her go'.

Another example of incompatible values was given by informant #106. Asked whether she had ever sacked a PA, this informant – a Black British woman of Caribbean heritage – replied 'yes... there is an issue around culture, Afro-Caribbean culture'. This informant indicated that cultural differences meant that some PAs were more likely to hold discriminatory attitudes and beliefs about disabled people; 'not all cultures are as enlightened as the UK when it comes to disabled people'. This informant explained that she tended not to employ PAs from different cultures, particularly from countries in which negative stereotypes of disabled people obtain;

‘If you’ve come from a country where disabled people don’t have any rights, you’re obviously not going to be used to be working with them on an equal basis, so when you come to this job it’s going to be a shock that you have to listen to them and follow what they’re asking, because that’s not your norm’.

Despite these misgivings, #106 was equally clear that her views were not steadfast, and when asked about the nationality of her longest-standing PA, she replied ‘Jamaican’.

PA informants were less likely to speak about conflict involving values, but several discussed disagreements of a deeply personal nature. Informant #218 spoke about one such dispute with a long-standing employer; ‘I met this person when I was about 25, I was a PA for her when she was a parent when I was about late 30s’. This informant explained that this relationship involved mutual affinity and strong affection; furthermore, #218 had played a central role in assisting her employer to raise her son, ‘I had enabled her to have a proper bond, I saw that as my role... to cement that bond and that connection in a positive way’. However, #218 proceeded to recount her employer’s decision to employ #218’s former partner, despite knowing this had been an acrimonious relationship and that #218 harboured deep animosity towards this person. Reflecting on this episode and the significance of her employers actions, #218 said ‘she went and employed my ex, and it really annoyed me’, adding;

‘I found it very difficult, because she employed someone that shouldn’t have been employed, and it was a bit like she chose him over me. Even though I had given her years of utter devotion and exceptional, exceptional PA support’.

Feeling betrayed by her employer, #218 felt unable to continue working with her and their relationship, both personal and professional, ended soon afterwards.

Proximal conflict stems from the social and practical organisation of personal assistance. Personal assistance work usually involves working with a single person, often for prolonged periods of time in relatively close confines. These dynamics of proximity were identified by several informants who said they exacerbated existing problems between employers and workers.

Several disabled employers described measures they had taken to ensure they had a variety of PAs to call upon. Informant #107, who had employed personal assistants for over a decade, explained how his preferred pattern of support had changed over the years.

‘It’s kind of weird, because I have always wanted to have one person, when I was younger when I was at college it made it easier, but when I got older... I found that having one person 9-5 every day of the week; it was difficult’.

This participant likened the intense interpersonal dynamics of PA relationships to a marriage, saying ‘I just find that I can work with someone for two or three days but after two or three days it becomes difficult... on an emotional level’. This informant preferred to employ four or five PAs, and to arrange his support so that each PA worked a similar number of hours. Reflecting on his experiences, this informant used spatial metaphors to further emphasise the difficulty of working with a single person;

‘you’re with someone all the time, little things... something they may forget to do – because people aren’t perfect we all make mistakes – you have to give space for that to compensate. But when you’re with someone too much, it becomes too much’.

PA informants also raised issues of interpersonal proximity, and informant #219 provided a clear example when discussing the breakdown of a former relationship. This informant said that conflict with her employer had not occurred immediately, but rather ‘came over time’;

‘I was spending a lot more time with her, she built in more hours, a morning and an evening thing... then she added an early morning and late evening... I think she was going to give that to a different PA, but she just said to me did I want it, and I said yes’

This informant explained that as she spent more time with her employer, her employer grew frustrated at her continual presence; ‘I was there a lot. She is disabled... but it doesn’t mean she always wants someone around. It is a lot to have somebody in your home’. #219’s employer became increasingly critical of her work and began to act in a passively aggressive way, which ultimately led #219 to end the relationship. When asked whether she attributed her employer’s behaviour to the amount of time they spent together, #219 said; ‘Yes. I do wonder if I hadn’t have done so much, whether it would have been different’.

Informant #223 spoke of similar issues and described her experience of PA work as a ‘kind of prison’. This informant had worked 12 hour shifts as a live-in PA, with only a single day off each week. She explained that this working pattern left her feeling isolated and without the time or energy to pursue her own interests;

‘I couldn’t leave the house, or do anything because at any moment she could wake up and have some need – it doesn’t work at all. So you are all the time on the standby, twenty four hours, and that is very tiring, a mental tiredness not physical’.

After a year in this role, #223 said she began to feel fatigued, lacking in motivation, and irritable towards her employer. She explained that these feelings stemmed from the all-consuming nature of the role, and the sense that her employer’s wellbeing took precedence over her own life; ‘being a PA, you are living somebody else’s live... I didn’t have my own life at all’.

Conclusion and recommendations

To summarise our findings in a paragraph, personal assistance relationships are complex, variable, and involve power, ethics, and emotions. Personal assistance is empowering, flexible and desirable for both employers and workers, when it goes well. It has been shown by our partner Equal Lives to be more cost-effective to employ your own personal assistants than rely on agency support. However, personal assistance can sometimes go wrong. The relationship can become wounded, or even ruptured. Every single one of our respondents had sometimes had a problem with their PA relationship. Consequently, we need to give both disabled employers and personal assistants the skills and knowledge they need to manage these relationships effectively

To expand these thoughts, contrary to the classic Independent Living model, we interpret our findings as demonstrating, first, that you cannot remove emotions from the personal assistance approach to support. PA is an ongoing relationship between two or more people, so it is inevitably emotionally complex. Both parties have to do emotion work (Hochschild1979). It is important to recognise and validate emotions.

Boundaries are crucial: employers and workers often have different expectations around boundaries. For example, workers may not want to share their private life. But for employers, the workplace is their home: there is less distinction between public and private. This asymmetry of privacy is difficult. Where people do not know what is going on, this can be a point of conflict. There may be a lack of clarity and established norms of conduct. It is possible to reflect upon and understand boundaries and doing so is likely to improve outcomes.

Third, conflict within PA relationships is common. Working for long periods in close proximity risks disagreement or misunderstanding. This can be personal, procedural or simply to do with proximity. Most people have experienced some form of dissatisfaction or disaffection in their personal assistance relationships at some time. Our data suggests that a substantial minority have experienced a rupture in a personal assistance relationship at some time. Bearing in mind that the turnover rate in adult social care is high - more than one third of care workers leave their jobs each year – this generates anxieties about continuing availability of workers.

Finally, simple practices around support, oversight and communication may reduce the likelihood of conflict.

General recommendations:

1. A good match between employer and worker is important. Both parties need to reflect on the kind of relationship they are looking for, and would be happy with. This has implications for boundaries – for example, how much a disabled person might reveal about her private life, and to what extent they discuss their personal assistant's life. Making expectations more explicit could minimise misunderstanding and tension. The type of relationship that has been agreed has implications for issues such as socialising out of hours, doing favours for one another, or confiding personal matters.
2. Respect difference – respect the personality and values of other people; be willing to accommodate difference, be that personality, culture or ways of practice. Tolerance may also extend to things not always being done exactly as you would do them yourself.

3. To reduce difficulties of working in close proximity, it can be useful for a disabled person to have multiple workers, both so that people are not spending too much time in the dyad but also to arrange the working week to ensure variety. This also minimises the dependence on one individual. To reduce the difficulties of proximity, some respondents also found it useful for the PA to have her own private space in the house, where this was possible.
4. Clear communication and willingness to listen are important. This includes having a forum for safe conflict – regular meetings in which problems may be discussed without the danger of any concerns being construed as personal attacks. In the event of conflict, external mediation may be helpful.

For disabled people as employers:

1. Vet your applicants – understand your own expectations, values, and limitations; make these explicit; ask other applicants to do the same; seek to employ those with whom you have affinity. Vetting is vital to minimise risk.
2. ‘Probation’ – a probationary period may help to ‘make sure they can do the job’; and also ‘make sure we get on’.
3. Provide planning and guidance around tasks – to avoid practical conflict, provide clear and up-front descriptions of routine tasks and how these tasks are to be completed. Review this planning and guidance periodically.
4. Employing a personal assistant can involve emotional work. For example, personal assistants may be young, maybe far from home, and may have support needs. However, it is important to set boundaries, and be clear to what extent you are willing to offer support.
5. Finally, bear in mind that your home is now someone else’s workplace.

For personal assistants:

1. It will be easier for you to empower your employer if you yourself feel empowered.
2. Dialogue between employer and worker is very important.
3. Remember, being a personal assistant can involve emotional work, for example, feeling unable to express things like anger, resentment or dissatisfaction. Some personal assistants have highlighted how issues spill over into the rest of their lives, for example worrying about the employer when one is home from work. Finding a forum for venting feelings can be important, whether with a supervisor or other assistants in a network.
4. Supervision: where there are multiple personal assistants, potentially one personal assistant, or a third party, could offer supervision to the personal assistant team.
5. Bear in mind that your workplace is also someone’s home.

For policy-makers and infrastructure organisations

1. More efforts are required to recruit people into the PA workforce. Lack of choice in recruitment or retention may force people into poor relationships or prevent them exiting them: lack of supply restricts choice. Promoting the idea of personal assistance as a worthwhile occupational role, so as to ensure continued entry to the social care workforce.
2. Provide funding, training and support to allow disabled people to develop their understanding of their role as employers and how to manage assistance relationships. Those new to personal assistance need to be aware of their responsibilities as employers, including statutory issues such as holiday pay, sick leave and disciplinary procedures.

3. Provide funding, training and support for personal assistants, to understand their role. Training in the social model of disability would be a useful foundation for good personal assistance, for example, the role of personal assistants as helping to overcome disabling barriers. Disabled people's organisations are in a good place to provide this training.
4. Personal assistance can sometimes be isolating for both parties. Therefore it might be helpful to ensure that both disabled people, and personal assistants are connected with others to provide peer support.
5. Disabled people and personal assistants need to have access to a source of independent legal advice around grievances and dismissal.

Appendix

Study methodology

The data presented in this paper are taken from an ESRC funded study into personal assistance relationships entitled 'Personal Assistance and Disabled People: Emotions, Ethics and Power' [ES/L007894/1]. The aims of this study were to gain a better understanding of the relationships that occur when disabled people directly employ PAs, and to explore how both parties experience and manage challenges within these relationships.

Sampling and recruitment

Disabled informants were sampled using purposive sampling. Disabled informants were identified and recruited through a network of disabled people's organisations (DPOs). A sampling frame was developed and implemented to guard against parochialism and to ensure that we captured a variety of experiences. The sampling frame included DPOs in both rural and urban areas, as well as purposively sampling non-white-British informants. Further, a range of impairments were purposively sampled, including congenital impairments as well as impairments acquired in later life. Exclusion criteria included being under the age of 18 years and lacking mental capacity to provide informed consent (cite MCA).

PA informants were sampled initially using purposive sampling and later through snowball sampling. PA informants were recruited through informal contacts within the same network of DPOs, through blogs, and the study was also advertised on a national internet based PA forum; the informants garnered through these efforts then provided further contacts through snowball sampling.

Data collection

Disabled informants were offered three modes of interview: face to face, telephone, and email. Email correspondence was offered as an alternative to verbal interviews for informants with impaired speech. The majority of disabled informants took part in a face to face interviews, all but one of which took place in informant's own homes, the other took place in a public space. PA informants were offered two modes of interview: face to face or telephone. The majority of PAs took part in telephone interviews, largely because they were geographically more dispersed than disabled informants.

Interviews followed a topic guide informed by extant literature and refined iteratively throughout data collection. Where interviews were conducted using email, informants were sent a document containing a topic guide, which they annotated and returned to the research team. Interviews were conducted by each member of the research team. All interviews were transcribed verbatim. Data storage, administration, and analysis were conducted using QSR Nvivo 11.

The sample

The sample is detailed in Figure 1. and Figure 2.

Data analysis

Constructivist Grounded Theory (Charmaz 2006) provided the framework for analysis. The first stage of coding was 'initial coding'. Initial coding is marked by close attention, sometimes line-by-line coding, which promotes attentiveness to detail and helps prevents tacit assumptions about larger

excerpts of text being inaccurately coded. Following initial coding, increasingly directed and conceptually driven ‘focused coding’ was undertaken. Following Charmaz, focused coding involved identifying and expanding the most theoretically significant and frequently occurring codes delivered through initial coding. A final stage of ‘theoretical coding’ analysed categories of codes generated through focused coding. In practice, as recognised by Charmaz (2006), the distinction between each coding stage was flexible, and coding an emergent process – as concepts emerged, initial coding was revisited and re-coded in light of subsequent theoretical coding. The stages of focused and theoretical coding were subjected to peer review by all members of the research team, with the aim of cross validating data interpretation.

Figure 1: Disabled Informants

ID	Interview type	Sex	Self-defined Impairment	Ethnicity
101	Face to Face	F	Familial Dysautonomia	White British
102	Face to Face	F	Spinal Cord Injury	White British
103	Face to Face	F	Multiple Sclerosis	White British
104	Face to Face	M	Multiple Sclerosis	White British
105	Face to Face	M	Cerebral Palsy	British Asian
106	Face to Face	F	Cerebral Palsy	Black British
107	Face to Face	M	Cerebral Palsy	British Asian
108	Face to Face	F	Muscular Dystrophy	White British
109	Telephone	M	Musculo-Skeletal Condition	White Non-British
110	Telephone	F	Physical Impairment	White British
111	Face to Face	F	Phocomelia (congenital)	White British
112	Telephone		Multiple Sclerosis	White British
113	Face to Face	F	Physical Impairment	White British
114	Face to Face	M	Spinal Muscular Atrophy	White British
116	Face to Face	F	ME	White British
117	Email	M	Physical Impairment	White British
118	Face to Face	F	Spinal Muscular Atrophy	White British
119	Face to Face	F	Friedreich's Ataxia	White British
120	Face to Face	F	Spinal Cord Injury	White British
121	Face to Face	F	Multiple Sclerosis	White British
127	Telephone	M	Physical Impairment	White British
128	Face to Face	F	Multiple Sclerosis	White British
129	Telephone	M	Physical Impairment	White British
130	Telephone	F	Multiple Sclerosis & Sensory Processing Disorder	White British
131	Face to Face	F	Myalgic Encephalomyelitis (ME)	White British
132	Face to Face	M	Muscular Dystrophy	White Non-British
133	Telephone	F	Mother to daughter with Down's Syndrome	White British
134	Face to Face	F	Mother to son with Learning Disability	White British
135	Telephone	F	Mother to son with Down's syndrome	White British
136	Telephone	M	Scoliosis	White British

Figure 2: PA Informants

ID	Interview type	Sex	Nationality
201	Face to Face	F	EU
202	Face to Face	F	GB
203	Face to Face	F	GB
204	Face to Face	M	GB
205	Face to Face	F	GB
206	Face to Face	M	EU
207	Telephone	M	GB
208	Face to Face	F	GB
210	Telephone	F	EU
211	Telephone	F	GB
212	Telephone	F	GB
213	Telephone	F	GB
214	Telephone	F	GB
222	Telephone	F	GB
224	Telephone	F	GB
217	Telephone	F	GB
216	Telephone	M	GB
218	Telephone	F	GB
215	Telephone	F	GB
219	Telephone	F	GB
220	Telephone	M	GB
221	Telephone	F	GB
209	Telephone	M	GB
223	Face to Face	F	EU
225	Telephone	F	GB
227	Telephone	F	GB
226	Telephone	F	GB
228	Telephone	F	GB

Study limitations

No informants were recruited with learning disability.

References

- Ahlström, G., & Wadensten, B. (2010). Encounters in close care relations from the perspective of personal assistants working with persons with severe disability. *Health & Social Care in the Community*, 18(2): 180-188
- Ahlström, G., & Wadensten, B. (2011). Family members' experiences of personal assistance given to a relative with disabilities. *Health & social care in the community*, 19(6), 645-652.
- Ahlström, G., & Wadensten, B. (2012). Enjoying work or burdened by it? How personal assistants experience and handle stress at work. *Journal of Social Work in Disability & Rehabilitation*, 11(2): 112-127
- Austin, W., Bergum, V., Nuttgens, S., & Peternelj-Taylor, C. (2006). A re-visioning of boundaries in professional helping relationships: Exploring other metaphors. *Ethics & Behavior*, 16(2): 77-94
- Bahner, J. (2013). The power of discretion and the discretion of power: personal assistants and sexual facilitation in disability services. *Society, Health & Vulnerability*, 4: 1-22
- Banks, S. (2008) *Ethics in Professional Life: Virtues for health and social care: character, conduct and caring*, Basingstoke: Palgrave Macmillan.
- Charmaz, K. (2006). *Constructing grounded theory*. London: Sage.
- Christensen, K. (2012). Towards sustainable hybrid relationships in cash-for-care systems. *Disability & society*, 27(3): 399-412
- Clark, M. J., Hagglund, K. J., & Stout, B. J. (2004). Job Experiences of Personal Assistants Employed in a Consumer-Directed Personal Assistance Services Programs. *Rehabilitation Nursing*, 29(5): 174-179
- Clevnert, U., & Johansson, L. (2007). Personal assistance in Sweden. *Journal of Aging & Social Policy*, 19(3): 65-80
- Duffy, S. (2011). A fair society and the limits of personalisation. *The Centre for Welfare Reform, Sheffield*.
- Earle, S. (1999). Facilitated sex and the concept of sexual need: disabled students and their personal assistants. *Disability & society*, 14(3): 309-324
- Falch, W. (2010). *Står til tjeneste: Emosjonelt arbeid i tjenestemøtet*. [Doctoral Thesis]. Karlstads universitet.
- Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K., & Tyrer, J. (2000). New kinds of care, new kinds of relationships: how purchasing services affects relationships in giving and receiving personal assistance. *Health & social care in the community*, 8(3): 201-211
- Grossman, B. R., Kitchener, M., Mullan, J. T., & Harrington, C. (2007). Paid personal assistance services: An exploratory study of working-age consumers' perspectives. *Journal of Aging & Social Policy*, 19(3): 27-45
- Guldvik, I., Christensen, K., & Larsson, M. (2014). Towards solidarity: working relations in personal assistance. *Scandinavian Journal of Disability Research*, 16(sup1): 48-61
- Hall, S., Kolliakou, A., Petkova, H., Froggatt, K., & Higginson, I. J. (2011). Interventions for improving palliative care for older people living in nursing care homes. *The Cochrane Library*.
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American journal of sociology*, 85(3): 551-575
- Hochschild, A. R. (1983). *The Managed Heart*. Berkeley: CA: University of California Press.
- Kelly, C. (2011). Making 'care' accessible: Personal assistance for disabled people and the politics of language. *Critical Social Policy*, 31(4): 562-582
- Leece, J. (2006). It's not like being at work': a study to investigate stress and job satisfaction in employees of direct payment users. *Developments in Direct Payments*. The Policy Press, Bristol.
- Leece, J. (2010). Paying the piper and calling the tune: Power and the direct payment relationship. *British Journal of Social Work*, 40(1): 188-206

- Leece, J., & Peace, S. (2010). Developing new understandings of independence and autonomy in the personalised relationship. *British Journal of Social Work*, 40(6): 1847-1865
- Matsuda, S. J., Clark, M. J., Schopp, L. H., Hagglund, K. J., & Mokolke, E. K. (2005). Barriers and satisfaction associated with personal assistance services: Results of consumer and personal assistant focus groups. *OTJR: Occupation, Participation and Health*, 25(2): 66-74
- Milligan, C. (2003). Location or dis-location? Towards a conceptualization of people and place in the care-giving experience. *Social & Cultural Geography*, 4(4): 455-470
- Morris, J. (1993). *Independent Lives? Community Care and Disabled People*. London: Palgrave.
- Morris, J. (1997). Care or empowerment? A disability rights perspective. *Social Policy & Administration*, 31(1): 54-60
- O'Brien, J. (2013). "It's Not So Much a Job But a Relationship": A Response to Romer and Walker. *Research and Practice for Persons with Severe Disabilities*, 38(3): 196-201
- Pearson, C., Barnes, C., Jolly, D., Mercer, G., Priestley, M., & Riddell, S. (2005). Promoting personal assistance in the UK: What's the problem with direct payments? *Disability Studies Quarterly*, 25(1).
- Romer, L. T., & Walker, P. (2013). Offering person-centered supports on a daily basis: An initial appreciative inquiry into the relationship between personal assistants and those seeking support. *Research and Practice for Persons with Severe Disabilities*, 38(3): 186-195
- Joseph Rowntree Foundation (1995). Employing personal assistants, *Findings: Social Care Research* 61. York: Joseph Rowntree Foundation.
- Schelly, D. (2008). Problems associated with choice and quality of life for an individual with intellectual disability: a personal assistant's reflexive ethnography. *Disability & Society*, 23(7): 719-732
- Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited*. London: Routledge.
- Skills for Care (2016) The size and structure of the adult social care sector and workforce in England, 2016. Leeds: Skills for Care.
- Tronto, J. (1993) *Moral Boundaries: a political argument for an ethic of care*, London: Routledge.
- Twigg, J. (1999). The spatial ordering of care: public and private in bathing support at home. *Sociology of Health & Illness*, 21(4): 381-400
- Twigg, J. (2000). *Bathing: the body and community care*. London: Routledge.
- Ungerson, C. (1997). Social politics and the commodification of care. *Social Politics*, 4(3): 362-381
- Ungerson, C. (1999). Personal assistants and disabled people: An examination of a hybrid form of work and care. *Work, Employment and Society*, 13(4): 583-600
- Vasey, S (2000). *The Rough Guide to Managing Personal Assistants*, London: National Centre for Independent Living.
- Wadensten, B., & Ahlström, G. (2009). Ethical values in personal assistance: narratives of people with disabilities. *Nursing Ethics*, 16(6): 759-774
- Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter) Dependence, needs and care: the potential for disability and feminist theorists to develop an emancipatory model. *Sociology*, 38(2): 331-350
- Williams, V., Ponting, L., & Ford, K. (2009). 'I do like the subtle touch': interactions between people with learning difficulties and their personal assistants. *Disability & Society*, 24(7): 815-828
- Williams, V., Ponting, L., Ford, K., & Rudge, P. (2009b). 'A bit of common ground': personalisation and the use of shared knowledge in interactions between people with learning disabilities and their personal assistants. *Discourse Studies*, 11(5): 607-624
- Woodin, S. L. (2006). *Social relationships and disabled people: the impact of direct payments*. [Doctoral Thesis]. The University of Leeds.
- Yamaki, C., & Yamazaki, Y. (2004). 'Instruments', 'employees', 'companions', 'social assets': understanding relationships between persons with disabilities and their assistants in Japan. *Disability & Society*, 19(1): 31-46