**Personal Assistance:
The Challenge of Autonomy**

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others.

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Abstract

This thesis investigates the employment of personal assistants (PAs) by disabled individuals in the UK. Personal assistance is considered to be one of the most essential services necessary for disabled people to achieve 'independent living', and as such the right to directly employ PAs and to receive the funding needed to do so has been a central campaign objective of the Disabled People's Movement (DPM) in the UK and elsewhere.

However, both the employment of PAs and the concept of 'independent living' contain contradictions. Waged employment has been identified as a source of disabled people's oppression, but in the personal assistance relationship it is treated as a means to their emancipation. The concept of 'independence' within the DPM framing of 'independent living' can be equated to autonomy, but the autonomy of disabled people is arguably achieved at the expense of that of PAs as workers.

Semi-structured qualitative interviews with both PAs and disabled employers of PAs were used to attempt to gain new insight into these contradictions. Topics covered in these interviews included the relationships between PAs and employers, their interaction with other social relationships, the occupational status of PAs and possible ways to improve it, and barriers to the implementation of personal assistance as it was envisaged by the DPM. Both PAs and their employers are severely impacted by the political economics of austerity and the cultural devaluation of 'dependence' and the labour associated with it.

Potential exists for organising personal assistance in ways other than direct employment of PAs by individuals, such as through co-operatives or informal collective models. However, all of these have advantages and disadvantages compared with direct employment. The thesis concludes with recommendations for policy, for further research and for action priorities within the DPM on personal assistance.

Contents

Glossary of abbreviations used in this thesis

BCODP = British Council of Organisations of Disabled People

CCG = (NHS) Clinical Commissioning Group

CIL = Centre for Independent (also Integrated or Inclusive) Living

CRPD = (United Nations) Convention on the Rights of Persons with Disabilities

DAN = (Disabled People's) Direct Action Network

DCIL = Derbyshire Centre for Integrated Living

DIG = Disablement Income Group

DLA = Disability Living Allowance

DPM = Disabled People's Movement

DPO = Disabled People's Organisation

ESRC = Economic and Social Research Council

EU = European Union

ILF = Independent Living Fund

JAG = Jämlikhet Assistans Gemenskap (Equality, Assistance and Inclusion in Swedish; the acronym is also the Swedish pronoun equivalent to "I")

LA = Local Authority

LGBT+ = lesbian, gay, bisexual, transgender and other minority gender/sexual identities

NCIL = National Centre for Independent Living

NHS = National Health Service

PA = Personal Assistant

PAC = Profession Allied to the Community

PAM = Profession Allied to Medicine

PSW = Personal Support Worker

RADAR = Royal Association for Disability and Rehabilitation

STIL = Stockholm Co-operative for Independent Living

ULO = User-Led Organisation

UPIAS = Union of the Physically Impaired Against Segregation

Chapter 1: Introductions

This thesis is about personal assistance. In this introductory chapter I first give a very basic overview of personal assistance, the central topic of study of this thesis. I then give an autoethnographical account of my interest in the topic and the seeds of my thinking about it which led me to undertake the research of which the rest of this thesis is an account. Finally, I summarise the other chapters and the overall structure of the thesis.

Personal assistance

While the term 'personal assistant' has other meanings in other contexts, in the context of the Disabled People's Movement (DPM) in the UK, a personal assistant (PA) is a person who is employed by a disabled person to assist them in their everyday life. PAs typically assist disabled people in their own homes with activities of daily living that they are unable to do for themselves due to the effects of living with impairments in a disabling society, but that would be considered 'normal' for non-disabled people to do for themselves. This may include assisting people to get out of bed, to dress and undress, to prepare and eat meals, etc. In some cases PAs may also accompany and assist disabled people in work or educational environments.

Much of what PAs do is traditionally considered 'care work', but not necessarily all. Boundaries may be unclear between work that is and is not considered appropriate for PAs to do; at one extreme, PAs may carry out complex and life-critical tasks involving medication or medical equipment that would be considered 'nursing' if done in a hospital setting rather than in a disabled person's home, while at the other PAs may do household tasks, such as gardening or decorating, that non-disabled people might also hire a paid worker to do. However, PAs are distinct from 'carers' in a traditional sense in that they are directly employed by disabled people and the disabled person is unambiguously the one 'in charge' in the relationship (Morris 1993). The establishment of this model of assistance was the result of sustained

campaigning by the DPM, and it is deeply valued by disabled people as a means of emancipation in everyday life; Vasey (2000, no page numbers), for example, describes using PAs as "a distinct disability experience of the liberating kind".

Considerable previous research has been done on personal assistance by many authors in the UK and elsewhere (notably Canada and the Scandinavian countries), within both academic frameworks and policy contexts. Some of these have focused on the relationships between PAs and their employers (e.g. Shakespeare et al 2017, 2018; Williams et al 2009a, b, 2010; Woodin 2006), while others have focused on the funding and policies that have enabled personal assistance, such as 'direct payments' from local authorities (LAs) and the Independent Living Fund (ILF) in the UK (e.g. Gramlich et al 2002; Leece & Bornat 2006; Morris 1993; Pearson et al 2014; Zarb & Nadash 1994). Some have gathered the views and experiences of both employers and PAs (e.g. Adams & Godwin 2008; Glendinning et al 2000; Shakespeare et al 2017, 2018; Woodin 2006) while others have focused primarily on PAs (e.g. Ahlström & Wadensten 2012; Christensen & Guldvik 2013; Rivas 2002; Ungerson 1999) or on employers (e.g. Grossman et al 2007; Morris 1993; Wedgwood et al 2018). A significant activist literature from within the DPM, in the UK and internationally, also exists on personal assistance (see for example Barnes 1993; DeJong & Wenker 1983; Heumann 1993; Ratzka 1986, 2015; Vasey 1996, 2000; Zarb 2003); however, most of this has not been based on primary or empirical research.

Consequently, my aim in my research was to draw equally on perspectives from both sides of the personal assistance relationship. Chapter 3 details my research interviewing both disabled people and PAs. I have also drawn on published accounts by both PAs and personal assistance users. As a disabled person (though not myself a personal assistance user) and an activist in the Disabled People's Movement, the foundations of my thought and my research are in the social model of disability (see Chapter 2). My aim is thus not merely to describe a phenomenon, but to create an analysis which can aid the struggles for liberation of disabled people, workers including PAs, and all other

groups experiencing oppression in present-day society. My allegiance to the DPM is not uncritical (indeed, I am dispositionally incapable of being uncritical of anything); however, my aim is for my critique to be constructive.

One key critique of the direct employment paradigm of personal assistance, as developed in the DPM, is that it is centred around a particular archetypical disabled person. This imagined 'typical personal assistance user' is generally a disabled person with a physical impairment, likely a wheelchair user, whose assistance needs concern everyday physical tasks, but do not include cognitive or emotional assistance. The archetypal personal assistance user is also likely to be conceived of as privileged with regard to social locations other than disability; thus 'he' is implicitly male, white, cisgender, heterosexual, and relatively wealthy. This means that assumptions about personal assistance, including about the typical tasks involved in the job, what the relationship between employer and PA should be like, and what forms of support services would be useful for PAs and/or employers, are arguably based on the typical needs and preferences of a relatively small subset of all disabled people with personal assistance needs. These issues are discussed in several chapters of this thesis, and particularly in the conclusion. However, as discussed in the methodology chapter, the disabled employers interviewed for this research, while somewhat diverse in terms of gender, ethnicity and economic status, were relatively homogeneous in terms of assistance needs, for the most part conforming to the archetype of a personal assistance user.

Key themes

While the individual chapters of this thesis focus on specific themes arising from the research (see chapter summaries below), there are a number of key themes that run through the whole thesis. Foremost among these is autonomy, as befits the thesis title. Autonomy is a crucial concept in analysing the various forms of oppression and exploitation that both disabled and non-disabled people are subjected to in contemporary capitalist society, and potential routes to overcoming them. This thesis does not address all possible aspects of autonomy as they apply to disabled people and PAs; in particular, psychological

perspectives on autonomy and non-autonomy as they are applied internally to the self are not covered. However, autonomy is approached in it from two main angles. Firstly, the denial of autonomy in daily living to disabled people through segregation, institutionalisation and various paternalistic forms of 'care' provision is one of the most significant aspects of disabled people's oppression in modern times. Therefore autonomy, albeit more often conceptualised in terms of 'independence' (I argue in Chapter 2 that the definitions of 'independence' used in this context refer to autonomy rather than to 'independence' as more commonly understood in contemporary society) has been a central focus of disabled people's movements in the UK and elsewhere. Personal assistance has been a crucial component in these struggles (Davis 1990; DeJong & Wenker 1983; Ratzka 2015).

Secondly, autonomy has been a key term in analysis of, and in struggles against, the exploitation of workers in the capitalist wage labour system (see e.g. Berardi 2009; Gorz 1982; Weeks 2011). PAs, as waged workers, can be seen as selling their autonomy to disabled people so that they may realise their own autonomy, raising the central question of whether the autonomy of disabled people and of workers assisting them are inevitably in conflict with one another. Thus another key theme in this thesis is work and its various meanings and connotations; not only the paid work of PAs, but also the unpaid and often unrecognised work done by disabled people in managing and otherwise interacting with PAs, and the work (paid and/or unpaid) by disabled people in many other contexts that personal assistance can enable.

Another key theme connected to the above is the relationships, including affective relationships and power relationships, between disabled people with assistance needs and those who assist them. Relationships, as many authors have argued (e.g. Arneil 2008; Nedelsky 1989; see Chapter 2), are the foundation of individual autonomy. Both PAs and their employers have power over one another in various forms, and the shift in the balance of power from non-disabled 'carers' to disabled people has been a central objective in the establishment of personal assistance services by disabled people's movements. The complex and contested concept of 'care' and its various connotations and

contradictions is thus another theme that runs through this thesis, though it is not directly focused on.

A final theme running throughout this thesis, though coming particularly to the forefront in Chapters 6 and 7, is the urgent political and economic situation facing disabled people in the UK today. As an activist in the British DPM, I have aimed to make this thesis not merely of academic interest, but also relevant to disabled people's lived experiences, day-to-day struggles and collective organisation against oppression. In the UK in 2018, the policies of austerity and cost-cutting that have been relentlessly pursued by Conservative-led governments since 2010 have had a vastly disproportionate impact on disabled people (Dodd 2016), and arguably constitute the most acute form of disablement currently experienced by people with impairments, but perhaps particularly those with significant assistance needs. This forms the background context to many of the arguments made throughout this thesis.

My journey here: an autoethnographical account of my interest in Disability Studies and in personal assistance

In including an autobiographical section in this introduction to my PhD thesis, my aim is not to be one of what Barnes (1998, p.146) calls "the true confessions brigade; those intent on writing about themselves rather than engaging in serious political analysis of a society that is inherently disabling for increasingly large sections of the population". Rather, my aim here is to present what is simultaneously a potted political autobiography (in a similar vein to Finkelstein's (2001, 2008) and Oliver's (2009) writings on the origins of their theorisation of disablement in their lived experiences) and an autoethnographical account contributing to my research by using my own lived experience to "elucidate larger cultural meanings" (Castrodale & Zingaro 2015, no page number) of disability and assistance that are embedded within it. In the spirit of Thomas's (1999) inclusion of her own experiences alongside those of her research participants in her discussion of 'disability and the social self', I also aim to trouble the separation of researcher from research in considering my own experience as an additional source of 'data' (for more on reflexivity and the

impossibility and undesirability of 'independence' in politically committed disability research, see Chapter 3).

My interest in personal assistance as a research topic stems from multiple dimensions of my political and personal life experience. Its earliest roots are arguably in my experiences as a teenager - not yet identified as a disabled person - in the mid to late 1990s involved in volunteer work with a local youth organisation which ran 'after-school clubs' and daytime activity sessions during the school holidays for teenagers and young adults with learning difficulties and/or physical impairments, with (supposedly) non-disabled young people of a similar age group volunteering as supporters. (Looking back, I am sure that I was not the only person with an undiagnosed neurodivergent condition among the supposedly non-disabled volunteers, and that many of us got involved because of an unformed awareness of our own divergence from cognitive normalcy.) This led to further volunteering on a summer holiday camp run by a major disability charity, for a similar 'client group', while I was at university, and to my considering working as a 'carer' for people with learning difficulties as a career.

Throughout these volunteering activities, I was conscious of an uncomfortable divide between the non-disabled volunteers and the disabled 'client group', whose presence and involvement was not so clearly voluntary, one that seemed similar yet different in its power relations to the 'class divide' between workers and employers, and which I did not really know how to deal with. I remember wishing that it would be possible for the two groups of young people to relate to one another without barriers or boundaries as genuine friends and equals, and yet feeling that an inescapable yet hard-to-define structure made this in practice impossible. At a deeper and even more uncomfortable level, I felt an undeniable and disturbingly strong identification with many of the young disabled people, feeling that I had in some ways more in common with them than with my 'typical' age-peers. Simultaneously, and perhaps or perhaps not coincidentally, my radical politics were developing through my experiences as a young student living in poverty, partially estranged from my parents, living in the private rented

sector and struggling to keep various low-level jobs in supermarkets and warehouses.

When I got to university, studying politics and international relations, I rapidly became involved in student activism on left-wing and environmental issues and in the movement against the wars in Iraq and Afghanistan, and developed a political identity as an anarcho-communist. While at university I had a relationship with a fellow student activists who had physical and visual impairments and lived in university accommodation with assistance from Community Service Volunteers (see Parker 1999), with whom I remember feeling complex tensions around physical intimacy and informal assistance with daily tasks. This relationship was my introduction to many disability issues from a very different perspective to my previous benevolent/charitable one, including the idea of self-directed personal assistance.

After the break-up of that relationship in 2003, I temporarily dropped out of university due to its emotional impact leaving me unable to concentrate on my studies (as well as some disillusionment with my degree subject), and I contemplated instead seeking a career in the 'care' sector, with the reasoning (common in my experience among people with broadly anti-capitalist politics) that it was one of the most genuinely useful and least ethically problematic types of job available in a capitalist society. I got a job with an organisation which ran residential homes for adults with learning difficulties, working temporarily in one of their existing homes before the new one for which I had been recruited was opened; however, I rapidly found the organisation to be problematic in ways that I had not expected, and their policies and procedures clashed directly with my ethical instincts.

One incident particularly stands out as highlighting this: an older man with learning difficulties living in the home regularly visited a transport museum (enabled by the staff) because of his interest in trains. In an attempt to make casual conversation, I asked him if he was going to the museum that week and what he liked to look at there. A senior member of staff told me that I should not talk to him about this because it was "encouraging his obsession". When I

countered that he was as entitled to his interests as any of us, I was met with a reply that it was in his 'care plan' to discourage him from talking about topics he was considered to be 'obsessed' with and that not adhering to this plan constituted 'neglect'. After this incident, other staff members became passive-aggressively hostile to me, setting me up to be considered 'useless' by doing tasks that were supposed to be my responsibility and not telling me they had already been done. While I was told that I would be informed when the new home would open and what my work rota would be there, I was left with no information for several weeks, and then when I called them to ask I was told that they were not giving me a permanent contract because of 'incidents' making me 'inappropriate' for the job.

The emotional impact of this, following on from the relationship break-up and dropping out of university, led me to a 'rock-bottom' realisation that the many social and interpersonal difficulties that I had had in every phase of my life, which I had previously attributed to many different causes, were connected, and that the level of identification - in stark contrast to most of the non-disabled staff in the care organisation - that I felt with the people with cognitive impairments who I had known through voluntary and paid work experience was undeniable evidence of an identity as an autistic person, of which I had previously been somewhere between not consciously aware and in denial. I was lucky enough to find the online writings of several autistic activists on the now defunct website autistics.org, and to make contact with a local autistic social/support group run by someone who was also involved in the Disabled People's Movement. This, combined with conversations I had had with my ex-partner, let me to discover and start reading about the social model of disability, at the same time that I sought assessment and diagnosis for myself, which I eventually got through university disability support services when I returned to complete my degree in 2005. The social model was a revelation to me, seemingly filling in the 'missing pieces' in my patchwork analysis of the society I lived in, and I set out to find whatever literature and discussion that I could on the subject.

I was at the same time involved in direct action movements on anti-war and environmental causes, and thus was desperate to make contact with the

Disabled People's Direct Action Network (DAN), which I had first heard about through a Big Issue article in 1999. I finally made contact with DAN at a demonstration outside the Labour Party conference in Manchester in September 2006, and was introduced to a DAN activist who lived locally to me. While DAN itself was in a period of relative inactivity at the time, I got involved with his (ultimately futile) attempt to rebuild a local disabled people's organisation which had, at the time we met, recently lost its funding. This eventually led to him employing me as his personal assistant in 2008.

My job as a PA was in many ways a relatively easy one, as my employer did not need particularly extensive personal care; thus my duties mostly consisted of housework such as cooking and shopping and accompanying him to various events and meetings. However, there were tensions around the boundaries of the working relationship, in particular the borderlines between me working for him as a PA and he and I 'working' - or perhaps better put collaborating - together as political activists. While one of these relationships was an obviously hierarchical one, with me carrying out as directly instructed by my employer those tasks that he was physically unable to do himself, the other was supposedly - or at least ideally in my vision of it - a non-hierarchical one between equals. However, these boundaries became blurred, leading to situations that I felt uncomfortable with, such as having lengthy debates about political tactics while supposedly on my paid work time as a PA (thus resulting in household tasks going undone), or my employer asking me to write press releases or letters to the council for him, neither dictating nor writing collaboratively, but asking me to do the creative work of writing while representing his views only. These tensions came to head after a year and half in the job, over my involvement in planning a direct action that he did not support, which led to him sacking me as his PA. Friends suggested that I could take him to an employment tribunal for unfair dismissal; however, I saw no point in this as I saw the situation as a 'falling out' with both of us equally at fault and felt that no one would gain from a punitive legal process that would likely further divide activist communities.

At the same time as I was working as a PA, I was involved in other activist projects outside the Disabled People's Movement, within a broad anti-capitalist milieu, including Food Not Bombs, the Camp for Climate Action and a number of squatted social centres and short-term building occupations. The majority of other people involved in these groups and movements were non-disabled people, and they often involved significant unexamined ableism (see also Fenney 2017); indeed, some of the social centres and building occupations were not even wheelchair-accessible. Many of the people involved worked in the "care" sector and talked about the disabled people they worked with in ways that made it clear that they did not realise, despite subscribing to political ideologies that were ostensibly against all 'power-over' (Gordon 2008), that they were exercising power over them and that the relations in institutional 'care' were relations of oppression. Most were unfamiliar with the social model of disability and the concepts of 'independent living' and self-directed personal assistance; frequently, when I told people about my job, they responded by saying that it sounded similar to ruling-class people employing household servants (on this see also Shakespeare et al 2017; Vasey 2000).

I remember one conversation, in the kitchen of a Radical Routes housing co-op, involving someone who had grown up in a Camphill community (see Chapter 8), in which I was trying to explain how PAs being directly employed by disabled people reversed the power relations of traditional 'care' models because the PA's need for the income from the job balanced out the disabled person's need for assistance; she responded "so you think it's better for people doing care work to be motivated by a profit motive than by an altruistic motive?". Around the same time (about 2010), I remember trying to explain the principles of anarchism to someone I knew through the DPM - who like many in that movement positioned herself strongly within the social-democratic Labour Party tradition - and getting the response that "it sounds a lot like David Cameron's 'Big Society'" (see Chapter 8 for further discussion of this in the context of personal assistance).

These conversations, among others, contributed to my growing feeling that there were unexplored tensions and possible contradictions between the DPM

and other 'radical' or 'activist' movements and communities (see also Horsler 2003). The 'non-disabled' activist groups that I was involved in had a strong ethos of 'DIY culture', emphasising autonomous capacity, learning and practicing skills for action (whether that action was disrupting the activities of opponents like the military or environmentally damaging corporations, or building alternative infrastructures) that often required normative physical and cognitive abilities, and avoiding reliance on professional elites or the state (though many activists did claim state benefits and saw this as taking resources from the system to use against it).

I also felt like questions around work and employment were central to these potential contradictions on multiple levels. My own political conviction, like that of many if not all within the movements I was involved in, was strongly 'anti-work', opposed to notions of productivity and the 'Protestant work ethic' employed as an ideological tool by capitalism, and regarding most paid jobs as pointless at best and actively harmful at worst (see also Graeber 2013; Weeks 2011). Where productive activity was genuinely useful and/or necessary, the general consensus was that the best way to organise it would be in non-hierarchical collectives or co-operatives, in which no one was anyone's 'boss' or got to exploit anyone else's labour. This was informed both by a communist opposition to the notion of exchange-value and by an anarchist opposition to all 'power-over' relations (though, as hinted at above, there was sometimes a failure to adequately analyse 'power-over' relations that were not directly about the exploitation of the less powerful by the more powerful).

The analysis of founding theorists of the DPM such as Finkelstein (1980), Oliver (1990) and Abberley (1996) that the transition from agricultural to industrial society and the capitalist organisation of manual work was the primary cause of (the modern form of) disabled people's oppression thus made perfect sense in the context of my wider politics, but the irony of the fact that I was in a hierarchical boss-employee relation with the fellow activist who I worked for as a PA, as part of a practice held to be essential for disabled people's liberation, did not escape me. On one level I felt that, like the use of unemployment benefits to fund unpaid activist work, this was a subversive use of state funding against

oppressive systems; on another, I wondered whether the position of authority held by employer over PA could be justified within an ethical position of opposing all authority, and this led me to the question of how disabled people could possibly get their assistance needs met in a non-oppressive way in a society without either a state or money, like the one I claimed to be fighting for.

Moving to another city after the loss of my PA job led to me making contact with the academic Disability Studies community for the first time through a series of free conferences (my previous knowledge coming from what literature I could find online or in second-hand bookshops). This led to my second significant personal relationship, with someone who was at the time doing a PhD in Disability Studies, and friendships with others in the same academic scene, including both postgraduate students and established academics, through which I was empowered to enter the academic Disability Studies world myself, first through presenting at conferences and then through getting a place on the MA in Disability Studies at Leeds.

At this point personal assistance was only one of several areas that I had a particular interest in related to my own experiences, and I could have seen myself just as easily at that point focusing on (for example) the experiences of people with cognitive or 'non-physical' impairments in the DPM or the relationship between concepts of 'impairment' and 'disability' with regard to neurodivergence and/or 'mental health' experiences. However, when I saw that ESRC funded PhD positions were being advertised, I chose the personal assistance idea to base my application on because, out of all the areas within Disability Studies that I would have liked to research and write about, it fit best with the themes specified in the call for proposals.

I did this knowing that I was choosing a research topic that would involve very big questions, both politically and personally, that I both felt compelled to and thought it might not really ever be possible to answer. I was somewhat amazed that a research council had even agreed to fund a research proposal with such an obviously anti-capitalist theoretical foundation and on such an arguably obscure topic (while my experiences had led me to find the question of PA work

personally compelling, on an intellectual level I fluctuated between feeling like it was potentially the key to a new anti-capitalist analysis of the whole of present-day life and like it was such an obscure and specific area as to be only of interest to a tiny number of people with personal connections to it).

Thus I set out with a grand vision of drawing from both academic and activist literatures from the DPM and anti-work/anti-capitalist movements to attempt to resolve the central contradictions raised up by the concept of personal assistance - between wage employment as the system excluding and oppressing disabled people and as a tool for their liberation, and between the autonomy of personal assistants as workers and the autonomy of disabled people in their everyday lives - and to set out a utopian blueprint for how it might be possible for disabled people's daily assistance needs to be met in a stateless and moneyless anarcho-communist society. In this spirit, I came up with the list of research questions presented below.

Research questions

The initial research questions which I sets out to answer in this thesis were:

> 1) How is the work of personal assistance understood/conceptualised
> by both those who 'give' and 'receive' it?
> > 1a) What, if anything, meaningfully distinguishes PA work from
> > other forms of heteronomous labour (i.e. work done for a 'boss' in
> > exchange for a wage)?

> 2) What advantages and disadvantages does direct employment of
> PAs have over other possible models of assistance, for disabled
> people and for PAs as workers?

> 3) What are the power relations between disabled people who need
> personal assistance and those who assist them?
> > 3a) Are these power relations fundamentally different depending
> > on whether those who assist are paid a wage or not?

4) Does the direct employment model of personal assistance actually emancipate disabled people in the way it is claimed to (or in the way that the Disabled People's Movement wanted it to)?

5) What are the tensions between (a) the anti-capitalist foundations of, and critique of waged work as a cause of disablement by, the Disabled People's Movement, and (b) that movement's promotion of the direct employment of PAs by disabled people as a means to their emancipation?

6) How can disabled people get the assistance they need with everyday living without denying the autonomy of either disabled people or those whose role it is to provide them with assistance?

7) How could disabled people who need personal assistance be given control over their daily lives in a society that was not based on capitalist concepts of waged labour and exchange value?

Not all of these questions were ultimately answerable, and my focus became necessarily narrower during the process of conducting research (which is documented in Chapter 3). In particular, questions 6 and 7 proved almost impossible to get answers to through qualitative interviewing. However, I have attempted to address this deficit as far as possible through the use of relevant literature (see in particular Chapter 8).

Summary of other chapters of this thesis

Chapter 2 covers the conceptual and theoretical background to this thesis. Starting with the policy context of personal assistance in the UK, I briefly consider its history in order to place it in relation to the Disabled People's Movement and its concept of 'independent living'. This constitutes a significant reinterpretation of the meaning of the term 'independence' from its 'common-sense' meaning of self-sufficiency or doing things for oneself. Therefore, I

analyse usages of the term 'independence' and argue that, while it remains widely used, the more accurate term for the goal of the 'independent living' movement is autonomy. Autonomy is also a concept which can be used to analyse and problematise wage labour and capitalism, and bodies of theory which do so have potential for productive synergy with the theory and practice of the DPM (Graby 2015; Richter 2017). Therefore, it can be used to connect both 'sides of the dialectic' (Erevelles 2011) of personal assistance, disabled people as employers and PAs as workers. In this chapter I also explain important background concepts such as the individual and social models of disability.

Chapter 3 details my research methodology and my experience of carrying out a qualitative research project as a disabled researcher who is ambiguously positioned as 'insider'/'outsider' (Vernon 1997) with regard to participants in the research. In it I explain my rationale for choosing semi-structured qualitative interviews as a research method, and consider whether or not research done for a doctoral thesis can be regarded as 'emancipatory research' (Oliver 1997; Stone & Priestley 1996), concluding that the methodology of research is arguably less important in determining this than its findings and impact. I also discuss issues around sampling, demographics and representation, and the reflexive and relational ambiguities of interviewing friends and movement comrades for academic research (Taylor 2011).

Chapters 4 to 8 present some of the findings of my research, each focusing on different aspects of personal assistance that were discussed by my interviewees and connecting them with previous research and with social theory. This does not cover anywhere near the whole of the data which was generated by my interviews (I hope to cover some of the findings not covered here in future publications). Instead, in order to fit within the length requirements of a PhD thesis, I have chosen some of the key emergent themes from the data that help to shed light on the core themes outlined above of autonomy, power, work, relationships and the contemporary conditions of disablement in 'austerity Britain'.

Chapter 4 focuses on relationships, including both the relationships between PAs and direct employers and the impacts (positive and negative) of personal assistance on direct employers' other relationships. While there is a 'received wisdom' (Vasey 1996) in the DPM of relationships between direct employers and PAs being purely transactional and emotional intimacy being inadvisable, intimate relationships nonetheless existed and were seen by many employers as unavoidable. Drawing on Woodin's (2006) concept of 'paid friendship', I examine sociological literature on friendship to consider whether friendship between employers and PAs can and/or should exist, and the role of differences between types of impairment and consequent support needs in determining this. Personal assistance also has wider impacts in direct employers' relational lives. While for many it removes burdens of informal caring labour from other relationships, the presence of a PA can also inhibit and/or complicate interaction with other people in direct employers' 'personal communities' (Spencer & Pahl 2006). This arguably relates to a lack of recognition of the role of PAs in wider society.

Chapters 5 and 6 both consider the status of personal assistance as an occupation, through the lenses of different concepts within the sociology of employment. **Chapter 5** focuses on the concept of professionalism, the terminology of which was used by interviewees in several different (and sometimes contradictory) ways to describe both desirable and undesirable occupational norms. The role of PAs exists in contrast to that of the traditional 'professions allied to medicine' (Finkelstein 1999a, b), which are characterised by occupational autonomy and authority over their 'clients'. However, in discussions of personal assistance, the term 'professional' is used both in a negative sense consistent with this and in an apparently positive sense which describes desired characteristics of PAs as an occupational group, reflecting the distinction made by Evetts (2013) between 'occupational' and 'organisational' professionalism. In this chapter I attempt to disambiguate these usages and to address the question of whether PAs can be said to be an example of the 'professions allied to the community' that Finkelstein (1999b) argued must be established, replacing the 'professions allied to medicine', in order to bring about disabled people's liberation from paternalistic 'professional' domination.

Chapter 6 looks at other aspects of PAs' occupational status. The work of PAs is neither well-paid nor well-recognised, despite its being socially necessary and more likely to be appreciated by workers as 'meaningful' than many other jobs with comparable pay and status. This is arguably connected to the devaluation of both disabled people themselves and of work connected with them, which may be additionally stigmatised by its association with 'dirty' aspects of the body and with femininity (Ashforth & Kreiner 1999; Casas-Cortés 2014). PAs are also precarious workers, lacking many forms of employment security (Standing 2011). Unlike many other precarious workers, however, PAs are in an unusual position relative to their (direct) employers, as they too are subject to 'precarious life' (Bates et al 2017) and do not hold the economic power over workers that typical employers do; instead, both employer and PA are at the mercy of governmental actors who control the distribution of funding. This mutual dependence and relative equality creates possibilities for solidarity between PAs and employers that are hard to imagine elsewhere, and constitute a significant difference between personal assistance and most forms of employment. I also argue that efforts to improve the occupational status of PAs must pay attention to both redistribution and recognition (Dodd 2016; Fraser 1995).

In **Chapter 7**, I examine the barriers to personal assistance functioning how it 'should' (or was intended to) for direct employers and consequently also for PAs. These include the insufficiency and insecurity of public funding for employing PAs, a lack of adequate support with many administrative aspects of employment (including things like tax and payroll management as well as recruitment, training and retention of PAs) and attitudinal barriers within local authorities. The context of these barriers is the politics and economics of austerity, which in the UK since 2010 has has a disproportionate impact on disabled people in general and on those with personal assistance needs in particular (Dodd 2016). Various potential solutions were suggested by participants to these barriers, at several levels of divergence from the status quo. Some of these solutions could be implemented, with sufficient funding, by

local authorities, while others could best be achieved by strengthening of peer support from Disabled People's Organisations (DPOs).

Chapter 8 follows on from Chapter 7 to consider more radical potential solutions in the form of alternatives to the direct employment of PAs by disabled individuals. These could include the employment of PAs by DPOs or co-operatives instead of by individuals, which could lessen the administrative burden on the individual without necessarily altering the fundamental relationship between PA and 'employer' (Priestley 1999; Roulstone & Hwang 2013). Other possible alternatives include a variety of models of support which are not based on waged employment. Some of these models, frequently developed in response to the support needs of people with cognitive rather than physical impairments, rely on voluntary commitment and/or sharing of home life in 'intentional' communities. These typically do not originate from disabled people; however, one alternative model emerging from the more radical strands within the North American DPM is that of 'care collectives' (Hande & Kelly 2015). These models in some ways challenge capitalist and patriarchal norms more radically than the direct employment of PAs, but also run a risk of co-optation by conservative and individualistic agendas (Beresford 2016).

In my concluding chapter (**Chapter 9**) I bring together and summarise the findings presented in chapters 4 to 8, attempting to draw out and synthesize the important threads of knowledge and theory contained therein. Rather than merely recapitulating the chapter summaries here, I connect these threads between the chapters to better present the findings of my research as a whole body of work. I then revisit the concept of 'independent living', as first discussed in Chapter 2, in the light of my findings, examining its relationship to shifts in recent decades in the forms of oppression most acutely experienced by disabled people from paternalistic social protectionism to individualistic marketisation (Dodd 2016). Finally, I give recommendations from my findings for policy, for further research and for the Disabled People's Movement.

Chapter 2
Personal assistance, (in)dependence and autonomy: an overview

This chapter gives an overview of the theoretical and policy background to this thesis. Firstly I place personal assistance within the policy and economic context of the present-day UK. The history of the establishment of the direct employment model of personal assistance shows its conceptual roots in the struggles of the Disabled People's Movement for 'independent living', a concept which challenges normative definitions of 'independence', aligning it not with self-sufficiency but with autonomy. This concept of autonomy is not in opposition to relatedness with or material dependence on other people, but is rooted in relational concepts of interdependence, which are consistent with the social model of disability. The relationship of autonomy to waged work and anti-capitalist struggles against it is then examined in relation to the PAs' perspective on personal assistance.

Personal assistance in the UK policy context

In the UK, disabled people typically get funding for personal assistance from the social services departments of local authorities. This is generally referred to as 'Direct Payments' (Glasby & Littlechild 2016), as it constitutes a payment directly to an individual with support needs, which they then use to purchase a service, rather than the provision of a service to an individual by the local authority. While there are other services that direct payments can be used to purchase, the typical paradigm in the UK is for disabled people to directly recruit and employ their own PAs, paying the PAs a wage from the money they receive as direct payments (and/or the aforementioned other sources) and taking on the legal and financial responsibilities of an employer (with or without support from their LA or other agencies). In this thesis, I refer to this paradigm as the 'direct employment model' of personal assistance, and to disabled people who employ PAs as 'direct employers'.

Some disabled people may also employ PAs with funds from other sources, such as NHS continuing healthcare funding, Access to Work for those who employ PAs in the workplace or Disabled Students' Allowances for those who employ PAs in educational settings (Dunn 2016; Hale 2017; NHS England 2014). Until 2015, some disabled people, particularly those with the most extensive impairments, also received funding from the now-closed Independent Living Fund (Porter & Shakespeare 2016). However, the model of employment is usually the same regardless of the source of funding.

The majority of the disabled people who employ PAs in the UK have physical impairments, or if they have multiple impairments use PAs primarily for assistance needs relating to physical impairment. This may because the direct employment model of personal assistance is more suited to the types of assistance that are needed by people with physical impairments, which may be easier for the disabled person to direct another person to provide (Gramlich et al 2002; Williams et al 2010). However, evidence shows that it has been more difficult for people with 'non-physical' impairments (such as mental health conditions or learning difficulties) to access direct payments (Glasby & Littlechild 2016; Ridley 2006; Williams & Holman 2006). This may be connected to the fact that the early DPM in the UK primarily consisted of people with physical impairments and that the philosophy of 'independent living' was developed largely in the context of the specific assistance needs of people with physical impairments who were struggling for their right to live in the community rather than in institutions (Barnes & Mercer 2006; Hall 2009). However, some people with other types of impairment such as mental health conditions or learning difficulties do also employ PAs, though in these cases the relationship between employer and PA may be somewhat different from that typically assumed in the direct employment paradigm (Gramlich et al 2002; Williams et al 2009a); this will be discussed in greater depth in Chapter 4. Members of these groups who get direct payments may be more likely to use them to purchase other types of services (Gramlich et al 2002; Maglajlic et al 2000).

The direct employment model of personal assistance also exists in other countries, including Australia, Canada, Norway, Sweden and the US (Askheim

et al 2014; Kelly 2016; Matsuda et al 2005; Wedgwood et al 2018), with some differences in eligibility and varying funding sources between jurisdictions. In most of these countries, as in the UK, it was established as a result of campaigning by disabled people's movements, as part of a broader campaign to achieve 'independent living' for disabled people (see below section).

The direct employment of PAs by disabled people in the UK began in the early 1980s with individuals and small groups of people who managed to get funding to employ PAs at home, either from national government through the benefits system or from LAs through the budgets with which they funded residential institutions, or a combination of both (Evans 2003). These groups were in some cases the starting point for the development of Centres for Independent Living (CILs) and other formalised DPOs in the UK. Some of the arrangements negotiated with LAs involved direct payments from the LAs to individuals, whereas others were 'indirect' payments via trust funds or other intermediary bodies (Barnes & Mercer 2006; Zarb & Nadash 1994).

Somewhat larger numbers of disabled people were enabled to directly employ PAs by the Independent Living Fund (ILF), which was created in 1988 after lobbying by the Disablement Income Group (DIG) in response to the cutting of other state benefits which had enabled some disabled people to purchase at-home services (Morris 1993; Porter & Shakespeare 2016). The ILF was administered as a charitable trust rather than as part of the 'mainstream' state benefit system (Kestenbaum 1993), which meant that the numbers of disabled people who could access it were always limited by the amount of money in the fund, and its eligibility criteria were tightened several times before its eventual closure to new applicants in 2010 and complete abolition in 2015 (Pearson et al 2005; Porter & Shakespeare 2016). However, its strong appeal to and appreciation by disabled people provided evidence for the desirability of direct employment of PAs over traditional LA provision (Barnes & Mercer 2006).

The making of direct payments to individuals by LAs' social services departments was made a part of mainstream provision by the Community Care (Direct Payments) Act 1996 (Barnes & Mercer 2006). This followed policy

guidance issued in 1990 by the Department of Health stating that cash payments to individuals by LAs were illegal in England and Wales under the 1948 National Assistance Act (Morris 1993), and a consequent campaign by the British Council of Organisations of Disabled People (BCODP) for the law to be changed to allow direct payments, which gained support from MPs and associations of local authorities (Evans 2003). The campaign was also supported by the research of Zarb and Nadash (1994) for the Policy Studies Institute (commissioned by the BCODP), which showed that direct payments were cheaper for LAs than direct service provision (Pearson 2000).

Initially the Community Care (Direct Payments) Act was permissive rather than mandatory legislation, giving LAs the power to make direct payments at their own discretion within the eligibility criteria (Barnes & Mercer 2006; Glasby & Littlechild 2006), which resulted in uneven provision and relatively low numbers of disabled people using direct payments (Barnes 2007a). The National Centre for Independent Living (NCIL) was established by the BCODP in 1999 to "provide a coordinated approach to developing independent living-type services" (Barnes & Mercer 2006, p.5) and thus address these issues. Among other activities such as publishing a national database of personal assistance support schemes, NCIL commissioned the 'Creating Independent Futures' research project, which provided further evidence for the value of independent living to disabled people in the UK, the centrality of user-controlled personal assistance to independent living, and the need for funding of CILs and other DPOs to support personal assistance provision (Barnes et al 2000; Barnes & Mercer 2006; Morgan et al 2001).

The Health and Social Care Act 2001 made offering direct payments to eligible people who "consent to and are able to manage payments" mandatory for LAs in England and Wales (Glasby & Littlechild 2006); the 2002 Community Care and Health (Scotland) Act did the same for Scotland (Pearson et al 2005). This was arguably the start of a move towards user-controlled personal assistance, and 'independent living' principles more generally, becoming a much more mainstream part of adult social care provision in the UK, which was given further impetus by the publication by the New Labour government in 2005 of the

report 'Improving the life chances of disabled people' (PMSU 2005) and by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006 and ratified by the UK in 2009 (United Nations n.d.). Article 19 of the CRPD, focused on independent living, grants disabled people the right to "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community" (United Nations 2006, p.37).

While "the promotion of independent living" was considered to be "the centrepiece of the strategy" (PMSU 2005, p.12) set out in the 2005 report, and personal assistance was acknowledged in it as complementary with other services needed for achieving independent living (such as accessible transport and housing adaptations), the report also marked a shift from the promotion of direct payments specifically for personal assistance, towards a broader and vaguer concept of 'individual budgets'. Individual budgets were intended to combine "existing funding streams that are currently fragmented" (p.12), thus reducing the need for multiple assessments, and to be provided as a choice of either direct payments, services provided by LAs, or a combination of both. This shift has continued in more recent years with use of terms such as 'personalisation'. This has been argued to be a move away from the original values of direct payments and towards cost-cutting and privatisation (Beresford 2011; Williams-Findlay 2015).

Many of the recommendations of the 'Improving Life Chances' report were also never implemented and efforts to implement them were largely abandoned after the election of a Conservative-led coalition government in 2010. Direct payments are still only received by a minority of people eligible for adult social care provision (Glasby & Littlechild 2016). The accessibility of direct payments to many disabled people has also been increasingly threatened since 2010 by cuts to local authority budgets and the introduction of charging policies (Duffy 2013; Graby & Homayoun 2019); this will be discussed in greater depth in Chapter 7.

'Independent living' in the Disabled People's Movement

Although it arguably had precursors in countries such as Sweden and Denmark in the early decades of the 20th century (Ratzka 1986), the movement for 'independent living' in its currently understood sense is generally regarded as having begun in the US in 1962 with a housing and personal support programme for disabled students at the University of Illinois. It gained wider recognition with the establishment of the first CIL in Berkeley, California in 1972 after a group of students who had been provided with personal assistants at university wanted to continue living with independent assistance after graduation (DeJong 1983; Finkelstein 1984). Disabled activists from the UK, as well as other European countries, travelled to the US to visit the Berkeley CIL in the late 1970s and early 1980s and returned with the intent to create similar resources in the UK; this led to the nearly simultaneous foundation of the first two CILs in the UK in Hampshire and Derbyshire in 1984-5 (Davis 1990; Evans 2003).

CILs are organisations run and controlled by disabled people, and in the UK are part of the broader Disabled People's Movement (DPM) and are often connected to other local disabled people's organisations (DPOs). Their functions include providing information, peer support, advocacy, supporting individuals with getting and managing funding and employing PAs, assessment of support needs, campaigning and lobbying (Priestley 1999, Barnes & Mercer 2006). Some CILs have historically also employed PAs on behalf of disabled people who did not want or feel able to take on the responsibilities of an employer themselves (Priestley 1999). An original major aim of many CILs was to achieve deinstitutionalisation of disabled people in their local areas (Davis 1984, 1990).

In a relatively narrow sense 'independent living' can be seen - particularly in the historical context of its rise as a concept and slogan of the movement - as being about disabled people getting out of institutions and achieving control over their housing and personal assistance, but in a wider and more holistic sense it is about disabled people having equal rights and opportunities to non-disabled

people in all aspects of life (Morris 1993; Zarb 2003). Therefore it is inextricably linked with other key concepts of the DPM, such as the social model of disability (Finkelstein 2007; Oliver 2009). Hasler (2003, no page number) describes independent living as "the emancipatory philosophy and practice which empowers disabled people and enables them to exert influence, choice and control in every aspect of their life". For Morris (1993, p.21), this philosophy is based on four core assumptions:

- that all human life is of value;
- that anyone, whatever their impairment, is capable of exerting choices;
- that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;
- [and] that disabled people have the right to participate fully in society.

The Derbyshire CIL identified the 'Seven Needs for Independent Living', which provided it with a framework for practical service provision and were taken up by DPOs across the UK (Davis 1990; Barnes & Mercer 2006). These needs, in their original order, were:

- (accessible) information
- counselling (perhaps better referred to as 'peer support' or 'advocacy', as it was not intended to mean the individual therapeutic support that the word 'counselling' now generally refers to)
- (accessible) housing
- technical aids
- personal assistance
- (accessible) transport
- access (to the wider built environment)

Of these, housing, technical aids and personal assistance were seen as the "three key elements" which were "tightly inter-related" and were "thought about

in that sequence" (Davis 1990, p.6), because accessible housing was the first necessity for moving disabled people out of institutions, housing design then facilitated the use of assistive technology, and this in turn had an impact on the rehoused disabled person's level of need for personal assistance. Independent living is thus not reducible to personal assistance; personal assistance is one necessary, but not sufficient, requirement for disabled people to achieve equal autonomy with non-disabled people (Barnes & Mercer 2006). However, personal assistance is regarded by many disabled activists as very much central to the concept of independent living, because of the crucial importance of the shift in power relations between disabled people with daily assistance needs and those who deliver that assistance (DeJong & Wenker 1983; Vasey 2000).

The term and concept of 'independent living' have been criticised from anti-capitalist perspectives within the DPM (e.g. Finkelstein 2004; Richter 2017). These critiques have tended to focus on the problematic concept of 'independence' and its potential associations with individualism and capitalism (see below section). Finkelstein (2004, p.29), for example, declares 'independent living' to be a 'lie' because of the necessary interdependence of all human beings in society, and thus to pretend that 'independence' is possible is to "accede to a humiliating deception propagated by USA cultural imperialism". Disabled people, in Finkelstein's view, thus need to "fearlessly challenge the 'independence lie' championed by protagonists of the competitive market economy". Richter (2017, p.160) similarly argues that "instead of recognizing that disability, as a concept, requires interdependence, an ideology of independent living left the atomized capitalist notion of individualism stable", meaning that deinstitutionalised disabled people would represent less of a threat to capitalist social values than if the necessity of interdependence was fully recognised.

Arguments have also been made from intersectional feminist viewpoints that 'independent living' centres the needs and experiences of the most privileged disabled people, particularly white men with physical impairments (Kelly 2010a) and ignores or erases the labour of assistance providers, who are frequently

marginalised women (Hande 2017; Rivas 2002). Kelly (2010) describes independent living activism as a form of 'strategic essentialism', adopting a unified position to achieve the goal of deinstitutionalisation despite the contradictions and exclusions of the concept. Independent living is thus a politically ambiguous concept which, as Barnes (2007a, p.349) argues, "appeals directly to advocates of the politics of the right and of the left". Perhaps in response to this, some CILs in the UK, including Derbyshire, have chosen to name themselves centres for 'integrated' or 'inclusive' rather than 'independent' living (Davis 1984; Priestley 1999). Finkelstein (2004, 2007) argues that 'integrated living' was a distinct socialist model of service provision controlled by disabled people which was overtaken by, and wrongly conflated with, the market-based 'independent living' model originating from the CILs in the US; however, his interpretation of the meaning of the word 'integrated' in the alternative acronym (that services controlled by disabled people would be integrated within 'mainstream' state provision) arguably differs from that of many people involved in the CILs using that term.

Meanings of 'independence' and 'autonomy'

The concept of 'independent living' for people with severe physical impairments and consequent needs for assistance with activities of daily living could be seen as paradoxical if the word 'independent' is taken to have its commonly understood meaning in everyday English. It may be fair to presume that the term 'independent living' was chosen by activists within the DPM, over possible alternatives such as 'autonomous living' or 'self-determined living', because 'independent' is a much more common and familiar term in everyday English usage (Leece & Peace 2010). However, this usage is potentially misleading, as the 'independent' in 'independent living' is arguably defined in direct opposition to the dominant conception of 'independence' as meaning self-sufficiency (Beresford 2008; Brisenden 1986; Davis 1984). It is therefore necessary to examine in greater depth the various meanings given to the word 'independence'.

The word 'independence' is formed from the negative prefix 'in-' and 'dependence', the etymology of which derives from a root meaning 'to hang' (Fraser & Gordon 1994). Therefore a person (or other entity, e.g. a nation or organisation) that is dependent on another metaphorically 'hangs from' that other, in terms of requiring the support of that other to maintain its existence, while an 'independent' person (or organisation etc.) supposedly stands alone and separate, not requiring the direct support of any other person or entity. 'Dependent' and 'independent' as adjectives can be used absolutely or relatively (in the sense of being 'dependent on' or 'independent from' someone or something in particular), and both the range of meanings and the (positive or negative) values attached to the word have changed according to historical and cultural contexts (Fraser & Gordon 1994; Hartblay 2014). As a result of this, "meanings of the concept of independence are often confused and contradictory" (Leece & Peace 2010, p.1848).

As many authors (e.g. Barron 2001; Davis 1984; Leece & Peace 2010; Oliver 1989, 1999; Sheldon 2001; Vernon & Qureshi 2000) have noted, when the word 'independence' is used by disabled activists, its meaning differs significantly from more traditional definitions of 'independence'. This has led to misconceptions about the aims of the independent living movement due to people unfamiliar with it interpreting the term "in an ordinary, commonsense way, i.e. that disabled people want to be self-reliant without help" (Davis 1984, p.2). Conflict has also occurred because professionals in the fields of health and social care (see Chapter 5) have typically used the traditional or 'common sense' definition when emphasising 'independence' as a goal in everyday life, thus assuming 'independence' to mean being self-sufficient in 'self-care' skills (Oliver 1989, 1999). In contrast, within the DPM 'independence' is defined as "the ability to be in control of and make decisions about one's life, rather than doing things alone or without help" (Oliver 1989, p.14). Similarly, Brisenden (1986) argues that disabled people "do not use the term 'independent' to mean someone who can do everything for themself, but to indicate someone who has taken control of their life and is choosing how that life is led".

Numerous authors have attempted to draw distinctions between these contrasting usages of the word 'independence'; for example, Zola (1983, p.346) distinguishes "physical independence" from "social and psychological independence", while Corbett (1997, p.93) refers to "distinguishing between independence as a skills-based process and independence as a mark of individuality". Montgomery (2001, no page numbers) draws attention to the conflicting meanings of the word 'independent' as "self-governing" or "self-reliant" and 'dependent' as meaning "controlled by others" or "requiring the support of others". Leece and Peace (2010, p.1850) argue that "when disabled activists talk about independence, they are referring instead to the concept of autonomy", thus equating autonomy - a term often used interchangeably with 'independence', though they can be distinguished (Chirkov et al 2003) - with the sense of the word 'independent' used in the phrase 'independent living'.

Autonomy is closely related to independence conceptually, but arguably as a term has a somewhat different focus. Its etymological meaning is 'self-rule' (Collopy 1988) or 'to be governed by one's own law' (Nedelsky 1989), and its relatively rarely used opposite is heteronomy (Gorz 1982; Chirkov et al 2003). Like independence, it has multiple and contested meanings (Collopy 1988); Mackenzie & Stoljar (2000, pp.4-5) note that there is no consensus about what "autonomy" means, as the term is used differently by writers who espouse different political philosophies, but all uses of the term share a basic concept of "self-determination or self-government". Autonomy is also associated, particularly in feminist discourses, with freedom from coercion and the ability to exercise choice (Mies 1986; Oshana 1998). Perhaps the clearest way to disambiguate independence and autonomy from one another is by the conditions that they are opposite to, dependence and heteronomy: while the former means being reliant on others to meet one's needs, the latter means to have one's actions controlled, coerced or compelled by others (Chirkov et al 2003; Leece & Peace 2010). Thus it is possible for a person to be "autonomously dependent" on another if they are able to maintain control within the support relationship.

Thus there is an argument that the term 'independence' should be discarded altogether in favour of a less ambiguous term such as 'autonomy' or 'self-determination'. Indeed, my preference throughout most of this thesis (except when quoting others) is to use 'autonomy' rather than 'independence' for this concept. However, the use of the term 'independence' is deeply entrenched in the DPM and attempts to replace it are likely to be fiercely resisted by activists who have a profound personal investment in the concept that, for them, it embodies; thus, abandoning it completely in a Disability Studies context is arguably counterproductive. In this chapter I therefore follow the usage of Vernon and Qureshi (2000) by distinguishing, where necessary, the concepts of 'independence as autonomy' and 'independence as self-sufficiency'.

(In)dependence, capitalism and models of disability

So many authors have pointed out that independence as self-sufficiency is actually impossible for any person, not just for disabled people, that it can probably be called one of the most frequently made points in Disability Studies (see for example Arneil 2008; Erevelles 2005; Finkelstein 1980, 2004; French 1993; Montgomery 2001; Morris 1991, 1993; Oliver 1989, 1990; Shakespeare 2000; Taylor 2004; Withers 2012). Morris (1991, pp.137-8) illustrates this argument well:

> "In terms of the physical world, none of us - whether disabled or not -
> is completely independent in the sense that we rely on nothing and
> nobody. However, the meaning of our dependence on others and on
> the physical world is determined by both its socio-economic and its
> ideological context. For example, we all depend on water coming out
> of the tap when we turn it on, while a disabled person... depends on
> someone to help her get dressed in the morning. However, when
> non-disabled people talk about water coming out of the tap, the issue
> is whether the water company is reliable; when they talk about [the
> disabled person] being dependent on an assistant, the issue for them
> is what they see as her helplessness created by her physical
> limitations."

This results in the erasure of the forms of 'dependence' that are accepted as 'normal' for non-disabled people and the pathologisation of the 'special' ways in which disabled people are 'dependent' (Montgomery 2001). Withers (2012) describes this false dichotomy between 'dependence' and 'independence' as a "myth perpetuated by disablism and driven by capitalism" (p.109). This myth has served the ideological role of justifying the segregation of disabled people from the mainstream of society and their exclusion from the rights and responsibilities of 'citizenship' typically granted to 'self-determining' adults (Erevelles 2011), with adulthood itself frequently being defined in terms of independence as self-sufficiency (Slater 2015). Public policy about meeting the needs of disabled people in Western countries has thus typically taken the form of paternalistic 'social protection' (Dodd 2016) and disabled people have frequently been infantilised or seen as requiring a non-disabled person in a position of 'guardianship' over them (Shakespeare 2000).

Fraser and Gordon (1994) locate the origin of the stigmatisation and pathologisation of 'dependency', here using the term primarily in an economic sense, in the transition from feudalism to industrial capitalism. They argue that in pre-industrial society dependency was "a normal, as opposed to a deviant, condition, a social relation, as opposed to an individual trait" (p.313), and being in waged work was regarded as a 'dependent' condition just as much as that of the unwaged poor. However, "[w]ith the rise of industrial capitalism, the semantic geography of dependency shifted significantly... What in preindustrial society had been a normal and unstigmatized condition became deviant and stigmatized" (pp.314-5). The concept of dependence was not only increasingly gendered and racialised, but also individualised, coming to refer not only to a social relation but to an individual character trait, creating a "moral/psychological register" (p.315) of the term, closely related to the Protestant work ethic of individual responsibility. At the same time working for a wage changed from being viewed as one of many forms of dependency to being seen as constituting 'self-sufficiency' (thus, as Fraser and Gordon argue, mystifying the relations of hierarchy and dependency between factory owners and workers).

However, as working for a wage rapidly "became increasingly normative - and increasingly definitive of independence - it was precisely those excluded from wage labor who appeared to personify dependency" (p.316). While the categories of "those excluded from wage labour" included in Fraser and Gordon's analysis were primarily women and/or colonised and racialised peoples, their work has clear applicability to disabled people, and closely parallels the historical materialist analysis of the origins of disablement by many authors in Disability Studies (e.g. Finkelstein 1980; Gleeson 1999; Oliver 1989, 1990; Russell 1998). Oliver (1989, pp.8-9), for example, argues that the "common-sense usage of the term dependency" (i.e. to mean the lack of self-sufficiency) depends on psychological and sociological reductionist explanations, which pathologise individuals and groups respectively. In counterpoint to these reductionist explanations, Oliver argues for an economic basis of disabled people's 'dependency' in the "onset of industrial society" (p.10).

This argument is rooted in the analysis of the pioneering disabled activist group UPIAS (Union of the Physically Impaired Against Segregation), which was formed in 1972 with founding members including Vic Finkelstein and Paul Hunt, both foundational authors in the early development of Disability Studies, and Ken and Maggie Davis, who also co-founded Derbyshire CIL (Campbell & Oliver 1996). In their influential pamphlet 'The Fundamental Principles of Disability', UPIAS (1976, p.14) first distinguished between the terms 'impairment' and 'disability':

"In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society... we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of

people who have physical impairments and thus excludes them from participation in the mainstream of social activities."

This 'social interpretation of disability' (Finkelstein & Stuart 1996) was developed by British disabled people's organisations into the social model of disability, a phrase coined by Oliver (1983), which has come to form a major ideological foundation of the DPM, particularly in the UK (Hasler 1993; Campbell & Oliver 1996). In the social model, while impairment may in itself cause some restrictions on a person's life and possible activities (Thomas 1999), much if not most of the disadvantage experienced by people with impairments is not an inevitable consequence of their physical (or cognitive, as Oliver (2009) acknowledges UPIAS did not include in their analysis) difference from the 'norm', but is instead the result of socially created barriers, which society also has the capacity to remove. The social model is frequently opposed in popular discourses to the 'medical model' (e.g. Brisenden 1986), but is more accurately opposed to the individual model, of which medical and charity models can be seen as subsets (Oliver 2009).

The social model has been endlessly debated and reinterpreted (see for example Crow 1996; Finkelstein 2001, 2007; Oliver 2009; Thomas 1999, 2004, 2007), has been argued by some to have been superseded by other models (Withers 2012) or not to be applicable to all impairment groups (Chappell et al 2001; Plumb 1994), and it has sometimes been reduced, arguably unhelpfully, to a technical focus on barrier removal (Finkelstein 2001; Thomas 2004). However, in its 'strong' or 'radical' form it contains a profound critique of many of the foundational assumptions of 'modern' (capitalist) society, one of the most important of which is the 'universally' positive value of waged employment (Abberley 1996; Taylor 2004). UPIAS (1976, p.14) explicitly identified the organisation of employment as a cause of disablement:

"In the final analysis the particular form of poverty principally associated with physical impairment is caused by our exclusion from the ability to earn an income on a par with our able-bodied peers, due to the way employment is organised. This exclusion is linked

with our exclusion from participating in the social activities and
provisions that make general employment possible."

Gleeson (1999) develops this analysis further in his account of the lives of people with impairments in feudal peasant society and in the early industrial city. Gleeson argues that in pre-industrial peasant households, "work and domestic life combined without the formal distinction between paid ('productive') and unpaid ('reproductive') spheres that characterised industrial capitalist social relations" (p.71); therefore peasants had a higher degree of autonomy than industrial workers in determining the appropriate work of individuals (whether impaired or not). This leads him to the conclusion that people with impairments were not distinguished as particularly 'dependent', but were allowed, indeed required, to contribute to the undifferentiated household economy in whatever ways were possible for them. In contrast, the rise of capitalist commodity relations "lessened the ability of disabled people to make meaningful contributions to their families and households" because the "competition of labour-powers... devalorised the work potential of anyone who could not produce at socially necessary rates" (p.100).

This was accompanied by changing discursive and ideological norms; indeed, as Davis (1995) argues, the word 'norm' and related words such as 'normal' and 'abnormal' only entered the English language in the mid-19th century. Davis argues that the concept of the (unattainable by anyone) 'ideal' human body that existed in pre-industrial Western society was replaced by that of the 'normal' body, which people were expected to conform to or else be regarded as deviant and pathological. The ideological shift between the feudal era, in which the 'deficiency' of all people in comparison to the unattainable ideal was recognised - and thus 'dependency' could be accepted as a typical and unremarkable human condition - and the capitalist era with its new concept of the 'normal' human body is, for Davis, symptomatic of "an industrial mentality that saw workers as interchangeable and therefore sought to create a universal worker whose physical characteristics would be uniform, as would the result of their labours - a uniform product" (p.36).

These analyses should not be taken to mean that people with impairments did not experience social exclusion or oppression before the advent of industrial capitalism. Gleeson's claim that "the particular social oppression of disability was weakly developed, even largely absent, within the feudal social form" (1999, p.98) is called into question by historical evidence of people with impairments being stigmatised and subjected to various forms of socially sanctioned violence at least as far back as ancient Greece and Rome (Barnes 1997; Garland 1995; Stiker 1999). Barnes (1997) therefore argues that attention must be paid to cultural as well as economic factors to explain the social disablement of people with impairments; however, he also argues that this should not be viewed as a human universal, but as historically specific to 'Western' societies with identifiable roots in the Greco-Roman and Judeo-Christian traditions. Ideological constructions of disabled people as 'unproductive' and therefore not deserving of full membership of society can thus be traced back to ancient ideas of bodily perfection, related to the 'ideal body' as discussed by Davis (1995); however, industrialisation brought about a distinctly modern material and ideological form of disablement.

The work of Fraser and Gordon (1994) can therefore be taken together with that of social model disability scholars (e.g. Davis 1995; Finkelstein 1980; Gleeson 1999; Oliver 1989, 1990; Russell 1998) to show that the view of 'dependency' as an abnormal or pathological condition, while commonplace in contemporary society, is an ideological construct of capitalism, which results in (primarily male and non-disabled) wage workers perceiving themselves as 'self-sufficient', erasing their real dependencies, including both the (arguably unnecessary and exploitative, but still materially real) dependence of workers on employers for a wage, and the dependency of both workers and capital on the unwaged reproductive labour of women and colonised/racialised 'others' (for a more detailed analysis of this particular dynamic of dependency, see for example Bubeck 1995; Federici 2004; Mies 1986). In the personal assistance relationship, there are thus complex bidirectional power relations between two groups of people (disabled people and PAs as workers, who are largely women and frequently members of racialised and/or immigrant groups (Rivas 2002;

Ungerson 1999)) who are both 'dependent' on one another in different ways, and who are both oppressed and marginalised within capitalist society.

Individual model ideologies of 'independence' and normalisation

As well as being impossible to reach, the ideal of independence as self-sufficiency can also be actively harmful when promoted to disabled people as something to get as close to as possible. A professional ideology of aiming to maximise disabled people's 'independence', while viewing independence only as self-sufficiency - the dominant paradigm in 'rehabilitation' in both the US and UK (DeJong 1983; Oliver 2009) - can in fact have the result of reducing disabled people's autonomy. For example, disabled people are often encouraged or even coerced by professionals to 'independently' achieve mundane tasks such as putting on or taking off clothes or preparing basic meals, even when it takes them far longer than it would take for them to be assisted by another person, and uses up their time and energy that could much more usefully be spent on other things (Corbett 1989, 1997; DeJong 1983; French 1993). French (1993, p.47) argues that the promotion of a 'narrow' definition of independence "can give rise to inefficiency, stress and isolation, as well as wasting precious time", whereas appropriate assistance given recognising an ongoing need for it can avoid these problems.

The pervasive influence of this definition of 'independence', including on disabled people who are not aware of the DPM or the 'independent living' philosophy, is shown by the findings of Gramlich et al (2002), who report people with learning difficulties turning down direct payments because they thought of independence as "something really difficult, that meant they had to be clever enough to do everything for themselves" (p.73). If 'independence' is defined in these terms, the reaction of many disabled people could very understandably be to declare, with one of the disabled students whose experiences of a further education college's 'independent living' programme was documented by Corbett (1989, p.155), "I don't want to be independent!".

DeJong (1983, p.24) demonstrates the different perspective that becomes possible if 'independence' is viewed in terms of autonomy rather than self-sufficiency:

> "The fact that a disabled person needs more assistance from a human helper does not necessarily imply that he or she is more dependent. A person who can get dressed in fifteen minutes with human assistance and then be off for a day of work is more independent than the person who takes two hours to dress and then remains homebound."

As demonstrated here, the professional ideology of physical self-sufficiency can, ironically, even prevent disabled people from achieving financial 'independence' within the terms of contemporary capitalism, even when they would be capable of paid work with appropriate provision of personal assistance.

As Corbett (1989, 1997) demonstrates, this ideology of independence as self-sufficiency is closely associated with the concept of normalisation (Wolfensberger 1972), which was influential in movements towards the deinstitutionalisation of disabled people, particularly those with learning difficulties, in Europe and North America in the 1960s and 70s. The principle of normalisation was that, rather than being segregated, disabled people could and should live 'ordinary lives' in mainstream society. Support given to disabled people is thus seen as a pedagogic or rehabilitative effort to develop their skills for self-sufficiency, rather than as something to be accepted as an ongoing need. These principles are frequently found in professional training of support workers, particularly for people with learning difficulties (Drinkwater 2005). Pearson (2000, p.472), for example, reports a PA for a person with learning difficulties, being "told that his role had a long-term goal to 'do himself out of a job'" because of the aim of seeking "maximum independence", clearly defined as self-sufficiency rather than as self-determination.

This paradigm has been criticised by proponents of the social model of disability for seeking individualistic solutions to the problem of disabled people's social exclusion and oppression, as it requires the individual disabled person to be 'normalised' and made acceptable to society, rather than society to be changed to accommodate their difference (Brown & Walmsley 1993; Oliver 2009; Swain et al 2003). Normalization is, for Oliver (2009, p.95), "part of a discourse which is predicated on the normal/abnormal distinction", which its proponents regard as real rather than socially constructed. This leads to an emphasis on conforming to 'normal' social roles as a condition of disabled people's 'successful' integration into mainstream society - thus overruling their individual choices - as well as to the denial of real need and real difference (Brown & Walmsley 1993).

Morris (1991) argues that attempting to 'normalise' disabled people is futile because the reality of impairment means that disabled people will never conform to the 'norm' in the sense of typical or average functioning. However this does not mean that disabled people's 'abnormality' is inherent to them as individuals, but rather that the socially constructed 'norm' is disabling; indeed, as Davis (1995) argues, the concept of the 'norm' is itself tied up with capitalism and the social exclusion of disabled people. Thus, as Abberley (1991) argues, disabled people's 'abnormality' is neither a product of individual psychology, nor of prejudice or stigma, but of society's failure or refusal to meet their material needs (a restatement of the social model of disability). As this material inequality is shared with other oppressed groups, which together make up the majority of the population, it is thus arguably actually a 'normal' condition. Normalisation can thus be seen as part of a capitalist individual model of disability which blames the individual disabled person (rather than the social and environmental barriers created by capitalism) for their inability to achieve the same level of autonomy as their non-disabled peers.

Personal assistance as refusal of disabling ideology

This normalising ideology of independence as self-sufficiency pervades all aspects of disabled people's lives in modern industrial society, and can manifest

in different and sometimes mutually contradictory forms. For example, disabled people are sometimes discouraged from using assistive technology, such as when walking, even if it is painful, slow, exhausting and potentially dangerous (due to the likelihood of falling or other hazards), is promoted over using a wheelchair because of the value attached to the appearance of normalcy and the stigmatisation of 'disability' technologies as associated with impairment and thus dependence (Zola 1983; Oliver 2009). However, technological 'solutions' can also be valued over dependence on human assistance (French 1993; Sheldon 2001). French (1993, pp.44-45) describes one example of this: a failed attempt to install an adapted computer in a library, supposedly to enable her and other visually impaired students to find references more 'independently', which "would, at best, enable [her] to cope inefficiently with half a task, while at the same time disallowing [her] from asking for help" from the librarian with whose assistance she had previously been "very satisfied".

Here, reliance on assistive technology is valued over human assistance (although still seen as inferior to doing things 'unassisted') because it is seen as more like the 'normal' dependence of non-disabled people which is perceived as 'independence' (Montgomery 2001; Morris 1991). A person who achieves daily living tasks with the aid of machines can be seen as 'self-sufficient' - ignoring the labour of many other people in designing, manufacturing, transporting and maintaining those machines - when the same person would be seen as 'non-self-sufficient' if they received assistance, with the same tasks, directly from another person. This "atomistic, technologically-assisted 'self-sufficiency'" (Sheldon 2001, p.46) can be seen as an attempt to square the presumption that independence as self-sufficiency is a prerequisite for autonomy with the belief that it is possible for people in a complex industrial society to be 'independent'.

This is not to demonise assistive technology or to argue that personal assistance and assistive technology are opposed to one another; both are among the 'Seven Needs for Independent Living' (Davis 1990) and they can and should be complementary to one another (Kelly 2016). Some needs are also more appropriately or efficiently met by technological means, but because it is much more obviously a direct dependence on another person, the use of

personal assistance can be more undeniably regarded as acceptance of the impossibility of self-sufficiency than the use of assistive technology. However, the direct employment model of personal assistance also places the decision-making authority in the hands of the 'dependent' person. Thus it is an assertion that autonomous control over activities of daily living is possible even when they cannot be performed without the assistance of others.

Being able to control one's own personal assistance is highly valued by disabled people, with many personal testimonies in the literature of how great a change it has made to their quality of life (see for example Briggs 1993; Galvin 2004; Heumann 1993; Leece & Bornat 2006; Morris 1993; Vasey 1996, 2000). However, achieving this choice and control requires clearly defined roles in which the disabled person has authority over the PA and not vice versa, and a mechanism for ensuring that these roles are maintained. This requires a clear distinction from traditional, paternalistic models of 'care' for disabled people (either in institutional settings or 'informal care', usually within the family); in the words of Morris (1993, p.23):

> Once personal assistance is seen as 'care' then the 'carer'...
> becomes the person in charge, the person in control. The disabled
> person is seen as being dependent on the carer, and incapable even
> of taking charge of the personal assistance s/he requires.

Many of the tasks performed by personal assistants for disabled people are, in crude physical terms, the same as those which are performed by 'carers' in either institutional or family/'informal' care settings - for example help with 'personal care' tasks like bathing, dressing, eating, using the toilet, getting in and out of bed, etc., as well as 'domestic' tasks like cooking, cleaning and shopping (Heumann 1993; Vasey 2000). However, the crucial distinction is who has choice and control over what is done and when, where and how it is done: a PA, unlike a 'carer', acts under the direction of the disabled person. Thus what defines the role of PA as opposed to that of 'carer' is that it supports rather than negates the autonomy of the person receiving the assistance. However, notions of dependence on assistance for daily living tasks equating to an essential non-

autonomy are deeply entrenched in society (Erevelles 2011). Disabled people's movements have thus frequently made it a matter of political principle to refuse the terminology of 'care' (Kelly 2016; Shakespeare 2000).

It is in this context that the direct employment model of personal assistance was developed. This employment relationship defines the disabled person as the 'boss' and the PA not as an altruistic 'carer' but as a waged worker, selling their labour to the disabled person just as to any other employer (Prideaux et al 2009). The ability of disabled people to 'hire and fire' PAs is regarded as crucial to the power shift from 'carer' to recipient (DeJong & Wenker 1983; Ratzka 1986; Ungerson 1999). Bubeck (1995) argues that the "power differential" between the giver and receiver of 'care' is "irreducible" due to the "one-sided dependency of the person in need of care" (p.141). However, in the direct employment model of personal assistance the balance of power between direct employer and PA is altered by making dependence bidirectional rather than unidirectional, as while the employer is dependent on the labour of the PA, the PA is also dependent on their employer for an income.

Work and autonomy

As discussed by Fraser and Gordon (1994), the construction of the concepts of autonomy and (in)dependence in modern society is closely related to that of work and its economic and ideological centrality to that society. Various authors in Disability Studies (e.g. Abberley 1996, 2002; Barnes 2000, 2012; Gleeson 1999; Prideaux et al 2009; Richter 2017; Russell 1998, 2002; Taylor 2004; Withers 2012) have discussed the question of work and how it relates to disabled people's oppression and potential liberation, mostly focusing on disabled people's exclusion by/from paid work and the disablism inherent in valorising both paid work in particular, and 'productive contribution' more generally, as necessary conditions for full membership in society. However, focusing on the direct employment model of personal assistance illuminates another, perhaps less recognised, connection between disabled people's (in)dependence/autonomy and waged work - one in which disabled people

occupy the role of employers rather than that of (non-)workers (Prideaux et al 2009).

Here framing the issue in terms of autonomy rather than (in)dependence is particularly useful, as autonomy is "a term that can be applied to both users and workers" (Leece & Peace 2010, p.1850). Leece and Peace suggest that autonomy is a more helpful concept than independence in analysing the relationship between disabled people and those who assist them precisely because of this wider applicability, as conflicts between the desires and interests of disabled people and of their 'helpers' (whether employed PAs, informal carers or others) can be seen in terms of conflict between the autonomy of one group of people and that of the other.

To determine whether there is a way out of this conflict, it is necessary to turn to the relationship between autonomy and waged labour in general. Many authors from various critical traditions, including 'libertarian' Marxists (such as the Situationists and the Italian Autonomists), anarchists, radical and socialist feminists, and eco-socialists (e.g. Anarchist Federation 2008; Berardi 2009; Black 1991; Gorz 1982; Kropotkin 1990[1913]; Mies 1986; Vaneigem 1967; Weeks 2011) have criticised wage work on the basis that it denies the self-determination of workers who are effectively forced to sell their time to employers or else starve. Gorz (1982, p.1), for example, describes 'work' as

> "an activity carried out: for someone else; in return for a wage; according to forms and time schedules laid down by the person paying the wage; and for a purpose not chosen by the worker... Work is an imposition, a heterodetermined, heteronomous activity, perceived by most of those who either 'have' it or are 'looking for' it as a nondescript sale of time."

Several critics have argued that, because heteronomous work is something that is effectively forced on people for whom selling their labour is the only alternative to starvation, it is necessarily authoritarian and disciplinary in structure; for example, Vaneigem (1967) describes work as "punishment for

poverty" (p.52), Berardi (2009) calls it "a matter of discipline, the production of docility" (p.17), and a pamphlet produced by the Anarchist Federation (2008) argues that "the imposition of work - the socially-created need and compulsion to work - is a prison we are desperately seeking to escape" (p.16). Therefore work is oppressive not only because workers are alienated from the products of their labour, but also because they are required to submit to the authority of employers. Work is thus a "fully political rather than a simply economic phenomenon" (Weeks 2011, p.3). This analysis is particularly useful, in contrast to an orthodox Marxist one focusing only on exploitation, with regard to work - such as personal assistance - which does not always have an easily identifiable 'product', but which does involve power relations between employer and employee.

While they generally do not explicitly acknowledge disability, these 'anti-work' perspectives, as I have argued elsewhere (Graby 2015), fit well with many perspectives on work from disabled standpoints (e.g. Abberley 1996, 2002; Russell 1998; Taylor 2004) in their rejection of the work ethic and refusal to equate human value with labour-power. Where orthodox Marxist traditions and trade union movements tend to focus on the valorisation and 'dignity' of work, autonomist movements have adopted the refusal of work as a core tactic in the struggle against capitalism (Weeks 2011). Weeks's critique of 'productivism' as a value shared by both capitalism and orthodox Marxism parallels Abberley's assertion that 'classical social theories', including Marxism, were fundamentally inadequate as the intellectual basis of a liberation politics of disability because of their focus on work as the basis of an essential human identity; thus he argues, diverging from the UPIAS position, that it is necessary to "recognise that full integration of impaired people in social production can never constitute the future to which we as a movement aspire" (1996, p. 77).

The refusal of (heteronomous) work does not necessarily mean the abandonment of all purposeful activity; indeed, many 'anti-work' or 'post-work' authors emphasise the distinction between work and socially necessary action (Weeks 2011). While a few, mainly anarchist, authors seem to think heteronomous work can be abolished entirely (e.g. Black (1991, no page

numbers), in whose utopia productive activities would become "indistinguishable from other pleasurable pastimes except that they happen to yield useful end-products"), a more pragmatic perspective is that of Gorz (1982), who contends that "the sphere of autonomy cannot embrace everything" (p.94) and a 'sphere of necessity' remains which both cannot and should not be made autonomous, because it is impossible for all the labour that is necessary to maintain society to coincide perfectly with the choices and desires of the individuals making up that society. The recognition and social management of that necessarily heteronomous sphere of activity is thus necessary for autonomy to be maximised.

Bubeck (1995) has a similar analysis which, unlike that of Gorz, does specifically focus on 'care' as a distinct category of work, which for Bubeck is that work that is necessary to meet "needs that are absolute in the sense of being part of human life regardless of the society one happens to live in and particularly urgent in that they cannot be met by the person in need herself" (p.133). Bubeck contrasts this to 'service' work, which meets needs that could, at least in principle, be met by the person in need him/herself instead of purchasing the service (although she does not distinguish 'care' in the traditional paternalistic sense from personal assistance as conceptualised by disabled people). She argues that "If care is necessary labour, then certain parts of necessary labour cannot be abolished without letting society die out and abandoning people in need", and therefore "individuals will never be entirely free" (pp.30-31). The tactic of the refusal of work has also been problematised from a feminist standpoint as not necessarily applicable to forms of work, such as 'care' for disabled and otherwise dependent people, which are genuinely socially necessary, even if they are currently arranged in unethical and exploitative forms (Federici 2008).

From ethics of care to relational autonomy

The fact that autonomy can never be total does not necessarily invalidate having the maximum possible degree of autonomy for all as a political goal. The autonomy of any given individual is also necessarily limited by the fact that, if

autonomy is to be regarded as a universal value, that individual does not have the right to act in ways that deny the autonomy of others (Oshana 1998). In the real world, then, as opposed to an unreachable utopia, autonomy is necessarily relative rather than absolute. This seems consistent with the feminist argument that autonomy is only possible in a supportive social and relational context, but that the necessity of this context does not negate the value of autonomy itself (Barclay 2000; Davy 2015; Mackenzie & Stoljar 2000; Nedelsky 1989; Oshana 1998).

This concept of 'relational autonomy' was developed by feminist theorists in response to critiques of autonomy which conflate the entire concept with 'independence' and self-sufficiency (Mackenzie & Stoljar 2000). Some of these critiques are associated with the development of an 'ethic of care' by feminist writers in philosophy and psychology (e.g. Gilligan 1982; Kittay 1999; Noddings 1984; Sevenhuijsen 1998; Tronto 1993). This ethic is defined in opposition to what is seen as a patriarchal and masculine-biased dominant ethical system based around 'justice' and 'rights', and is not based on rules or abstract principles, but "always a response to concrete situations" (Bubeck 1995, p.157), and many of its proponents argue that it is a distinctively feminine 'moral voice', derived from the specific experiences and perspectives of women as carers (Bubeck 1995; Gilligan 1982). Thus, as Erevelles (2011, p.176) argues:

> "unlike the individualism of traditional ethical theory that manifests itself solely in the public sphere, the feminine ethic of care emphasizes interdependence and the maintenance of relationships between family members and friends in the private sphere of female domesticity."

Care ethicists have several (interconnected) critiques of the concept of autonomy. They tend to regard "notions of autonomy, independence, and individual rights" as "based on a masculine view of people as separate from each other" (Morris 2001, p.13), and thus biased in favour of men and traditionally 'masculine' spheres of activity. Kittay (1999, p.50) argues that "the conception of society as constituted by free and equal autonomous agents

poorly serves the needs of dependency workers" (a term she is here using primarily to refer to informal carers), while Sevenhuijsen (1998) claims that the "Western male ideal of autonomy and non-connectedness" (p.52) encourages negative moral judgements of those who are seen as non-autonomous (such as women, children, colonised peoples and (implicitly) disabled people). Some, such as Lynch et al (2009), also make the claim that "autonomy may not be prioritised or desired" by some "severely dependent persons", because "it may involve too high a level of responsibility, energy and risk" (p.115).

However, proponents of relational autonomy criticise these dominant conceptualisations of "autonomy understood as substantive independence" (Mackenzie & Stoljar 2000, p.9) without rejecting it altogether. Nedelsky (1989), for example, argues that the "prevailing conception" of autonomy "carries with it the individualism characteristic of liberalism", and therefore cannot be feminist, but the "basic value of autonomy is, however, central to feminism", meaning that feminists "must retain the value, while rejecting its liberal incarnation" (p.7). Similarly, Mackenzie and Stoljar (2000, p.5) claim that the target of feminist critiques of autonomy is often a caricature of a "self-sufficient, rugged male individualist, rational maximising chooser of libertarian theory", and argue that while it is important for feminists to challenge this (mis)conception of autonomy,

> "it is also imperative for feminists to reclaim and reconceptualise the concept of individual autonomy and to articulate conceptions of choice and of political rights that are more adequate from a feminist perspective. To do so, feminist theorists must draw on both mainstream philosophical theories of autonomy and on feminist critiques of culturally dominant conceptions of individuality, selfhood, and moral and political agency."

While these feminist authors do not explicitly mention disability, their critiques are consistent with the social model of disability, which, as Reindal (1999, p.357) says, "needs an understanding of the subject as relational", and fit well with disabled feminists' critiques of the ethic of care as potentially entrenching hierarchical relations of 'caring' which oppress those in the recipient position

(e.g. Morris 2001; Silvers 1995). Silvers, for example, argues that "far from vanquishing patriarchal systems, substituting the ethics of caring for the ethics of equality threatens an even more oppressive paternalism" (1995, p.40).

Relational autonomy offers a framework in which it can be recognised that dependence is not in itself necessarily oppressive, but only becomes so when the false assumption is made that autonomy requires self-sufficiency. In fact, in a relational view of autonomy, its prerequisites can be seen in completely opposite terms to these; as Nedelsky (1989, p.12) argues "relatedness is not, as our tradition teaches, the antithesis of autonomy, but a literal precondition of autonomy, and interdependence a constant component of autonomy". Erevelles (2011) argues that feminist reconceptualisations of autonomy have the potential to "redefin[e] disabled people as autonomous agents" (p.179), but in practice have not been because feminists have held onto individualist and normalising assumptions. However, more recently relational autonomy has been linked explicitly to critiques of the normalcy of 'independence' from the standpoint of disabled people (Arneil 2008; Davy 2015).

In this context, personal assistance can be seen as a means to establish relational autonomy. Its being publicly funded, far from rendering its recipients non-autonomously dependent on state 'welfare' (Fraser & Gordon 1994; Beresford 2016), arguably embodies Davy's (2015) claim that "the onus of responsibility for activating autonomy needs to be shared on a community and society-based level, rather than placed primarily on the individual". This means that, contrary to some of the rhetoric of the independent living movement (Kelly 2016; Shakespeare 2014), intimate and complex emotional relationships between disabled people and PAs do not necessarily result in loss of autonomy (for the disabled person) or the re-establishment of paternalistic 'care' paradigms, as long as those relationships value disabled people's self-determination (this is addressed in more detail in Chapter 4).

Conflicts between the autonomy of disabled people and assistance providers

However, the question of the autonomy of those who provide assistance to disabled people (whether as formal or informal 'carers' or as directly employed PAs) remains unresolved. It may be argued that, in particular when carried out by informal carers, the work of 'care' may be autonomous for the provider if it is motivated by a genuine desire and/or felt need to care for the recipient. Indeed, as Twigg (2000) documents, even when it is done for a wage, 'caring' work may be valued over other forms of work with comparable pay and status because it is seen as comparatively autonomous due to its "relative absence of direct supervision" (p.126). However, as Twigg herself notes, "careworkers in private homes also exercise disciplinary power" (p.180) over care recipients, implying that the relative autonomy of care work for workers, compared to other forms of wage labour, comes at the cost of the autonomy of those who need care.

Twigg is critical of the direct employment model of personal assistance, arguing that "the ideal of the personal assistant can seem to imply a denial of the personhood of the worker who is required to efface him or herself totally" (p.193). A similar critique is made by Rivas (2002), who argues that for disabled people to maintain the "illusion of independence" (p.74), their PAs and the work they do must be rendered 'invisible', so that the employers (or, as Rivas calls them, consumers) "can feel that they have accomplished their daily activities by themselves" (p.75). Rivas argues that this illusion of independence is achieved by "transferring the authorship" of tasks from the worker to the employer (p.76), and argues that this is "a negative phenomenon even for those who consciously work to make it happen", because it represents "the most extreme form of alienation" (p.79). Thus, for Rivas, personal assistance is among the most oppressive and exploitative forms of wage labour, and arguably PAs have even less autonomy than other wage workers. This is arguably in part because the work they do is devalued by association with sexist and racist stereotypes of women and immigrants/racialised peoples as 'natural carers', whose work is thus seen as not deserving of social reward (Erevelles 2011; Glenn 2010).

These arguments give the impression that, in the dialectical relationship between people who need personal assistance and those who provide it, autonomy is zero-sum - either person in the relationship gains autonomy only at

the cost of the other person losing it (Erevelles 2011). Therefore it would seem that conflict between the interests of disabled people and of PAs is inevitable; indeed Twigg (2000, p.193) argues that "conflict is endemic in such relations". However, it is possible that the appearance of a zero-sum nature of autonomy is an illusion, and the conflict between disabled people's and PAs' self-determination only appears to be inevitable because of the currently existing social and economic relations of capitalism; the question of what form personal assistance could take in a post-capitalist society has not been answered. In support of this, several authors have argued that direct employers and PAs have a common material interest in increasing funding to improve PAs' pay rates and working conditions (Prideaux et al 2009; Spandler 2004; Thomas 2007).

An argument could also be made that in paradigms other than that of direct employment, disabled people and 'carers' are both denied autonomy; in institutional settings, and even in the 'home care' model documented by Twigg (despite its comparatively self-managed working conditions), workers are still selling their labour to an employer, even though that employer is not the direct recipient of the care. Informal carers, while their 'care work' is not done for a wage, are arguably still exploited (Bubeck 1995), are very likely to be in poverty (Carers UK 2014), which is a condition that limits autonomy (Kupfer 1990), and women in particular are likely to feel that they have 'no choice' in being informal carers due to the patriarchal ideology that it is their 'duty' as women (Lynch & Lyons 2009). Therefore a shift from traditional models of either formal or informal 'care' to the direct employment model of personal assistance may constitute a shift from neither participant in the 'helper-helped relationship' having autonomy to at least one person having it.

One defence of the direct employment model of personal assistance (at least in an idealised form in which disabled people were always given enough money to employ PAs for as many hours as they needed and at a decent living wage) could thus be the argument that, if a calculus of autonomy is possible, the direct employment of PAs by disabled people is therefore the system of 'care' provision that maximises the total amount of autonomy between both 'carer' and

'cared-for'. However, there are at least two problems with this (essentially utilitarian) idea: firstly, it presumes that such a calculation is both possible and desirable, i.e. that the autonomy of different persons is interchangeable. Secondly, it does not address the more fundamental contradiction that the direct employment model presupposes the maintenance of the capitalist norm of wage labour, which is built on the oppression and social exclusion of disabled people (Abberley 1996, 2002; Gleeson 1999; Russell 1998; UPIAS 1976), and on the oppression and exploitation of both the working class in general and the 'unwaged working class' of (primarily) women as 'reproductive' workers (Federici 2004), including carers, in particular.

Conclusions

I have attempted in this chapter to flesh out the framework of concepts and relationships that inform my research questions by placing personal assistance in both theoretical and policy contexts. Personal assistance needs to be understood within the political context of 'independent living' as a core campaign objective of the Disabled People's Movement. The redefinition of the term 'independence' inherent in the concept of 'independent living' has far-reaching implications for how individuals and the relationships between them are socially constructed, and exposes the contradictions within capitalist ideologies that are typically seen as unquestioned fact by most non-disabled people. The use of personal assistance by disabled people can be seen as an intentional refusal of ideological norms which equate 'dependence' with an inherently inferior, non-adult or non-autonomous status.

Personal assistance is thus 'about' autonomy from several different perspectives. As a practical tool and as a role or concept distinguished from paternalistic manifestations of 'care', it is central to the achievement of personal autonomy for many disabled people in the domain of basic daily living activities. This makes it fundamental to the DPM, in the UK and elsewhere, both as a means to make self-organisation of disabled people possible and as a terrain of struggle (historically for permissive legislation and ongoing for adequate funding

and support services). Indeed, the use of personal assistants has been seen as a community norm of a distinctive 'disability culture' (Vasey 2000).

From another perspective, the autonomy of those who work as PAs is central. The establishment of state-funded personal assistance services can be seen as having liberated not only disabled people from institutions or otherwise unjustly restrictive forms of 'care' provision, but also family members, primarily women, from the burden of unpaid caring labour (Morris 1993). However, in creating a new form of employer/employee relationship between disabled people and PAs, in which the empowerment of disabled people is achieved precisely by the relative disempowerment of those assisting them, the autonomy of disabled people and that of PAs as workers are arguably placed in direct opposition to one another. This also potentially contradicts the analysis by theorists from the DPM (e.g. Finkelstein 1980; Oliver 1990) of capitalist labour relations as fundamentally disabling and the root of disabled people's exclusion from the mainstream of society.

The next chapter details the research that I undertook to seek potential solutions to these contradictions.

Chapter 3: Methodology

In this chapter I detail the research process used to generate the findings set out in the remainder of this thesis, my primary research method being semi-structured qualitative interviews with (current or former) PAs and direct employers. I also consider relevant methodological issues, including whether research done by an individual can be emancipatory, the advantages and disadvantages of having friends and colleagues as research participants, my ambiguous positioning as an 'insider' or 'outsider' researcher, and issues around data analysis.

Choice of methods

This research project was conceived from the beginning as one using qualitative rather than quantitative methods. This was, in part, both because qualitative methods have historically been preferred within Disability Studies and other social justice-oriented fields such as feminist research (Stone & Priestley 1996; Westmarland 2001), and because of my own aptitude and enthusiasm being for qualitative methods. This does not mean ideological opposition to quantitative research, which - although it has historically been associated with disempowering 'top-down' paradigms of supposedly 'objective' research 'on' (rather than 'with' or 'for') oppressed peoples (Abberley 1992; Oakley 1981) - can still be used for emancipatory ends (Kelly et al 1992; Westmarland 2001). Indeed, I have supplemented my own findings with literature drawing on quantitative or 'mixed methods' research (e.g. Adams & Godwin 2008; Duffy 2013; Zarb & Nadash 1994) at several points in this thesis. However I would argue that qualitative research methods are more suitable than quantitative for the questions addressed in this thesis because they provide greater flexibility to explore the details and complexities of fluid social phenomena (Bazeley & Jackson 2013; Woodin 2006).

Within the range of qualitative research methodologies, I chose interviewing as my primary research method both for the practical reason that it yields large

quantities of data relatively quickly (Marshall & Rossman 2006), and because its open-ended nature allows the voice of participants to be heard on their own terms (Swain & French 1998). Parker (2005) argues that interviews in qualitative research are always 'semi-structured', as both fully structured and fully unstructured interviews are impossible in practice. My approach to interviewing was intentionally semi-structured in order to strike a balance between the advantages and disadvantages of more and less structured interviews. Less structured approaches to interviewing arguably give participants more control over what subject matter is treated as relevant (Patton 2002), which is in keeping with emancipatory disability research principles (Barnes 1992; Priestley 1997). However, overly unstructured approaches arguably rely too heavily on normative conversational skills, which may have made it inaccessible both for some disabled participants, particularly those with communication-related impairments, and potentially for me as an interviewer given my own access needs. A sufficient degree of systematisation is also needed to ensure that data from different interviewees is at least broadly comparable (Marshall & Rossman 2006; Woodin 2006).

I considered and rejected other qualitative methods, including participant observation and focus groups. Observation would in some ways have seemed a logical choice for this research because it is well suited to researching relationships involving interaction over time (Gerson & Horowitz 2002), such as that between disabled people and their personal assistants. However, Gerson and Horowitz also argue that observation is an inductive research strategy, in which themes and findings emerge from data, whereas interviewing is suited to a more deductive approach in which data analysis is based on an existing framework (Patton 2002). Therefore interviewing is more likely to yield appropriate data for research which, like this project, "begins with an empirical or theoretical puzzle" (Gerson & Horowitz 2002, p.201). Additionally, observation can be ethically problematic because it can be dubious with regard to informed consent and tends to be from an 'outsider' rather than an 'insider' perspective (Banister 2011). It can also be practically difficult because it is time-consuming and labour-intensive, and likely to be "more challenging and

exhausting than conducting interviews" (Mason 2002, p.87), perhaps particularly for a disabled researcher.

Focus groups have been used successfully in disability research (e.g. Barr et al 2010; Priestley 1999; Rainey 2011), and have been suggested to have practical advantages over one-to-one interviewing in terms of cost, speed of data generation and increasing the number of different people's experiences that can be included in the research (Marshall and Rossman 2006). They have also been argued to be potentially empowering for disabled participants (Llewellyn 2009). However, focus groups are also likely to present ethical problems which are much less likely with one-to-one interviews, including with confidentiality and with potentially distressing interactions between participants (Gomm 2008). Focus groups could also have been problematic in terms of my own access needs; as I have impaired auditory processing, it is difficult for me to follow conversations involving several simultaneous voices, and they would also have been likely to present me with significant difficulty in organisation and time management.

Emancipatory research?

Due to my political commitments and the relationship of my research topic to them, it was important to me that this research project did not merely extract knowledge from participants, but would be of material benefit, if not directly to the individuals interviewed, then to the wider groups that the research was concerned with (disabled people and those who are paid to assist them). I also more broadly desired my research to produce knowledge and analysis that could inform political action by and for those groups, and constructively critique the practical work of disabled people's and allied (e.g. labour and feminist) movements. Both feminist researchers (e.g. Acker et al 1983; Lather 1986; Oakley 1981) and those affiliated with the DPM (e.g. Barnes 1992; Oliver 1992, 1997; Priestley 1997; Stone & Priestley 1996) have contributed to the development of 'emancipatory research'. This can be defined as research that is engaged with and informed by oppressed peoples' political struggles, focused on systems of oppression rather than on oppressed people as individuals, and

intended to be of practical benefit to the cause of its subjects' emancipation (Barnes 1992; Lather 1986; Stone & Priestley 1996). In Disability Studies specifically, Stone and Priestley (1996) argue that emancipatory research necessarily has the social model of disability as its epistemological foundation.

This raises the question of whether this project - or any research project undertaken with the aim of getting its author a PhD - can be fairly considered to be emancipatory research. Traditional academic paradigms position individual researchers as 'experts', while emancipatory research aims to centre the expertise of the 'researched' on their own experiences and to deliver 'ownership' of research and its outputs to them (Priestley 1997). Seymour and Garbutt (1998) argue that a doctoral research project cannot by definition constitute 'true' emancipatory research, because this would require everything from the definition of the research topic onwards to be a 'joint enterprise' between all involved, and a PhD thesis is authored by one person, and founded on an 'intellectual puzzle' (Mason 2002) set by that person (a possible exception being if it is based on research which was commissioned by the group being researched, such as Priestley's (1997, 1999) doctoral research with Derbyshire CIL).

However, this relies on 'emancipatory research' being defined in terms of its methodology. Swain and French (1998, p.52) argue that emancipatory research "cannot be defined solely by power-relations internal to the research". Thus the more meaningful judgement of whether research is 'emancipatory' or not is arguably its impact, i.e. whether it contributes concretely to struggles for liberation (Oliver 1997; Swain & French 1998). Thus research can be 'emancipatory' in form but not in content, or vice versa. Kelly et al (1992, p.150) make a similar argument that "what makes feminist research feminist is less the method used, and more how it is used and what it is used for". Additionally, emancipatory intent on the part of a researcher is no guarantee of the research having an emancipatory outcome (Acker et al 1983). Oliver (1997, p.25) therefore argues that "research can only be judged emancipatory after the event".

Therefore, this research project cannot be considered 'emancipatory' in a methodological sense. It may, however (and I hope it will) have emancipatory impact in terms of contributing knowledge and ideas that can be strategically useful to movements for radical social change, including but not limited to the Disabled People's Movement. However, this fundamentally depends on dissemination (as well as on the quality of the ideas and arguments themselves). As well as this thesis, I intend to disseminate the knowledge produced from this research in various forms including publishing in open access journals and presenting at conferences and other events, as well as in more informal ways through conversation within the movements I am involved in. There are complex issues surrounding the accessibility (or inaccessibility) of ideas, theory and critique that there is not sufficient space to consider properly here, but I feel it necessary to acknowledge that - in part also due to my own limitations in the types of writing that I have the skills to produce - this is likely to be a significant barrier to the emancipatory potential of my work.

Recruitment and sampling

For recruitment I created a website containing an overview of my PhD and a call for participants and advertised this on Facebook, Twitter and the JISCmail Disability Research list, asking people to share it. I also sent the call for participants by email to friends, academic colleagues and other contacts who I thought might either be interested in participating themselves or know others that might be interested, and to local Disabled People's Organisations (although in the end I did not recruit any participants through organisations). I intended to use the 'snowball' method (Browne 2005) of asking already-recruited participants to suggest others who they thought would be good people for me to interview; however, while some participants did suggest others, in most cases these people did not contact me. Two participants, however, did contact me because others who I had interviewed had told them about my research - in both cases, these were PAs who had been told about my research by employers who had developed significant informal networks of PAs, former PAs and other employers through a combination of developing friendships from PA/employer relationships and shared activist and/or intellectual interests.

'Snowballing' also arguably occurred in a broader sense, as several participants were put in touch with me by mutual friends who were not themselves research participants.

My choice to adopt a sampling strategy which does not attempt to be 'representative' of either PAs or PA employers was informed by political and epistemological considerations. While Gerson and Horowitz (2002, p.205) argue against "self-selection" methods of recruiting such as 'snowballing' or advertising because they are 'unrepresentative' and may introduce 'bias' to data, the ideas of representative sampling and of avoiding bias are founded in notions of 'objectivity' and 'generalisability' which derive from a positivist epistemology of research as 'neutral' or 'independent' (Oliver 1992). Feminist qualitative researchers (e.g. Lather 1986; Oakley 1981) and emancipatory disability researchers (e.g. Barnes 1992, 1996; Stone & Priestley 1996) argue that 'neutrality' or 'independence' in social research is neither possible nor desirable (a critique that can perhaps be connected to the feminist and disability critiques of 'independence' explored in Chapter 2). It is also arguable that representative sampling is in any case impossible in qualitative research (Barbour 2008; Mason 2002), and therefore attempting to be representative "may not be the most effective and efficient way either to generate data which will address the research questions of the study, or to develop analysis and theory" (Mason 2002, p.126). Therefore my aim was for my sampling not to be representative, but to be 'strategic' (Mason 2002) or 'purposive' (Guest et al 2006); i.e. to select participants on grounds of relevance to the research questions and the ideas involved in the rationale for the research.

On these grounds, my aim was to recruit participants with the widest available variety of experiences of providing and receiving personal assistance in order to get a wide range of perspectives on the issue (i.e. to seek out 'information-rich' cases (Patton 2002). I originally intended to look for individuals to interview who either particularly strongly demonstrated in their lived experience the archetypal features of the employment relationship between disabled people and PAs, or who had unusual experiences of that relationship which are likely to cast light on under-theorised aspects of it, hopefully adding up to a range of interviewees

providing as broad and comprehensive as possible a range of perspectives on my research questions.

I intended to interview approximately 15 each of direct employers and PAs, a number chosen based on both estimates given in research literature of the number of interviews needed for a qualitative research project to reach the point of data saturation (Guest et al 2006; Mason 2010) and my estimate of what would be practicable within the constraints of available resources and time. However, any such number is inevitably somewhat arbitrary (Mason 2010). I eventually interviewed 27 participants, of which 13 were employers, 12 were (current or former) PAs and 2 participants had experience of both 'sides' of the PA/employer relationship, in both cases having worked as PAs before themselves developing chronic conditions which stopped them from being able to work and necessitated them becoming employers of PAs themselves.

Data saturation is arguably impossible to precisely define or to fully reach; however, it has been argued that it is reached when data has been gathered "to the point of diminishing returns" (Bowen 2008, p.140) or when "new interviews are more likely to confirm earlier insights than to spark new discoveries" (Gerson & Horowitz 2002, p.211). Thus I cannot say definitively that saturation was reached in this research, but towards the end of the interviewing process I did notice that new interviewees were talking about the same themes, and in some cases giving similar anecdotes, to previous interviewees. Therefore saturation was likely, if not reached, then at least approached within the boundaries of the themes that I chose to focus on.

Participant demographics

I did not explicitly collect demographic information from my participants. My reasons for not doing so were that asking them such questions felt like an intrusion or interrogation that could have made interviewees feel uncomfortable and decreased rapport with them (Patton 2002), and also because it felt largely irrelevant to the purposes of my research. It was only later that it occurred to me that demographic information might be useful from an intersectional perspective

(Liasidou 2013) in analysing how social locations and experiences of oppression other than disability might affect the relationship of PA and employer (see for example Begum 1990; Vernon 1999). However, some broad sketches of the demographics of my interviewees are possible from information revealed by them in interviews or already known by me. The demographic information that is most relevant to the findings of my research is presented in a table, which for formatting reasons is located at the end of this chapter.

The majority of both PAs and direct employers were women. This was expected with regard to PAs, as it is a heavily female-dominated occupation (Kelly 2016; Woodin 2006), but less so with regard to employers; however, it may reflect bias in recruitment strategies. LGBT+ groups were represented among both PAs and employers at higher rates than in the general population (likely representing Disabled People's Movement social circles). The majority of both categories were white and British, though there were employers of African and South Asian origin and PAs who were immigrants from EU and non-EU countries. Employers ranged in age from early 20s to over 70; PAs were somewhat more homogeneous, being mostly in their 20s and 30s with one exception who was around 60. Employers varied widely in socio-economic class, from wealthy homeowners to people living on benefits in social housing, while PAs were more typically working-class, though arguably more educated than average (again, this may reflect recruitment strategies).

All of the direct employers had assistance needs primarily relating to physical (and in a few cases additionally visual) impairments. This arguably reflects the dominant impairment groups both among direct employers of PAs (Gramlich et al 2002; Hall 2009) and within the Disabled People's Movement in the UK (Shakespeare 2014). My sample was thus less diverse in this regard than I had hoped for; however, its relative homogeneity may have made saturation easier to reach (Guest et al 2006). The absence of other impairment groups (particularly including those with assistance needs relating to mental health conditions and/or learning difficulties) from this research is a significant flaw in it, and one which I have attempted to remedy, to the greatest extent possible, by referencing and incorporating perspectives from literature on these groups and

personal assistance (see in particular Chapters 4 and 8). Some experiences of personal assistance for people with learning difficulties were also gathered from PAs who had worked with this impairment group.

A perhaps surprisingly large number of PAs interviewed (even not counting the 2 former PAs who had developed physical impairments forcing them to stop working as PAs and had since become employers) were themselves disabled people, with various 'non-physical' impairments. This is likely to reflect the social circles from which they were recruited, but also perhaps reflects the fact that PA work is more accessible than many other forms of employment to people who find themselves on the margins of the labour market due to factors such as disability, other minority status, or previous long-term unemployment (this is discussed in Chapter 6).

Friends as research participants

Of the participants I interviewed, 8 (4 employers, 3 PAs, and one of the 2 who had been both) were existing friends. 4 (2 employers, 2 PAs) knew me through academic circles within Disability Studies and one PA knew me through being involved in DPOs. The other person who had both been a PA and employed PAs was put in touch with me by a mutual friend who I did not interview, but who is also a disabled person involved in the Disabled People's Movement, and one employer was put in touch with me by a relative of mine who had briefly worked as his PA. The aforementioned two PAs were put in touch with me by other participants I had interviewed, and all other participants contacted me because they had seen my call for participants online or had it forwarded to them by people unknown to me.

This is likely to have influenced my data in more than one way. The friends who I interviewed had all arguably informed my planning of this research through the conversations about personal assistance that I had had with all of them and the influence they had already had on my thoughts on the topic. In this my experiences were similar to those of Kelly (2013, 2016). The data given during interviews is also likely to have been influenced by my position as an 'intimate

insider' (Taylor 2011). Several authors (Garton & Copland 2010; Kelly 2013; Taylor 2011) claim that not enough has been written about how data generation is influenced when pre-existing friendships lead to researcher-informant relationships, as opposed to friendships developing out of research relationships; thus this merits deeper methodological consideration. As Kelly (2013) points out, there are interesting parallels here between the relation of 'friendship' to the relationship between researcher and interviewee and to that between PA and direct employer (which is discussed in Chapter 4).

Gomm (2008, p.232) argues that people are likely to "disclose some things to a stranger which they will not disclose to a friend, and vice versa, and probably people differ in this regard". It is hard to tell what data I got from interviewing friends that I would not have got from strangers, or whether or not there were things that the friends I interviewed would have said to an interviewer who was a stranger to them, but not to me (e.g. for fear of my opinion of them being negatively changed and damaging the friendship). However, like Garton and Copland (2010), I believe that my data was probably made richer by the pre-existing rapport and foundation of past conversations and shared experiences that I had when interviewing friends. In some ways I found friends easier to interview than strangers because familiarity made me feel less anxious and, for example, more able to expect a friend to 'forgive' me for mangling a question (and to understand what I was trying to ask, due to familiarity with me and my differences from normative communication styles). Having shared values and experiences of the same social movements made talking about some topics easier in interviews with friends and/or DPM comrades (see also Browne 2005; Taylor 2011), and it was also often easier with friends or acquaintances to be enthusiastic about doing the interview and to be open about myself and my standpoints as researcher and interviewer.

However, interviews with friends did also present some difficulties: with some friends, especially those whose experiences with either side of the PA/employer relationship I had previously been involved with as a supportive friend, the 'asymmetrical' (Garton & Copland 2010) conversational role expected of an interviewer felt 'unnatural' and sometimes difficult to stay in. This led to a few

interviews slipping into the kind of more 'naturally' reciprocal and mutually supportive conversation that I would generally expect to have with friends, at times perhaps bordering on 'woven autoethnography' (Castrodale & Zingaro 2015). Having a 'foundation' of past conversations and shared experiences to draw on can thus be a double-edged sword in terms of data generation: on the one hand it can be easier to have a conversation that has already in a sense been 'rehearsed', and the analysis occurring in that conversation can be more sophisticated for having that foundation, but on the other hand the shared knowledge which can be assumed - and thus does not need to be made explicit - can mean that the recorded conversation leaves out important implicit context to what is said explicitly, making it more difficult to quote or paraphrase such 'data'.

It can be harder to ask friends questions that might imply criticism or negative judgement of them (Kelly 2013), and participants may have a stronger motivation to avoid offending, upsetting or strongly disagreeing with a friend as interviewer (Browne 2005). However, it was not my intent to be oppositional or confrontational in my interviews, in part because of my desire to stay on friendly terms with my participants. While this was of course stronger with my existing friends, it was still present with other participants, as most if not all were either themselves involved in, or as PAs allies to, the Disabled People's Movement. The potential restriction of data caused by this is mitigated by following Taylor's (2011, p.15) recommendation not to exclusively rely on friend-informants, but instead to aim to have "a mix of intimately familiar and unfamiliar informants" as a "checking mechanism" to avoid too much homogeneity of opinion and cultural perspective.

Kvale (2007, p.29) is critical of researchers having such close ties to participants, arguing that this may compromise the integrity of the research because interviewers "may identify with their subjects so closely that they do not maintain a professional distance, but instead report and interpret everything from their subjects' perspectives". However, this assumes a positive value of 'professional distance' (a concept critiqued in other contexts in Chapter 5 of this thesis), and invites the same criticisms from emancipatory research

perspectives as the aim of 'representative' sampling. Browne (2005) also argues that being 'embedded' in the same social networks as participants is an ethical positive as it allows participants to be more informed about the research and the researcher and to be likely to feel more comfortable about taking part in research.

Consent and related ethical considerations

I considered it a fundamental ethical principle that everyone involved gave informed consent to participate in this research. Beyond this, I aimed to give participants as much control as possible over the interview process. All participants were sent a consent form and participant information sheet (see Appendix A) before interview. Participants were informed that they may withdraw their consent at any time, though none did so. I offered participants the choice of using their real names, choosing pseudonyms for themselves, or letting me choose a pseudonym for them. Anonymity in qualitative research is ethically complex, and ethical guidelines are often based on the assumption that all research participants desire anonymity (Giordano et al 2007; Grinyer 2002). My decision to offer the choice was informed by the experience of other disability researchers who report participants in their research expressing strong wishes to be publicly identified (Galvin 2004; Grinyer 2002; Thomas 1999; Vernon 1997), and by the emancipatory principle of giving participants choice and control over their involvement in research. Parker (2005) also argues that concealing the identities of participants "confirms one of the prevalent images of those who are researched... as fragile beings needing to be protected by others" (p.17). For disabled people, such paternalist attitudes potentially replicate the frequent use of paternalist justifications for their oppression and exclusion from mainstream society (Shakespeare 2000).

Of the 27 people I interviewed, 3 (2 PAs and 1 employer) wanted me to use their real names, and the rest preferred to use pseudonyms. I ended up changing the name of the employer, on advice from my supervisors, because of the risk of other people they talked about (such as former PAs) being identified. As this participant was a friend, I was able to contact them about this, and they

were happy with the decision. I decided, for consistency, to use only the first names (whether real or pseudonymous) of all interviewees and, following Grinyer (2002), not to distinguish in the text of this thesis between real and false names as a compromise between allowing those interviewees who wished to be able to recognise themselves to do so and preventing unnecessary or harmful identification by others.

Conducting the interviews

I carried out my research interviews between March and September 2015. I mostly met my participants for face-to-face interviews, but 5 interviews were done via the Skype online video call service, and one by telephone. The length of interviews varied from just under an hour to over 2 hours, but most were between an hour and an hour and a half. One interview was split over two sessions due to the participant's access requirements (this participant had a speech impairment and for her speaking for long periods is very tiring, which results in her speech becoming harder to understand). The choice to interview via Skype or phone rather than face-to-face was due to participants' access needs in some cases, although in others it was simply more practical than travelling to meet participants, particularly those who lived in rural areas.

All interviews were recorded with a portable mp3 audio recorder. I also took notes in a notebook during the interviews, both in case of a recording failure and because I find taking notes helpful for focusing on what people are telling me and asking follow-up questions. In one interview the recorder stopped recording unexpectedly, and probably somewhere between 10 and 20 minutes of the interview was 'lost', but I was able to reconstruct what the interviewee said from my notes, albeit perhaps not to a level of accuracy that would allow direct quotation of that section. I always told participants that they could contact me afterwards if there was anything they had intended but forgotten to say in the interview, or only thought of later, and I also always asked if it would be OK for me to ask them follow-up questions by email after reviewing the recording of the interview. In the end I both of these only happened in the case where the recorder failed.

All my interviews were transcribed from the mp3 recordings. This was done verbatim, but without using the specialised transcription conventions used, for example, in conversation analysis (Kvale 2007), because my intent was not necessarily to focus on the precise wording participants used but on the 'bigger picture' of standpoints, relationships and experiences that the interviews revealed. After transcribing the interviews (between 4 to 9 months after interview depending on the individual), I contacted all participants again by email to ask whether they still consented to my use of their interviews in my PhD thesis and/or in associated publications, whether they wanted to read the transcript of their interview, and whether they wanted to be kept informed about publications and other outputs of the research. All participants were happy for their interviews to be used, and most wanted to be informed about publications and other outputs of the research. Nearly half (12 of 27) asked to read their transcripts. Decisions about how to transcribe speech always involve some compromise and potential for misrepresentation of the speaker's intent (Alldred & Gillies 2002). While I had been concerned both about misrepresentation and about potential negative reactions by participants to verbatim transcripts because the presentation of their speech may have seemed incoherent or inarticulate (Mero-Jaffe 2011), no participants who read their transcripts objected to them. However, one replied after reading with some corrections and additional information clarifying some points discussed, and another supplied some information that she had forgotten at the time of the interview.

Questions

I started out with a list of questions, some of which were the same for all participants and some only for employers or only for PAs (this list is reproduced in Appendix B). These questions were developed from my original research questions (see Chapter 1). However, some questions that were on my original list were removed after attempts to ask them in early interviews did not result in very informative answers, and other questions were added because of topics that came up in the course of interviewing. This both reflected and influenced a general shift in emphasis over the course of my interviews. The questions that I

dropped were largely those about participants' 'ideal world', which I found very difficult to coherently ask, possibly because they were too speculative and/or too disconnected from the other questions and topics covered in the interviews (for further discussion of this see Chapter 7). I also started to ask several other questions over the course of the interviews that were not originally on my list, but which became 'standard' questions by the time of my later interviews. These new questions included:

- questions about taking initiative in work (to PAs how much initiative they felt they could take in their daily work, to employers how much initiative they liked PAs to take) - this fit into the themes of the initial questions and I think gave me some interesting and valuable data about meanings and conceptions of autonomy.

- questions about training for PAs (and/or for employers) and whether it is desirable and about the relationship of ideas around 'professionalism' to PA work (often related to the topic of the generalisability of norms about PAs' roles and PA/employer relationships).

- a range of questions about interactions between the employer/PA dyad and other people, including interactions with employers' friends and families and perceptions of PAs or of employers and PAs together in public or in workplace/educational/social settings, and strategies used by employers and PAs to manage these, which sometimes also led into wider questions about public awareness of PAs and what they do, and what could be done to improve this.

This shift in the questions asked arguably reflected a broader shift in the focus of my research over the course of my interviews. Some aspects of my original plan (particularly the more theoretical or speculative elements oriented towards a hypothetical better society) dropped out of my focus, while other aspects (particularly relating to the emotional and power relationships within the PA/employer dyad and to how PAs and their employers fit into wider communities) became more interesting to me. Thus the final form of my thesis is both 'data-driven' and 'theory-driven', with a dynamic relationship between the two, but much of its content is derived from emergent data that I had not

planned to collect before starting the interviewing process. In particular, Chapter 4 is heavily based on emergent themes about PAs and social interaction, and Chapter 7 was inspired in part by the difficulty my interviewees experienced with the more speculative questions due to these being overshadowed by more immediate concerns.

Self-positioning as disabled and privileged researcher

The data obtained from my participants was also influenced by many aspects of my own position as researcher and interviewer. All social researchers "are integral to the social world we study" (Mauthner & Doucet 2003, p.416), but feminist (e.g. Oakley 1981; Lather 1986) and Disability Studies authors (e.g. Barnes 1996; Stone & Priestley 1996; Vernon 1997) have argued for the ethical relevance of researchers' standpoints relative to the groups of people they are researching. The question of whether research in Disability Studies should (only) be conducted by disabled people has been hotly debated (see e.g. Branfield 1999; Humphrey 2000; Sheldon 2006). More broadly, the principle that research is best conducted by those whom it directly affects is a core issue in debates about emancipatory research (Gillies & Alldred 2002; Mercer 2004).

However, there are two complications to this in this case. Firstly there is the question of whether 'disabled people' is a unified category, encompassing as it does a wide range of people with different impairments and consequently different experiences of disablement (Humphrey 2000). I am a disabled person (and an activist in the Disabled People's Movement, as, to greater or lesser extents, are many of my participants including the majority of the employers and a few of the PAs). However, I do not have the kind of impairment-related assistance needs that require employment of PAs, which arguably puts me in a position of privilege over my employer participants. I am not sure of the extent to which participants who did not already know me were aware of my status as a disabled person; while I did make this clear on my research website, it was on a different page to the call for participants. I did not explicitly describe myself as a disabled person in my email to the Disability Research list, but I did link to the 'about me' page on my site which did do so.

Secondly, in this research project there were two groups of participants (disabled employers and PAs), both of whom are in simultaneous power relations of opposite direction (disabled/non-disabled, or perhaps more accurately 'dependent' and 'depended-upon', and employer/employee) to one another. This is further complicated by the fact that some PAs were themselves disabled people and by the two participants who had experienced both sides of the PA-employer relationship. As I have in the past worked as a PA, I am perhaps aligned most closely with the PAs who were also disabled people (with impairments that did not, or did not particularly, affect their ability to perform the physical tasks required in the job). My position as an 'insider' or 'outsider' researcher (Taylor 2011; Vernon 1997), already rendered mixed and ambiguous by these factors, is further complicated by my 'intimate insider' status with friend-participants as discussed above.

The impairment effects (Thomas 1999) that I experience as an autistic person also influenced the research process. For example, my atypical vocal intonation, facial expressions and other non-verbal communication all likely affected how I was perceived as an interviewer. Many of the techniques described by Duncombe and Jessop (2002) for achieving 'rapport' with interviewees (such as "keep[ing] eye contact, speak[ing] in a friendly tone, never challeng[ing], and avoid[ing] inappropriate expressions of surprise or disapproval" (p.110)) are difficult or impossible for me. However, this was offset by familiarity in my interviews with people I already knew, and may not have been a disadvantage in other interviews with disabled people, who may have good reason to be suspicious of these techniques. Duncombe and Jessop criticise such techniques as ethically insincere and manipulative of interviewees in such a way as to compromise the principle of informed consent (see also Oakley 1981); they may additionally be considered ableist and culturally normative (Kvale 2007) in their assumptions about what interviewees find (un)comfortable.

Social location is always partial, and it is not the only dimension of reflexivity. Doucet and Mauthner (2002) argue that reflexivity should not just consider

social location but also "the personal, interpersonal, institutional, pragmatic, emotional, theoretical, epistemological and ontological influences on our research" (p.125), and that this broader conception of reflexivity is essential for research to satisfy the ethical values of transparency and accountability. Therefore it is necessary for me to be open about my personal and political motivations for doing this research. This research topic can be regarded as 'fully mine', as I came up with the topic myself and proposed it in my application for funding to do a PhD (although this was one of several potential topics I could have based a PhD proposal on). My initial inspiration for wanting to do research on personal assistance came from my experiences, as described in Chapter 1, of working as a PA for a fellow activist in the Disabled People's Movement, while also being involved in wider anti-capitalist movements and agreeing with the 'anti-work' and 'anti-productivist' analyses of anarcho-communists, autonomists and radical environmentalists (see for example Federici 2004, 2012; Gorz 1982; Kropotkin 1990 [1913]; Weeks 2011). These experiences created a growing awareness of potential contradictions between my political and theoretical positions on wage work and my job being an example of wage labour being used as a means to disabled people's liberation. More selfishly, my motivations for wanting to do this research as a PhD also involved my own need for an income from Research Council funding and my desire to achieve social status and opportunities to promote and disseminate my ideas within academic circles.

In choosing this PhD topic over potential others, I was motivated by the desire to 'solve' contradictions within the Disabled People's Movement over the question of waged work, as well as to have 'joined-up' politics encompassing analysis and action on both disablement and other aspects of globally interconnected systems of oppression including capitalism, imperialism and patriarchy, and to address the personally important question of how disabled people's assistance needs would be met in my (anarcho-communist) ideal society. My theoretical influences include the aforementioned 'anti-work' perspectives, as well as the theories of disablement developed within and from the Disabled People's Movement (including but not limited to the social model of disability; see Chapter 2); for my earlier attempt to synthesise these perspectives, see Graby (2015). However, I see the relationship between theory

and data in this research as reciprocal; while theoretical stances informed my research design and questions, and thus data generation, new analysis and new theory has also emerged from the data. In this I follow Lather (1986), who argues that "not only must theory illuminate the lived experiences of progressive social groups; it must also be illuminated by their struggles" (p.262).

Coding and analysis of data

Analysis of my interview data arguably started during the interviews themselves, in the notes that I took during them, and in particular while transcribing the audio recordings. Data is arguably always already being analysed in the transcription process, whether intentionally or not (Alldred & Gillies 2002; Kvale 2007); however, as Parker (2005) advocates, I intentionally used the process of transcription for "anticipation of the themes that you may want to highlight and extract for the analysis" (p.66). After transcribing (and often annotating the transcripts with, for example, connections between different interviews or to literature), I already had a loose list of emerging themes. In an attempt to approach these more systematically, I coded the interview transcripts using the qualitative data analysis software Nvivo (Bazeley & Jackson 2013). This resulted in the creation of over 100 'nodes', each consisting of sections from the transcripts that had been labelled with codes such as 'boundaries of PAs' role', 'PAs and employers' family' or 'solidarity between PA and employer' (many of which substantially overlapped with each other). These can also be regarded as interpretive indexing categories (Mason 2002). In attempting to map the connection of these 'nodes' to one another, I ended up with 'clusters' of related themes, some of which ended up forming the basis of thesis chapters.

This process was useful for 'reducing' data into manageable 'pieces', particularly as data management was something that I knew I would struggle with due to impairment effects on executive function. Thus for me Nvivo can be regarded as a piece of assistive technology. However, it arguably had the side effect of lessening my ability to review the 'bigger picture' of my interviews as accounts of my interviewees' experiences (Coffey & Atkinson 1996). The grouping of interview quotes into coded themes undoubtedly strongly influenced

the structure of the overall thesis by narrowing focus, without which I might not have been cognitively capable of a project of this size at all. However, this also resulted in the exclusion of "chunks of data" (Coffey & Atkinson 1996, p.47) which did not easily fit into these themes, and the consequent potential loss of important insights.

My indexing categories included both 'a priori' codes, which are derived from prior reading and theoretical understanding, and 'in vivo' codes, which emerge directly from data (Bazeley & Jackson 2013). These respectively correspond to 'indigenous' and 'sensitizing' concepts and to emic and etic perspectives on the phenomena being studied (Patton 2002), and to 'data-driven' (or inductive) and 'theory-driven' (or deductive) approaches to research (Boyatzis 1998; Gerson & Horowitz 2002). My approach to this research was both 'data-driven' and 'theory-driven', as I conceptualised it as a critical synthesis of insights gained both from interviewing participants and from existing theories, concepts and literature. In this, I followed Coffey and Atkinson (1996, p.23) who argue that "dialogue between data and theory should be a recurrent, pervasive feature of all qualitative research".

In being neither fully inductive nor fully deductive, my approach thus has some similarities with abductive reasoning, which starts from a particular phenomenon and seeks to explain it by associating data with existing ideas (Coffey & Atkinson 1996; Richardson & Kramer 2006). This allows both for the incorporation of existing theory into an otherwise data-driven project and for the generation of new theory from it (Timmermans & Tavory 2012). The abductive approach, while it may be problematic in terms of generalisability (Lipscomb 2012), arguably better reflects how most qualitative research works in reality (Coffey & Atkinson 1996). However, Mason (2002) argues that neither inductive, deductive nor abductive research strategies exist in a pure form.

Coding of data, while it may be part of a process of analysis, does not constitute data analysis by itself (Coffey & Atkinson 1996). After coding, my analysis of the data was not systematic or rigorous; indeed, it was difficult for me to distinguish 'analysis' as a separate phase of work from 'thesis writing'. While I had

previously read about various methods or techniques of qualitative data analysis, such as content analysis, discourse analysis, narrative analysis and thematic analysis (Gomm 2008; Kvale 2007; Patton 2002), I did not strictly follow any of them. However, Coffey and Atkinson (1996, p.10) argue that analysis "is not about adhering to any `one correct approach or set of right techniques", and Kvale (2007) argues that in practice many analyses of interviews freely mix analytic techniques, which he terms 'bricolage'.

In practice 'analysing' my data consisted largely of reading through the nodes and connecting them with relevant literature and concepts. In Wolcott's (1994) terms, this was arguably more interpretation than analysis. Rather than adopt a particular analytical method, I relied heavily on (more or less intuitive) pattern recognition, which is central to my cognitive style and has been argued to be an autistic trait or aptitude (Mottron et al 2006). This arguably corresponds well with abductive reasoning. Boyatzis (1998) argues that pattern recognition is a necessary competency for thematic analysis of qualitative data; thus in this case it is arguable that my impairment effects gave me an advantage in 'doing analysis' intuitively. Nevertheless, it is likely that a more rigorous analysis of the same data, perhaps by a neurotypical and/or more experienced researcher, would yield insights that I missed.

Data from my interviews is presented and interpreted, alongside relevant literature, in the following 4 chapters. As Coffey and Atkinson (1996, p.146) argue, "Analysis is never complete. There are always more ideas and more lines of inquiry open to us than we can ever hope to exhaust." Therefore, what is contained in this thesis is only a fraction of what could be generated from the data collected in my interviews. I hope to be able to (partially) rectify this at some future point by re-examining my interview transcripts and incorporating material from them into other publications, though this will always be an incomplete endeavour. Nonetheless I hope that this thesis fairly represents the views of my interviewees, while going beyond their data to inform both theory and action.

Appendix to Chapter 3: Table of research participants

Name	Relationship to personal assistance	Age	Gender	Nationality/ ethnicity	Housing arrangements	Employment status	Involved with DPM?
Ada	Employer	50s	Female	White British	Alone	Self-employed	Yes
Agatha	Former PA	20s	Female	White European	Unknown, former live-in PA	Employed	No
Anita	Former PA and employer	30s	Female	Black British	With housemates	Employed/ student	Yes
Anne	Employer	60s	Female	White British	Alone	Retired	Yes
Carol	Employer	40s	Female	White British	With partner and child	Self-employed	Yes
Charlie	Former PA and employer	20s	Non-binary	White British	Co-operative with partner and others	Student	Yes
Daisy	Former PA	30s	Female	White British	With housemates	Employed	No
Dawn	Employer	30s	Female	Mixed race British	Alone	Unemployed/ unable to work	Yes
Ede	Employer	60s	Female	White British	Alone	Retired	Yes
Elizabeth	Employer	20s	Female	White British	With live-in PAs	Employed	Yes
Emily	Former PA	30s	Female	White British	With partner	Unemployed	Yes
Emma	Former PA	30s	Female	White European	With partner	Employed/ student	Yes

Name	Relationship to personal assistance	Age	Gender	Nationality/ ethnicity	Housing arrangements	Employment status	Involved with DPM?
Grenville	Employer	30s	Male	White British	With housemates	Student	No
Jack	Employer	40s	Non-binary	White British	With partner and children	Carer for family	Yes
Jane	Employer	50s	Female	White British	Alone	Unemployed	No
Joanna	PA	30s	Female	White European	With housemates	Employed	No
Joe	Former PA	60s	Male	White British	Alone	Retired	Yes
Katherine	Former PA	30s	Female	White British	Unknown	Employed	No
Lisa	PA	30s	Female	East Asian	Unknown	Employed	Yes
Malcolm	Former PA	20s	Male	Black British	Unknown	Student	No
Phoebe	PA	30s	Female	White British	With partner and children	Employed	Yes
Sarah	Former PA	30s	Female	White British	With partner	Unemployed	No
Slav	Employer	20s	Male	White British	With family	Student	Yes
Stan	Employer	30s	Male	White British	Alone	Unemployed/ unable to work	Yes
Tom	PA	30s	Male	White British	Unknown	Employed	No
Yahya	Employer	40s	Male	South Asian British	With partner and children	Employed	No

Chapter 4

Personal assistance and relationships: from paid friendship to social enablement and disablement

Personal assistance is 'personal' in more than one sense of the word. A major theme in all my interviews was the variety and complexity of the interpersonal relationships between PAs and direct employers, and the strategies used by both sides of this dynamic to negotiate it; while not central to my original research questions, this can be regarded as an emergent theme as interviewees, particularly direct employers, were keen to bring it up and it rapidly became a part of the interview schedule (see methodology chapter). Recent research by Shakespeare et al (2017, 2018) with a similar purposive sample of employer and PA participants has similarly explored these complexities, leading them to argue that relationships between direct employers and PAs are more complex and involve a greater range of emotions and "social, psychological and ethical dimensions" (2017, p.11) than the 'Independent Living' philosophy allows for. My findings partially reflect theirs, but I argue that the emotional complexity of the employer/PA relationship does not necessarily negate the principles of independent living if these are defined expansively rather than narrowly and with regard to relational autonomy (see chapter 2).

This chapter will address the complexities and ambiguities of the relationships between direct employers and PAs, as well as the related issue of the impact of personal assistance on other relationships in the lives of direct employers and (to a lesser extent) PAs. The role of PAs can be regarded as, at least in part, to overcome disabling barriers experienced by their employers in an inaccessible society (Snow 2015). While the DPM and its 'big idea' (Hasler 1993) the social model of disability have largely focused on barriers in the public sphere (e.g. barriers to physical access in the built environment), disabled people may also experience many forms of barriers to social relationships in the 'private' sphere (Thomas 1999). The extent of PAs' role in helping to overcome these social barriers and the means by which they can and/or should do so are debatable; for some PAs should enable, or assist in the development and maintenance of,

other social relationships (e.g. Adams & Godwin 2008; Vasey 2000**)**, while for others they may be perceived as a source of social relationships in themselves (e.g. Shakespeare 2014; Wedgwood et al 2018). There are also circumstances in which the presence of a PA can sometimes itself be a barrier to other social relationships (Parker 1999; Skär & Tam 2001).

Relationships between employers and PAs

In clear contrast to many other worker/employer relationships, the relationship between direct employers and PAs was regarded by most of the direct employers, and several of the PAs, who I interviewed as highly intimate and involving an emotional intensity which is generally not considered typical of the workplace (Vogelmann 2016). (For more on comparison between personal assistance and other paid work and on emotion work within personal assistance, see Chapters 5 and 6.) This was often connected by interviewees with the criticality of personal assistance to direct employers' lives and thus high risk of serious endangerment from things going wrong in that relationship. For example, one employer, Dawn, said "when things go bad it's really, really, really difficult for me, because there's no two ways about it, it's an extremely intimate relationship", and another, Yahya, described it as:

> "It's much more intimate and private a relationship [than other employment]. There's so much that a PA will find out about you and know about you, just from their work with you... if workers in an office were to take holiday or sick leave, it wouldn't really make much difference to managers, there are plenty of people there to cover for that and get on with their work. When it comes to a PA and a disabled person, if they have to take that time off, then it is a big deal to that disabled person."

Sarah, a PA, similarly observed:

> "I think there is always going to be a difference [from other employment relationships] because it's so much more intimate, so

much more hands on, and you get to see all the different aspects of a person's life, depending on how much you're working for them, and especially when you're doing such a long shift... you're kind of living with them temporarily."

Intimacy is also arguably inherent in personal assistance because of the physically intimate nature of the tasks performed by many PAs, particularly for people with extensive physical impairments. For at least some disabled people and PAs, this physical intimacy inevitably results in some degree of corresponding emotional intimacy (Begum 1990; Snow 2015; Woodin 2006). This was compared by some employers to intimate relationships outside the world of employment, such as marriage or family relationships; for example, Anne said:

"It is a unique form of trust, and I don't think that that is ever enforced enough in everything I've ever read about it - it is a remarkable bond of trust that you have with these people who come to your house, and very soon become part of your family, and in many ways closer to you than members of your family to be quite honest."

Similarly, Ada said:

"the relationship with your PAs is more intense, pretty well, than any other relationship in your life... you discover and have to learn to live with other people's quirks in way that only married couples ever really need to deal with, and actually some married couples don't even need to deal with."

This comparison was also made by some PAs, though sometimes in a context of describing how their employers felt; for example, Joe said:

"I know with the person that I've been supporting for a long time, he often described it as having, say, six PAs at any one time was like having five or six marriages, given the level of intimacy and the

periods of time together."

Comparisons have also been made in literature between the personal assistance relationship and other intimate relationships, such as friendships, romantic partnerships and familial relationships (e.g. Callus 2017; Kelly 2016; Shakespeare et al 2017, 2018). However, the views of participants on the level of similarity to or difference from other relationships varied considerably. Some felt that terms like 'friend' were perfectly adequate to describe the relationship they had with their PAs or employers. Others, however, felt strongly that a clear distinction had to be made between 'purely personal' relationships and that between PA and employer, which they felt needed to be defined clearly as an employment relationship, albeit one with some unusually intimate qualities. This reflects the distinction developed by Woodin (2006) between 'employment' and 'paid friendship' stances taken by direct employers. For Woodin, the concept of 'paid friendship' is distinct from both typical employer/employee relations and typical 'social' friendships; she argues that paid friendship:

> "has the capacity to develop in a more formal or informal direction over time and is a consciously chosen relationship. It shares more characteristics with friendship than employment and this is recognised by both parties in the relationship. Friendship relationships are bounded by the presence of payment." (p.142)

However, Woodin argues that there is a continuum between the 'ideal types' of 'employment' and 'paid friendship' stances, with most employer-PA relationships somewhere in between or using elements of both. Most of the employers I interviewed felt that there was some degree of 'friendliness' in their relationships with PAs, although opinions differed on how close to a 'true friendship' the relationship between employer and PA could be. Some felt that the inherent intimacy of the relationship made it inevitable that (something like) a friendship would develop, and therefore a pure 'employment stance' was impossible; for example, Grenville said "I think the friendship develops through employing people", and Elizabeth said:

"I think when you're living with someone 24 hours a day for half a month, you do become... like friends. That probably isn't the healthiest thing to do but I think it just kind of happens."

Similar opinions have been recorded in other research about personal assistance (Kelly 2016; Woodin 2006) and in published personal accounts (Heumann 1993; Snow 2015; Vasey 1996). Despite this, many employers felt that there was a norm or expectation in the Disabled People's Movement and/or in communities of PA users that relations between employer and PA 'should' be strictly 'professional' (for more on this and other meanings of 'professional' in the context of personal assistance see Chapter 5), i.e. that an employment stance is the 'correct' one. This has been related to an 'independent living' philosophy (Kelly 2010b) or ideology (Shakespeare 2014), in which personal assistance is regarded as an exchange-based employment relationship, in which direct employers are fully in control of PAs' actions and emotions such as gratitude are unnecessary; this is frequently referred to as PAs acting as the 'arms and legs' of their employers (Kelly 2016; Shakespeare 2014; Shakespeare et al 2018; Vasey 2000; Yamaki & Yamazaki 2004). In this paradigm, direct employers being or becoming friends with PAs can be seen as risky or a bad idea. For example, Jack described a training course, delivered by a DPO, that she went on when she started employing PAs as involving "very sort of heavy politicised training in how to train my staff... I think their way of how they expected employer and employee to behave was a little bit more formal than I prefer". Similarly, Ruth, an employer who tended towards a 'paid friendship' stance, said:

"I meet people in CIL meetings, and I get the impression that the way they work with their PAs is very much - it's very professional and they're just there to help them and that's it, you know... to me that's not appealing, it's a bit impersonal. I'd much rather my relationship with my PAs at the end of the day, although it does feel a bit complicated."

This is also mentioned in accounts of personal assistance in Disability Studies literature at least as far back as Vasey (1996):

> "I am the sort of person who relies on liking a person in order to work with him or her. There is a received wisdom in the use of personal assistants which states that they should not be friends with the disabled user. I personally think it is virtually impossible to employ a personal assistant whom the user does not like at some level." (p.85)

Similarly, Marfisi (2002, no page number) refers to a "rigid, even if unspoken, bias that those people who choose to engage in a friendship with their assistants are in some way violating a sacred edict". However, Snow (2015), a Canadian disabled activist, argues that it is "agency driven policy", rather than the preferences of disabled people, that leads to PAs being "expected to act like robots… leading to less participation from supported individuals and dissatisfaction among workers" (p.92). Drinkwater (2005) argues that in 'supported living' services an ideal of the 'substitutability' of individual support workers means that "while friendliness toward service users is generally advised and recognized as a useful individualizing force, friendship is strongly discouraged, and marks a transgression of professional boundaries" (p.239). This contrast between models of formality or 'professionalism' coming 'from above' and disabled people's own preferences for 'friend-like' working relationships has also been found in direct employment of PAs by people with learning difficulties (Williams et al 2009a, b), perhaps due to the influence of norms from older service models. Thus the dichotomy between 'formal' and 'friendly' relationships with support staff may not be perceived in the same way by all disabled people.

Several employers also compared themselves to other disabled people they knew who also employed PAs, feeling that others seemed to have a more 'professional' relationship than themselves, or something closer to Woodin's 'employment stance'. For example, Carol said, comparing a friend and fellow direct employer's approach to her own:

"her PAs are like shadows, you don't even know their names - you know, they just sit there in the background, and when you're out with her at dinner, she says sit on a different table, and that's fine, I respect that that's the way she wants to do it, but I don't find that works for me, because I've got a communication impairment which means sometimes my PA is needed to interpret what I'm saying - and I just find it a little bit socially awkward when I'm sitting there having dinner, and there's someone who's like not joining in."

This implies that the type and extent of an employer's impairments and specific assistance needs may influence whether they find an employment or paid friendship stance more appropriate. Dawn, who needs 24-hour assistance including with some life-critical medical tasks, said:

"I do think there are people who like to keep their relationships totally professional, but I don't think that way would work for me - I mean, perhaps if they were needed less, and not so intimately than I need them to be... I often think that it would be easier in my relationship with my PAs to be more professional, but I don't think it can be, just because we spend so much time together, I need them to assist me with every aspect of my life, pretty much, so I can't not be 'near-friends' with them."

The direct employers who I interviewed were relatively homogeneous in terms of type, if not extent, of impairment and assistance needs (see Chapter 3). However, it was notable that those with a greater extent of needs and those whose needs involved some element of communication support (e.g. those whose speech was affected by their impairments and might need interpreting to others - which included both Dawn and Carol - and those who had visual impairments and whose PAs therefore had to read out written information to them) tended somewhat more towards a paid friendship stance. Literature (e.g. Callus 2017; Gramlich et al 2002; Mason et al 2013; Williams et al 2009a, b) suggests that people with learning difficulties or other cognitive impairments may also tend to prefer a paid friendship stance towards their PAs, and Romer

and Walker (2013) argue that PAs for people with learning difficulties are also likely to see friendship as an inevitable part of their role. However, Williams et al (2009b, 2010) argue that having a 'friendly' relationship with PAs does not necessarily mean that people with learning difficulties want to actually 'be friends' with their PAs; this recalls Woodin's (2006) distinction between paid friendship and social friendship.

One former PA, Malcolm, had worked for two employers, one of whom had a physical impairment and the other had learning difficulties. The first employer took a strong employment stance, whereas with the second Malcolm's role as a PA was almost entirely that of a 'paid friend', to the extent that he described it as "the least demanding job you could have as a support worker or personal assistant", often consisting of accompanying the employer for leisure activities such as going to pubs or to the cinema, and at times feeling little different from doing the same activities in an ordinary friendship. In contrast, Malcolm found working for his first employer stressful and exhausting, comparing it to working in a busy shop or restaurant. This perhaps reflects the difference in the types of support typically provided by PAs to people with different impairments; the tasks usually performed by PAs for people with physical (and not cognitive) impairments, while often physically intimate, are 'instrumental' in the sense that the disabled person directs them, and thus more resemble other employment, whereas PAs for people with cognitive impairments may need to assist them with decision-making and management of areas of life, such as budgeting, in which they may not be able to 'self-direct' (Kelly 2016; Shakespeare 2014; Williams et al 2010). This may challenge the paradigm of the direct employer as having decisional autonomy and the PA following their instruction, and thus may lead to more blurring or 'grey areas' (Williams et al 2010) between the role of a directly employed PA and more traditional, paternalistic 'care' roles. Agatha, who had worked with disabled people with various impairments both as a directly employed PA and through an agency, said:

> "When I was helping a person with physical disability, I would wait for
> them to tell me what they wanted me to do. Or I would do things that
> I knew that they would ask the next minute. But when I was working

with children with autism, or adults with autism or schizophrenia, it would be like a more caring relationship. I would feel like their sister or their mother, something like that. I would have to take care of them."

However, the preference of employers with cognitive impairments for a more 'paid friendship' stance may also reflect differences in the usual power relations between different impairment categories of disabled people and their PAs or support workers. People with learning difficulties, in the contemporary context, are arguably more likely to have experienced paternalistic support in which workers had power over them (Williams & Holman 2006; Williams et al 2010), and thus for them the relationship becoming more like friendship (a relationship between equals) could mean a shift in power towards the disabled person (Callus 2017); however, for people with physical impairments who have experienced being accepted as having the authority of an employer over PAs, a shift towards friendship may mean power moving away from them and towards the PAs.

Similarly, Beresford et al (2007) document service users describing palliative care social workers as 'friends' and particularly valuing those social workers who were willing to act in a 'friendly' (as opposed to 'professional' manner towards their clients. Social work is traditionally a 'profession allied to medicine' (Finkelstein 1999; for more on this see Chapter 5) in which workers had significant power over service users. The terms in which the service users quoted by Beresford et al described the 'friend-like' relationships they had and valued with 'good' social workers frequently paralleled those used by direct employers in this research, both in terms of the 'friendly' nature of the relationships and of the recognition that this 'friendship' had limits and could not be completely equated with a typical friendship. Notably, in both cases the perception of 'equality', rather than a hierarchical power relationship, between service user and service provider, was valued by those on the 'receiving' end of the 'helper-helped' dichotomy.

Friendship, reciprocity and assistance

Friendship is notoriously difficult to precisely define (Ellis 2015; Shakespeare 2014; Schleien et al 1999); as Spencer and Pahl (2006, p.58) argue, "the word 'friend' encompasses a dizzying array of relationships". However, key features that distinguish friendship from other types of relationship have been identified by many authors, including emotional intimacy (Hall 2012; May 2012), mutual enjoyment (Castrodale & Zingaro 2015; Sigstad 2016), shared leisure activities (Chappell 1994; Fischer & Galler 1988) and the voluntary and 'chosen' nature of the relationship, as opposed to 'given' relationships such as family relationships that people are born into (M. Barnes 2012; Bowlby 2011; Schleien et al 1999; Spencer & Pahl 2006). Perhaps most crucially, one core aspect of friendship stressed by authors across many disciplines is its inherent reciprocity (Begum 1990; Bowlby 2011; Chappell 1994; Ellis 2015; Fischer & Galler 1988; Hall 2012; Lutfiyya 1991; Schleien et al 1999; Shakespeare 2014; Traustadottir 2000); in a functional friendship, if A regards B as a friend, B also regards A as one. While reciprocity "may not operate in the same way in all types of friendship" (Chappell 1994, p.421) and does not have to mean precisely equal exchange of material and/or emotional support, this core feature implies that friendship is, at least as an ideal type, a relationship between equals (M. Barnes 2012; May 2012; Traustadottir 2000; Woodin 2006).

Several authors (e.g. Bowlby 2011; Castrodale & Zingaro 2015) have stressed the importance of ongoing active choice to maintain a friendship, arguing that the unique value of friendship is in its voluntary and consensual nature. Defining friendship in these terms may imply that it can be easily and intentionally chosen. However, friendship is also, as Van der Klift and Kunc (1994, no page number) argue, "an elusive thing which cannot easily be engineered"; the development of new friendships often involves spontaneity and unpredictability, and it may be difficult to explain why friendships develop between individuals in some instances but not in others where conditions seem similar. The development of new friendships and the maintenance of existing ones may be more difficult for many disabled people than for non-disabled people, due to many and various forms of disabling barriers (Fischer & Galler 1988; Shakespeare 2014; Welsby & Horsfall 2011).

One such barrier is often attitudinal; non-disabled people may assume that befriending a disabled person would necessitate them taking on (practical and/or emotional) 'caring' labour which the disabled friend would be unable to reciprocate (Castrodale & Zingaro 2015; Shakespeare 2014). In response to this, disabled people may feel a need to hide or deny their impairments or assistance needs in order to maintain friendships (Fischer & Galler 1988). While friends generally do not feel the need to precisely balance one another's 'contribution' to the friendship, as Bowlby (2011, p.608) argues, "persistent inequalities in the exchange of care between friends may lead to the loss of the friendship". Similarly, May (2012, p.111) argues that:

> "There are limits to the gift-giving of friendship. In particular, if one friend is always on the giving side and the other always on the receiving side, this will debilitate the friendship... From the side of the benefactor, to be always the bearer of gifts is likely to lead to resentment."

This points to some of the problems that may occur when interventions to support the social inclusion of disabled people (particularly children and young people in education settings) are framed in terms of friendship. Authors such as Van der Klift and Kunc (1994) and Gold (1999) criticise formalised systems such as 'buddy clubs' and 'circles of friends' intended to integrate disabled children in 'mainstream' schools with their non-disabled peers, in which the non-disabled students involved are often motivated by a desire to 'help out' which cannot be equated with friendship as such. Van der Klift and Kunc (1994, no page number) argue that this emphasis on unilateral assistance rather than reciprocity promotes perceptions of disabled people as "perpetually needy" recipients of help rather than potential contributors to friendships and communities:

> "Clearly, there is nothing wrong with help; friends often help each other. However, it is essential to acknowledge that help is not and can never be the basis of friendship... Unless help is reciprocal, the

inherent inequity between 'helper' and 'helpee' will contaminate the authenticity of a relationship."

This arguably helps to explain the 'received wisdom' that direct employers should not regard their PAs as friends; disabled people have sought to define personal assistance as clearly distinct from paternalistic paradigms of 'care' which presume disabled people are passively dependent (Ahlström & Wadensten 2010; Kelly 2016; Morris 1993), and thus have sought to stress the instrumental over the relational aspects of PAs' work in public discourse. Kelly (2016, p.76) quotes one employer in her research, Julie, describing "the people who sent [her first] attendant" as having the "crazy idea... that I needed a friend" - as opposed to someone competent at the physical tasks she needed assistance with - and thus sending her "someone with no attendant skills at all", to which her response was "I can make my own friends, thank you. I need someone to do attendant care".

However, as seen above, this separation of "attendant care" skills from friendship is predicated on the types of assistance typically needed by people with physical impairments, who have historically been the main drivers of 'independent living' campaigns (Gramlich et al 2002; Hall 2009). It is noteworthy that the Canadian direct funding scheme through which Kelly's participants accessed personal assistance explicitly excludes people with learning difficulties or mental health needs "unless a physical impairment is also present and the individual can demonstrate the ability to self-direct" (2016, p.10). Thus the deprecation of the 'paid friendship' stance by some disabled people can be seen as reflecting an unexamined bias towards the needs and preferences of one subcategory of disabled people.

It can be argued that, if friendship is necessarily voluntary, 'paid friendship' is a self-contradictory concept; Traustadottir (2000, p.128), for example, argues that "By definition, a friendship should be 'free' - you cannot buy friends or pay people to be your friends." The idea of paid friendship was sometimes found counter-intuitive by participants; as one PA, Emily, said: "if the relationship between the two of you is like a friendship, then it is quite strange for one of you

to be being paid for it". This, combined with the assertion by Van der Klift and Kunc (1994, no page number) that "help is not and can never be the basis of friendship", would make it impossible for genuine friendship to exist between direct employers and PAs. However, friendship is varied and has been typologised by various authors into different forms, not all of which meet the same defining criteria. May (2012), following Aristotle, divides friendships into three ideal types; the common but primarily instrumental 'friendships of usefulness' and 'friendships of pleasure', which together form the category of 'lesser friendships', and the much rarer 'true', 'deep' or 'communicating' friendship.

May notes that 'friendships of usefulness' are said by Aristotle to be "more common among the elderly" because they "are often in need of the kind of benefits conferred by friendships of usefulness" (p.59); the same may plausibly be said of younger disabled people, and friendships can be important sources of informal support for many disabled people who either do not have access to personal assistance or do not have sufficient funding to meet all their assistance needs through employing PAs (Begum 1990; Heumann 1993; Morris 1993). Indeed, autobiographical accounts by people with physical impairments describe how they intentionally cultivated friendships in settings such as universities and workplaces in order to have a source of necessary assistance, reciprocating for this by finding other ways to be 'useful' such as taking on intellectual tasks that others disliked, and thus encouraging general interdependence (Panzarino 1994; McBryde Johnson 2005). Lack of funding to employ PAs has also been one motivation for the formation of informal 'care collectives' (Hande & Kelly 2015; Rainey 2011) in which friends, partners and others may do personal assistance tasks out of solidarity and in loose exchange for other forms of support (this will be discussed in more detail in Chapter 8).

Paid friendship, as defined by Woodin (2006), is clearly not 'true' friendship, as defined by May (2012), but may be regarded as a subtype of 'friendships of usefulness', which for May are not necessarily to be deprecated or avoided because of their 'lesser' status, but may still have real value. May's typology may thus provide a way to recognise personal assistance relationships as

genuinely involving friendship, despite diverging significantly from the normative characteristics of friendship as typically regarded. However, in my study as in Woodin's, those employers who did see their relationships with their PAs in terms of friendship still treated such paid friendships as "qualitatively different" (Woodin 2006, p.186) from ordinary social friendships. Therefore, for many employers, a paid friendship stance had to be accompanied by a clear statement that it still (also) was an employer-employee relationship. Ada, for example, clearly viewed the extremes of both employment and paid friendship stances as undesirable:

"I've employed people throughout my career [so] I understand the concept of employer-employee relationships, and I would argue that the relationship between a PA and their employer is not like that and it cannot be like that, it just can't be. You would have the most miserable life in the universe if you tried to make it like that... I know people who engage with their PAs as if they are their best buddies and that I don't think is a good idea either, because you do need - both sides need to understand that there is a boundary and there is a boss. The one [former PA] that I am now, I would say, friends with, that does the occasional bits of work, I would not have back as a full time PA because that wouldn't work either, because she's too much of a friend."

Similarly, Dawn said "I like to be as friendly as possible, but there's always a distinction, and don't forget it... I'm still the boss", and Jane said "I do think you've got to keep a line between being friends and being an employee, because ultimately they've got to do what you want them to do in order to enable you to lead a life". One PA, Joanna, also referred to "the friendship that develops but that also is very different from an actual friendship".

Anne probably took the strongest 'paid friendship' stance among all the employers I interviewed, repeatedly stressing that personal assistance was profoundly different from any other employer/employee relationship:

"I certainly think of them as friends - it is not the same situation you have where you're an employer, for example in a shop, where you've got staff, and you're very much the boss, and there is a distance between you, and, you know, if there's a distance between your carer and the disabled person I'm not quite sure how the hell it's supposed to work"

However, Anne still distinguished the relationship she had with her PAs from other friendships as conditional on the employment relationship: "they are my employees, I don't have a choice, but they become friends, and I don't treat them as staff". Similarly, Grenville, who also generally preferred a paid friendship stance with his PAs, said "the fact that there's an employment relationship is part of that relationship - which makes it different from any friend or family".

PAs also felt tensions between the 'professional' and 'friend-like' aspects of their relationships with their employers. While in general employers were more likely than PAs to describe the employer/PA relationship in terms of friendship, some PAs did feel that they were friends with their employers. This had some advantages (notably making the working environment much more pleasant than many other comparably-paid jobs), but also some drawbacks; Emily, for example, said:

"that was the strange thing with it, we were friends as much as me working for her, and that sometimes made things difficult, because… sometimes I'd be really tired, and I really felt like I couldn't - you know, I was like 'I really don't feel like I can do this', but I felt sort of obliged to because we were friends too."

This reflects claims by several authors (e.g. Ahlström & Wadensten 2009; Karner 1998; Shakespeare et al 2017) that friendship between PAs (or other 'care' workers) and employers or clients may create greater obligations for the workers, including feeling obliged to work for longer than contracted hours or do more than they are paid to. Kelly (2016) describes the "relaxed, informal work

environment" (p.124) of personal assistance as "an appealing feature of the work" for PAs (p.125); however, Kelly argues that the cultivation of an informal and 'homelike' environment, along with the rhetoric of PAs being 'part of the family', can contribute to the exploitation of PAs by discouraging them from viewing their work as worthy of payment. This is arguably reflected by the perception by several PAs in this study of their work as 'not really feeling like work' (see also Leece 2006; Romer & Walker 2013), and can be connected to the gendering and subsequent devaluation of 'care' work as belonging to the 'feminine' private sphere of love and ethical duty rather than the 'masculine' public sphere of employment and exchange value (Rivas 2002; Ungerson 1999; these issues are further explored in Chapter 6). Conversely, it may be difficult for employers to fire or discipline PAs who they view as friends and thus feel loyalty to (Matthias & Benjamin 2008), even if their work is inadequate or their behaviour unethical.

Tensions may also arise when the employer and PA do not have the same perception of the relationship between them, making the relationship asymmetrical. Ellis (2015) reports people with learning difficulties describing support staff as their 'friends', when the support workers would likely not share that perception of their relationship; this may be caused by people having different and incompatible definitions of friendship (Schleien et al 1999), but it is also likely that the discrepancy relates to the relationship being a job for one party but not the other. The social workers documented by Beresford et al (2007) whose clients described them as 'friends' likely had a similar asymmetrical perception of the relationship. Ahlström & Wadensten (2009) refer to the 'incomplete mutuality' of relationships between PAs and employers, where "the assistant includes the disabled person in the relationship but the disabled person does not include the assistant" (p.185). This can result in disabled people feeling that their PAs are their friends, while the PAs themselves feel conflicted and alienated. Joanna, who had worked for several direct employers, described such an asymmetry with one employer:

> "I don't think he's very comfortable in that role [of employer]... I think
> that he would like to see us as friends. I don't know if he's thought

very much about what the friendship is like on the other side for his assistants. He was talking about how he really wants to see me as a friend and he doesn't want to be 'just a job' to me - when you have someone so close to you in your life, you don't want them to just see you as work... I guess I did become his friend but we're very different people so we're never going to be really good friends."

Sarah also felt frustrated by the asymmetry of emotional intimacy between her and her employer, who:

"would often express a lot of things about their personal life and... to do with emotions and things like that, but actually working in a professional capacity I wasn't really supposed to respond to it, just be there... just sort of listening - it wasn't a two-way conversation in that sense... I felt like it wasn't necessarily wanted for me to contribute to that, to say oh, well, actually I had this experience as well, or I experienced stuff too."

Joanna felt that an expectation of 'true' friendship with PAs from an employer was unrealistic because of the asymmetry inherent in an employment relationship:

"I think the fundamental difference is that when I'm working for somebody, I am there for that person. And I deliberately try to fit in around them as much as possible. And if you do that, that can never really be a friendship, in a way. If that's how you approach a person, you're not going to have an equal friendship."

An example of this that Joanna gave is that, while she would challenge a decision made by a friend that she saw as "stupid" (and would reciprocally expect the same for herself), she would never consider challenging a decision made by an employer unless it directly endangered her. This clearly contradicts May's (2012) definition of true friendship as not only necessarily between equals, but also requiring a level of trust and honesty sufficient for friends to

ethically challenge one another and reciprocally support one another's development.

In some cases it may be possible for a 'true' friendship and an 'instrumental' personal assistance relationship to exist in parallel, with the two relationships, despite existing between the same individuals, being distinct from one another and acknowledged by both parties as such (with the potential for demarcation in space and time between situations in which one or the other relationship is 'operative'). Kelly (2016, p.89) argues that "attendants and self-managers may relate as friends in one instance, as employee and employer in others", and Marfisi (2002, no page number) similarly claims that "[m]any people are able to very effectively flow back and forth in the relationship from that of business to that of friendship and vice versa"; however, as Kelly notes, "this constant shifting of roles requires skilled relational work", and Marfisi argues that for this strategy to be successful both employer and PA need "a clear understanding of expectations and how the relationship will manifest itself in different contexts".

In this analysis, 'paid friendship' and true friendship might not be mutually exclusive with one another, and friendship between PA and employer might not be necessary for their working relationship to succeed, but might (or might not, according to individual preferences) be welcome if and when it did develop; thus Kelly (2016, p.75) refers to the personal assistance relationship as involving "mandatory relational labour" and "optional friendships". The two main sets of circumstances among my participants in which friendship and employer/employee relationships arguably existed simultaneously were where existing friends of the employer were employed as PAs, and where a 'true' friendship seemingly developed out of the 'friend-like' elements within a PA/employer relationship, but was maintained after the PA/employer relationship ended.

Friends becoming PAs

Employing existing friends of the direct employer as PAs is documented by many authors (e.g. Adams & Godwin 2008; Dale et al 2005; Matthias &

Benjamin 2008; Morris 1993; Wedgwood et al 2018) as either a preference or a solution to difficulties with recruiting PAs by other means. This practice was controversial among my participants, with both highly positive and highly negative experiences being reported. Agatha, who had worked for several different employers, described one employment relationship that worked well between her and an existing friend, because:

> "[when] I first started working for him, the very first thing he told me [was] that we are friends before anything else - so if you don't feel comfortable with something, please let me know. If you think that something's too much or if you are tired, please let me know. So he established that relationship between him and me."

However, employers also described negative consequences of employing friends as PAs, ranging from loss of the friendship caused by the formal employment relationship taking precedence over it to resentment and conflict caused by the blurring of roles and relationships (Matthias & Benjamin 2008). Jack had employed friends for short-term cover work as PAs without problems, but when she employed a friend as a longer-term PA, the end result was loss of the friendship:

> "when she started working for me, that was quite regular and quite a lot, for a while, maybe she worked 6 months or so, full time, sort of doing the main PA job, and then when she moved on to another job, then I just - I basically haven't seen her, cos it changed our relationship, you know - you stop seeing somebody because they're your friend and you start seeing them because they pay you, and that's sort of only to be expected - not saying I necessarily wanted that, I think that's what felt natural for her, so I left it with that."

Jack did describe this friend as "someone I'd known years, but never was that close to", implying that the outcome might have been different if the friendship had been closer and more highly valued by both people involved, but she also

recounted similar anecdotes about the experiences of other direct employers among her friends.

Slav described his one experience of employing a friend as a PA as "a complete disaster... I suppose it was quite useful in one way because it just gave me a harsh lesson to never do it again". He originally hired a friend as an emergency cover PA for a work-related trip abroad, but the friend then asked Slav if he could give her ongoing employment. After the first few weeks of employment,

> "what I started to notice was that they were slowly slipping from being
> a PA into being a paid friend, almost - so, for example, when I have a
> PA I expect them to help me at my convenience, whereas if I ask a
> friend for help I'll do it at their convenience. And I started to notice
> that this person in particular was slipping from being a paid PA into
> being a friend, so when I asked them for help they'd be like, 'Yeah,
> yeah, I'll do it in a minute. I want to finish this first', etcetera."

This attitude led to Slav feeling like "[his] whole role as an employer was being undermined or questioned", and eventually to him dismissing the PA after she demanded that he apologise to her for criticising her behaviour at work, after which the PA "turned against" not only Slav himself but their entire circle of mutual friends. As a result of this experience, Slav felt strongly that:

> "there will always come a time when your friend or yourself, you will
> blur the line, and you will not treat them or not see them as
> somebody who is working for you in that role as a PA, and once that
> line becomes blurred and your behaviours and values change, to
> each other, it can be very dangerous going further on from that."

Charlie similarly described problematic blurring of boundaries between friendship and the working relationship:

> "I've known a lot of people who seem to have had really bad PA
> experiences because they've been employed by a friend, [and] then

they would go to work and find that the person hadn't thought that the whole day was work and thought that some of it was just social time, and so they hadn't got paid for the hours that they thought they were going to get for, and then it had got really messy and ruined the friendships, and that's happened to probably 3 separate people that I know, so it seems to be quite a pervasive issue... so I try and be really clear about that with my PAs."

This is very similar to an experience recounted by Vasey (1996, p.87):

"On one occasion when I employed a friend we had a long conversation before she started work, which I assumed was just a long conversation, but it transpired later that she expected to be paid for that time. This seemed a little odd to me but I was not assertive enough on that occasion to make any comment."

These accounts suggest that maintaining friendships and employer/employee relationships in parallel is likely to be difficult, perhaps especially when the friendship came first. The employment of family members as PAs has been controversial for similar reasons. In the UK, it is generally not permitted to use direct payments to employ family members who live in the same house unless the local authority considers it to be necessary, e.g. where other options are not available (Brindle 2015). However, Adams and Godwin (2008, p.44) report that some disabled people were enabled by direct payments to "employ a family member or other personal friend who would not previously have received any financial support for caring for them", and felt happier with the situation as a result. Matthias and Benjamin (2008) report the same phenomenon from a direct employment program in California.

In Sweden, where employing family members as PAs is more generally permitted, Dunér and Olin (2017) document an ambiguous situation, with some, though not all, of their participants successfully managing to maintain separate family and employer/PA relationships. One of their participants, who employed her sister as a PA, distinguished between how she related to her sister within

her paid PA hours and in informal situations: "I tell her nicely when I talk to her as a sister but give instructions when she is an assistant" (p.11). However, several of their participants also found maintaining parallel relationships difficult, and resolved the difficulty either by stopping employing family members as PAs or by choosing to blur the roles, essentially paying their family members to act as informal carers rather than as PAs. Wedgwood et al (2018, p.134) similarly report a "deliberate blurring of the personal and the professional" in a case of a disabled person employing a friend as a PA; however, this employer still wanted to maintain a "clear distinction" between her friend's working hours and socialising outside that time.

Several interviewees (including direct employer Grenville and PAs Joanna and Lisa) felt that the best circumstances for employing friends as PAs were temporary situations, such as travelling for holidays or conferences. This recalls Kelly's (2016) concept of the 'frien-tendant', a term coined by Kelly to attempt to describe her ambiguous relationship with a friend with physical impairments to whom she provided unpaid and occasionally paid assistance, "not fully employee, nor friend, nor family member, nor stranger" (p.77). This relationship developed while Kelly and her friend were at a multi-day sports event. In circumstances like these, where PAs may have to work more hours than usual and may have to share living and sleeping environments with their employers or be around them with nothing else to do outside of their working hours, the greater flexibility and potential for blurring of boundaries with a friend as assistant may have advantages that it would not have in more typical day-to-day situations.

PAs becoming friends

Friendships also formed through the working relationship between employers and PAs that lasted beyond the end of their employment; for example, Elizabeth spoke about one former PA:

"she left me last September to go back to uni. She's now one of my best friends that I see most weeks, we always hang out and go on

holiday together... I think because we get on so well, because we're the same age and have the same interests, I think it's quite easy to have that relationship that forms outside of work - and just because I know when I go out and see her, I can be like, 'can you cut my food up please?' or 'can you get a straw?' Because they just know, it's quite a natural thing then, in normal life."

This can be seen as a former PA evolving into a 'frien-tendant'. Begum (1990, p.31) reports a similar process with one participant, who said: "On the whole I try not to mix caring with friendship but my helper was first my carer and then my friend so that made the relationship different." This perhaps suggests that the transition from PA to friend is easier than that in the other direction, potentially because the more specific intimacy of the personal assistance relationship can lay a foundation for the more generalised intimacy of friendship, whereas being used to the reciprocity of friendship may make it harder to accept the asymmetry of the personal assistance relationship. M. Barnes (2012, p.88) claims that it is "hard for friendships to develop among work colleagues who are in a hierarchical relationship to one another" because of the egalitarian and reciprocal nature of friendship. Thus friendships are more likely to develop out of such working relationships "after the initial focus of the relationship has been superseded". Barnes's example here is of academic supervisory relationships, but the principle would seem to apply equally well to directly employed personal assistance relationships.

This perspective was held by some employers; for example, Slav said:

"If we become friends as a result of you being at work for me, that's fine. But you don't come into it as a friend… The identity of a friend doesn't come before the identity of being a PA, in that sense."

Slav used the metaphor of "work colleague friends" who "may go for a drink together outside of work", but would not have a friendship without the work connection, to describe these friendships with PAs. Ada also used a similar metaphor to describe her feeling that PAs could become friends but not vice

versa: "you can make friends with your business partners, but don't go into business with your friends".

Like the employment of existing friends as PAs, the development of friendships between PAs and employers may have negative consequences for the functionality of the assistance relationship. Kelly (2016, p.79) argues that if friendship develops between PAs and employers, the PAs "may come to expect to interact as they do with other friends, and no longer with the unique requirements of attendant work." Employers who took a paid friendship stance had experienced this; for example, Ruth said "sometimes it does get a bit too friendly, and they kind of forget that they're here as employees... I think I just have to keep reminding them that this is a job after all". Jane, who started employing PAs after the death of her husband, who had provided her with informal support, described experiences when her first PA became "too familiar", which resembled Slav's of employing a friend as described above:

> "she took over, if you know what I mean, and I think it was insidious, and I hadn't realised, and she'd sort of come in in the morning and I'd ask her to do something and she [said] 'You'll have to wait until I've had a coffee.' She wouldn't pick my dog poo up which really annoyed me... I had to let her go in the end."

As a result of this experience, Jane argued:

> "I do think you've got to keep a line between being friends and being an employee because ultimately they've got to do what you want them to do in order to enable you to lead a life."

From the PA perspective, Emily also described negative impacts of feeling loyalty to her employer due to friendship as well as to an employment contract:

> "sometimes I felt sort of that I was being coerced into doing things [such as working late nights or early mornings with little notice] cause we had a friendship as well - I'd feel more guilty for not doing things if

I was really exhausted and she asked me to go out with her and I just thought 'I really don't want to go out tonight'"

However, Emily did remain friends with her employer after she had to stop working as a PA due to illness, as she found that maintaining the friendship was easier after there was no longer a formal employment relationship existing alongside it. Similarly, Joanna described how her relationship with a former employer was able to develop into a more genuine friendship after she stopped working for her:

"We're still friends and I still go and see her once or twice a month and that's really nice. So it's turned into friendship... I guess after two years we knew each other quite well, and I really liked her, but it's difficult to really be friends, because you're always in a role that isn't just being relaxed and being yourself... I think it became quite a tiring job and so a lot of my energy went into just doing the job and trying not to get really frustrated with it or show her how tired I was, you know, whereas going to see her now... I'm being me and not worrying about whether it's part of my role to say this or to do this."

Malcolm also developed a lasting friendship with his second employer, persisting after the end of the formal employer/PA relationship:

"The relationship, years after, is still ongoing... my sister, when she came to 18 took over the work, but now when I go back to [home city] the friendship is still maintained. So we'll go to the cinema, it won't be paid work, but it's just... it was kind of that slow transition from paid work to a friendship, now we've fully reached a friendship but along the way it was a transition from me being paid for 6 hours but doing 8 and slowly, now, it is just a friendship."

However, Malcolm did feel that this situation was unusual, as this employer lived "around the corner from where I [Malcolm] grew up... so we were in such a

close community that we were on the edge of knowing each other anyway through family members".

The persistence of friendships formed between PAs and direct employers after the end of the employment relationship is also documented in literature; for example, Wedgwood et al (2018, p.134) report that the young disabled woman in their case study "spoke at length... about how most of her support workers have become her friends and that she usually remains in contact with them after they leave her employ." Similarly, Snow (2015, p.90) argues that friendship between "a well supported individual and a truly attentive personal assistant... often lasts long after the job has ended, and may even deepen into love." This last claim is supported by accounts of romantic relationships developing out of PA/employer relationships (Browne & Russell 2005; Flynn 2005; Wedgwood et al 2018; Woodin 2006). However, in most of these cases the relation between the personal assistance relationship and the friendship (or otherwise intimate relationship) to develop out of it is serial rather than parallel, with the ending of the employment relationship seemingly necessary for a truly symmetrical relationship to come into full fruition.

PAs and their employers' other social relationships

Another key issue is the impact of PAs on their employers' other social relationships, which may be both positive and negative. As noted above, disabled people, particularly those with unmet assistance needs, may have difficulties with forming and maintaining friendships because of expectations of reciprocity. While other types of personal relationships, such as 'given' relationships within families, may not always have the same expectation of reciprocity as friendships, these relationships are still likely to be strained or negatively affected by material dependencies that are not culturally normative for that relationship and/or life stage (Begum 1990; Heumann 1993). While there has been some analysis of the intersection of personal assistance with sexual or romantic relationships (Bahner 2012; Browne & Russell 2005; Earle 1999; Rainey 2011) and with family dynamics (Dunér & Olin 2017; McKinney 2017; Ungerson 1999), there has been less attention paid to its effect on

friendships and social relations with peers more broadly. Morris (1993, p.153) argues:

> "Those people who have significant personal assistance requirements and who have been able to participate fully in society and in personal relationships, have done so because they have not had to rely solely on family and friends for the help they need."

If disabled people have to rely on family members, partners or friends for assistance with daily living needs, this can cause severe restrictions on the lives of both disabled people and those who 'care' for them, and can lead both to paternalistic dynamics of dependence and to resentment and frustration that can result in intimate relationships breaking down or becoming abusive (Begum 1990; Heumann 1993; Woodin 2006); this arguably constitutes one of the ways that disabled people experience oppression in the private as well as the public sphere (Thomas 1999). This has a disproportionately gendered impact, both because disabled women are likely to be more severely affected than disabled men due to the intersections of disablement and gendered expectations (Rae 1993; Orme 2001) and because 'caring' labour is socially constructed as the 'natural' domain of women (Dalley 1988; Rivas 2002), meaning that the family members, partners or friends who feel obliged to take on such unpaid work are more likely to be women than men.

Feminist authors in the 1980s and 1990s (e.g. Dalley 1988; Finch 1983) were therefore critical of 'community care' policies involving the deinstitutionalisation of disabled people because, as they argued, these policies would result in the transference of responsibility for 'care' of disabled people from the state to women in the 'private sphere' of the home; some thus argued for a return to residential care institutions (Morris 1991; Thomas 2007). In response to this, disabled feminist authors (e.g. Keith 1992; Morris 1991, 1993) argued that provision of paid personal assistance under the direct control of disabled people could prevent this imposition of unpaid labour on women; as Keith (1992, p.174) argues:

"If disabled people were given the economic basis which gave them the right to pay for the personal care they need, it would allow many women the right to choose not to care, relinquish them from the `burden of caring' and give a greater degree of independence to both sides of the caring relationship."

The direct employment model of personal assistance is thus an alternative both to paternalistic forms of publicly funded 'care' (which deny disabled people freedom and autonomy) and to reliance on informal support (which can deny freedom and autonomy to those, primarily women, who feel obliged to provide that support), and one of its intended purposes is to allow disabled people's friendships and family relationships to be on equal terms to those of non-disabled people (Heumann 1993; Morris 1993). This was reflected in the accounts of some of the direct employers in my interviews; however, for many this potential positive impact of employing PAs was limited by inadequate funding and other administrative and bureaucratic barriers which resulted in the direct employment model not being implemented in a way that lives up to its intentional promise (this is more fully dealt with in Chapter 7). There were also cases in which PAs had some (often unintentionally) negative effects on employers' other personal relationships, perhaps especially where the roles of PAs were not adequately defined or understood.

In general employers felt that the impact of having PAs on their personal relationships was positive; for example, Charlie said that employing PAs made them able to "feel like I'm contributing to my household", and that it had been "really positive for my relationship with my partner", because their partner no longer felt obliged to provide informal care for Charlie on top of their own job and household duties. For some employers, having PAs also enabled them to fulfil 'caring' roles in other relationships; for example, Jane talked about how her PA assisted her to help her elderly mother. However, the role of the PA in this was not understood by a social worker who was involved in the assessment of Jane's assistance needs:

"I like to support my mum and I physically cannot support my mum. So [name of PA] and I go over to see my mum and we will take my mum out shopping... we both help her, but [name of PA] is helping her doing what I would do if I could do it, you see what I mean? And somebody said 'But *she's* helping your mother!', and I said 'No, she's helping *me* help my mother'. And they couldn't quite understand that at all - it's like they thought [name of PA] was caring for my mum... If I could get out of the house and go and get my mum and take my mum shopping on my own, and pass things off the shelf, that's what I would do, but I can't - so we both go and [name of PA] passes the things off the shelf for my mum. I'm there, and I go round, and I'm talking to my mum, but the actual things that I can't do, [name of PA] does, and the social worker thought that was quite odd."

Similarly, Jack, giving the example of taking her children swimming, said that:

"just having someone there for that physical support... enables me then to give the children the support they need at the pool. One of the reasons why having a PA helps me as much as they do is to make sure that I've got energy that will last til the end of the day, [because] my children will need feeding later, and all that stuff... so it's really helpful in those terms - basically, you know, helping me get on, getting about, doing my day-to-day life, it's just that with them my day-to-day life in this case happens to be doing things with my children."

The extent to which enabling social relationships in a broader sense was part of the role of PAs varied according to employers' specific impairments (and thus the specific barriers they experienced to social participation), as well as individual employers' preferences. Malcolm said of his first employer:

"I would become part of his social life when I was on shift... we'd go out to bars and that would be his social life, so while to some extent I would say that he required a PA, but part of my role he would say

would be to accompany him to bars and to help him to meet people
and start talking, purely because he would have to type on his
keyboard to communicate. So he might type something to me, like, I
want to spark up a conversation with these people. So I would help
him to do that."

However, in other parts of this employer's social life, such as with his family, he
preferred Malcolm to assist him to travel to see them, and then leave:

"I was never really invited into that setting - thankfully, really, I think it
would have been quite awkward. He was probably very happy to get
away from his PAs in those instances."

With Malcolm's second employer the situation was quite different:

"The second person, I was very much 100% - that *was* his social life,
it was the hours a week when he would come out with me. And that
was more than enough for him. You know, saying how much he liked
routine, if I'd have ever rang up and said, do you want to go out this
third or fourth day a week, as much as he did like spending time with
me, it was like, no, that would really disrupt his routine way too much.
So yeah, those 6/7 hours a week was his social life."

Malcolm's second employer is perhaps an example of a disabled person who
has what Spencer and Pahl (2006) call a 'professional-based personal
community', one "characterised by [its] heavy reliance on professional sources
of support, from such as counsellors, therapists or social workers, rather than
friends or family" (pp.148-149). This situation is common among socially
isolated disabled people, perhaps particularly those with learning difficulties or
other types of cognitive impairments (Worth 1999; Ellis 2015); however, where
the 'professionals' involved are directly employed PAs rather than those like
"counsellors, therapists or social workers", whose relationship to the disabled
person is more likely to be one of paternalistic dominance, the implications of
this for the person's self-determination and access to social participation are

likely to be very different (see also Chapter 5). Additionally, it could be argued that if a disabled person in such a position is able to employ people already in or close to the boundaries of their existing personal community, their personal community will seem less professional-based, and their relationships more 'friend-like', than otherwise.

PAs as barrier to social relationships?

Whether intentionally or not, the presence of PAs can also inhibit the development of reciprocal social relationships by disabled people. The presence of assistants in school settings has been argued to contribute to the frequent lack of age-typical friendships experienced by disabled children, particularly if the assistants were perceived by other children as having a supervisory or 'parental' role (Shakespeare 2014; Skär & Tam 2001). A similar phenomenon can occur even when disabled people are adults and their PAs are under their own direction. Parker (1999) quotes one disabled university student as saying "it [having a PA] posed a problem in the class in mixing with the other students... other people felt I always had a member of staff present". Both PAs and employers who I interviewed described similar occurrences. One particularly vivid example was given by Emily about her employer, who, as noted above, took a strong paid friendship stance:

> "when she goes out with a PA she has them as friends, and she said it prevents her from making new friends, it prevents her from finding like a relationship, you know, cos people assume she's with the person she's with... she does find it sort of means that people don't come over and chat to her cos they think... she's already got someone with her, if that makes sense."

While Emily's former employer was a heterosexual woman, Emily is lesbian and both moved in strongly LGBT social circles, and Emily said that her employer complained that "she can't find a boyfriend, because everyone assumes she's gay and she's with the PA that she's with". Similarly, Grenville said that in many social situations, people tend to assume that his PA is a friend or partner if he

does not explicitly introduce them as his PA. This tendency for employers and PAs to be perceived as 'together' and already socially interacting with one another was also noted by Parker (1999, p.492):

> "Within the University, the use of an assistant seemed to have an influence on relationships with other students, and staff, in some circumstances. Freda [a disabled student] identified a tendency to 'get viewed as a pair until others know you - we can also see ourselves as a pair - sometimes when we are in a tutorial, tutors talk to both of us and not just to me... Vera [Freda's PA] is conscious of this and makes me go to tutorials alone'."

Being perceived to be already 'with someone', and thus in a sense to be 'taken' in such social situations, makes one less likely to be approached by 'unattached' others, and thus constitutes a barrier to the establishment of new relationships. While one strategy for dealing with this may be for the employer to ask the PA either to leave the room or situation, or to act in a way that makes it clearer that they are not 'filling the slot' of conversation/interaction partner, this may not be possible if someone's impairment-related needs mean that they need a PA with them, either at all times or in that specific situation (e.g. if they need assistance with eating at a social event involving food, or if they have a speech impairment and may need a PA to 'interpret' in a conversation). Employers in this situation therefore need to find other strategies to manage interactions between their PAs and other people present.

Similarly, though sometimes differently in terms of specific strategies, careful management was needed when employers were interacting with people who they already had established relationships with, such as friends and family members, to prevent PAs from taking up too much space in the conversation or undermining the employer's place in their own relationships. For some, like Malcolm's first employer, in this situation it was easier simply to ask PAs not to be present, but for some employers and in some social situations, the practical necessity or convenience of having a PA present outweighed the potential awkwardness and necessary management work.

When asked how she liked PAs to act when in social situations, Dawn replied "basically so they're not overshadowing me...for example when they're with my friends, of course it's nice if they talk to them, but not more than me". While Dawn felt it necessary to put limits on her PAs' interaction with her friends in some circumstances (she gave one anecdote of her getting upset on a holiday with friends when a PA monopolised conversation with a friend, excluding Dawn herself), she did not think it was appropriate to stop it altogether:

> "I want them to be like companionable, cause it'd be weird and awkward if they weren't, but... never to forget that they're *my* friends, and it's *my* social occasion."

Elizabeth similarly mentioned the 'awkwardness' of having PAs present in a social situation but not participating in it:

> "I don't like them to be a spare part - I think it's really awkward when they're just sitting there. I know some people say they can't say anything, they can't join in, but I don't really agree with that because I think it makes a really awkward environment for my friends, so I'd rather they enjoy themselves as well and make it better for everyone."

Grenville, while acknowledging the same awkwardness, pointed to the presence of PAs also being helpful in some types of social situations; this led to him varying his strategy according to both the type of social occasion and the personality of the individual PA:

> "with friends at home... I like them to join in, if they want - I don't mind too much if they don't want, [but] it can be awkward. I want somebody [as a PA] who likes being sociable, because I'm sociable and it makes it easier when I'm socialising... but that does mean that I think you have to make it kind of routine that they do socialise. Sometimes it's frustrating because they can derail the conversation,

or they can be feeling particularly gregarious or they're really wanting to be the centre of attention."

Rainey (2011) also documents tensions caused by the presence of PAs, quoting one focus group participant as saying that "You almost feel like you have to entertain that person that is there to help you" (p.128). Vasey (2000) and McKinney (2017) both describe conflict occurring when others present at social events were angered by a disabled person's decision not to include their PA in conversation, failing to understand the desire to interact with friends as a non-disabled person would expect to, without the constant presence of another person who is not part of the friendship. Grenville also noted that in 'open' social situations, such as conferences, "in general people tend to react to somebody as another person in the room", meaning that if people are not already familiar with the specific role of a PA, not treating them as an equal participant in the social situation is counter-intuitive.

PAs also talked about negotiating these situations; for example Charlie said that, when in public with their former employer:

> "I would kind of generally err on the side of caution and be quite quiet within conversations - like if it was just me and them out somewhere, then we would chat a lot, but if it was me and them and one of their friends, I would try and like not say too much, but also not make it weird by not saying anything at all... I think they said when they were hiring actually that that was kind of one of the main skills they were looking for was someone who was good at getting that balance right"

Similarly, Joanna, when asked if she interacted much with her employer's friends or family as part of her job, said:

> "in the sense that I'm there when they're there, you know, but... I don't really join in very much. The person I'm working for now, when he has friends around, I wouldn't join them usually, maybe occasionally... we have friends in common, so when they're around

it's a bit different I guess. Then we all hang out - which again blurs the boundaries... [are we] hanging out as friends, or am I there because I'm working?"

This negotiation is an example of the "skilled relational work" (Kelly 2016, p.89) undertaken by PAs that frequently goes unrecognised or is 'naturalised' as a personality trait (often a gendered one) rather than a skill (on which see also Chapter 6).

Interactions involving PAs and employers' family members were often particularly difficult; for example, Ada described the 'struggle' that she experienced with a particular PA when visiting her father (who lives a long drive away, and that PA was at the time the only one available to drive her):

"I really struggle with her on those days, and actually I really don't like it… because she now has the kind of relationship with my dad that I don't think she should have. [My parents] wanted people to look after me like they looked after me and that's how they perceive it, so when I rock up with PAs who are evidently looking after me they're really grateful and they engage with those people. But it doesn't work for me because [name of PA]'s quite touchy-feely and she hugs my dad. Well I can't, because I've got a bloody great big bit of metal between me and him. And... so she has more of a physical relationship with my dad than I can have and I really object to that. So that's a bit of me not being in control."

Conversely, PAs also sometimes found interactions with employers' partners or families tricky to negotiate; for example, Katherine found interaction with her employer's husband one of the more difficult aspects of the job, finding it "a bit awkward" when she came in in the morning to help her employer get out of bed and her husband was still asleep in the same bed, despite the fact that "he was used to having a PA coming in every morning and getting her out of bed, so, you know, he wasn't bothered about it." Katherine also found it difficult when her employer and her husband were at home together at evenings and weekends,

feeling "a little bit like [she was] intruding because she had her husband there as well", and saying that doing housework while her employer was "sitting in the living room with her husband watching the telly" made her feel "just like a cleaner"; because of this she preferred working for her employer at work rather than at home.

This points towards the obvious asymmetry of personal assistance work that the employer's home is the PA's workplace (Browne & Russell 2005; Woodin 2006); thus what for the employer is the private sphere is arguably part of the public sphere for the PA. Therefore it can be expected that direct employers would be more likely to desire a friendly or informal relationship that is more suited to the home or 'private life', whereas PAs would be more likely to desire a more boundaried relationship typical of the workplace; as Woodin (p.132) argues, "the construction of the relationship as a friendship may be seen as employers establishing their ownership of the home as their place for living, rather than the workplace of the employee". Both PAs and employers in my sample were aware of the fact that, in a home context, it could be easier for the PA than for the employer to detach themselves from the interaction. However, where direct employers were themselves employed and their PAs worked in their workplaces, this dynamic could be reversed; Daisy, who primarily worked in her employer's office, said:

> "To me it felt like our relationship was very important for my work, and it felt like sometimes my employer didn't look at it, or didn't work on it, as much as I would have liked her to... she's got a whole lot more to her work role than just me, but I didn't have much more to my work role than just her, so in a way the relationship, in some ways, was more important to me, because it defines my whole work, whereas for her, she's got a whole load of work that she's doing, that's nothing to do with her relationship with her PA, but I didn't really have work that I was doing that wasn't connected with my relationship with my employer."

Those employers who had children found that the role of PAs could be ambiguous, particularly in terms of their children's perceptions of the PAs; for example, Jack said:

> "I think it's harder for children to get it [the role of a PA]... there are times when the child might interact with the staff member even before you're properly awake yet, and what might happen then might be different to what would happen when you're up... basically what we try and teach the children is to just go through me, you know, if you need help with something it's me, please ask me, and if it's not something I can do with you then I will ask the PA to help you, and we try and sort of use that structure - but I would say at 10 mine are only just beginning to really get the hang of that properly."

Likewise, Carol talked about ambiguities about her PAs in relation to her daughter, who was 6 at the time of the interview:

> "it's a bit like a nanny, but not a nanny role... they're there to support me, they don't usually look after [daughter] without me instructing them - however it has been occasions, if I've been just dreadfully ill, that they have say taken her to school, or picked her up or something like that... occasionally I do think are they taking over too much with childcare issues, and occasionally I feel guilty as well, thinking am I letting them do too much"

Carol found that her management of her PAs shifted after the birth of her daughter from an employment to a paid friendship stance, because if PAs are assisting with intimate care for a child "you need to trust that these are people that [the child] can trust", as well as because Carol's daughter had "her own little relationships with all of them", which Carol thought it was neither possible nor desirable to discourage: "How does your child learn that, oh no, you are not to interact with that person, because children... can't do that as far as I can see". Carol also felt that when meeting up with other parents and children "it didn't really work either, that I had this person who sat there, not communicating

with the group of kids"; therefore, she preferred her PAs in that situation to be "a bit more interactive with people, but still respectful that they're here to help me, you know - so just chatting a little bit but not over the top."

However, it was still important to Carol that PAs did not substitute for her role as parent:

> "it was important that they didn't take over, and that they always kind
> of would turn to me, and say mummy, you know, what do you think,
> or mummy, er... like I was in charge"

McKinney (2017), writing as the partner and co-parent of a personal assistance user, similarly documents feelings of emotional conflict over PAs developing independent relationships with her and her partner's children and taking on roles in the children's lives that would typically be those of the parent, and Anne Wallis, one of the direct employers quoted by Vasey (2000, no page numbers) in her 'rough guide' to personal assistance, describes the "fear that [her children] might not know who was really their mother" caused by the closeness of their relationship to her PA at a very young age. This suggests that interactions between PAs and employers' children may be especially fraught with implications about disabled people's role as parents, particularly given that disabled people are frequently considered unfit or incompetent to parent children, and needs for personal assistance have been treated as equating to incapability to perform a parenting role (Morris & Wates 2006).

The impact of PAs' work on their own social lives

While this section has largely focused on the impact of personal assistance on direct employers' social lives and relationships, there is also the converse question of the impact of working as a PA on the PAs' social lives and relationships outside of the PA/employer dyad. This both came up much less in my interviews and has had far less attention paid to it in the literature. This may be because the reality is asymmetrical; as the hours and working conditions of PA work are similar to those of many other jobs (for more on the employment

status of PAs and comparisons to other jobs, see Chapter 6), it could perhaps be assumed that its impact on PAs' lives outside work is similar to that of other such jobs, and is not dependent on the 'content' of the work. There is also, as discussed above, perhaps likely to be more of a separation between PA work and 'life' for PAs than there is for direct employers.

In addition to some PAs reporting that long hours or exhaustion affected their social lives outside the job, one PA, Sarah, talked about how she felt that being required by her employer to stay quiet and not actively participate in conversations with her employer's family and friends had the unexpected impact of making her feel more anxious and less empowered to speak in social situations outside work:

> "I think it affected my self-esteem actually, a bit - you know, outside of work, I found that I was a bit quieter, and wasn't always confident, to respond to people... I didn't mind at the time, but as the years progressed, those little things started to kind of wear away at me a bit."

This may have been influenced by the fact that Sarah felt that her employer treated her more harshly than some of his other PAs, who had been recruited from within the employer's existing social circles, and thus with whom he had relationships closer to friendship, discouraging Sarah from participating in social situations that she felt he encouraged other PAs to participate in. Vasey (2000) reports similar dissatisfaction on the part of a PA who felt their employer was discriminating in favour of another PA by reserving the "exciting things", such as going shopping or swimming, for that PA due to a difference in working styles.

However, sometimes employers did give significant (emotional or practical) support to PAs. Both Grenville and Elizabeth described acting as a 'mentor' towards (mostly young) PAs, giving advice about life decisions, while Slav talked about introducing a PA to someone who could have an impact on their longer-term career prospects. Several PAs, including some who identified as disabled people themselves (for more on this see chapters 3 and 6), talked

about the positive impact on them of learning about disability politics and communities from their employers. Direct employers are documented giving emotional support to PAs in other research (Browne & Russell 2005; Shakespeare et al 2017). Browne and Russell quote a participant describing this as "probably completely inappropriate in terms of the way that the industry would see the role" (p.383), reflecting the transgressive status of friendship between PAs and disabled people in the eyes of some service providers (Drinkwater 2005; Snow 2015). This arguably points to a difference between personal assistance and traditional 'care' work, in that direct employment permits reciprocity between disabled people and PAs in which support can flow in both directions rather than only one. Beresford et al (2007) also report users of palliative care social work services valuing reciprocity in their relationships with social workers, despite this not fitting into the norms of the social work profession.

Conclusions

Personal assistance relationships are complex and varied. From a relatively small qualitative sample it is hard to draw solid conclusions about the experiences or preferences of direct employers and/or PAs, and it is notable that even in a relatively homogeneous sample (compared to the breadth of assistance needs and employment situations that exist, though arguably representing fairly well the type of PA/employer dyad that has been assumed to be archetypal) there were a wide range of attitudes towards possible and preferred relationship styles. Literature suggests that surveying a wider range of disabled people with different assistance needs would reveal even greater diversity. However, it is notable that the great majority of participants, particularly direct employers, rejected or problematised the 'received wisdom' (Vasey 1996) that friendship or emotional involvement with PAs is undesirable. This might suggest flaws in the principles of 'independent living' that arguably underpin that 'received wisdom' (Kelly 2016; Shakespeare 2014). However, with a more expansive understanding of 'independent living', based not on a caricature of an 'independent' disabled person with PAs as one-dimensional 'arms and legs', but on a nuanced understanding of interdependence and

relational autonomy, the apparent contradiction may not necessarily be so; indeed, emotionally intimate relationships between PAs and direct employers may enhance the subjectively felt autonomy of both parties.

Relationships between PAs and direct employers are asymmetrical and are recognised as such by both parties; however, they can be mutually beneficial and real emotional attachment, loyalty and solidarities exist in both directions. (More economic and political aspects of solidarity between direct employers and PAs will be discussed in Chapter 6.) Despite this, the economic context of the relationship and its asymmetry are important, and even strongly emotionally involved relationships between direct employers and PAs are not usually the same as 'ordinary', socially reciprocal, friendships, though they may sometimes coexist with or evolve into them. While PAs may sometimes be a significant source of social interaction for disabled people, none of the direct employers who I interviewed regarded them as a substitute for other social relationships.

The intersection between the personal assistance relationship with other relationships in the lives of both direct employers and PAs is also significant and deserves further research. While in many circumstances the employment of PAs enables direct employers to have the same choices and opportunities in other relationships (such as friendships, romance and family roles) that non-disabled people would typically expect, thus successfully overcoming disabling barriers, on other occasions the presence of a PA may itself be a barrier to social interaction. These situations require careful negotiation and emotion work (Hochschild 1983; for more on this see Chapter 5) on the part of both direct employers and PAs. This also raises issues relating to the (lack of) general recognition of the role of PAs outside of disability-focused communities (for more on this see Chapter 6).

While the personal assistance relationship often begins like other employment relationships with the recruitment of a PA who is a stranger to the employer, it can also arise from within direct employers' and/or PAs' existing personal communities (Ungerson 1999). The ways in which these relationships evolve can be fluid and unpredictable, but arguably they can take the form of the

introduction of payment into already-existing mutual support relationships. This suggests that relationships other than the archetypal direct employment may potentially be enabled by the provision of direct payments to disabled people with assistance needs; both the employment of family members as PAs (Adams & Godwin 2008; Brindle 2015; Dunér & Olin 2017) and the informal 'care collectives' being developed in some disabled activist communities (Hande & Kelly 2015; these will be discussed in more detail in Chapter 8) are potentially examples of this.

While this chapter has looked at personal assistance as a relationship in the private sphere, and thus has arguably focused primarily on direct employers and their perspectives, the following two chapters will examine personal assistance through the lens of the sociology of work and employment, and thus primarily take the PAs' side of the dialectic.

Chapter 5: Personal assistance as work, part one: (non-) professionals allied to the community?

This and the following chapter together deal with the occupational status of personal assistance work. Personal assistance is generally considered to be a casual or non-professional job. This is in contrast to the traditional 'caring' or 'helping' professions, which tend to be relatively prestigious and characterised in popular perceptions by expertise and authority. As discussed in Chapter 2, part of the significance of direct employment model of personal assistance to disabled people is its transfer of authority from 'provider' to 'recipient' of assistance. Therefore, it may seem inevitable that directly employed PAs have a 'low' occupational status as subservient to direct employers. However, there is no necessary correlation between this and the low pay and poor working conditions often experienced by PAs. Both PAs and direct employers in my interview sample felt that improvements in the pay and working conditions of PAs, and greater social recognition of their work, was possible and desirable. Therefore these two chapters critically investigate the reasons for PAs' low occupational status and suggest possible means to improve it without undermining the advantages of the direct employment model of personal assistance for disabled people.

Professions and professionalism

Within my interviews with PAs and direct employers, questions of occupational status were often discussed in terms of 'professionalism'. The terms 'professional' or 'professionalism' were used by 15 of my interviewees (8 PAs and 5 employers, as well as both of those who had been both) in relation to PA work, but with several significantly different (and sometimes contradictory) meanings. These disparate senses of the same word arguably correspond to different sociological understandings of professions and professionalism.

'Professional' and related terms can refer to a particular category of occupations, to a desirable or privileged occupational status, or to a behavioural

norm associated with either paid work in general or work within those jobs considered to be 'professions'. Which occupations can or should be considered 'professions' is contested and there is not necessarily a consensus definition (though medical doctors and lawyers have often (Malin 2017; van Mook et al 2009a) been considered the archetypical professions); Adams (2010, p.66) claims that "it is unlikely that there is one set of traits that defines a profession across time and place" and Evetts (2013, p.781) argues that "sociologists have been unsuccessful in clarifying the differences between professions and other occupations and identifying what makes professions distinctive".

However, concepts which are frequently considered to be central to the definition of professions include specialist knowledge (Dahle 2012; Malin 2017) and/or the requirement for specific formal education (Guldvik et al 2014; Witz 1992), autonomy (Freidson 2001; Witz 1992), authority or expertise (Illich 1977; van Mook et al 2009a), duty or responsibility (van Mook et al 2009b), public trust (Evetts 2013; Fournier 1999; van Mook et al 2009a) and confidentiality (Evetts 2013). Professions are generally taken to require specific knowledge and/or teachable skills, which justify their being 'closed' occupations, only allowed to be practised by those with the requisite formal qualifications; establishing this closure is argued in some analyses to be an intentional part of 'professional projects' by occupational groups seeking professional status (Malin 2017; Witz 1992); however, Adams (2010) argues that the expansion of the 'knowledge economy' means that professions are becoming less distinct from other occupational groups in this respect. Malin (2017, p.8) additionally includes in a list of basic characteristics of professions that they are "interest groups... engaged in competition with each other and other groups in society, up to and including the state", that they are "concerned with providing services to people rather than producing inanimate goods" and that extensive training is required to achieve professional status, with the length of training positively correlating with the social status of professions.

Freidson (2001, p.12) argues that a profession comes into existence when "an organised occupation gains the power to determine who is qualified to perform a defined set of tasks, to prevent all others from performing that work, and to

control the criteria by which to evaluate performance". When this monopoly of expertise is established,

> "neither individual buyers of labor in the market nor the managers of bureaucratic firms have the right to themselves choose workers to perform particular tasks or evaluate their work except within the limits specified by the occupation".

Professional workers are thus "free of control by those who employ them." Freidson thus describes professions as operating according to a 'third logic', neither that of the market and consumerism nor that of state control and bureaucracy. Members of professions are therefore distinguished from other workers both by the unusually high degree of autonomous control that they have over their work, and by the authority or expertise that they are considered to have in their 'professional field'. However, Witz (1992, p.59) argues that

> "the autonomy of professional groups has been somewhat overstated... professions have been crucially dependent upon state sponsorship. There is then a symbiotic relationship between professions and the state."

Similarly, Evetts (2013) argues that historically the "acceptance of the authority of professional experts went together with the consolidation of the authority of states" (p.783). Professional authority is therefore not necessarily as distinct from state or bureaucratic authority as Freidson's 'third logic' framework would suggest, and, as Witz (1992) argues, it is necessary to locate professional projects "within the structural and historical parameters of patriarchal capitalism" (p.53). Professions and professionalism can thus be criticised from standpoints critical of capitalism, patriarchy and the state, including those of Marxism, anarchism, feminism and the Disabled People's Movement. Such critiques can be subdivided into those that consider professions and/or professionalism oppressive to 'professional' workers themselves and those that consider them oppressive to the recipients of 'professional' services.

Critiques of professionals from the perspective of those subjected to them

One of the most famous of the latter type of critiques is that made by Illich and co-authors in the book 'Disabling Professions' (1977). As part of a wider critique of capitalist and technological society, Illich argues that the paternalistic dominance of professions, established through their claims to expert authority, is destructive to human creativity and liberty. Illich claims that "the professional has mutated into a crusading and commandeering philanthropist... Professionals assert secret knowledge about human nature, knowledge which only they have the right to dispense" (p.19). McKnight (1977, p.83) in the same book argues that "professional distance" is a tool to maintain this monopoly of knowledge and authority:

> "a basic definition of 'unprofessional conduct' is 'becoming involved with the client'. To be professional is to distance - to ensure that the relationship is defined in terms that allow the client to understand who is really being serviced. In spite of the democratic pretence, the disabling function of unilateral professional help is the hidden assumption that 'You will be better because I, the professional, know better'."

Criticism of professional authority, particularly that of the medical and 'caring' professions (or as Finkelstein (1999a, b) describes them, the "professions allied to medicine" (PAMs)), has also been central to the Disabled People's Movement. These critiques have often echoed those of Illich and his co-authors; for example, Wood (1991, p.200) says that "disabled people's lives are often dominated by professionals and services which de-skill us and turn us into passive recipients of care". Similarly, Davis (1993) refers to professionals such as occupational therapists and social workers as "professional disability parasites" (p.199) whose "careful crafting of our [disabled people's] dependence" (p.200) is responsible for disabled people's disempowerment and marginalisation. Davis criticises the language of 'professionals' and 'clients' as making the relationship between disabled people and service providers appear

voluntary when there is in fact no real choice and "they decide what we get" (p.198). Oliver (1999, p.378) directly contrasts the direct employment of PAs - which had recently been legalised by the 1996 Direct Payments Act - with "professional services" provided by local authorities, explicitly in terms of autonomy:

> "When given this cash disabled people are using it almost exclusively to purchase our own personal assistance schemes rather than to buy professional services, seeing personal assistance as the key to ensuring autonomy and control in our lives."

These critiques from the DPM are not necessarily of the fundamental concepts of professions or professionalism, but focus on the specific professions with the power to affect the lives of disabled people; however, they fit well with, and arguably add depth to, the broader critique of professional authority from authors like Illich and McKnight (1977). Kelly and Chapman (2015) make an important further critique of the 'helping professions' when they argue that "the moral exaltation of professionals is tethered to the moral denigration of those who use services" (p.46). In this framework, the social status of professionals is dependent on a hierarchy in which they occupy a relative position of greater esteem than the recipients of their services. Therefore, while "[m]any practicing professionals understand themselves as allies to the communities they work with" (p.48), they are not necessarily 'good' allies from the viewpoint of those communities, and relationships between professionals and 'service users' can be seen as "paradoxical adversarial alliances" (p.47), in which professionals can simultaneously occupy the roles of needed and valued helper and of harmful adversary.

In all these critiques, professional authority is contrasted with the principle of subsidiarity (Gordon 2018) common to the DPM and many other 'grass roots' or 'bottom-up' activist movements, in which the people directly affected by something (e.g. disabled people in the case of their assistance needs) are accepted as those who 'know best' about that issue and whose perspectives on it should be given priority (see Chapter 8 for further discussion of this). Kelly

and Chapman (2015), for example, contrast the common teaching given to professionals-in-training that "professional knowledge is objective and impartial and that they therefore know better than client groups" with "anti-oppressive scholarship" which "posits that marginalized groups know more about social injustice and their own day-to-day struggles and victories than groups with greater social power" (p.55). The activist scholarship of the DPM, including the theoretical frameworks of the social model and independent living, can thus be seen as an example of 'situated knowledge' (Haraway 1988) in counter-claim to the "second-hand knowledge about disability" (Davis 1993, p.200) used to give 'professionals' their authority.

Activist scholars in DS have thus called for a fundamental transformation in the relationship between disabled people and 'professionals', and arguably also in the nature of professions themselves. Werner (1995, p.23), for example, argues:

> "it is time for non-disabled professionals to recognise the right of disabled persons to self control, and therefore to gracefully step to one side, into a role where they, as professionals, are no longer on top but rather on tap."

Similarly, Kelly and Chapman (2015) argue that it "make[s] strategic political sense for at least some activist and scholarly efforts to work toward changing the norms that govern professionalism" (p.59) and that those working in 'helping professions' must "work actively to form alliances, recognize our implication in adversarial structures and practices, and forge new and unique relationships with clients" (p.60).

Finkelstein (1999a, b) argues that the 'professions allied to medicine', such as social workers and occupational therapists, must be replaced by 'professions allied to the community' (PACs). Finkelstein claimed that the development of PACs was beginning to occur through disabled people's organisations, in particular CILs, which would "generate new services and service providers" and the workers in these would "constitute our own trade union" (1999a, p.23). The

development of a PAC could "[have] the potential to reintroduce innovation, initiative, excitement and personal reward in delivering the community based support that disabled people want" (1999b, p.3) - but, apart from asserting that workers in CILs are "an embryonic Profession Allied to the Community" (1999b, p.6), Finkelstein does not provide any detailed 'job descriptions' for these proposed new professions. Some authors, such as Shakespeare et al (2018), have described PAs as a potential PAC; similarly, Kelly and Chapman (2015) argue that "informal attendants" (here meaning paid PAs recruited directly by a disabled person through informal networks) "approach the elusive status of political ally" for their employer, an activist in the Canadian independent living movement, in contrast to her more 'adversarial' relationship with professionally trained care workers.

Critiques of 'professionalism' as disciplinary discourse

Another critique of professionalism focuses not on how 'professionals' disable their 'clients', but on how ideological mechanisms of 'professionalism' may actually restrict rather than enhance the autonomy of 'professional' workers. Authors making this critique (e.g. Adams 2012; Evetts 2013; Fournier 1999) argue that the concept of 'professionalism' has been applied beyond the traditional professions and become a normative value within many occupations that do not share the classically 'professional' characteristics (such as specialist knowledge, expertise and autonomous control of work); thus use of the term 'professional' with regard to a job does not in fact necessarily mean that the person doing that job holds 'professional power' on an individual level.

Fournier (1999) argues that the concept of professional competence is defined in terms of responsibility, duty and accountability to clients. This allows the creation of a 'disciplinary logic' in which, while individual professionals have more apparent autonomy than other classes of workers, and are not for example under the direct command of a manager or supervisor, the condition of their autonomy is their adherence to the norms and duties of their profession. This disciplinary logic has been extended beyond the occupations traditionally considered to be 'professions', producing "norms and work ethics which govern

not simply productive behaviour but more fundamentally employees' subjectivities" (p.293). Adams (2012) similarly argues that the concept of 'professionalism' is thus "a mimetic response – an attempt by individuals, occupations and organizations to replicate the social, moral and political power of established professions" (p.329). However, where occupations do not possess that power, and in particular where workers do not have the individual choice and control over their work of traditional 'professionals', the discourse of 'professionalism' can be used by managers as a disciplinary regime for workers, which serves to normalise thought and action within 'acceptable' limits and enforce "neoliberal discourses of obedient, entrepreneurial workers" (p.336) by internalising them in workers' 'professional' identities.

Evetts (2013) draws a distinction between occupational groups which become professionalised 'from within' and 'from above'; while the discourse of professionalism is one of "dedicated service and autonomous decision-making", which "makes professionalism attractive to aspiring occupational groups", when this is imposed from above (e.g. by managers and supervisors in fields like health and social care) it is "a false or selective discourse because autonomy and occupational control of the work are not included", and is thus "used to promote and facilitate occupational change (rationalization) and as a disciplinary mechanism of autonomous subjects exercising appropriate conduct" (p.786). Therefore, while a discourse of professionalism may improve an occupational group's perceived status, it may paradoxically result in less rather than more control by workers over their work.

There is a confluence here with Finkelstein's (1999b) argument that 'modernisation' of social services in the 1990s resulted in a 'de-skilling' process and a redefinition of 'professional' practice in that sector away from individual judgement and discretion on the part of 'professionals' (Finkelstein gives examples from his own experiences of interactions with an occupational therapist and a chiropodist) and towards acting as "rule-following technicians who rigidly follow a covert cost-cutting agenda" (p.2). Finkelstein therefore argues that, as well as disabling their clients, workers in the PAMs are themselves 'disabled', in the sense of having "external barriers imposed on the

ability to control [their] own decision-making" (p.6), by the bureaucratic systems they are embedded in; therefore, for Finkelstein, 'social care' professionals do not follow Freidson's (2001) 'third logic' but have become subordinated both to the logic of bureaucracy and (implicitly, given that their 'modernisation' is driven by a "cost-cutting agenda") to that of the market.

Crossley (2017) argues that in the context of contemporary austerity politics, there has been a trend towards the creation of 'new professions' (for example 'family workers' or 'social work assistants' in the social work field), which are cheaper than their established equivalents (such as 'traditional' social workers). These 'new professions' can be seen as embodying the disciplinary discourse of professionalism described by Evetts (2013) as 'professionalisation from above', while lacking the autonomy and knowledge-based authority of more traditional professions whose professional status was achieved 'from within'. While the latter professional groups, such as medical doctors, may retain more autonomy, the compromise with state authority necessary for the maintenance of their status means that their autonomy is never total and they are also not immune to discipline 'from above'; as Fournier (1999, p. 284) argues, "the enrolment of the professions in the network of liberal government is predicated upon the professions subjecting themselves to the liberal rationality of government." It can thus be argued that even the traditional professions are undergoing a process of 'de-professionalisation' (Crossley 2017; Siebert et al 2018), which Siebert et al link to "an ideology of public sector managerialism" and "a political discourse emphasizing rationalism and standardization through accountability, transparency and constant evaluation against targets" (p.332).

It is therefore tempting to argue that the establishment of user-controlled personal assistance, in which the former authority of 'care' professionals over the lives of disabled people has been replaced by disabled people's authority as employers over PAs as employees, is a part of this neoliberal process, particularly given that arguments involving the lower cost of user-controlled personal assistance, such as those made by Zarb and Nadash (1994), have been used to bring about its establishment (Pearson 2000). PAs can be compared to Crossley's 'new professions' in that both are lower-paid and

arguably less 'skilled' jobs, requiring less specialist knowledge and/or training than their predecessors (though opinions on this notably differed between PAs and employers in my research - see later in this chapter and Chapter 6). However, an important distinction is that PAs are explicitly not intended to have the bureaucratic restrictions of the 'new professions', but in being directly accountable to disabled people themselves rather than to administrative hierarchies, the role of PAs is rather to enable the autonomy, and the decision-making 'authority' within their own day-to-day lives, of disabled people who would formerly have been disempowered 'clients' beholden to the arbitrary bureaucratic restrictions on service provision described by Finkelstein (1999b).

The use of 'professional(ism)' terminology by PAs and employers

The several ways in which the PAs and employers who I interviewed used the language of profession and professionalism reflected varying definitions and characteristics of professions. 'Professionalism' or simply 'being professional' were spoken about by both PAs and employers as a norm of 'correct' or 'appropriate' conduct for PAs, and thus connected to definitions of professionalism emphasising accountability or duty (Evetts 2013; van Mook et al 2009b); for example Katherine (PA), when discussing the possibility of conflict between the interests of PAs and employers, said: "if as a PA you are professional and you turn up when you're supposed to turn up and do what's asked of you, I don't think there's a problem". This usage accords with the claim by Malin (2017, pp.22-23) that:

> "For many ordinary people the word 'professional'... implies
> competence, efficiency, altruism and integrity. Hence, the converse of
> this is the everyday notion of what it means to be 'unprofessional' - to
> behave incompetently, inefficiently or unethically."

However, in this sense 'being professional' does not necessarily mean possessing the characteristics of traditional professions such as expertise, authority and self-regulation, but rather adhering to the norms of conduct particular to the job of PA and displaying competence in the job role; thus

Adams and Godwin (2008, p.30) report direct employers describing their PAs as "more competent and professional across the board" than support workers employed by local authorities. In the terms used by Evetts (2013) this is therefore an example of organisational (rather than occupational) professionalism, constituting a disciplinary structure for workers (see also Adams 2012; Fournier 1999). The particular norms of conduct associated with the job of PA were frequently referred to by PAs using the language of professionalism. Thus several PAs talked about 'professional boundaries', a concept linked to definitions of professionalism that focus on trust and confidentiality (e.g. Evetts 2013). Phoebe, for example, said:

> "it's important to maintain professional boundaries and confidentiality around your employer, both for protection of the employer and just in general protection of the trust in the relationship".

Similarly, Tom described the need to be "very aware of professional boundaries", with this being a particular concern in PA work because of the fine line between "build[ing] a rapport when you spend time with people, you get to know them" and "crossing the boundary of personal, sensitive information". Interestingly, the example of this discussed by Tom involved personal information about the PA's life outside work rather than (as might have been expected) the employer's:

> "two of the people I work with aren't interested whether I have a family or not, whereas the other two like to ask about it. So of course you would share appropriately, you know, what you felt was right at the time. Cause if someone who had the capacity asked me if I had a family, and I said 'I don't want to talk about it', you're hardly building rapport if you wanted information back from them, in the role of support worker or PA. It's slightly different with a social worker, cause people don't tend to ask you those questions. In the role of the PA you'd build that relationship."

Tom was at the time of interview training to qualify as a social worker while working part-time as a PA for several different direct employers, and connected his awareness of 'professional boundaries' with his career ambitions and his being a "registered practitioner" and therefore having to follow codes of practice. Therefore for Tom there was a connection to occupational professionalism, not necessarily in the role of PA itself but in the sense that he saw working as a PA as a kind of apprenticeship for the professions allied to medicine, and thus felt that he was required to conform to their professional norms. Tom was clearly aware of the difference in perception by 'clients' of a PA and a social worker, and considered the former to be more appropriate to relate to in an informal or 'friendly' way than the latter. However, as Beresford et al (2007) document, 'friendly' attitudes and relationships to service users may also be valued in social workers, in some cases precisely because of the contrast between the comfortable, 'everyday' nature of friendship and the strictly defined particular norms of a 'professional' relationship.

Emma described her conflict as a 'work PA', supporting her direct employer in his job at a policy-focused organisation, between staying within the 'professional' role of PA and making her own contribution to discussions:

> "sometimes like when it comes to accessibility, like it's my thing, you know, I'm really very passionate about that, and sometimes I don't have that self-awareness of just being like, you know, silent and saying nothing... on one hand I could act as, you know, a proper professional PA, and say nothing, even if I know that actually, yes, all the work that you're doing is really very important and good, but there are a few other things that should be considered that would make this particular building more accessible for people with other impairments - so there is a moral question for me, whether I should be only professional and say nothing, or whether I should act"

The solution to this dilemma that Emma and her immediate employer came up with together was that she would give a non-verbal signal to him if she had something to contribute to the discussion, so that when he was asked if he

would like to say anything he would give her the opportunity to speak. Here Emma seems to see being 'professional' as a PA as in conflict with acting according to her own conscience and applying her own knowledge and understanding, in direct contrast to definitions of 'professional' that focus on occupational autonomy and/or expertise (e.g. Freidson 2001), but in accordance with what Evetts (2013) describes as "altruism or the 'service' orientation of professionalism" (p.784), in which "[f]or the professional, of all kinds, the needs and demands of audiences, patients, clients, students and children become paramount" (p.787). Reflecting this aspect of professionalism, other PAs also described 'being professional' in terms of putting the employer's needs or desires first; for example, Lisa said:

> "I think a key thing is actually that professionalism [as a PA] is just stepping back and being that person's - just supporting that person... and I wonder - this is kind of reflecting more from an employer's perspective - I wonder if when they pay you, they feel more entitled to ask you to do things"

Professionalism, again used in an organisational rather than an occupational sense (Evetts 2013), is here connected to the waged and contractual nature of the PA job, in contrast to 'care' activities carried out within informal relationships (which Lisa, like several other PAs who were connected to DPM social circles, also had experience of).

'Professional' as formal/contrasted with 'friendly' relationships

A related sense of 'professional' used by both employers and PAs, which arguably connects to both 'occupational' and 'organisational' meanings of the word, is to denote a formal relationship, existing within explicitly defined boundaries, and contrasted with other, less formal, relationships (Shakespeare et al 2017). In this sense of the word, 'professional' was frequently contrasted as an adjective with 'friendly', either in direct comparison or in terms of striking a balance between the two (see also the discussion of 'paid friendship' in Chapter 4). This distinction, also made with regard to the relationships between palliative

care social workers and their clients by Beresford et al (2007), has similarities with McKnight's (1977) concept of 'professional distance'; however, a difference in the usage of some participants from this concept is that McKnight assumes that 'professional distance' is a tool used by professionals to maintain power over 'clients' (with a friendlier, less boundaried relationship presumed to more closely approach equality), whereas for some (though not all) direct employers 'professional' boundaries were seen as a way to maintain the authority of the disabled person as employer, with more informal relationships seen as potentially increasing the power of the PA.

Participants saw both advantages and disadvantages to maintaining 'professionalism' in this sense in their relationships with PAs. Stan, for example, said that he preferred a "relaxed relationship, rather than anything too professional" with his PAs, but qualified this with:

> "Don't get me wrong, they are professional, the carers, but I mean
> too regimented - too sort of detached and clinical, and just doing their
> jobs, whereas the carers I've got now are more like friends - but that
> does make it difficult when you want a change".

(Stan here, as at several points in the interview, casually used the term 'carers' to refer to his PAs; he explained this usage as one that he had fallen into because the term 'personal assistant' was often not recognised as referring to someone assisting a disabled person with daily living tasks, rather than a secretary in an office. Therefore he, like some other direct employers, found that the term 'carer' was closer to conveying the intended meaning to the general public. The lack of recognition of the role of PA which informed this is examined in the next chapter.)

Here for Stan the 'formal' sense of 'professional' seems to be linked to the undesirable idea of occupational professionalism, with terms like 'regimented' and 'clinical' having connotations of the oppressive paternalism and bureaucratic authoritarianism of 'professions allied to medicine' (Finkelstein 1999a, b). However, in saying "don't get me wrong, they are professional", Stan

simultaneously uses an organisational definition of professionalism as occupational competence, which is still considered desirable in PAs. This ambiguity has similarities to that described by Williams et al (2009b), who document PAs working for people with learning difficulties seeking to avoid 'professional distance' by sharing personal information about themselves and their families and consciously interacting with their employers in an informal and 'friendly' rather than typically 'professional' style. However, Williams et al argue that this can itself be regarded as a form of professionalism in terms of following the occupational norms of PAs rather than those of traditional professions allied to medicine. This arguably reflects the difference in attitude between disabled people with physical and cognitive impairments with regard to friendship with PAs due to the difference in the power relations implied by formality or informality, as discussed in the previous chapter.

Also as discussed in the previous chapter, some employers, such as Dawn, felt that the inherent intimacy of the relationship between PA and direct employer meant that maintaining 'professional distance' was impossible, regardless of whether or not it was desirable. For others, such as Ruth, it was undesirable regardless of how possible it might be:

> "[I] don't really have many professional boundaries because... I'm quite a friendly person and I don't want to create a hierarchy, I don't want to be an employer and have employees, you know, especially when they work in my own house, so it's very difficult to maintain a professional relationship... especially as they're all around my own age, and they're the kind of [people] who would be my friends, or [if they] work for a long time, they become my friends, you know, so it's... [a] very difficult relationship"

Here, interestingly, Ruth associates professionalism with hierarchy, but seems to see this in terms of herself as an employer being in a position of power over PAs as employees, rather than PAs as 'professionals' having power over her; thus this also appears to be a usage of the term 'professional' in the disciplinary sense of 'organisational professionalism', rather than in the 'occupational' sense

of professional authority. Ruth contrasted her approach to employing PAs with that of other disabled people who she met through her local CIL:

"the way they work with their PAs is very much - it's very professional and they're just there to help them and that's it, you know, and obviously I don't know the ins and outs of the relationship... but to me that's not appealing, it's a bit impersonal"

However, several interviewees felt that a balance was necessary between informality and professionalism, and/or that a spectrum of conduct acceptable for PAs existed between the two, depending on the individual PA/employer relationship, similar to the spectrum between 'employment' and 'paid friendship' stances as described by Woodin (2006). Charlie, for example, described their relationship with their former employer as "more of a professional but friendly relationship, not professional in the sense like you would be professional with a normal boss, and be very formal"; however, this was in contrast to that employer's relationships with other PAs, some of which were more formal and others of which more resembled 'paid friendship', with Charlie considering their own case to be in the middle of the spectrum. Agatha made a similar distinction between two people she had worked for as a PA, one of whom was an existing friend and the other not, saying of the latter: "I *felt* like I had to be more professional around him. So if he - if we would go out, I wouldn't drink, for example, if he didn't tell me to do so."

Professionalism as 'invisibility' and emotional labour

When asked what she felt "professional" meant in the context of PA work, Agatha replied:

"first of all to give someone their personal space, and I think it's also professional to ask them. Maybe it gets tiring sometimes but you should ask. I think that I have to ask all the time - what I should do, how I should do it, if they need something... and also it's about putting your needs after theirs. So if I'm really tired and I'm outside

with an individual that I'm helping and we are out in a bar for example, even though I'm tired I won't say, "Oh I'm tired, I really need to go to sleep!" for example - I will stick around and be as helpful as I can be and put a smile on my face and have fun, because that's what we are there to do, in any case."

Here the concept of organisational professionalism accepted by PAs clearly involves a kind of self-erasure and subordination of one's own needs and preferences to those of the employer. This can be regarded as part of the transference of power and authority from 'care provider' to disabled person that is central to the concept of 'independent living' (Oliver 1999; Rivas 2002). However, this clearly can result in feelings of disempowerment and alienation on the part of the PA. This was evident from the accounts of PAs who I interviewed; for example, Sarah described how she felt she had to act in her job as a PA as "almost like a silent waiter... about the other person rather than your own personality", and as a result of this felt she had to repress her natural extroversion to such an extent that it even began to affect her interaction with other people outside work. Daisy similarly said:

"it feels like in a way the ideal PA could be considered like a machine, like not a human, and that was quite difficult to like always act like that... I felt like it was hard to not be able to put any of myself into the job, and in a sense not use sort of my mind, but just sort of only be enabling someone else to use theirs... I found it quite frustrating."

Rivas (2002) argues that PAs are among the most alienated and disempowered of workers because of the 'invisibility' of their labour, which is constructed, along with the 'independence' of their employers, through "transferring the authorship" (p.76) of tasks performed by the PA to the employer. Rivas poses the question: "Are workers who articulate a desire to be invisible oppressed by being made so? Must one feel oppressed to be oppressed?", concluding that "the transfer of authorship is a negative phenomenon even for those who consciously work to make it happen" (p.79). However, at least one PA writing from personal

experience (Clayton 2006, p.138) appears to see such 'invisibility' as a positive and laudable professional value:

> "Being a personal assistant is a bit like being a shadow in as much as you have to learn to move with your client while not blocking the sun from their face... A colleague of mine calls this 'invisible support'; I call it professional care."

Rivas (2002, p.77) describes the "obligation to manage their emotions" which she argues is inherent to the work of PAs as "the most oppressive aspect of the job", one which she claims is not even recognised as work by most direct employers. This is reflected by Agatha's mention of "put[ting] a smile on my face and hav[ing] fun" as "what we are there to do, in any case". This can be viewed as an example of emotional labour, defined by Hochschild (1983, p.7) as "the management of feeling to create a publicly observable facial and bodily display", when it constitutes an integral part of the job that a worker is paid to do. Emotional labour is thus part of the broader category of 'emotion work' (the conscious management of one's emotions in interactions with other people), but is distinguished from other forms of emotion work by being "sold for a wage and therefore [having] exchange value" (p.7). Hochschild's archetypal example of a job involving emotional labour is that of airline flight attendants, but her definition encompasses work done in a large variety of 'customer service' jobs, as well as arguably the 'care' professions. In these occupations, she argues that:

> "the emotional style of offering the service is part of the service itself… Seeming to "love the job" becomes part of the job; and actually trying to love it, and to enjoy the customers, helps the worker in this effort." (p.5)

Hochschild (1983) further defines 'surface acting' (performatively feigning emotional affects appropriate to a job) and 'deep acting' (attempting to regulate one's emotions in order to actually attain the affect required by a job) as key elements of emotional labour. However, Cranford and Miller (2013) also argue

that 'personal support workers' (PSWs, a category broader than but encompassing directly employed PAs) "are in a structurally different relationship with service recipients than are commercial employers with customers" (p.787) because, while in the occupations analysed by Hochschild customers typically have greater power than workers, and in traditional 'caring' professions "workers probably have greater power than clients", "in the case of personal home care, which is not considered a profession, clients and workers are both marginalized but along different axes" (p.789). Because of this structural difference, and because they argue that the requirement for emotion work in personal support settings is "not motivated by commercial gain" (p.794), for Cranford and Miller the emotion work carried out by PSWs is better characterised as 'relational service'. Similarly, Kelly (2016, p.81) argues that the relational work of PAs differs from emotional labour as conceptualised by Hochschild in that "it is about not only managing one's own emotions to produce a state of mind in others but also managing an ongoing relationship" and in that it often has a "sense of genuineness… that is lacking in other work environments requiring emotional labour".

This "sense of genuineness" is reflected by the accounts of some of the PAs who I interviewed, particularly those who felt that their employers had genuine loyalty and solidarity towards them that would be unlikely in other 'service sector' jobs. For example, Charlie described their employer's willingness to retain them as an employee when they developed health problems that eventually forced them to give up working, beyond what might have been considered 'reasonable accommodation' by most employers:

> "my employer was very good about me leaving as well, like it took like a year after I'd left work before they finally were like 'oh, you're definitely not coming back' and actually hired someone else permanent... if I'd have realised they were holding the job for me for that long I would have let them know that no, that isn't going to happen"

Another factor that distinguishes the PA/direct employer relationship from the

'customer service' occupations analysed by Hochschild is that direct employers may also have to perform emotion work in their interactions with PAs. Anita, for example, describes difficult interactions with PAs who "had a lot of their own emotional problems, and they'd kind of come and tell me all about them... if I was not smiley or friendly to them every time they came, it seemed like they weren't very happy". In this case the requirement of emotion work for the relationship between PA and employer to 'work' was bidirectional; Anita's need for PAs to be able to put aside their own emotions when working for her was a product of the emotion work that she herself felt required to do for the PAs, and the fact that this was not sustainable for her given the effect on physical and emotional energy levels of her impairment. Shakespeare et al (2017, p.21) similarly document direct employers struggling with "onerous" levels of "emotional investment" in their PAs' lives.

This bidirectionality of emotion work can perhaps be related to the difference in power relations, compared to many other 'service' jobs, created by the similarly bidirectional relations of need in which the need of the PA for a job and income is balanced by the need of the employer for assistance. Kelly (2016, p.73) argues that PAs feel a strong sense of obligation towards their employers because:

> "Unlike many other jobs at a similar pay, deciding not to go into work one day has profound physical and psychological consequences for the self-managers, especially for self-managers who live alone. The attendants also feel this sense of urgency."

This recalls the distinction made between 'care' and 'services' by Bubeck (1995), in which 'care' "meets needs which neither derive from the social division of labour nor are satisfiable by the person in need, but which are absolute in that they make those in need necessarily depend on others" (p.132); in contrast, services could in principle be done by the person receiving them, even if this is not immediately practical. While personal assistance is distinguished from 'care' as negatively conceptualised by many disabled writers and activists (e.g. Morris 1993; Wood 1991), its scope is determined by "the

tasks that adults who are not incapacitated undertake for themselves" (Flynn 2005, p.17). It thus clearly is 'care' rather than 'service' in Bubeck's sense, further distinguishing it from such occupations as flight attendants or bar or shop workers.

This was reflected in the way that PAs described their work, with several contrasting it to other jobs in emotional affect (see also the section on 'meaningful work' in Chapter 6). Malcolm, for example, described 'petty' behaviour from his first employer, such as insisting that he prepare food in highly specific ways, that he would not have tolerated in a different job:

> "if it was any other kind of employment situation, I perhaps would not be happy with the way that I was spoken to by a boss. So I think there's certainly a contradiction there. If I was working in McDonald's and I did something wrong and my boss raised his voice at me, the way that my temper often works is that I wouldn't be working at McDonald's any more, I probably would have stormed out. In this situation I had more empathy because I could understand - I think it's the contradiction of him being a boss, and I hate the word but it was the word he used, and a client at the same time."

Whether or not it can be characterised as 'emotional labour' in Hochschild's sense, emotion work is undoubtedly involved in the work of PAs (Shakespeare et al 2017), and can be regarded as a component of the disciplinary discourse of professional conduct which Fournier (1999, p.293) argues produces "norms and work ethics which govern not simply productive behaviour but more fundamentally employees' subjectivities". Hochschild (1983) argues that emotional labour is strongly implicitly gendered as feminine because it resembles the unpaid emotion work that women are socialised to carry out in everyday life. It is thus more prevalent in majority-female occupations, of which personal assistance is one, although possibly less extremely so than other forms of 'care work' (Christensen & Guldvik 2013).

If the shift to user-controlled personal assistance from more 'occupationally professional' forms of care work can be seen as part of a general trend of 'de-skilling' or 'de-professionalisation', it can also be connected to the feminisation of labour which Casas-Cortés (2014) argues is an element in the neoliberal trend of increasing precarity of employment (this will be covered in greater depth in Chapter 6). Casas-Cortés refers to the "feminisation of labour" as the "growing presence of servile traits, historically assigned to women's tasks, among different contemporary sectors" (p.219). These traits, such as flexibility and emotional sensitivity, overlap with those considered by direct employers to be skills or qualities of a 'good' PA. Guldvik et al (2014) highlight the 'other-oriented flexibility' of PAs' work and argue that "the subordination of personal assistants depends on the construction of the work as both non-professional and gendered, and the close connection between the two dimensions" (p.53), recalling the argument by Witz (1992) that divisions within 'service' occupations between higher-status occupational groups which are commonly regarded as 'professional' and lower-status ones which are not are gendered in ways which sustain "male privilege within professional hierarchy" (p.210).

'Professionalism' as expert status

While PAs primarily used the term 'professional' in an organisational or disciplinary sense, employers used it both in this sense and in the more traditional sense referring to expertise, authority and autonomous control over work, referred to as 'occupational professionalism' by Evetts (2013). Employers generally viewed professionalism in the former sense as a positive and desirable quality in PAs, while they generally viewed professionalism in the latter sense as undesirable. Yahya, for example, uses the former sense in describing the necessary qualities of a 'good' PA:

> "[PAs should be] professional in that they take their job seriously. That they're getting paid to do it, so they have to be honest and do the job that they're expected to do. They're professional in their attitude, in that they're not going to... talk about you with other

people, or break confidentiality. They should be professional in those ways."

However, when Yahya used 'professionalism' in a negative sense, he associated it with the paternalistic institutional norms of the traditional 'helping professions', as criticised by authors such as Davis (1993), Finkelstein (1999a, b) or Kelly and Chapman (2015):

"The professionalism I was talking about in terms of training is like nursing techniques and stuff like that... they shouldn't have those, you know the techniques of doing things, I much prefer to tell them how to do it and the ways to do it. For instance I wear calipers, long-leg calipers. Medically or clinically there's a particular way that calipers should be put on and taken off, but I don't like that way of doing it, and I have my own way of doing it, so that's the kind of thing I'm talking about."

Anita similarly described the negative aspect of 'professionalism' in terms of PAs presuming expertise of how best to do the job, which had been a source of conflict between her and PAs she had previously employed:

"there's an element of like sometimes they see it as a profession, so they're the professional, and they have a job, and they should be the experts on what they're doing, there was an element of that, and I do ask them to have some initiative, but that's different from thinking you know the best way to like wash my clothes or do the dishes."

These usages reflect the strong anti-professionalism of Independent Living pioneers and other DPM activists (e.g. Davis 1993; Kelly & Chapman 2015; Oliver 1999; Wood 1991), whose opposition is to the paternalism and assumption of 'expert' status of the 'professions allied to medicine' (Finkelstein 1999a, b). This conceptualisation of professional status is related to the 'third logic' of Friedman (2001) and to Illich's (1977) critique of 'professional power', but is arguably at times conflated with a broader sense of the word

'professional' to connote a job which has a high social status and/or is highly respected by the general public (Adams 2010). While these senses of the word are closely related, they can usefully be disambiguated as the latter sense has more potential positive connotations and does not necessarily imply an oppressive 'power-over' position.

This sense of the word was frequently contrasted by PAs with terms such as 'menial' and associated with the arguably under-recognised complexity, difficulty and/or social importance of PAs' work. Guldvik et al (2014, p.52) describe personal assistance work as "typical non-professional, unskilled work characterized by relatively low wages, low status, minimal benefits and a high worker turnover rate"; however, PAs tended to view their work as qualitatively different from other jobs in that category, such as shop or bar work (other aspects of this will be discussed in greater depth in Chapter 6), and often argued that it ought to be more highly regarded and given 'professional' status. Katherine, for example, said:

> "I think it's thought of as being menial when actually I think there are professional qualities to it, you know as a job there are things you can learn and do well and that side of it isn't, I don't think ever, talked about."

Katherine's use of the phrase "professional qualities" here seems to mean that PA work is not just simple manual labour that could be done by any sufficiently 'able-bodied' person, but (also) requires both the above-mentioned emotion work and cognitive labour such as making difficult judgements about the appropriateness of actions according to a complex ethical framework. This usage can be seen not so much as an assertion that personal assistance already is a 'professional' job, as a call for it to be given the esteem and recognition that is given to jobs regarded as 'professional'.

Training, qualifications and 'transferable skills'

There is considerable controversy among disabled people about the value of

formal training for PAs and the relevance of concepts such as 'transferable skills' to personal assistance work (see for example Glendinning et al 2000a; Kelly & Chapman 2015; Morris 1993; Shakespeare 2014), which was a major theme in my interviews with both PAs and employers, particularly with relation to the questions of what qualities are desirable in a PA and what could be improved about personal assistance (the latter of which is dealt with in Chapters 7 and 8). The terms in which both employers and PAs described the skills necessary for being a 'good' PA often suggested that such skills cannot necessarily be taught, but might be better construed as aptitudes or even personality traits, reflecting the findings of Adams and Godwin (2008, p.8) that direct employers "tend to value personality traits over proven skills and experience when it comes to selecting Personal Assistants". For example, the five skills listed by Dawn, as essential for a 'good' PA for her were "reliability, flexibility, trustworthiness, willingness to learn" and "good attitude", the last of which she further described as being "pleasant and positive" and doing tasks they were asked to do without complaining. Reliability, flexibility and trustworthiness were also emphasised by several other employers as essential qualities. Other skills or attributes mentioned by employers included "emotional intelligence" (Ada), a compatible sense of humour (Jack), being "sensitive towards what the employer wants, needs, feels" (Ruth), honesty and "be[ing] of a personality where they don't want to be in charge" (Jane), patience (Yahya) and confidence (Ede). These notably correlate with the traits of 'feminised labour' as described above (Casas-Cortés 2014; Guldvik et al 2014).

Many employers expressed a strong preference for hiring PAs who did not have previous training or experience, and for training their PAs themselves rather than letting them have external training; this reflects the views of direct employers documented in other research (e.g. Adams & Godwin 2008; Flynn 2005; Wedgwood et al 2018). For example, Ada said "I don't send my PAs on any training course at all and I recruit people who don't have any experience, preferably, because I don't want them to come as carers." Likewise, Anita felt that "people who have got less experience of doing it, who are more just people, trying to figure out how to help" made better PAs than those who "see it as a road to their career". This preference was often connected to the

assumption that formal training would be likely to instil in PAs the paternalistic values and assumptions of authority over 'clients' associated with professions allied to medicine. Direct employers thus tended to prefer to hire PAs who did not have previous related work experience; as Jack said:

> "A lot of us put on our adverts 'no experience necessary' for a reason, and it's not just because it's no experience necessary, which is true - it's actually because we don't particularly want to attract other people who've worked in the care industry."

Kelly and Chapman (2015, pp.58-59) similarly quote Shauna, a disabled activist and direct employer, discussing the need to "un-train" new PAs who had undergone formal training and certification because they

> "come with the attitude that they know more than you do... cause many of these courses are taught by nurses, many of them come out with the notion that you're a sick person and you need to be looked after."

Some employers not only preferred not to employ people as PAs with formal training or 'care' work experience outside the direct employment paradigm, but also preferred not to hire people who had previously worked as PAs for other disabled people (also documented in other research; see for example Glendinning et al 2000a; Guldvik et al 2014; Morris 1993). Elizabeth, for example, said:

> "I don't like hiring people with experience, that might actually put me off... I just think everyone is so individual and everyone likes things done the way they like it - so how I transfer into bed is going to be different from the last person they worked for."

In contrast, untrained and inexperienced PAs could more easily be trained by the employer in the skills and values that were important to them; as Yahya said:

"I have a problem with people who become too professional as personal assistants. I think it's much better, for me anyway, when the person being the PA actually knows nothing about anything, and it gives you the opportunity to train them in the ways that are best for you, like in the way that you get dressed in the morning, or you have a shower or whatever. Sometimes you can get personal assistants who think they know how to do it all and they'll just do it that way, but actually you want it done in a different way. So it's just nice to have people who are... like a clean slate, you can just start them fresh and train them in the ways you want."

These skills were thus often highly specific to working for the individual employer, and not necessarily transferable (Kelly 2016; Shakespeare 2014). Kelly (2016, p.104) argues that this is "not... a *rejection* of expertise, but a *redefinition* of expertise" (italics in original), such that while disabled people are "the experts in their needs", PAs "become experts in individual people". Joe, a PA with a background in the DPM, similarly emphasised the specificity of PAs' skills and aptitudes to individual employers:

"I think it's a really important and yet extremely difficult area because the worry is that PAs might start to be encouraged to do all sorts of training and all sorts of qualifications, almost professionalise it, but... there is a danger that that takes you away from the person, because it's not about having a set of skills or values, or insights, but it's how one applies those skills, values and insights by being directed by the person that you're working for. And to assume that you can be an effective PA with a whole group of individuals is - you may have the skills of being able to listen, to reflect, to be honest, all of those things, but it doesn't mean to say automatically that you are then going to be able to apply those skills effectively to the next person you meet. So therefore, how do you prepare somebody to be, or train somebody to be, an effective PA, without them losing sight of the fact that they have to be malleable to match the requirements of the

particular person? And if they're not, they can't be an effective PA for
that person. They might be for somebody else, but not for that
person."

This is in contrast to the skills involved in professions as commonly understood,
which can, indeed must, be acquired through formal training, and are certified
by standardised qualifications (Adams 2010; Guldvik et al 2014; Witz 1992).
Guldvik et al (2014) cite the fact that "there are few entry requirements in terms
of qualifications" (p.52) as one of factors classifying PA work as 'unskilled' and
'non-professional'. The question of whether a qualification for PAs would be
desirable drew a wide range of responses from both employers and PAs. Anita
expressed her ambivalence about it:

"the care system's... very professionalised, there's training courses,
you can get qualifications in it - I'm not sure if that would be the best
way or not [for PAs], really, because some of my best PAs are people
who don't know anything about the job, they're just good people, and
maybe making it a profession, and people having qualifications would
put people in an expert position... but there does need to be
something, I don't know what it would be - maybe training that
doesn't necessarily result in a qualification, or training that's really,
really thoughtful about not saying that PAs now have expertise cause
they've been on training"

Slav supported 'professionalising' personal assistance in the sense of raising
the social status of PAs' work, but argued that formal training and
standardisation were not required to achieve this:

"I do want the role of the PAs professionalised, in the way that we
value certain professions, and see it as something that's valued,
something that's respected, etcetera. What I don't want with that is
actually, that mechanism for saying, you're only a PA when you
achieve this, this, and this, which has been set in almost a curriculum
kind of way... Because also what you're doing is you're standardising

someone's roles within the job... What I don't want to lose is that kind of respect that the role has with it. So when I talk about professionalism, that's what I see as professionalism - respect and value for the role, not necessarily for the route you've taken to become a PA"

Some PAs, such as Emma, also opposed standardisation, while supporting training in a more general sense:

"I would say that there is a need for training, I'm not sure if I agree with the fact that that training should be standardised... because, you know, standards can have a very negative impact, especially when it comes to working with people... so I would say yes, we need training, no we don't need standardised training."

Katherine similarly felt that the training available for PAs in her locality was inappropriately focused on specific tasks relating to employers' impairments, and that a more useful approach would be to train PAs in the roles and responsibilities associated with the direct employment model of personal assistance:

"sometimes people talk about training for PAs and they talk about lifting and handling and swallowing, and I know you can get that through the council, but I think in some ways, in a lot of ways, it would be more useful to have training about the history of the disability movement and independent living and that sort of thing, so you understand what you as a PA are facilitating... I think that would make it perhaps easier as a job to do, and to do well and to know that you're supposed to be stepping back and let the person do things themselves and facilitating them doing stuff."

Other PAs, however, differed on this issue. Tom, in particular, was adamant that all PAs should have formal training, repeatedly emphasising the issue at every opportunity possible during his interview, and arguing that a 'portable'

qualification was particularly important for PAs who worked for more than one employer:

> "I would love to see it in a standardised qualification, a portable qualification, cause a lot of PAs have more than one service user they work for, so a portable qualification that says once you're trained, let's say emergency first-aid in the workplace, once you're trained in first aid, you know, starting someone's heart is the same for anyone. But you know, every three years you need to be refreshed. Once you're trained in the hoist, you're done."

Tom was aware that this was potentially in opposition to the interests and wishes of employers:

> "One of the people I work with has just tried to sack someone because they wanted training... it's a particular tension for [him] about having staff trained. He does not want it, cause he sees himself as the boss and it's his choice."

These perspectives are also found in the literature. Glendinning et al (2000a) report PAs desiring training and qualifications, both to feel more confident in their jobs and to improve future career prospects. Clayton (2006), writing from experience as a PA, echoes Tom in expressing his strong belief that "being a personal assistant is a profession rather than a job" (p.137), and therefore ought to require a degree-level qualification, and that PAs should be "professionally screened before they are allowed near vulnerable people" (p.138); however, similarly to Tom within my interview sample, Clayton's views diverge from those of other PAs in the same anthology of personal accounts (Leece & Bornat 2006).

It is perhaps notable that both Tom and Clayton (2006) also saw themselves as having a pedagogical or transformative role towards their employers, which in both cases included young disabled people still living with their parents. Clayton described his work as a PA for a new employer as involving "understanding the

individual and his family and then beginning to help them to create structures in their lives that would allow for their greater independence" (p.137), while Tom described his role as being "about promoting change", giving as an example of the kind of change he meant "being able to make a cup of tea if you weren't able to do it before, even if it's just for the first time being able to put a teabag in". This is likely to reflect the influence of ideologies of rehabilitation and/or normalisation (see Chapter 2), focused on the achievement of 'independence' in the sense of self-sufficiency, which are arguably particularly strong in the provision of support to people with learning difficulties (Yates et al 2008). Pearson (2000, p.472) reports a PA for a person with learning difficulties, in a pilot project for the implementation of direct payments by a local authority, being "told that his role had a long-term goal to 'do himself out of a job'" because of the aim of seeking "maximum independence", fundamentally ignoring the redefinition of 'independence' by disabled people as self-determination.

Many direct employers would have been unlikely to tolerate these approaches, likely perceiving them as intrusive, paternalistic and similar to the undesirable 'expert' attitude of the professions allied to medicine. Adler (1993), another PA writing from experience, takes the opposite viewpoint, declaring himself "strongly against" a certificated training course, despite recognising the great importance of the "issues of training and certification" for the perception of personal assistance as a "real job":

> "The primary reason for my opposition is that the attendant is trained by the person he or she is helping in that person's needs. These people know more about their limits and needs than anyone else... The person who hires an attendant is looking for someone who has the right attitude, not someone who knows about particular procedures." (pp. 226-227)

Like several of the employers who I interviewed, Adler considers it to be a risk of formal training for PAs that "the attendant may start to think they know more than their employer and, therefore, have a better way", which he argues is "against the main thrust of attendant service: that is, self-directed care by the

person receiving the service" (p.227). Heumann (1993, p.244) similarly argues that "When training programs exist, the individuals who need the service and their advocates must be significantly involved in the training" in order to avoid training making workers "believe they know what is best for the disabled person".

Several of both direct employers (Anita, Jack and Slav) and PAs (Joanna, Katherine, Lisa and Sarah) felt that, rather than training in the specific physical tasks of the job, a more appropriate form of training for PAs would focus on the role and responsibilities of a PA in supporting disabled people's autonomy and the ethical norms associated with this, potentially including the historical and political background of 'independent living' and the DPM. Katherine, for example, said:

> "sometimes people talk about training for PAs and they talk about lifting and handling and swallowing, that sort of training, and I know you can get that through the council, but I think in some ways, in a lot of ways, it would be more useful to have training about the history of the disability movement and independent living and that sort of thing, so you understand what you as a PA are facilitating."

However, it was acknowledged that this might not be a standardised training package, as individual direct employers' definitions of 'independent living' principles and feelings about the appropriate roles of PAs may differ. Lisa, for example, said:

> "I'm kind of wary of that idea of standardised training because people think 'OK, I know how to do this now', and I think that's very dangerous - that counteracts being a good PA, but I think some kind of... exploration of values is important."

From the direct employer's perspective, Jack felt that it was the individual employer's responsibility to train their PAs as they wanted them to act, but also said:

"I think maybe there's some sorts of general training - I don't even know whether its so much training as maybe... sort of general information that we can give them about what a PA is, and sort of [an] overall idea of what a PA does, rather than necessarily the actual tasks or the exact things to say in exact situations."

Jack contrasted this to the "very sort of heavy politicised training in how to train my staff" that she was given, which she felt was overly specific, and argued that having experienced PAs talk to new or prospective PAs about the roles of the job might be more appropriate. However, this reflected tensions in Jack's thinking during the interview about whether direct employers or PAs themselves should more appropriately be considered the 'experts' on personal assistance work.

Conclusions

As has been shown in this chapter, the meanings of 'profession' and 'professional' are multiple, diverse and contested. Thus whether or not PAs can be regarded as 'professionals' is not a question that can be simply answered in either the affirmative or the negative. In several common (and connected) senses of the word, PAs are not 'professionals'. Firstly, PAs are clearly not 'professional' according to autonomy-based definitions of professions, such as the 'third logic' of Freidson (2001), as this contradicts the fundamental point of the direct employment model of personal assistance; thus if 'profession' is defined in Freidson's terms, to 'professionalise' the status of PAs would be highly undesirable for direct employers. If PAs were to be "free of control by those who employ them" (Freidson 2001, p.12), then their role would effectively cease to be that of a PA as this has been defined in the DPM and the philosophy of 'independent living' and become another of the 'professions allied to medicine', and disabled people with significant personal assistance needs would once again lose the choice and control over daily living activities which was the core demand in the campaigns to establish the direct employment model. If professions are defined by having achieved occupational closure (Witz

1992), then PAs are clearly also not a profession, and achieving this criterion of professionalism seems unlikely given the great divergence of opinions among both PAs and employers on related issues such as training and qualifications.

Personal assistance is also not presently a 'professional' occupation in the sense of being highly esteemed by the general public and/or of having a high status comparable to other occupations. While this sense of 'professional' status is frequently linked to the former one (for example, in the case of the professions allied to medicine, by the negative relationship described by Kelly and Chapman (2015) between professionals and the 'lower-status' clients they are assumed to have power over), the link is not inevitable, as many highly socially esteemed occupations do not have the kind of autonomous control over their work that Freidson (2001) considers typical of professions; indeed, even the traditional professions such as medical doctors do not necessarily have as much autonomy as they are presumed to have (Evetts 2013; Witz 1992). Therefore, if 'professionalising' the work of PAs merely means to improve the social recognition and esteem of the job, it does not necessarily imply changing power relations between PAs and direct employers in such a way as to cause a loss of autonomy for the latter. (Indeed, as will be discussed in Chapter 6, to improve the social status of PAs' work arguably also requires a concurrent transformation in the social valuation of disabled people themselves.)

To regard the core defining criterion of a profession as autonomous control of work neglects other important aspects of the social construction of professionalism, perhaps most notably the idea of professional duty to employers and/or clients (Fournier 1999; van Mook et al 2009b). It is arguably this aspect of what it is to be a profession that has enabled 'professionalism' to become a construct of norms appropriate to either a particular job or to employment in general, which can then be used in disciplinary ways which decrease rather than increase the ability of workers to exercise autonomous decision-making in their work (Adams 2012; Evetts 2013; Fournier 1999). The particular professional norms of personal assistance work are shaped by the philosophy of 'independent living' and the social model of disability, and thus emphasise maximizing the autonomy of disabled people as employers of PAs;

as testified to by several of the PAs who I interviewed, and others (e.g. Adler 1993), these norms have been internalized and enthusiastically accepted by many PAs as admirable ethical principles that arguably add to their perception of their work as socially meaningful (see Chapter 6); however, in some cases these norms can also result in difficult emotion work and subjective alienation. Tensions over training and 'expertise' were also present in the accounts of both PAs and direct employers.

Thus whether or not PAs can be regarded as an example of Finkelstein's (1999a, b) elusive 'profession allied to the community' depends on which definition of 'profession' is being used. Finkelstein's critique of the 'professions allied to medicine', like that of others from the DPM and allies (e.g. Davis 1993; Illich 1977; Kelly & Chapman 2015; McKnight 1977; Oliver 1999; Wood 1991), focuses on the power over 'clients' that they have as a result of the high social esteem and 'expert' authority granted to them, though this is arguably being eroded by processes of 'de-professionalisation' (Malin 2017; Siebert et al 2017). Arguably, a 'profession allied to the community' would therefore in itself necessarily not be a profession by Freidson's (2001) 'third logic' or an 'occupational profession' as defined by Evetts (2013), leaving scope for PAs to be considered one; however, arguably greater social recognition of and investment in PAs' work would be needed before such a status could be said to have been achieved. However, PAs are regarded by many disabled people as important allies, both on the level of individual relationships (as seen in the previous chapter) and potentially to communities and movements.

The potential for politically meaningful alliance based on solidarity between direct employers and PAs will be discussed in the next chapter, along with other issues relating to the occupational status of PAs and the lack of appropriate social recognition given to personal assistance.

Chapter 6

Personal assistance as work, part two: poor work and precarious life

In the previous chapter, the potential 'professional' status of PAs was discussed; one reason why PAs arguably cannot be considered a 'profession' was the generally low social and material status of their work. Personal assistance is often what Shildrick et al (2012) describe as 'poor work'; low-paid, low-skilled, insecure, and frequently involving difficult or unpleasant working conditions. In this chapter, I explore the aspects of PAs' work that contribute to its 'poorness', including 'dirtiness', servility and precarity, and compare it to other forms of 'poor work', concluding that despite these negative qualities, there are positive aspects to it for many PAs which go unrecognised. Thus I argue that better recognition of PAs' work, as well as material improvements such as increased pay, are necessary to improve its social status.

Precarious work

In recent years there has been a boom in analysis of precarious work and the broader associated concept of 'precarity' (e.g. Berardi 2005; Casas-Cortés 2014; Lorey 2015; Neilson & Rossiter 2005, 2008; Standing 2011). Shildrick et al (2012, p.20) offer a 'common-sense' definition of precarious work as "work that does not last and carries the threat of its ending", thus focusing on the increasing use of temporary contracts in the 'post-Fordist' era of employment, while admitting that this is an over-simplification because distinctions between 'permanent' and 'temporary' work are increasingly blurred. Similar working conditions have previously and otherwise been described using terms such as 'contingent', 'non-standard', 'atypical', 'non-traditional' and 'insecure' work, of which 'non-standard work' is possibly the commonest (Shildrick et al 2012; Shuey & Jovic 2013; Wilton 2006). Berardi (2005, no page number) traces the origins of precarity in its current form back to the 1970s, but argues:

> "what [then] seemed a marginal and temporary condition has now
> become the prevalent form of labour relations. Precariousness is no

longer a marginal and provisional characteristic, but it is the general
form of the labour relation in a productive, digitalized sphere."

Precarity has been described as a consequence of a move away from the 20th-century norm of 'Fordist' employment patterns, defined by large-scale, centrally-controlled workplaces such as factories with a high degree of specialisation of workers for particular roles, and a general expectation that a worker would stay in one job as a long-term career (Neilson & Rossiter 2008). However, many authors (e.g. Berardi 2005; Neilson & Rossiter 2008; Jørgensen 2015; Lorey 2015) have argued that it is the relative stability of Fordism, rather than precarity, that is the exception when looking at capitalism from a wider historical and geographical perspective; thus precarity can be considered the globally typical condition for workers within capitalism.

Feminist writers and activists such as Federici (2008), Casas-Cortés (2014) and the Madrid-based activist research collective Precarias a la Deriva (2004, 2006; see also Lorey 2015) have also drawn attention to precarity in reproductive work, including both waged and unwaged forms of 'care' work (as a broad category potentially including the work of PAs) and to the connections between the precarisation and the feminisation of labour, arguing that domestic and reproductive work have always shared the features ascribed to precarious work as a 'new' phenomenon. For these critics, this points towards an expanded view of precarity as extending beyond the workplace into domestic and personal relationship spheres, because "production and reproduction are so interwoven that it is no longer possible to speak just about precarious labor, but rather precarious life" (Casas-Cortés 2014, p.220).

The figure of the migrant worker - particularly those from the 'Global South' working within Europe and North America - has also been central to discourses of precarity (Jørgensen 2015; Neilson & Rossiter 2005). Many PAs, in the UK and in other 'Global North' countries including Norway, Canada and the USA (Christensen & Guldvik 2013; Cranford 2005; Hudson 2017; Kelly 2016; Rivas 2002), are transnational migrant workers, arguably falling into a broader category of, primarily female, migrant workers in 'care' and domestic service

sectors who form a substantial and increasing proportion of the precarious workforce, with their contributions to the functioning of society frequently erased or devalued (Erevelles 2011; Glenn 2010). Migrant workers from EU countries in particular have been argued to play an essential role in maintaining the PA workforce in the UK (Hudson 2017; Lawson & Sayce 2017).

Christensen and Guldvik (2013) argue that, in both the UK and Norway, migrant 'care' workers (including directly employed PAs) are more likely to be more or less temporary migrants - often moving back and forth between the countries they work in and their home countries - rather than immigrants intending to settle permanently, and that for many such migrants working as a PA or 'care' worker constitutes 'downwards' social mobility, as they are often highly educated and qualified but working in jobs which require no formal qualifications (as well as being poorly paid and broadly regarded as low in social status). Several (4 of 14) PAs interviewed in this study were migrants broadly fitting this profile.

PAs as precarious workers

Standing (2011, p.10) characterises precarious workers as lacking seven forms of "labour-related security": labour market security, employment security, job security, work security, skill reproduction security, income security and representation security. While the definitional boundaries of these may be questioned, most if not all of them are highly relevant to the working conditions of many directly employed PAs.

PAs lack **income security** because the insecurity of funding for employers is necessarily transferred to their PAs. While PAs are subject to minimum wage legislation in the UK, there are ambiguities such as whether they need to be paid a full wage for overnight 'sleep-in' shifts, which has recently been subject to legal dispute (Brindle 2017; Schwehr 2018). In general, rates of funding are such that employers often have to make choices between paying PAs minimum or near-minimum wages, despite considering their PAs' work to be 'worth' more than that, or not having PAs for all the hours that they need. This has been

intensified in recent years due to the 'austerity' economics of the UK under Conservative-led governments since 2010, which has had a disproportionate impact on disabled people in general and those with personal assistance needs in particular (Dodd 2016; Duffy 2013); this is discussed in greater detail in Chapter 7.

A large proportion of PAs work part-time (Adams & Godwin 2008), either because their employers do not get sufficient funding to employ someone full-time, or because employing multiple part-time PAs was the only workable way for an employer to arrange things to get their specific needs met at appropriate times. While this suits some PAs well in terms of their own situations or preferences (e.g. being able to combine work with study or unpaid care for dependent children), many would likely prefer to work full-time if this were possible.

PAs may lack **employment security** - defined by Standing as "Protection against arbitrary dismissal, regulations on hiring and firing, imposition of costs on employers for failing to adhere to rules and so on" (2011, p.10) - both because the right of individual disabled employers to hire and fire PAs at will has been considered central to the shift in power from assistance worker to disabled person that was a core aim of the Independent Living movement, and because of the aforementioned funding insecurities, potentially meaning that PAs may arbitrarily lose their jobs due to a cut in their employer's funding even when their assistance is still needed. The death, hospitalisation or movement to a different area of an individual employer may also unexpectedly end a PA's employment.

The **work security** of PAs may also be threatened by insufficient levels of funding (see Chapter 7) forcing employers to require PAs to work more hours than is reasonable, doing work that can be physically exhausting and may also be emotionally and relationally difficult (see also Chapters 4 and 5). This was a reason that many PAs did not want to stay in the job in the long term; for example, Agatha said: "I think I wouldn't do it as a long term job, because it can be quite difficult and quite demanding physically", while Joe said:

"I could not have sustained it as a full time occupation. It was too
intense, and it did require a lot of intense support. And from that point
of view, giving myself to another person, even though that was
beneficial to me at times, was just too intense. I just couldn't sustain
it over a long period of time."

Two participants, Charlie and Emily, had to give up working as PAs because
their own impairments and/or health problems worsened while they were in the
jobs, though in both cases they would have liked to stay in the job longer if they
had been able to. Similarly one employer, Dawn, had one particular PA, with
whom she had a very close and mutually beneficial relationship, who she would
have kept employing for longer but "her physical health and her back pain got
too bad and she had to stop". While in these cases the health problems
experienced by PAs were not necessarily caused by the work itself, it is
plausible that PA work, like the physically similar jobs done by workers in 'home
care' agencies (Shildrick et al 2012; Wilton 2006) may contribute to the social
creation of impairment (Abberley 1987; Thomas 1999) through the physical
consequences of work on workers.

These issues, especially when combined with low hourly rates of pay (Adams &
Godwin 2008; Leece 2010), may cause difficulties for employers with
recruitment and retention of PAs, which can become a vicious cycle in which an
employer being unable to recruit sufficient PAs to meet their daily needs results
in the PAs they do have being required to work harder and faster and/or do
large amounts of overtime, endangering the health of both PA and employer.
This had been a particular problem for Dawn, who needed 24-hour support due
to the extent of her impairments, and had been forced to rely on unpaid
assistance from her mother to fill in the gaps that existed because of difficulties
recruiting enough employees; Glendinning et al (2000b) report similar
experiences of disabled people with greater support needs finding it harder to
recruit PAs because those who worked for "less impaired" employers were
"getting more pay for less work" (p.207). One PA, Malcolm, also spoke about
tensions that arose with one of his former employers because of the intensity of

24-hour shifts causing a high turnover of PAs due to them 'burning out'. Malcolm himself worked for this employer for 6 months, but his "perception of it was that... it was rare that a staff member would last more than 3 months."

Job security is defined by Standing as "Ability and opportunity to retain a niche in employment, plus barriers to skill dilution, and opportunities for 'upward' mobility in terms of status and income" (p.10). PAs usually lack such opportunities, both because increases in income are usually made impossible by the limits of funding, and perhaps more fundamentally because the nature of their work is such that 'upward mobility' for PAs as workers is difficult to imagine. This was acknowledged by both PAs and direct employers. One PA, Daisy, said:

> "Let's say if you worked in care work, for instance in a care home - I don't know how it works but I imagine that your pay will increase over time, you can get more responsibilities perhaps, you could perhaps move up through the ranks or whatever, become a manager, you know, have other levels of responsibility and your pay would increase as your career sort of progressed... [and] with PAs, I don't see any way that that could work - there isn't like a managerial role, because it is just doing the work... there isn't like a clear career progression, or pay progression, at all."

Similarly, Joanna, who was working as a PA when interviewed but did not see it as a long-term job for her, and would have liked to change jobs to "something more challenging, something where I'd have more responsibility", said when asked if she thought it would be possible to have more responsibility as a PA:

> "I don't really see that to be honest, because ultimately you are just there for someone else. It would be odd to be in a situation of that much responsibility as a PA because that would mean you'd taken something away from the person you're working for."

Ada, a direct employer who had also employed and supervised staff in other contexts, concurred: "My sense of long term career... there has to be some

element of 'up' or 'broader' to it, and I'm not sure how you get that as a PA. I don't know where it comes from." Likewise Elizabeth said, discussing the fairly high turnover of her PAs:

"I think it's a really good job when you're just discovering what you really want to do, if you're in education as well. But I think that because there's not really anywhere you can go, there's not any chance of a pay rise... I've never seen it as a long-term thing for any of them [her current and past PAs] - personally I don't see it as a long-term career for anyone, as it is now."

Elizabeth considered the possibility of creating a 'manager' role for more 'senior' PAs, taking on administrative aspects of employing PAs that employers may find difficult or overly time-consuming to do themselves, but thought this would only be viable if there was a "large team" of PAs:

"If you had a small team I'm not really sure what that [possible career progression] would be - I don't really see how, where you would go, unless you go and get a qualification. No, because once you're in that job, you're in that job. A PA's a PA, isn't it? There isn't really anything better, does that make sense? Obviously you can improve the pay as they get more senior, but you can't change the role, it'll always be the same."

This is closely related to the issue of **skill reproduction security**, which Standing defines as "Opportunity to gain skills, through apprenticeships, employment training and so on, as well as opportunity to make use of competencies" (p.10). PAs can be said to lack this because of the lack of formal training or recognised occupational qualifications and the common preference of employers for untrained and inexperienced PAs (discussed in Chapter 5). Glendinning et al (2000a) argue that this may be a reason for difficulties experienced by direct employers in recruiting and retaining PAs. This also contributes to a perception of PAs' work as 'unskilled' and a lack of recognition of the real skill involved in it. On this, PA Joe said:

"I think it's generally seen as, well, anybody can do it and anybody could be another person in the presence of another person. But whether or not they're doing that effectively is a very different issue. I do think that we don't generally as a society recognise the significance of - even, I've noticed, PAs themselves don't notice the skills that they've acquired by being effective PAs. It's often seem as, you know, a transitory job, it's a fill-in job, because it's not valued generally."

Another PA, Phoebe, connected this to several of the other dimensions of labour-related security:

"it's seen as unskilled labour, so the skills that I've developed in terms of interpreting, dealing with needs, ad hoc wheelchair repair, nursing skills that I've picked up that I've been trained by the local nursing service, numerous other things that potentially could feed into something else, the truth is I don't have any qualifications, so however many years I've spent doing this... all those skills that I've developed over 7 years pretty much count for nothing if I want to go looking for work elsewhere. It feels like after all of these years, it should mean something and I should have had more security built up as a result of it, and I don't - if my boss became unwell, or if the funding gets cut by government, or if any number of things happen, I just don't have a job any more, and if I take it to someone else they won't understand it, and all the various things I've had to learn how to do doesn't mean anything to anyone."

Thus, as Shakespeare (2014, p.179) argues, PA work can constitute a "career cul-de-sac" because "after many years of working for one employer, a worker may not be able to demonstrate transferable skills". The impact of this on PAs is likely to be particularly acute when an employer dies, resulting in PAs, especially those who have had emotionally close relationships to their employers (as documented in Chapter 4), simultaneously experiencing

bereavement and redundancy (see for example Adler 1993). Here the lack of skill reproduction security exacerbates the potential consequences of employment insecurity, and makes job security significantly harder to achieve if not outright impossible.

Finally, PAs lack **representation security** because of the difficulty of collective organisation for workers who do not necessarily have colleagues (and if they do, they may not have the opportunity to meet or interact much with them) and whose 'workplaces' are individual private homes (and/or their employers' places of work, study, etc.), and who therefore are isolated from one another (Flynn 2005). This isolation was frequently mentioned by PAs as one of the worst aspects of the job, particularly in comparison to other jobs; for example Anita (one of the two participants who had both worked as a PA before acquiring a physical impairment and becoming a direct employer) said:

> "I think what I can remember of working as a PA, what was quite hard is that it's very isolating... you don't really have anyone else to talk to about your job, especially if you're just this one outsider in somebody else's family".

Katherine (who had worked part-time as a PA while in postgraduate study) connected this isolation to the affective intensity of the job, saying:

> "the thing about it is there's only two of you, you don't have a load of colleagues - I suppose in that way it's a bit more of an intense relationship than other jobs, really. You can absorb it in a team if there's one person you don't get on with, but in some ways it's quite an isolating job because you don't have a load of colleagues and I probably wouldn't want to do it full time."

As well as the isolation which is arguably inherent to working for an individual employer, some PAs reported being discouraged by their employers from interacting with their colleagues; for example, Daisy said that she "had a sense that my employer did not want her PAs to be in contact with each other" and

that while she "never really tried to get in touch with... the other people who were working as PAs for the same person", she "felt like there would definitely be a resistance to that from [her] employer". While Daisy could appreciate that her employer's reasons for this were valid and stemmed from the complex, bidirectional power relations between PAs (with non-disabled privilege and the ability to physically overpower their employer) and direct employers (with the power to hire and fire PAs), she also felt that this was a problematic restriction because "PAs, you know, are workers as well, and I think it's your right as a worker to organise with your colleagues, and to have contact with your colleagues". Glendinning (2000a, p.207) similarly reports that PAs "missed the support which would normally be available from colleagues and supervisors in less isolated workplaces" and were "inhibited in talking to other PAs by the need to retain confidentiality vis-à-vis their employer".

This issue was also mentioned from the opposite perspective by direct employers; for example, Stan said that in the past he had had problems with his PAs being "cliquey with each other" and "laughing about [him]" - thus undermining his position as employer - but "right now things are better because I have individual relationships with [PAs] and they... don't really associate with each other". Similarly, Slav referred to the "issue of more PAs together, how that tips the balance, of the group of PAs hanging out together, talking to each other, how that impacts on the individual", and said that when he started employing PAs directly he was advised by more experienced direct employers: "don't have all [your] PAs together, or... don't put your PAs in a position where they can actually start talking about you, and that you're not actually directing the conversation".

However, this was not the case for all direct employers; some supported the idea of some form of collective organisation for PAs, and felt it would benefit their own PAs. As Ruth said:

> "I think they should have more opportunities to get together as PAs,
> because at the moment none of my PAs see each other, because
> they all work different hours, you know, so I think it would be good if

they can have some kind of union, [it] could be good for them to have a united voice... I think it might not necessarily benefit me, but it would be good for the PAs themselves."

Similarly, Yahya supported his PAs being members of a union because:

"I don't know who they're supposed to go to if there's any complaints about me. And I think those kinds of things are important for them. I mean, it is a job, they are employees, so they should have protections of their own."

It has been suggested that traditional trade union models of organising - built on the assumptions that many workers can organise together against one or a few large-scale employer(s), and that employers have levels of control over pay and conditions of work that individual direct employers of PAs are unlikely to have - are not necessarily appropriate to the situation of directly employed PAs (Cranford 2005; Spandler 2004). Therefore, even when highly politicised in other ways (e.g. being active participants in or allies to the DPM), PAs did not necessarily feel that union membership would be useful for them. Of the interviewees who were still working as PAs at the time of interview, only one (Phoebe) was a member of a trade union. Katherine was aware of a forum for PAs run by the public sector union Unison, but had not joined it. This arguably reflects perceptions of the lack of relevance of traditional unions to precarious workers in general (Jørgensen 2015; Standing 2011). As Lorey (2015, p.9) argues:

"The precarious cannot be unified or represented, their interests are so disparate that classical forms of corporate organizing are not effective... In all their differences, the precarious tend to be isolated and individualized, because they do short-term jobs, get by from project to project, and often fall through collective social-security systems. There are no lobbies or forms of representation for the diverse precarious."

Historically, there have been conflicts between trade unions and the direct employment model of personal assistance (Cranford 2005; Kelly 2016; Spandler 2004). Cranford (2005) argues that the traditional model of labour unions "premised on the large, industrial workplace" is not designed for the needs of workers, such as PAs, who "labour in small workplaces, where it is difficult and expensive to secure strong collective agreements" (p.112); therefore a more suitable model of collective organisation for PAs may be a form of 'occupational unionism', focused not on the mass workplace but on membership of an occupational group. Cranford argues that this is more suitable for workers whose "occupational identity... includes concern with providing good services to clients/consumers and is not based solely on opposition to a single employer" (p.114). This is particularly true of PAs, many of whom feel a strong sense of loyalty or solidarity towards their employers (see below), and thus would not consider it appropriate to unionise 'against' them. This reflects the dilemma described by Federici (2008, no page number):

"How do you struggle over/against reproductive work? It is not the same as struggling in the traditional factory setting, against for instance the speed of an assembly line, because at the other end of your struggle there are people not things. Once we say that reproductive work is a terrain of struggle, we have to first immediately confront the question of how we struggle on this terrain without destroying the people you care for."

Despite these tensions, interviewees including both PAs and employers did talk about possibilities for collective organising of/by PAs, and in some cases of/by PAs and disabled employers together, with many feeling that this was one of the major things needed to improve personal assistance for all participants, potentially ameliorating some of the difficulties faced by both PAs and employers. Phoebe, for example, felt that a major problem with the current organisation of personal assistance was that:

"there's no sort of nexus of workers' communication for PAs, there's no place to go and meet other PAs to talk about the issues that come

up on the job, or to co-ordinate about what might be done to ameliorate or standardise things, or how to deal with common problems that come up, everything's worked out between you and your boss, who has some needs and very little control about a lot of aspects of your contract."

Personal assistance work as 'dirty' and/or 'servile'

Another sense in which personal assistance work can be considered 'poor work' is its negative cultural associations. It can be considered to be what Ashforth and Kreiner (1999) categorise as 'dirty work': work that is "likely to be perceived as disgusting or degrading" (p.413) because of "physical, social, or moral taint" (p.414) and thus stigmatised by the general public, though often regarded as a 'necessary evil'. While some of the occupations categorised by Ashforth and Kreiner as 'dirty work', such as dentists and funeral directors, have relatively high social prestige and can be categorised as 'professions' (see Chapter 5), 'dirty work' is generally regarded as of low status and unlikely to be highly paid (Simpson et al 2014; Twigg 2000), despite workers in 'dirty' occupations frequently esteeming their work as 'good' and socially necessary (Ashforth and Kreiner 1999). Within Disability Studies, the concept of 'dirty work' has largely been applied in connection with disabled workers being regarded, or regarding themselves, as 'dirty' or 'tainted' in a workplace context, and thus being given 'dirty' work to do (Fine 2018; Holmqvist 2009; Vickers 2014, 2015); however, it is also arguably applicable to those, such as PAs, whose work is otherwise connected with disabled people.

Personal assistance, like other forms of 'bodywork' (Twigg 2000), can be regarded as having 'physical taint' because many of the tasks involved (particularly assisting people with toileting and other aspects of personal hygiene, but potentially also tasks such as household cleaning, assistance with eating or assistance with health-related needs) can be seen as physically disgusting or distasteful, and/or "humiliating or degrading" (Rivas 2002, p.76). This perception was acknowledged by interviewees; for example one employer, Stan, said "I think a lot of people are just put off by the idea of the whole

toileting thing, you know, and they don't see the whole role of a personal assistant." Similarly, one PA, Malcolm, said:

> *"*People quite often say 'oh, I couldn't do that'. And people seem fascinated about whether there is personal care involved or not. And if there's personal care, that's often the point where people might screw up their face, or say 'I couldn't do that' or 'you're a braver man than I' or whatever. So I think the public perception is daunted by the work. And I think generally people think it's very poorly paid for what it is."

This reflects Ashforth and Kreiner's characterisation of 'dirty workers' as frequently attracting questions such as 'How can you do it?'. Ashforth and Kreiner argue that these responses occur because "although people may applaud certain dirty work as noble... they generally remain psychologically and behaviorally distanced from that work and those who do it, glad that it is someone else" (p.415).

Social taint, for Ashforth and Kreiner, "occurs where an occupation involves regular contact with people or groups that are themselves regarded as stigmatized... or where the worker appears to have a servile relationship to others" (p.415). The work of PAs can thus be regarded as 'socially tainted' on both counts, because PAs can be regarded as having a 'servile relationship' (Shakespeare 2018; Ungerson 1999) to disabled people, a group who are not only socially stigmatised, but arguably defined as a group by the social oppression of which stigma is a component (Abberley 1987; Hunt 1966; Thomas 1999). This connection was made by both PAs and direct employers; for example, Anita, when discussing the difficulty of recruiting PAs and how the situation could be improved, said:

> "People's perceptions of disabled people have to change as well, otherwise it's seen as a rubbish job because disabled people are seen as kind of rubbish people, rubbish human beings - and if disabled people were seen in much more of a diversity of what they

actually are and their lives were seen as valuable, then the people
that would apply [to work as PAs] would be people who wanted to
support people having valuable lives."

Joe similarly argued that the typically low pay of PAs "is an indication of the way
we devalue disabled people in our society", with this devaluation of disabled
people themselves being the root of the devaluation of work associated with
them, and consequently of those who do that work:

*"because it's associated with people who are in receipt of support,
that is in itself seen - somebody who requires support is often seen
as a 'less-than' person, so by definition, it's almost as if because I'm
working with a 'less-than' person, I am 'less-than' myself by
association."*

Hughes et al (2005) connect the physical and the social taint associated with
the work of 'taking care of' impaired or 'dependent' bodies, arguing that
associations with stigmatised bodily wastes and their management, result in
'invalidation' and marginalisation for both the givers and the recipients of such
work. This means that, while some forms of 'dirty work' are stereotypically
associated with masculinity (Simpson et al 2014), personal assistance, like
other forms of 'care work' involving the same physical tasks, has strong cultural
associations with the feminine (Kelly 2016; Ungerson 1999). This may be
somewhat less the case for directly employed PAs due to a greater number of
men being employed as PAs compared to other 'care work' jobs (Christensen &
Guldvik 2013; Cranford 2005); however, Woodin (2006) reports male PAs being
viewed as incompetent at gendered tasks like cleaning and their work being
mocked or demeaned by other men because of its 'feminine' associations.

These gendered aspects of personal assistance, while extensively discussed in
the literature (Bahner 2013; Christensen 2012; Cranford 2005; Hughes et al
2005; Guldvik et al 2014; Kelly 2016; Rivas 2002; Ungerson 1997, 1999;
Woodin 2006) were not talked about much by my interviewees, despite the
majority of them being women. Casas-Cortés (2014) refers to the "feminisation

of labour" - which she places within a context of increasing precarity - as the "growing presence of servile traits, historically assigned to women's tasks, among different contemporary sectors" (p.219). Thus, there is arguably a mutually reinforcing relationship between the 'servility' of PAs' work, or what Guldvik et al (2014) refer to as 'other-oriented flexibility', and its gendered associations. Rivas (2002) argues that women, particularly mothers, may be preferred as PAs because they are more likely to be familiar with the 'dirty' work of dealing with human bodily functions due to their experience of doing the same tasks for children as part of a "naturalised and essentialised" (p.76) gender role.

Shakespeare et al (2018) report PAs comparing their work to that of domestic servants in a traditional British upper-class household, and argue that popular cultural images of this household dynamic "may... influence public perceptions of personal assistance" (p.172). Similarly, Ungerson (1997, p.378) considered the development of direct employment of PAs to potentially constitute a "revival of a form of domestic service, with all the connotations of subservience and unequal work relationships that this implies". Perceptions varied among my interviewees, both PAs and direct employers, about this. Some PAs did feel that their role was similar to that of a traditional domestic servant; for example, Katherine said: "I always thought of myself a bit like Jeeves, you know, in Jeeves and Wooster, knowing when to keep out of the way and to just provide things as they were needed without being intrusive." Grenville used a similar metaphor from the employer's viewpoint: "I still think it's a bit sort of 18th century, you know, that you kind of employ somebody that, like, helps you get dressed and does stuff, but is also kind of a friend in a way" (see also the discussion of 'paid friendship' in Chapter 4). Interestingly, here it is the combination of employment and 'friendliness' that brings to mind the 'servant' metaphor, contrary to the assumption by Shakespeare et al that the use of this metaphor corresponds to a strongly 'distant' and employer-employee rather than friendly relationship.

Ada described the internal conflict that she felt about the similarity of PAs' role to that of servants:

"It was a real shock to me when I had [a PA] at a meal or somewhere and suddenly she was part of the conversation and I'm thinking, 'Hang on a second! Out of my face, lady! You know? This is not your place!' And then I'd feel sort of 'Well, hang on a minute, that's a bit Victorian isn't it?'... And that whole kind of guilt-trips thing - sorry, I'm waxing very lyrical here, but the whole kind of - how is it right for me as a decent human being to treat someone, and what expectations can I have of them, that does not make me into 'this is my slave or my servant' and 'I am the Lady Muck of the manor'? All that stuff is really really difficult to manage I think."

Ada also mentioned the experiences of her late sister, who was also an employer of PAs:

"I remember her being deeply, deeply upset one day because she and her PAs had some very clear ways of working with each other, and one of them was she never introduced her PA anywhere. And somebody once said to her, 'I thought the days of slavery were over'. And she just found that so deeply hurtful. I'm not surprised really! And she didn't know how to respond to it."

A similar conflict, also involving racialised as well as classed aspects of servitude, was described by direct employer Anne Wallis in Vasey's (2000, no page numbers) 'rough guide' to employing PAs:

"One woman, who remains a friend to this day, come to me very soon after leaving her home in Jamaica. Our only problems lay in how others perceived our relationship. On her first day working for me it happened that I was due to visit an old friend, also black and from the Caribbean. My friend found the situation almost intolerable… it reminded of when her family used to have servants. Although she tried to tell herself there was nothing I could have done

differently. It seems to me that it started a rot in this my oldest and
dearest relationship, which withered away within two years."

Despite these perceptions, PAs did not necessarily view their own work as
'servile'; Leece (2006), for example, found in a comparative study that directly
employed PAs were less likely to describe themselves as feeling like servants
than home care agency workers. Tom felt that, while some employers did treat
PAs like servants, there was a distinction, and that employers ought to respect
the boundaries of a PA's distinctive role:

"I don't believe as a PA, I'm not there as a manual labourer or a
slave. You're there just to support people, to live their life as fully as
possible. Not just as a cheap option because they don't want to get a
gardener in."

This recalls the distinction made between 'care' and 'services' by Bubeck
(1995), in which 'care' "meets needs which neither derive from the social
division of labour nor are satisfiable by the person in need, but which are
absolute in that they make those in need necessarily depend on others" (p.132);
in contrast, services could in principle be done by the person receiving them,
even if this is not immediately practical. However, this distinction breaks down
when considering that a disabled person who employs PAs for daily living tasks
is also likely to be unable to do gardening or other manual labour themself; thus
the real distinction being made here is between tasks which meet 'absolute'
needs in which a typical person would be expected to be self-sufficient (see
Chapter 2), and those which it would be normative for a non-disabled person to
buy as services. Similar distinctions were made by some employers in
discussing what they considered it was and was not 'reasonable' to ask a PA to
do; for example, Jane said:

"I wouldn't expect a PA to do something that I wouldn't do myself. If
the toilet was blocked up and there was sewage coming up and
things like that, I would not expect her to get down and dirty and try
to clear it. I would bring a plumber in. I've got things covered like that

because I wouldn't do that for me, if I could do that for me - do you
see what I'm trying to say?"

Tom's assertion of the boundaries of PA work is arguably an example of what Ashforth and Kreiner (1999) refer to as 'selective social comparison', in which workers in 'dirty' occupations compare their work to other occupations in such a way as to reframe their own work as better or more desirable. While this form of comparison may be motivated, as Ashforth and Kreiner suggest, by desires for self-esteem and 'in-group' identity, several PAs who had also done other work of comparable pay and status compared their work as a PA favourably to other jobs. Emily, for example, who had worked in pubs and shops before working as a PA, explicitly considered her work as a PA less 'servile' than the other jobs:

"you're expected to be servile, aren't you, in those sort of jobs, like
you're expected to be sort of below the people that you work for, you
can be told what to do, you're just there for a wage really... [but] I feel
like working as a PA, I wasn't servile, I wasn't below someone -
actually, at the time, I thought it was quite radical, and I thought that
was important."

PAs' work compared to other 'poor work': dirty and precarious, but meaningful?

PA work can thus be considered archetypal 'poor work' (Shildrick et al 2012) in some ways, but it also has notable differences from much other work in this category. Most of the PAs interviewed had done other paid work, most of which also broadly fell into categories that could be considered 'poor', precarious or low-status work, with examples including shop, bar, restaurant and warehouse work, as well as more traditional forms of 'care' work, such as working in residential homes, for care agencies or for LAs as domiciliary care 'bank staff'.

Generally speaking, interviewees felt that working as a PA compared favourably to other such jobs. For some this was because the work felt more 'meaningful' or socially useful than other work; for example, Emily emphatically considered it

"the best job I'd had" because she "felt like working as a PA was meaningful", in contrast to other jobs which felt like her only purpose for doing them was "so you've got some money at the end of the week". Similarly, Joanna stated the reason she enjoyed working as a PA as: "I can see why I'm doing it. I'm not just doing it for money, I'm doing it because I can see that this person needs me to do it", Malcolm said "I felt a sense of fulfilment in the support work job. I definitely felt that I was helping", and Charlie considered one of the best things about the job to be that it was "something that I thought was important and worth doing".

This is reflected by accounts in other literature; Christensen and Guldvik (2013), for example, report that 'care' work done by migrant workers in the UK and Norway, including directly employed PAs, "can be experienced as more meaningful... than other types of unqualified work (in a warehouse for example)", and therefore that "while it is formally unqualified work, it attracts also workers who have high qualifications" (p.19). Bailey and Madden (2015) claim that 'meaningfulness', while traditionally associated with higher-status occupations, can also be experienced in what might typically be considered 'dirty work', and "arises when an individual perceives an authentic connection between their work and a broader transcendent life purpose beyond the self" (p.4). For PAs like those quoted above, the social value of their work arguably provided this. For some others (including Daisy, Joe and Lisa), who had come to PA work through having disabled friends who were themselves direct employers or through involvement with the DPM or related causes such as inclusive education, the political principles underpinning the direct employment model of assistance provided an additional dimension of 'meaning' or 'purpose' to their work.

Having some degree of autonomous control over working time is identified by Bailey and Madden as an important component of what makes work 'meaningful'; they report refuse collectors finding their work meaningful, despite its 'dirtiness', when they were "able to control the pace and timing of their own work, free from managerial controls" (p.10). Perhaps surprisingly given the stated purpose of directly employed PAs being to give autonomy in everyday life

to their employers, and thus the assumption of some authors, such as Rivas (2002), that PAs' work is extremely lacking in autonomy, several PAs in this study reported a greater felt sense of autonomy in direct employment as PAs than in their other employment experience (including other 'care' jobs, such as working for residential/nursing homes or care agencies, as well as in commercial workplaces such as shops, bars or restaurants).

For some PAs their work felt so much more autonomous and/or less alienated than other work of comparable pay and social status that they considered it at times not to 'feel like work'. Charlie, for example, in contrast to their previous job for a 'home care' agency, valued "having a job where I got to kind of listen to my own music and also had a lot of off time to do my own work and stuff while I was there", but also said "I kind of felt like... a bit bad for being paid when I'm not doing any work". Emily likewise sometimes felt that it was "weird getting paid to do that" because it felt like "do[ing] the things you'd naturally do with a friend anyway". Similar perceptions by PAs of their work 'not feeling like work' have been reported in other research (e.g. Leece 2006; Kelly 2016).

When asked why she thought this was, Emily replied that she thought it was because "people [i.e. direct employers] are able to employ who they choose", and "that sort of set up of it makes it like less likely that people [Emily clarified that here she meant both parties, but was primarily thinking of PAs] will feel sort of in a more negative side of a power relationship". This feeling that direct employers having choice and control over who they employed (particularly compared to disabled people receiving assistance in less user-controlled ways) resulted in a better work experience for assistance workers was shared by PAs who had also worked in more traditional 'care' jobs, notably Charlie and Malcolm. Similarly, Dawn said of one of her PAs: "I think she likes the fact that she doesn't have a direct boss over her telling her what to do or what not to do - I mean obviously I'm the boss, but... I allow her initiative and responsibility".

Both this and the issues around collective organisation discussed above point towards one notable difference between PA work and most other precarious or 'low-status' work; the unusually near-equal power positions of employer and

worker. The shift from Fordist to post-Fordist employment paradigms has been viewed as a further disempowerment of workers which gives greater power to employers, conceived of archetypally as large-scale corporations (Neilson & Rossiter 2008; Standing 2011); however, in the case of personal assistance, it is often local authorities rather than direct employers who have control over the terms and conditions of PAs' employment, including wage levels (Leece 2006), and direct employers may even be worse off economically than the workers they employ. Thus the claim of Hughes et al (2005, p.263) that the direct employment model "reverses the balance of power between 'carer' and 'cared for'" is arguably too strong; it is perhaps more accurate to say that it equalises it.

Bahner (2013) argues that multiple, conflicting power relations exist in the personal assistance relationship, with the physical dependence of direct employers on PAs balanced by the financial dependence of PAs on employers and the gendered devaluation of their work. Similarly, Cranford and Miller (2013, p.789) draw attention to the "complex, intersecting power relations among personal care recipients and their workers" due to both direct employers (as disabled people) and PAs (as working-class, frequently immigrant and/or racialised, (typically) women) experiencing oppression and marginalisation in contemporary society. Thus, unlike most employment situations in which powerful employers seek to extract as much surplus value as possible out of the worker for their own profit, in personal assistance both employer and employee are both relatively powerless and arguably exploited by another, much more powerful entity (typically a local authority). This was recognised by PAs; for example, Phoebe said:

> "Obviously your relationship with an employer is always going to be a pretty transactional one, but the difference is... a lot of the other places I've worked are basically organised around a profit motive rather than around getting things done in the least painful way possible. My boss has incredibly limited power compared with most managers... my boss isn't even necessarily given that level of responsibility to be able to secure loyal staff with small pay rises or anything, or to deal with inflation or anything, absolutely nothing, so

in fact I've taken several effective pay cuts over the last 5 years... I think that it's not so much where the money's coming from as the way it's being managed by the purse holders - it ends up being a sort of disjointed 3-tier system, that my boss holds very little of the power with regard to the sort of northbound financial structure, and is subject to unilateral decisions on an annual basis."

Similarly, Daisy said:

"In some jobs you would think, I'm working for an employer, they're trying to make a profit, they're running their factory or their business or whatever, and yeah, they might give me a pay increase, but at the end of the day they're trying to make money out of me, whereas as a PA, you know that your employer... effectively their hands are tied to some extent, they're not trying to make money out of you - they are sort of giving you what they can pay wise, and conditions wise, so in a way it's not them that's setting any bad conditions... In a way, you're sort of a team, like both of you want better pay and conditions for PAs - you feel like you're on the same side, against this sort of bureaucracy."

It is also arguable that some of the conditions of PAs' work which might be characterised as defining it as 'poor work' may actually be considered to be advantages by some PAs. Standing (2011, p.59) categorises the membership of the 'precariat' as consisting of "'grinners', who welcome precariat jobs, and 'groaners', obliged to take them in the absence of alternatives". Standing's category of 'grinners' includes students, retired people and those with partners whose earnings they can rely on, all of whom are likely to welcome casual or 'insecure' work as an additional option rather than a necessity. Many of my PA interviewees arguably fit into this category; several had worked part-time as PAs for added income while studying for postgraduate qualifications, while others, such as Tom, consciously saw their PA work as a 'stepping stone' towards a career in professions such as social work, giving them skills and experience that they saw as advantageous for getting future jobs in those fields. These PAs

were motivated by what Christensen (2010, p.248) called a "pragmatic strategy... to do something meaningful while preparing for another (and in this case higher) position in the labour market". Those of them who were migrants were arguably among the more privileged, being largely white and from EU countries, and often in the UK on student visas.

However, several PAs - including some of those who also fit into the aforementioned categories - themselves had impairments or other marginalised identities (such as gender identity) that meant they experienced significant barriers to finding and keeping other work. Particularly where attitudinal barriers were involved, these PAs may have particularly appreciated the relative informality and the one-to-one relationship of PA and direct employer, and the solidarities created by these aspects (see below). Shakespeare (2014, p.179) reports a direct employer saying:

> "There are people who come into the work, maybe care or personal assistance, it's like a refuge, because maybe they've had difficulty of getting work elsewhere, they could be anti-authority, don't operate well in social organizations."

PAs may also welcome the relative informality and flexibility of working for an individual, compared to more mainstream working environments (Adams & Godwin 2008; Shakespeare 2014; Ungerson 1999). The lack of requirement for qualifications or prior experience may also be positively appreciated by marginalised workers who may have missed opportunities to gain such credentials.

There is a particular contrast here with other 'care work' jobs, for example in residential institutions or for 'home care' agencies, which can also be categorised as precarious, 'poor' and/or 'dirty' work (Shildrick et al 2012; Twigg 2000). Wilton (2006) provides a case study of a woman with a visual impairment experiencing attitudinal barriers leading to the loss of her job in a home care agency, where a supervisor prevented her from using assistive technology at work because "it might worry [clients] about her capacity to provide care"

(p.144). Shildrick et al (2012) describe a similar experience of a home care worker damaging her back in an accident at work and receiving unsympathetic treatment from the agency over going on sick leave and subsequently experiencing pain affecting her ability to travel between house calls. Shuey and Jovic (2013) also report disabled workers being in general less likely to receive needed accommodations in precarious or 'non-standard' work. This strongly contrasts with the experiences of the disabled people directly employed as PAs in this study, whose employers did all they could to accommodate their needs until, as in Emily's and Charlie's cases, their impairments eventually made them unable to do the core tasks of the job.

All the PAs who had also worked in residential homes or for care agencies (Agatha, Anita, Charlie, Emily and Malcolm) considered working as a directly employed PA to be subjectively better than their other 'care' jobs, which they generally described as stressful, poorly managed and denying autonomy to both clients and workers, often using terms such as 'bureaucratic' and 'regimented'. Charlie, for example, said:

> "I felt very controlled and managed, and like there was a very big power dynamic between me and my bosses, like not the people that I did the care for, but the managers at the agency, and they were pretty horrible... [working as a directly employed PA] was very different, and it was a lot better."

This is corroborated by the quantitative findings of Leece (2006, 2010) that directly employed PAs reported lower stress levels and higher job satisfaction than home care agency workers, despite often receiving lower pay. Flynn (2005) also describes 'kidnapping' by direct employers of 'home carers' employed by local authorities with whom they had had good working relationships when they received assistance from them before getting direct payments. This was enthusiastically accepted by the 'carers' turned PAs due to the possibility of working shorter hours in better conditions. Thus, while directly employed PA work does have many of the characteristics of 'poor work', these are shared by non-directly-employed work in the social care sector, which

however lacks the advantages of direct employment both for direct employers themselves and for many PAs.

Shared precarity and solidarity between direct employers and PAs

As seen above, the devaluation of PAs' work is connected to the devaluation of disabled people themselves, and the precarity and insecurity of PAs' work has shared causes and a reciprocal relationship with the precarity and insecurity of disabled people's everyday lives. Therefore, the self-interests of PAs and direct employers, while not always identical, are certainly not wholly opposed to one another. This is not to say that the interests of PAs and employers are always identical; as in any asymmetrical relationship, there are instances of interests being opposed to one another (one example of this being the preference for many if not most direct employers to recruit PAs without training or experience, while many PAs would prefer there to be formal training and qualifications in personal assistance). Similarly, as Ungerson (1999) argues, the shared 'vulnerability' of PAs and employers may create a potential for abuse and exploitation on both sides, and indeed both PAs and employers in this study reported inappropriately controlling and verbally abusive behaviour from employers and PAs respectively. However, these conflicts may be mitigated by recognition of shared interests, for example in increased availability of funding for personal assistance and in greater recognition of PAs and their work in wider society.

Due to the funding insecurity mentioned above (and further discussed in Chapter 7), and sometimes to regulations imposed by funding providers, such as on which household tasks a person can get funding for a PA to do (Woodin 2006), not only PAs but also direct employers frequently lack meaningful control over many aspects of PAs' working conditions, often including rates of pay and shift patterns (Leece 2010). Spandler (2004, p.199) thus argues that it is "not necessarily the attitudes of recipients [of direct payments] that contribute to poor employment conditions, but rather the limitations of the context in which they are forced to operate." The risk of losing funding for personal assistance due to austerity policies represents serious, even life-threatening, risks to health and/or

the threat of being institutionalised for direct employers, while simultaneously threatening PAs with redundancy and unemployment. Conversely, other risks affecting PAs as precarious workers in a neoliberal austerity economy have a knock-on effect on disabled people.

An example of this is changes in immigration policy which put many PAs at risk of losing their right to work in the UK. Hudson (2017) draws attention to the potential impact on the adult social care workforce of the recently introduced "requirement that all skilled workers from outside the EU who have been living in the country for less than ten years will need to earn at least £35,000 pa to settle permanently" (p.28). PAs who are citizens of other EU countries (a category which included at least 3 of those interviewed in this study) will also potentially be put at risk of losing their right to work in the UK by Britain's impending exit from the EU. Disabled activists have argued that 'Brexit' could threaten direct employers left without a sufficient supply of potential PAs with loss of choice and control over daily living tasks or even a return to residential institutions (Lawson & Sayce 2017; Pepper 2017). This could potentially include several of the direct employers I interviewed, who relied largely on (EU and/or non-EU) migrants as PAs and tended to get few native British applicants for advertised vacancies.

McRuer (2018) connects the anti-immigration attitudes inherent in 'Brexit' to the ideological interconnection of disability and racialisation, suggesting coalitions of solidarity between disabled and racialised people as populations jointly devalued by an 'austerity capitalism' which is simultaneously racist and disablist. This was echoed in the connection made by Emma, a PA who had moved to the UK from another European country, between the low status, and consequent low funding, of PA work both with the fact that "disabled people are seen as those who consume the most resources of the government" and with the perception of PA work as largely done by immigrant women:

> "there are so many people here from other countries who work as
> PAs because they need to survive... it's like OK, I'm legally
> employed, but there are so many people who are employed as PAs

but they work illegally, so it is again a question of, you know, PAs are perceived as 'oh, these eastern European women', assisting British disabled people."

Precarity is thus not only a condition of work for PAs but a condition of everyday life that is mutually experienced by both PAs and direct employers; the experiences of disabled people and PAs reflect the arguments of many authors (e.g. Casas-Cortés 2014; Jørgensen 2015; Lorey 2015; Neilson & Rossiter 2005, 2008; Precarias a la Deriva 2004) that precarity is "a structural condition... [that] characterizes not only employment conditions but the social system as such" (Jørgensen 2015, p.960) and "extends beyond the world of work to encompass other aspects of intersubjective life, including housing, debt, and the ability to build affective social relations" (Neilson & Rossiter 2005, no page no). Casas-Cortés (2014, p.209) argues that precarity can be considered to be

> "a series of transformations related to issues of social citizenship,
> including the dismantling of welfare protections such as health
> insurance, the reforming of pensions, and the increasing privatization
> of the public sector."

This connects precarity to the politics of austerity and 'neoliberal-ableism' (Bates et al 2017; McRuer 2018), in which cuts to benefits and services for disabled people are justified in public discourse by individualistic conceptions of 'personal responsibility' and assumptions that working for a wage is the only meaningful way to contribute to society (Dodd 2016; Taylor 2004), discounting the economic contributions made by direct employers as employers (Prideaux et al 2009). Bates et al (2017) argue that disabled people are disproportionately affected by precarity, as they are by austerity politics, and that precarity "is felt just as acutely at the relational level as it is the economic" (p.172). Therefore, precarity is a condition shared by both PAs and direct employers, and the precarious work of PAs is intimately connected to the 'precarious life' (Casas-Cortés 2014) of disabled people (and even more so when PAs are, as discussed above, disabled or otherwise marginalised people themselves).

Other conditions that PAs found unpleasant or undesirable were similarly also experienced by direct employers; for example, the isolation of PAs as workers discussed above was paralleled by the isolation of many employers, especially those living in rural areas, from others. Jane, for example, said:

"I don't know an awful lot of people in same position as me with direct payments. I don't think [county] is very good with PAs. I know one other gentleman and I never really discussed it with him, and you know, so I don't know what his PA was like."

Joanna, from her perspective as a PA, explicitly regarded this as a shared problem:

"A big problem in this job is that it does become quite isolated for the employer, who doesn't have necessarily have any contact with anyone else who employs people in this way, and equally for the assistants, there isn't any contact."

While in some areas disabled people's organisations such as CILs facilitate contact between direct employers, this is by no means universal, and disabled people in general are disproportionately likely to experience social isolation because of exclusion from work, inaccessible physical and social environments, and attitudinal barriers including prejudice from others and negative self-image due to psycho-emotional disablement (Shakespeare 2014; Thomas 1999).

Aspects of personal assistance that are perceived as 'dirty' or degrading by PAs may also be similarly perceived by employers; for example, both the 'givers' and 'receivers' of help with bodily functions which it is normative for adults to manage for themselves may find it distressing or humiliating (Begum 1990; Rivas 2002). These shared experiences, and the unusual structural position of both direct employer and employee being financially dependent on a more powerful 'paymaster' (Cranford 2005), mean that in the direct employment paradigm of personal assistance there are possibilities for solidarity between

employers and workers that arguably have no obvious parallel in other sectors of the labour market.

Solidarity was a prominent theme in many interviews, going in both directions between PAs and direct employers, with both parties often being willing to make personal sacrifices for one another that would not typically be expected of employers or employees. For example, as discussed above, Charlie and Emily both described their employers' willingness to accommodate their own illness/impairment-related limitations, beyond what might have been considered 'reasonable accommodation' by most employers, and Elizabeth described how when she moved to a new LA area:

> "they really messed up in the transition and I had no money for 6 months... there were weeks when my PAs didn't get paid, and they stayed, and they worked for free until they got back paid. I think that is complete loyalty, despite the fact they're not getting paid for what they're doing, they're still there and still happyish, and they're not angry at me but angry at the council for what's happening, and I think that's really important that they know that I was always doing everything that I could to pay them and it was like half of what they should be getting. I'd give my salary up just to pay them."

This loyalty was sometimes enabled by the formation of close emotional relationships between PAs and employers (as discussed in Chapter 4), another key difference between personal assistance and most other forms of work of comparable conditions and status.

Improving the occupational status of personal assistance work

As has been discussed, the factors contributing to the devaluation of PAs' work are multiple and complex, and involve both material conditions (low pay and many aspects of precarity) and cultural perceptions (of both disabled people themselves and of the types of work that PAs do). These arguably correspond to the two dimensions of social justice as theorised by Fraser (1995),

redistribution and recognition, which she identifies as the remedies for 'economic injustice' and 'cultural injustice' respectively. Dodd (2016) argues that the oppression experienced by disabled people in contemporary 'austerity Britain' is, in Fraser's terms, bivalent, with dimensions of both economic 'maldistribution' and cultural 'misrecognition'. Following Anita's argument that PAs' work is perceived as "rubbish work" because of the perception of disabled people as "rubbish people" (itself an example of misrecognition), the factors contributing to the low occupational status of PAs can similarly be categorised as reflecting this bivalency. Thus the devaluation of PAs' work as 'dirty' and 'servile' constitutes misrecognition, while the low pay and precarious working conditions constitute maldistribution.

This suggests that to improve the occupational status of PAs a bivalent strategy is needed (Shakespeare 2014), including both economic change so that disabled people get enough financial support to pay PAs good wages, as well as other forms of material support (such as assistance with recruitment or payroll and other administrative services), and cultural change so that the work done by PAs is seen as valuable and respected, so that it can be seen as a viable career path. This latter requires public promotion of the role of PAs and the underlying principles of 'independent living', so that their enabling of disabled people's autonomy in daily life is understood as distinct from traditional 'care' roles and seen as an ethically laudable practice. Both these needs were recognised by interviewees; for example, on recognition Agatha said:

> "If people were more aware of the idea of independent living, I think they would be more aware of the role of the PA... they would understand why a personal assistant is necessary and what it is that we do. So this way I think more people could become interested in doing this job."

On redistribution (and also recognising its relationship to recognition), Joe said:

> "I would have the pay per hour available to the disabled person... three, four times the hourly pay there is now, because it's such a

hugely significant role and one that should be very significantly recognised. I'm not saying remuneration is the only way, of course not, but I think that is usually important, and… it does give some indication of the value that we ascribe to the disabled people."

The campaign strategies of redistribution and recognition are likely to be mutually reinforcing, as occupational groups that are highly respected tend to be perceived as deserving higher rates of pay, and better funding of personal assistance provision is likely to result in working as a PA being more attractive to applicants and more likely to be viewed as a 'good job'. Some suggestions by participants for concrete improvements to the status of PA work are covered in Chapters 7 and 8.

Conclusions

Subjective experiences of personal assistance are varied and complex on the part of both PAs and direct employers. While personal assistance work is typically low-paid and precarious, and tends to be culturally unrecognised and/or 'misrecognised' as 'dirty' and undesirable, it is also regarded by many PAs as more 'meaningful', interesting and socially or ethically valuable than many other jobs of comparable pay or status. The tasks typically done by PAs are strongly gendered as feminine and culturally associated with subservience, but the greater autonomy within the workplace subjectively experienced by some PAs and the accessibility of directly employed PA work to marginalised workers, including those with minority gender identities, may subvert these categorisations.

Both PAs and direct employers are devalued and subjected to precarity by social structures which neither group has real control over; however, this shared risk also creates opportunities for empathy and solidarity, particularly where PA and employer are able to recognise themselves as both oppressed by the same structural forces, and may therefore be an "opportunity to invent new and appropriate forms of political agency on the basis of precarious living and working conditions" (Lorey 2015, p.9). A joint campaign by direct employers and

PAs for better funding and support for personal assistance, addressing both cultural and economic dimensions of justice (Dodd 2016; Fraser 1995), could serve the purpose both of opposing the capitalist and patriarchal myth of the independent individual (see Chapter 2), which devalues both disabled people and the feminised 'dependency work' associated with them, and of challenging the material conditions of austerity by valuing alternative forms of socio-economic contribution (Prideaux et al 2009).

Guldvik et al (2014) argue that "solidarity... might serve as a principal framework for an organizational structure that will offer a sustainable balance between user control and assistant co-determination" (p.49); they conclude that solidarity could be encouraged in the PA/employer relationship by a third party acting as a "moderator and facilitator between the possible conflicting interests of the user and the assistant" (p.59). This hints towards the potential of support structures for both employers and PAs, such as those historically provided by Centres for Independent Living and other Disabled People's Organisations in the UK (Barnes & Mercer, 2006; Priestley, 1999) and those provided by personal assistance co-operatives in countries such as Sweden and Norway (Roulstone & Hwang, 2013); these possibilities will be more thoroughly considered in Chapter 8.

The solidarities that at least sometimes exist between PAs and their employers have the potential to extend beyond the sphere of 'labour' as traditionally conceived and into the (re)productive terrain of 'precarious life' (Casas-Cortés 2014), and thus to challenge the neoliberal-ableist (Bates et al 2017; McRuer 2018) logic of austerity and precarity from previously unexplored directions. PAs and direct employers could potentially be at the forefront of a broad solidaristic coalition of, as Precarias a la Deriva (2006, p.43) put it:

> 'those who join forces in order to demand that they be cared for as quadriplegics and not as 'poor things' to be pitied, as people without economic resources and not as stupid people, as immigrants without papers and not as potential delinquents, as autonomous persons and not as institutionalized dependents.'

There is therefore a need for more research on solidarity, as well as potential conflicts of interest (and how to resolve them) between PAs and direct employers; it may be productive for this research to involve 'matched pairs' of employers and PAs so that the perspectives of both parties in the relationship can be more directly explored in relation to the same situations.

Chapter 7

Personal assistance in practice: barriers to the implementation of independent living

The previous chapters have looked at the direct employment model of personal assistance, as experienced by direct employers and PAs, in terms of personal and social relationships (Chapter 4) and of the status and conditions of PAs as workers (Chapters 5 and 6). This chapter returns to the standpoint of direct employers to examine their experiences of barriers to the effective functioning of this model, analysis of which will suggest ways that it could be enabled to function better. Following on from this, the next chapter will discuss possible alternatives to the direct employment model. Most of the quotes from interviewees used in this chapter are taken from discussions that resulted from asking them the question "what would you like to change about the way personal assistance works?" (for more on the relationship between interview questions and research objectives, see Chapter 3).

Barriers to personal assistance working 'how it should'

While this question was asked with the intent of eliciting thoughts from interviewees about how personal assistance could be organised in ways other than the direct employment model, most of them, at least initially, answered in very pragmatic terms, talking primarily about barriers to the direct employment model of personal assistance 'working' effectively for them, whether as direct employer or as PA. One significant exception to this was one employer, Anne, who was extremely insistent that individual disabled people should not be made to be the direct employer (in the legal and financial sense of the term) of PAs, and that this role should instead be taken by local authorities:

> "I don't think I should be an employer at all, because that is a huge legal responsibility, and I know nothing about the law. I've always thought it was a disaster waiting to happen, the fact that we are legally responsible for this, because I don't know anybody who has

carers who knows the first thing about employment law... I'm perfectly capable and perfectly happy to pay time sheets, I just don't see why I should be responsible as the employer - [local LA] are funding it, [local LA] should be the responsible employer."

Despite this, Anne did not want major changes to the interpersonal relationship between disabled people and PAs (though, as seen in Chapter 4, her approach to her own PAs was much more one of 'paid friendship' (Woodin 2006) than of formal employer-employee relations), and the rest of the changes she suggested were similarly pragmatic and barrier-focused to those suggested by most other direct employers. This highlighted the difficulty, at an experiential level, of distinguishing between barriers to the existing paradigm working 'as it is supposed to' and problems that may be more deeply inherent in that paradigm itself. In general, it took me more specifically suggesting different scenarios (e.g. if direct payments did not exist) for interviewees to consider any possibilities substantially different to the direct employment model. However, some of the suggestions made by some interviewees, including both PAs and employers, for ways to remove barriers to the effective functioning of the current system of personal assistance contained within them the potential for changes of much wider scope.

The barriers identified by participants to personal assistance working 'how it should', according to their conceptions of an optimally functioning personal assistance system, fell into three main categories: insufficient funding, a lack of administrative support for many aspects of organising personal assistance, and negative or obstructive attitudes on the part of LAs or other funders. Of these, perhaps unsurprisingly, insufficient funding was the most frequently mentioned.

Funding as barrier

For many direct employers, funding was the first thing they mentioned when asked what they would like to change. Several employers specifically talked about the closure of the Independent Living Fund (ILF), which was pending in England at the time of the interviews, as a particular worry with regard to

maintaining the level of funding they were then getting for personal assistance. The ILF was established in 1988 as a replacement for additional benefit payments for social care that were abolished by the 1986 Social Security Act, initially with the expectation that it would only provide payments for a relatively small number of disabled people (Morris 1993; Porter & Shakespeare 2016). It was funded by national government, but administered as a semi-independent charity rather than as part of the state benefit system, for which it was criticised by some disabled activists (Pearson et al 2005). While its eligibility criteria were tightened several times in its history, its uptake by disabled people still far exceeded expectations, and it was appreciated by many recipients for having a much more flexible and supportive administrative culture than LA social services departments (Gradwell 2015; Porter & Shakespeare 2016).

The ILF was closed to new applicants in 2010, and then closed down totally in 2015, with the rationale that it was no longer necessary due to personalisation of local authority services (Porter & Shakespeare 2016). Responsibility for funding the personal assistance needs of those who had received it was transferred to LAs in England and to the devolved administrations in Scotland, Northern Ireland and Wales (Jones et al 2017). The government promised that funding equal to that previously provided by the ILF would be 'ring-fenced' within local authority budgets for meeting the assistance needs of the same people, but the delivery of this has been doubtful given that LAs themselves were and still are being forced to make deep cuts in social care expenditure themselves (Gradwell 2015; Porter & Shakespeare 2016).

Most employers, including those who were ILF recipients, already considered the funding they were getting to be less than would be ideal to meet their needs and to give their PAs the level of pay and working conditions that they felt they deserved; thus an imminent potential loss of funding was a major worry. For example, when Ede was asked about what constraints she felt there were on her autonomy (in a fairly abstract context of defining what terms like 'autonomy' and 'independence' meant to her), she replied:

"well, it's constrained at the moment because I don't know what's going to happen with my ILF funding, that's quite a big constraint, quite a big worry actually... you know, most non-disabled people don't have to go through the anxiety of being 'oh, will I be able to fund my social life...' that we have to go through".

For Jane, the psychological impact of the struggle to keep threatened funding was considerable, despite the fact that she eventually managed to get a promise from her LA to maintain her funding at the same level:

"Well, with the Care Act coming in and the Independent Living Fund being transferred over to the local authorities, I was reassessed and told that my care would be cut by two-thirds, and it ended up in a formal complaint. It went on for six months, but all my complaints were upheld and they're not reducing it by one second. But that has caused me an awful lot of stress, anxiety, panic attacks, because all I could see was my life being taken away. The whole idea, I think, of employing a PA, is to lead an independent life, have some wellbeing and the life you choose - and that's all I'm trying to do. And give back to the community all the time, you know. I work a lot with the hospitals and the councils, I'm just writing a comment on a planning application now, and I could see that being taken away from me."

Similarly Slav, despite at the time of interviewing having a funding package that he said met all his assistance needs, said he had

"the additional strain of always being concerned about what will happen going forward. So for example [the] ILF closure's now happened, at my local level. There's no mention of what will happen in a year's time."

Similar concerns were reported by Porter and Shakespeare (2016), who report former ILF recipients, interviewed around the same time, being left without any clear information about the transfer process, and fearing that in transferring

from the ILF to LA-funded assistance they would lose PA hours; some even thought that they could end up forced into institutional care because of LAs' likely unwillingness to fund the same level of support that they had previously got from the ILF.

The closure of the ILF was only one part of a much broader programme of cuts to benefits and public services implemented by the Conservative and Conservative-led coalition governments which have held power in the UK since 2010. This political economy of austerity, justified by claims of financial necessity (Runswick-Cole & Goodley 2015), has had a disproportionate impact on disabled people, and even more particularly on those disabled people whose impairments are severe enough for them to need assistance with daily living tasks (Dodd 2016; Duffy 2013). Thus many if not most direct employers of PAs will have suffered a cumulative impact from many other cuts to benefits and services that they are likely to have depended on, including the transfer from Disability Living Allowance (the care component of which was used by many disabled people to partially fund personal assistance) to the significantly less generous Personal Independence Payment, decreases in the level and increases in conditionality of 'income-replacement' benefits for people considered unable to work, and restriction of housing benefits by the so-called 'bedroom tax' (Cross 2013; Dodd 2016).

In the specific area of personal assistance, besides the closure of the ILF, disabled people have been severely affected by cuts to local government funding, which have been passed on to service users. Local authorities have been, alongside welfare benefits, one of the two primary areas targeted for budget cuts by national government since 2010 (Duffy 2013); this has been argued to be part of a systematic re-centralisation of political power in the UK accompanying the privatisation of public services (Crewe 2016; Duffy 2012). Adult social care, including direct payments for personal assistance, is one of the largest areas of spending in local authority budgets (Duffy 2013; Hudson 2017), but funding for LAs from central government has been cut by almost half between 2010/11 and 2017/18 (Thorlby et al 2018). This has led to a worsening 'social care crisis' with growing proportions of disabled people not getting basic

needs met and increasing reliance on informal carers (Care and Support Alliance 2018), which is only likely to be exacerbated by the growing financial crisis of UK local government in general (Graby & Homayoun 2019).

Some disabled people's access to personal assistance is also likely to have been impacted by cuts to Access to Work (for those in paid employment) and to Disabled Students' Allowances (for those in higher education), as both of these may be used to employ PAs within the workplace or educational setting (Dunn 2016; Hale 2017). For some people with particularly extensive personal assistance needs, including for tasks that could be considered health-related (for discussion of the blurred boundaries between 'health' and 'social care' tasks, see Glendinning et al (2000b)), 'continuing healthcare' funding from NHS 'clinical commissioning groups' (CCGs) has been available as a direct payment since 2014 (NHS England 2014). However, this too has recently come under threat due to the imposition of funding caps, putting some people at risk of reinstitutionalisation (Perry 2017; Ryan 2018a), and as with local authorities, funding levels can vary widely between CCG areas (Pring 2018a).

Funding was thus a serious worry for both direct employers and PAs, regardless of the specific source(s) of their funding. Several employers reported difficulty in maintaining wage levels for PAs due to cuts in funding; for example, Yahya said:

> "there was one time when each year I was able to increase my PAs' wages by, I don't know, 3% or something. I think it was a pretty good time financially to be able to do that. But now with all the cuts I think I've had to freeze their pay for the last, I don't know how many years. And it just doesn't seem fair when they do a good job, not to be able to reward your PA with something of an increase in their salary or something like that."

Jack, who had acquired additional impairments due to illness a few years previously, said:

"I'm the only person that I actually know in person that hasn't been losing money recently in their care package, and the only reason that I'm not losing money in my care package is because year on year my needs are increasing - so a gradual increase year on year is enough to keep you stable if it's enough of an increase... I'm considered to have sort of more complex needs now, so I'm in a higher need bracket than I was... but, like I say, that's only good enough to just about keep me the same - it's not good."

Several authors have argued that for personal assistance relationships to be functional, funding needs to be sufficient not only to pay for PAs' wages but for other expenses that are generally considered constitutive of good working conditions, including travel expenses, sick pay, holiday pay, etc. (Flynn 2005; Glasby & Littlechild 2016; Glendinning et al 2000a). Both employers and PAs reported that they or their employers did not get sufficient funding to cover these additional expenses, sometimes leading to difficult choices and tensions between employers and PAs. Jack, for example, said:

"We had to choose between losing loads of working hours or losing all of our staff's sick pay for 2 weeks, and I don't feel like we should be having to make those choices... that didn't help my pride at all, sort of having to sit down with my staff and say OK, these are the choices - either both of you lose some hours, or you lose your sick pay, which is 2 weeks per year, and that was the choice my staff had to make, and by losing their sick pay they managed to keep the same hours."

From the PA's perspective, Daisy described how, when her employer was required to go on business trips, neither the company the employer worked for nor Access to Work would pay travel expenses for the PAs that she needed to take with her, and so when Daisy and other PAs had to stay over in hotels they were not paid any more than their normal wages. Daisy found this "frustrating", but she resisted feeling angry towards her employer for it:

"I couldn't feel bad to my employer for doing that because it wasn't her problem... I don't want to say no to her, but I don't want to work for free, I don't want to come and stay over somewhere where I don't want to be, for nothing, just because you can't get any more funding for it."

These poor and precarious working conditions make the job of PA less attractive to potential applicants and send the social message that PAs' work is not highly valued (for more detailed coverage of these issues see Chapter 6). Recruitment and retention of PAs can therefore be very difficult for direct employers who have to manage with insufficient levels of funding, as PAs are likely to leave for other, better-paid jobs (Adams & Godwin 2008; Flynn 2005; Vasey 2000). Several employers had concerns about this; for example, Slav said:

"How do I keep morale going, when actually, there's been no increase in wage since 2007? ... and I think local authorities would say, well, those kind of issues are not our priority, but that has a knock-on effect on recruitment as much as retention."

Katherine expressed similar concerns as a PA:

"There does need to be enough money to pay enough PAs and to pay them well enough that they don't keep leaving for other, better-paid jobs. I think it's important to have consistent PAs once you've got a good one, that they're not running off to get an extra 50p an hour somewhere else."

Low funding not only makes PA work poorly paid, but can also worsen the conditions and increase the physical demands of the job; this has further impacts on recruitment and retention. Dawn, an employer with particularly intensive physical support needs (including daily physiotherapy), reported several times having hired PAs who then left the job after only a few weeks because they found the work, particularly overnight shifts, too exhausting; on

some occasions this left her having to rely on unpaid help from family members to fill in the gaps when a PA left because it was unfeasible to ask her other PAs to take on so many shifts. Dawn experienced the same problem documented by Glendinning et al (2000b) of being at a disadvantage compared to other direct employers with 'less severe' impairments who could afford to advertise higher rates of pay for shorter hours and less physically intensive work.

While employing more PAs for fewer hours each could have been a solution, this was complicated by difficulties with recruitment (potentially a vicious circle) and the additional time and effort involved in training and managing a larger number of PAs. Malcolm reported similar problems from a PA's perspective, when asked what would have made his job as a PA easier:

> "Shorter hours would have been far better for both of us. By the end of a shift I was absolutely exhausted, he was probably sick of the sight of me and any PA that had been on with him for 24/48 hours... I think the reason why it was long hours could again be attributed to the economic system. It's not feasible to have people travelling and changing over every 4 or 5 hours or something. People don't want to work for 4 hours, 4 hours is not enough money. So as much as I would sometimes resent the longevity of the shift, I was well aware that from my perspective it was better to groan and do 24 hours than to be travelling for 4-hour shifts... Whether shorter shifts are possible when people need money and have time constraints, because often people are working as PAs for numbers of people, so to manage your working week if you're supporting 3 different people, it's not practical to split it into 4 hour blocks."

While decisions made by individual employers obviously play some role in this, they are clearly decisions made within constrained circumstances, and higher and more reliable funding would enable employers to make less constrained decisions, with likely results of improved quality of life for both employers and PAs, and PAs being enabled to do their jobs more effectively. At least three of my interviewees had been forced to stop working as PAs because they had

either acquired or experienced a worsening of existing physical or mental health conditions. Two of these, Anita and Charlie, eventually needed to employ PAs themselves due to the impairments resulting from this. Several other PAs also had impairments or long-term health conditions; while these did not necessarily impact directly on their work, they did sometimes result in a need for time off work. The issue of sick pay was therefore a particular concern. Emily, for example, said that her employer

> "was lucky in that... whilst I was working for her she didn't have any of her payments cut or anything, so the only thing that was a problem was when I went off sick, and having to get sick pay, and she was worried that was going to come out of her money, like to pay her PAs, and that she'd be short of PA money... it didn't in the end, we sorted it out, and she did manage to pay me sick pay."

This issue was frequently an ethical dilemma for employers (see Jack as quoted above), who were sometimes put in financial difficulty when a PA went off sick. Charlie, who had also experienced the same issues from the PA's side, said:

> "I don't want to be an employer that doesn't give out sick pay, but at the same time I can't really afford to, which is a bit shit... and I do try and give out sick pay, but if someone calls in sick and then I get cover, then I don't have enough money to pay them and the person who I've got in for cover, but if for whatever reason I don't manage to find cover then I'll pay the original person the sick pay, or if someone in my house offers to pick up the shift for free then I'll pay them sick pay, and... I get my mum to keep hold of some money for me so that I can dip into it to pay people's holiday pay, so I don't need to remember not to spend that money".

This example also demonstrates how insufficient funding for PAs creates unpaid work for those in informal relationships with PA users, such as family members or housemates, at least when they have such relational resources to draw on (Charlie considered themself lucky to be living in a mutually supportive

communal household, without which their need for paid personal assistance would likely have been much greater). As argued in more detail in Chapter 4, an important part of the purpose of personal assistance was to relieve the burden of 'caring' from unpaid family members, thus liberating them as well as disabled people (Adams & Godwin 2008; Keith 1992; Morris 1993); therefore the consequences of insufficient funding go beyond direct employers themselves.

Other administrative and attitudinal barriers

In addition to insufficient funding, barriers mentioned by interviewees included administrative and bureaucratic procedures (such as applications and assessments for direct payments) that are unnecessarily complicated, difficulties with recruitment, lack of support with the responsibilities of employing PAs (such as tax, insurance and payroll), lack of information about what support was available, and obstructive, paternalistic or otherwise unhelpful attitudes from LAs (or other assistance providers such as Access to Work). Many of these have also been documented in other research on personal assistance in the UK (e.g. Adams & Godwin 2008; Flynn 2005). These issues are of course connected to funding, at least insomuch as higher levels of funding would allow disabled people to pay for support services that could help with many of these issues (which some direct employers did, using either part of their funding for personal assistance or their own private money).

Several employers mentioned income tax as a particularly difficult administrative aspect of employing PAs directly; for example, Ada said:

> "I'm just thinking about the practicalities of employing and taxing and all that sort of stuff. Actually that's a challenge I think... Actually I'd quite like to be able to pay them off the books. But I can't do that so it's a bit of a struggle, that kind of thing, and I don't agree with the black market of employment."

Ada went on to discuss having to use one-off 'emergency PAs' (often former PAs who had moved on to other jobs but were still contactable) in situations

such as regular PAs being unexpectedly off sick, and how it would be helpful to have an easier way to pay them outside the tax system, but she did not actually know whether such a (legal) option existed:

> "One of the things as a PA user is that it is quite complicated and you do have a lot of admin work to do. So I don't have the luxury of going off and finding out if there is a way to do that. You know, should I need to do that, would I be able to? Because I'm not sure where I'd find it out."

By many standards Ada would be considered an unusually privileged and highly-informed personal assistance user, having a high level of education and considerable economic privilege compared to many disabled people with a similar level of assistance needs; therefore it is safe to assume that information that is not easily accessible for her would not be accessible to the vast majority of disabled people who employ PAs.

Similarly, Carol said she thought it would be "really good to be able to pay people cash in hand now and again", and was frustrated that her LA social services department would not allow her to treat her PAs as self-employed (something that some of her PAs, who worked part-time for her but also did other work on a self-employed basis, would also have preferred to be possible) because "when a PA's off sick, it sort of prevents me from doing exactly what I want when I want, you know". The question of whether PAs can be self-employed seems to be one without a clear answer, and one on which policies vary between LAs, as Elizabeth said that both her current PAs were self-employed and her LA had no problem with it. However, it can be argued that self-employment of PAs is fundamentally incompatible with the principle of direct employers having choice and control over how, when and by whom their assistance needs are met (Hasler 2003), as, for example, a self-employed PA could theoretically send another person to do their work rather than doing it themself (Podro 2013).

Anita (who, like Carol, employed PAs with a combination of Access to Work funding and direct payments from her LA for 'at home' needs), said that she finds the bureaucratic requirements of Access to Work particularly difficult to deal with:

> "The whole payment thing is really complicated. I'm the authorised manager, I'd have to authorise the shifts, but I have to do it through this kind of online system, and I have to check it with somebody, who has to check it with somebody else, who has to check it with someone else, who has to check it with someone else, and sometimes it'll take like a month before [I get] the answer to some kind of very simple administrative thing, and in my profession they just don't have much of a clue as to how to support a disabled person, or even understand what her [the PA's] role is and how she can be incorporated into it".

Other employers highlighted obstructive attitudes within LAs as causing them particular difficulties, both at the level of getting funding to employ PAs in the first place and with the administration of funding packages. Charlie, for example, gave up on trying to get funding from their LA after a bad experience of assessment not long after starting to need regular assistance:

> "I'd inherited some money, so I decided that I would start employing a PA out of my own funds, and then I decided to have a care assessment to see if I could get funding for a PA, but my care assessment didn't go very well, and it was quite upsetting, and I kind of gave up on it. Then I went back into hospital again for another few months, and after I came out I managed to get awarded high rate DLA, which was enough money for me to employ my own PA out of that money, so I started to do that."

Some employers reported needing to argue for or "justify" their need for PA to LAs or other funding bodies; for example, Anita described her repeated struggles with Access to Work:

"At first, with work, I had to argue quite strongly that I needed somebody at work, and I'm sure I'll probably have to argue again, cause it's not something that you kind of do once and then you're free, because... every time you're newly employed, or you need more hours or less hours, you have to make those arguments."

The need to repeatedly argue with funding bodies after every change in circumstances was also mentioned by several other employers who were either not themselves in employment or who used PAs only at home, in particular by those whose impairment-related needs had increased over time due to progressive conditions. However, even an employer such as Grenville, whose impairment was acquired in an accident and whose assistance needs are unlikely to change, nonetheless feared reassessment by his LA, saying when asked what he would like to change about the organisation of personal assistance:

"it would be nice if you didn't have to kind of jump through hoops... it always feels like that's kind of hanging over my head, that someone's going to come away and come along and decide my needs have changed, or they can take away this money... and when they do come they come with a big clipboard and they're in charge and they're in control... because they hold the purse strings they hold that kind of power over you".

Jane described her LA trying to force her to accept a pre-payment card for paying her PAs, rather than a separate bank account, which she resisted by doing research to prove to the council that they could not legally impose pre-payment cards on Direct Payments recipients without a consultation. This practice has been criticised in a report by the Independent Living Strategy Group, both as costly to LAs (which costs are likely to be passed on to service users), and as potentially restricting choice and control and introducing unprecedented monitoring of personal data by LAs which "potentially represents

a gross invasion of privacy for disabled people" (Independent Living Strategy Group 2017, p.15).

Jane's statement that "Social Services for some reason think they can dictate to you, I don't know why, but they don't consult very well" was typical of how many employers felt about interactions with LAs. Arbitrary limitations placed by LAs on what direct payments could be used for or which tasks people would be funded for PAs to do (for example cleaning, childcare or other 'housework' being excluded from a budget because it is not counted as 'personal care') are widely documented (Barnes 2007a; Leadbeater et al 2008; Pearson 2000), as are boundary disputes between health and social care (Glendinning et al 2000b). Provision of direct payments, while an advance in choice and control over previous systems, has been argued to remain within a 'top-down' institutional culture in which professionals rather than disabled people get to define which 'needs' are considered valid (Pearson et al 2005; Scourfield 2005); thus Leadbeater et al (2008, p.31) argue that "the original aims of direct payments have been frustrated" by excessive regulation.

Attitudes could differ considerably between one LA and another, even in adjoining areas. Yahya, for example, described himself as "very fortunate" that his LA

> "pay[s] a fee to an accountant that looks after all that funding, Access to Work and [LA] and ILF funding, and they do all the wages, pay, taxes, National Insurance, that kind of thing... they also pay any cheques when it comes to insurance and stuff like that."

However, he also described how in a previous situation where that support was not provided by a different LA, "it was a nightmare, the paperwork was ridiculous".

Because of this 'postcode lottery', moving from one local authority area to another could be severely problematic for people reliant on personal assistance for day-to-day needs. Emily recalled a conversation with her former employer in

which she [the employer] talked about wanting to move to a neighbouring area, but not doing so out of fear of having her direct payments "cut massively", due to that LA's reputation for being less generous with funding packages. Elizabeth described how, when she moved to her current LA area, "they really messed up in the transition and I had no money for 6 months", requiring her to rely on savings and financial support from her family to pay her PAs until the problem was sorted out and the pay backdated (as discussed in Chapter 6, Elizabeth only avoided this becoming a major crisis because of the loyalty of her PAs who were willing to work while waiting for pay in arrears). This problem results in disabled people with personal assistance needs being effectively the freedom to move wherever they want within the UK, a right usually taken for granted by non-disabled people, and therefore fundamentally compromises the independent living principle that disabled people should have "the same choice, control and freedom as any other citizen - at home, at work, and as members of the community" (Zarb 2003, no page number).

Lack of support with employment issues

Several employers felt that it was difficult or impossible to get appropriate levels of support with employing PAs from their local authorities; for example, Dawn said (echoing the words of Leadbeater et al (2008, p.31) about difficulties with direct payments):

> "What I've often felt over the years is that I'm on my own, and it seems to be a choice between no one else helping me with anything, or... having it all done by an agency. I don't like that decision, all or nothing."

For Slav, a lack of recognition on the part of local authorities about the realities of being dependent on assistance with daily living tasks contributed to a lack of administrative support that had a knock-on effect of discouraging disabled people from trying to get direct payments, meaning that only the most determined or knowledgeable managed to do so:

"I don't think local authorities understand the pressures of being an employer... issues around pensions, issues around when PAs go off long term, those kinds of issues are never really addressed or incorporated into the induction of having PAs. I've worked it out myself because I've gone through the process for so long and been involved with, and talked to many PA users. But other people don't, and I think that's just another notch on the gate of saying, you shouldn't... you don't want to participate in using a PA model."

A lack of support for employers can also become a problem for PAs; as Joanna said:

"when someone is a private employer, it's a bit difficult to know who to go to with problems... there isn't really anywhere to go as far as I'm aware, to mediate or... if you have a dispute with your manager [in other jobs] you go to a higher manager, but everything has to be resolved between us."

This exacerbates the isolation experienced by directly employed PAs (described in Chapter 6). Joanna was experiencing difficulties in her current job (at the time of interview) because her employer had impairment-related difficulties with numeracy and organisation and was not getting sufficient support from his LA, resulting in problems such as delayed wages:

"[the LA] are not actually very good at organising the things that need to be organised. That seems a bit odd to me, that someone is put to do that sort of thing when clearly, they're not really capable of doing it. I don't know if there could be... help that he could get with it that he's not getting, or hasn't realised he could get, but that has been a problem."

Difficulties with recruitment were mentioned by the majority of the employers I interviewed as a barrier. Several employers had resorted, at least on some occasions, to using private agencies for recruitment; however, agencies

themselves are not necessarily a reliable means to recruit PAs, particularly in emergency situations (see for example Haines 2016). Several factors were mentioned as potentially contributing to these difficulties, including a lack of people interested in working as PAs, the unattractiveness of the job due to low pay and poor working conditions (as discussed above and in Chapter 6), or lack of understanding of the role and/or inappropriate attitudes on the part of those who did respond to adverts (see also Adams & Godwin 2008; Flynn 2005; Vasey 2000). Employers such as Elizabeth felt that this was something that LAs could and should assist people with:

> "I think the recruiting is really difficult and I think there should be more help available with that, just because... the demand for jobs is so incredibly high that you will get people that apply from every walk of life that really aren't suitable for the job, and I think that is kind of a lack of education about what the role is, and I think if it was more out there the right type of person would apply, not people that are completely unsuitable. Really I think that's quite an important point that there should be more help if you want it - which I don't ever get, there's never an offer of, 'oh, would you like me to help with your CVs?'. I've always been left to hire myself, interview myself. They [the LA] don't even ask the names of people I'm employing any more."

As well as a lack of support from LAs, this difficulty points to the general lack of recognition of both the overall concept and the skilled nature of PAs' work (for more detail on which, see Chapters 5 and 6). Several employers reported getting responses to their recruitment adverts for a 'personal assistant' from people who clearly assumed it was a secretarial role in an office environment. Some, including Anne and Stan, had therefore taken to using the term 'carer' instead (including in my interviews with them) because they felt that it was more easily understood by the general public. This arguably betrays a failure on the part of the DPM to change attitudes towards disabled people and their assistance needs by changing terminology with the hope that perceptions would change with it (Kelly 2016; Morris 1993).

The persistence of perceptions of disabled people as inherently 'dependent' or non-autonomous and in need of 'care' has contributed to paternalistic and risk-averse attitudes in LAs (Glasby & Littlechild 2016; Spandler 2004). However, in recent years the dominant negative public perception of disabled people has increasingly shifted towards one of 'scroungers' or non-contributing burdens on the economy (Briant et al 2013; Garthwaite 2011). Dodd (2016) connects this to the political economics of austerity, arguing that negative cultural representations and economic marginalisation of disabled people reinforce one another. These stereotypical characterisations of disabled people were recognised by interviewees as influential on the devaluation or non-recognition of personal assistance (see quotes from Anita and Joe in Chapter 6). They were also explicitly connected to cuts in funding and increases in restrictive bureaucracy on the part of LAs, particularly with regard to assessment of assistance needs; thus, Yahya said:

"you just have to fight for your hours every time you have an assessment. Everyone is doing that across the country because of all the cuts going on... you feel like in every assessment you have, like you're doing something wrong, like you're taking hours, or you're taking money away from the public pot, but I think that kind of attitude needs to change. That you're asking for this to support you, to live your life, to get on with work and with everything you're contributing to society for."

Similarly Elizabeth, when asked why she thought that personal assistance funding was not a political priority, replied:

"I think we're not always seen as contributing to society, so we're an easy target - but what they seem to miss is that we actually are working. The funding for PAs is allowing us to work and contribute and volunteer, and they just kind of skip over that completely, don't they? I think it's really worrying that they want us hidden back away at institutions... it's like hide them away, put them on the back burner,

don't let them come out in public, just because they're not doing anything that's valuable."

This focus on 'contribution to society' could be regarded as evidence of internalised ableism on the part of direct employers like Yahya and Elizabeth, in the form of the belief that 'productivity' is or should be a measure of a person's moral value (see e.g. Taylor 2004; Withers 2012 for deconstruction of this discourse). However, another way to view it is that, while dominant narratives may characterise the need for personal assistance as one of the ways in which disabled people constitute a drain on social resources, it is in fact personal assistance that allows disabled people to 'contribute' both in a narrow economic sense and in a wider, more holistic sense (Barnes & Mercer 2005; Zarb 2003). Both Yahya and Elizabeth worked full-time, but would have been completely unable to do so without adequate PA support and control over the hours PAs worked for them.

The employment provided by disabled people to PAs can also be seen as an additional form of contribution to the economy (Barnes & Mercer 2005; Beresford & Harrison 2017; Prideaux et al 2009). Slav made the point that PAs as well as direct employers would be affected by cuts to direct payments:

"A reduction in my support package not only means that my needs aren't met and I can't continue as a member of my community, but equally, it actually means that I then have to face redundancies. My staff, who, this could be their main job, then it's going to have a knock-on effect on their families as well."

Thus, perhaps ironically, providing funding to disabled people for self-directed personal assistance is likely to be a 'gain' and withholding it a 'loss' to society even from a capitalist economic perspective.

All of these barriers to accessing and effectively using personal assistance are connected to wider attitudes towards disabled people in an institutionally disablist society, in which the adoption of policies that have benefited disabled

people, such as direct payments, has never been solely motivated by disabled people's own interests, but has always also been influenced by market forces (Pearson 2000; Scourfield 2005; Spandler 2004). In many cases it is thus difficult to disentangle barriers that prevent the direct employment model of personal assistance from working how it 'should' (according to the original vision of the disabled people who campaigned for it, in the UK and elsewhere), from problems that may be inherent in the model itself. For instance, while some degree of conflict between the interests of PAs as workers and those of disabled people as employers may be inevitable (see for example Rivas 2002; Spandler 2004), this may well be exacerbated by a scarcity of resources which renders relations between PAs and employers more adversarial than they could be otherwise. Thus Thomas (2007, p.114) argues that an "obvious solution to the impasse" between the interests of direct employers and PAs as (primarily women) workers would be for both groups to jointly campaign for higher levels of direct payments. Prideaux et al (2009, p.563) similarly argue that direct employers are the wrong targets of criticism of the direct employment model as exploitative of PAs, and a more appropriate target would be "the policies of those who determine and control the levels of funding available to individual service users, which, in turn, determines the wage levels of PAs".

Participants' suggestions: administrative changes

The answers that many interviewees gave to my questions about how the organisation of personal assistance could be changed or improved arguably often referred more to barriers to the effective functioning of the direct employment model than to a need or desire to fundamentally alter the model itself. Arguably many of the employers and PAs had never truly experienced the PA/employer relationship as envisaged by the pioneers of independent living, due to factors such as insufficient funding and/or 'bureau-paternalist' (Scourfield 2005) restrictions, and thus could not provide the experience-based critiques of it that I had been hoping to obtain from them. However, some employers who regarded the direct employment model as positive were able to make a distinction between the core idea and its imperfect implementation. For

example, when asked what could be changed to improve "how personal assistance works", Elizabeth said:

> "Ideally I wouldn't change that much. I think the basic premise of it actually works quite well, if it works well, if that makes sense. I think generally it does work well, minus the funding... the actual independent living lifestyle does work if you get it done correctly."

For some employers, the current situation of funding cuts was so dominant that it was hard for them to think of possible changes beyond this immediate threat; for example, Jane said:

> "I wouldn't change anything for PAs. I'd just stop them cutting the funding like they're doing and cutting the Independent Living Fund. I think that is one of the most abhorrent things that this government's done."

However, Jane did also connect this to non-disabled privilege and consequent lack of awareness on the part of local authority staff, saying that she would like to "make social workers sit in a wheelchair for six months and see how they liked it before they start coming out and dictating to us what we need and what we don't need." Similarly, Stan said:

> "I like things the way they are - I don't really like change, you know, the Conservative government are creating loads of change, I don't like it, it makes me nervous... I think I'd keep everything, although there are things about security, because I'm not secure about the future, about future funding... but I'm sort of campaigning to try and keep things the way they are."

For direct employers such as Jane and Stan, while the present organisation of personal assistance might be imperfect, it was seen as so essential to daily life that defending it against an existential threat took precedence over thinking of

ways to change it for the better, and the scope of potential improvement was limited to making the current system more financially secure.

Perhaps unsurprisingly in this light, higher pay for PAs was the most common concrete suggestion, given by 6 each of PAs and employers (the latter including both of the employers who had worked as PAs before acquiring their own impairments). The other suggestions were varied, with some overlap between PAs' and employers' suggestions, but significant differences. There are many possible ways that these suggestions could be broken down into categories, but two factors that stand out from the data are whether the changes would be primarily material (e.g. provision of funding or specific services) or cultural and attitudinal (e.g. wider social recognition of PAs' role), and whose agency would be required to make the changes possible. However, in both cases these categories are not necessarily perfectly separable due to the interconnection of cultural and economic structures (Dodd 2016) and of local and national levels of governance.

Fernández et al (2007, p.103) divide barriers to the implementation of direct payments into 'management problems', which are "characterised by technical implementation difficulties", and 'political economy issues', in which "the distribution of power between actors and institutions is centre stage". Glasby and Littlechild (2016, p.129) argue that these categories of barriers require different levels of intervention to solve them, the former being arguably solvable at a local authority level, but the latter needing "national and more fundamental change" to overcome. While the issue of payment levels would superficially seem to be under the control (primarily, particularly since the closure of the ILF) of local authorities, the crisis of local government funding is primarily due to cuts in funding by national government (Crewe 2016; Thorlby et al 2018), and therefore any significant increase in payment levels would require new national investment.

In part because of this, Slav fundamentally opposed the idea of "local authorities taking responsibility for people's direct payments, which just creates problems of mobility", arguing that a national system of provision was the only

way to ensure that disabled people with personal assistance needs could have the freedom to move wherever they wanted within the UK:

"I didn't want the closure of the ILF, for a number of different reasons, but one of them was because it was national as well. I've always thought that social care... should be removed from local authority budgets, and should be ring-fenced and placed within a national framework. And that's the only way you can have a little bit more reassurance and have a better mechanism where you can have your needs met wherever you are, and actually get on with living your life."

Authors from the UK DPM, including Barnes (2007a) and Beresford and Harrison (2017), have similarly called for the responsibility for personal assistance funding to be taken out of the hands of LAs, and for the creation of a new centralised funding body, similar to the ILF, but unlike it providing direct payments as of right to all disabled people with personal assistance needs, rather than to a minority limited by the amount of money in a fund. This "universal national independent living service" (Beresford & Harrison 2017, no page number) would also fund and support local DPOs to provide direct payment support services (on which see below; see also Graby & Homayoun 2019).

The same relationship between local and national levels of control is applicable to suggestions such as specific entitlements to sick pay and holiday pay (made by employer Jack and PAs Daisy and Joe) and the suggestion made by employers Ada and Carol that employment laws should be changed to allow individual disabled employers to pay PAs in cash or outside the income tax system in particular circumstances (for more on this, see Chapter 8).

Another specific suggestion, made by Anita, was that "PAs should be paid more than carers" - here meaning paid workers employed in care agencies or residential homes, rather than unpaid informal carers - because "[PAs] need to use more of their emotional and intellectual energy in the work than they would [in] a residential home". This for Anita was connected to a broader project of

raising the profile and social status of the role of PAs (see also Chapter 6) and making directly employed PA jobs more attractive to applicants in comparison to institutional 'care' jobs, which she argued are currently able to attract more applicants because agencies and residential homes are able both to pay higher wages and to advertise jobs more widely and with more 'professional-looking' adverts than individual direct employers. In contrast to this suggestion, many LAs currently pay higher hourly rates to care agencies than they do to direct payments users who employ their own PAs (Glasby & Littlechild 2016).

The culture of how personal assistance (and 'social care' in more general) is administered was also an area of concern for participants, particularly direct employers. Employers including Grenville, Slav and Yahya regarded the culture of assessment for social care needs as something that needed to be changed, particularly the assumption of scarcity of resources and attitudes of distrust towards disabled people's self-reported needs, which turn assessment into a process of 'rationing' (Beresford 2016) and create an adversarial relationship between 'service users' seeking to maximise support received and 'service providers' seeking to minimise expenditure (Pearson 2000).

Anne more specifically called for involvement of disabled people in the assessment process, suggesting that the best way to achieve a "fair and respectful" assessment of personal assistance needs would be to "ask the disabled lobby to come together collectively to design it". This recalls the demand in the early years of campaigning for direct payments for self-assessment of assistance needs by disabled people, supported by DPOs (Barnes & Mercer 2006; Morris 1993; Priestley 1999). Peer-supported self-assessment was established in some LA areas where DPOs were strong in the 1990s (Priestley 1999) and to some degree was used by the ILF (Gradwell 2015); it was also partially adopted in test sites for the 'In Control' model of self-directed support used in Scotland, though fully adopting it was seen as potentially conflicting with the legal duty of LAs to make assessment decisions (Pearson et al 2014). However, as Beresford (2016) argues, there is still scope for "self-definition of needs" (p.308) within this legal requirement.

Anne also argued that more consideration of differences between disabled people was needed, both in terms of impairments and access needs and of other life circumstances:

"the needs of a disabled person like me who lives alone is not the same as a disabled person who's living in a family community, with other family members around, as well as maybe a PA that comes in for various reasons... there's a vast variation between somebody who is disabled as in born disabled, or for example somebody who's broken their back and has suddenly become wheelchair bound, as opposed to somebody like myself who's got a nasty illness that has made them disabled over time, and I would suggest the needs of the carers, PAs, whatever you want to call them, it will depend on the needs of the person they are caring for"

Related to this, some interviewees talked about the possibility of extending personal assistance to a wider range of disabled people; for example, Emily said:

"there could be greater access to it [personal assistance] for people who have mental health conditions as well... for example being able to have someone come and spend the night with you, if you find nights difficult - I definitely know that would help a family member of mine, if they were able to get that sort of thing."

However, people with different impairment-related needs could require PAs with different skills, due to different types of support needs requiring different roles and relationships (see for example Gramlich et al (2002) and Williams et al (2009a, 2010) on the needs and preferences of direct employers with learning difficulties; this is discussed in greater depth in Chapter 4). Emily felt that for employers whose assistance needs related to mental health:

"[the PA] would need to be somebody who was sort of aware of stuff surrounding mental health specifically, like you couldn't just throw

someone who'd been doing PA work like I was into doing that sort of PA work, cause it's really different... I think it does exist, I think some people do get direct payments and get people to support them, but I don't think it's very widely known about, or widely used."

While people with learning difficulties and/or mental health needs are eligible for direct payments in the UK (unlike in some other countries, for example Canada, where they are specifically excluded (Kelly 2016)), there is reportedly lower take-up of direct payments among eligible people in these groups than for people with physical impairments (Glasby & Littlechild 2016; Ridley 2006; Williams & Holman 2006). This may in part be because of the historical, and arguably continuing, dominance of people with physical impairments in the movements and organisations that campaigned for the establishment of the direct employment model of personal assistance (Hall 2009; Kelly 2016); however, it may also be because of stereotypical attitudes on the part of local authorities, particularly around 'ability to manage' direct payments, leading to exclusion on a local level (Glasby & Littlechild 2016; Hall 2009; Williams & Holman 2006).

Due to their impairment effects directly impacting on organisational capacity, a lack of support with administrative tasks may be a particularly onerous barrier for members of these groups; as Jack said:

"If you're somebody with learning difficulties there's no support, as far as I know there's no decent support structure to help you manage your own package even if you do get one, and the acquisition of a care package depends on you understanding the responsibility and making promises about that, and it's one of the ways they make it really hard for the people with learning difficulties to get [a] care package."

People with learning difficulties may have been particularly harshly affected by the closure of the ILF, as they made up a high proportion of its recipients compared to those getting direct payments from LAs; this may have been

because the ILF had a more supportive culture and less bureaucratic assessment procedures than most LAs (Gradwell 2015; Porter & Shakespeare 2016). Therefore direct payment support services are particularly crucial for ensuring equity of access to personal assistance services for this impairment group (Gramlich et al 2002; Hall 2009; Williams & Holman 2006; Williams et al 2014).

Participants' suggestions: organisational support

Suggestions for ways in which practical support could be provided on a local level to direct employers and/or PAs were also made by many participants. While some of these suggestions could be regarded as more for the benefit of PAs and others more for the benefit of direct employers, this did not necessarily correlate with whether employers or PAs suggested them. Many of these ideas could be put into practice by local-scale organisations, such as CILs or other DPOs, if they were sufficiently funded to do so. One such idea was the 'buddy' or mentor system suggested by Slav, in which:

> "somebody who's new into the system of having a direct payment or having self-directed support in whatever way that is, and is going to manifest into employing a PA, can... be supported by someone who's been in the system for a longer time"

to understand the roles of PA and employer and to manage their personal assistance in a way that works for them. While this would require the more experienced employer to have appropriate skills, Slav viewed this inclusively, saying "I think anybody who has a personal assistant has got something to say about it and it can help other people's view, at least be informed." This idea, for Slav, followed naturally from the collective self-help principles of the DPM:

> "I think there's a responsibility of employers, in the sense of those who are interested in disability rights and disability campaigning... to be almost like ambassadors of the personal assistance model. And I think that we need to have that opportunity."

Charlie, Jack and Ede all suggested that practical support with administration of tax, payroll and other technical aspects of being an employer would both make employing PAs easier for those already doing so and give access to user-controlled personal assistance to many more disabled people. Slav and Elizabeth also felt that assistance with recruitment of PAs (including both advertising of vacancies and assistance with things like writing application forms and interviewing applicants) could be provided by local organisations. All of these were also found by Adams and Godwin (2008) to be among the services that direct employers would like to see provided by LAs.

Ada and Yahya both suggested a formalised PA pool system as something that might help both with recruitment of long-term PAs and with emergency situations when, for example, a PA is off sick or fails to turn up for a shift. For Yahya, the one major disadvantage of employing PAs directly (which he generally regarded as far superior to using an agency) was that

> "when they're going to go on holiday or sick leave or whatever, then you're left stranded. Then I have to rely on my wife much more to take care of even me coming to work and stuff if I really have to during that time. So some kind of pool of people, like a pool of local PAs, who are looking for other work and could fill in those gaps would be a great resource to have. Right now I don't know of that in [home city]."

Likewise, Ada said that she "would really appreciate someone somewhere setting up a proper PA pool system". For her this "would need to be countrywide - there'd need to be one in [home town] and one in [other nearby town] and one in..." - requiring coordination between local 'pools' in case of eventualities like a need for emergency PA cover developing while travelling.

Assistance with relational aspects of management, including mediation of conflicts, was mentioned as a need by both PAs and direct employers. Joanna felt that conflicts she had had with employers she had worked for could have

been resolved if she had had "other people to talk to and check things with", because with no one outside the dyadic relationship of employer and PA to talk to about frustrations, "you don't really know if you're being unreasonable or if it's something real". Joanna felt that her current employer found it "embarrassing to talk about how we are together and to have to sort of look at that relationship and what might be going wrong"; at the time of interview Joanna dealt with this by talking to a disabled friend who employed PAs, but she felt that a formal provision was needed for those not lucky enough to have such an existing relationship.

Similarly, Elizabeth felt that "having somewhere the PA can go if they do have a problem they don't feel they can discuss with you personally" was essential for effective resolution of conflicts that might arise between employers and PAs. These participants' views are echoed by the argument by Guldvik et al (2014) that it would enable solidarity between direct employers and PAs, and thereby improve PAs' working conditions and make the employment relationships between them more sustainable, if a "third party (the other two being the assistants and the user as manager) could be a moderator and facilitator between the possible conflicting interests of the user and the assistant" (p.59).

Ada, who had managed staff in other contexts, nonetheless felt that managing PAs was different enough for her to want assistance with aspects such as appraisal:

"I've run teams, I've employed people, I've done appraisals... but doing an appraisal with your PAs, I just don't understand the concept, I can't get my head round it. But it might be quite useful to have somebody who did sit down with [a PA with whom Ada had just described some relational difficulties] and find out if there was something that actually I'm doing that really pisses her off that I could happily stop doing or change... I think to have that conversation with her myself would be difficult, I think she'd find it difficult and I'd find it difficult. I think to have a third party available who could do that kind of thing with me and her, for instance, and then... facilitate the

subsequent discussion, would actually be quite handy... I'd have to
trust them but I'd happily do that once a year."

Flynn (2005) also argues that a lack of external appraisal or "supervision or
discussion regarding their personal development" (p.41) is a problem for PAs
which may impact on recruitment and retention.

All of these suggested services - mentoring of new direct employers,
administrative support, assistance with recruitment, a PA cover pool, and
mediation between PAs and employers - have been provided by CILs or other
DPOs in various places and times (see for example Barnes & Mercer 2006;
Bennett & Stockton 2012; Gramlich et al 2002; Hasler & Marshall 2013;
Luckhurst 2006; Morris 1993; Priestley 1999). Indeed, such organisations may
be better placed than LAs to offer these forms of support; Williams et al (2014,
p.1199) argue that assistance with support planning for people receiving direct
payments is better provided by 'user-led organisations' than by LAs because of
"conflicts of interest which will come into play if the person who has to control
the resources is the same person expected to 'empower' and inform those who
use services". Bennett and Stockton (2012) also found that disabled people
were more likely to successfully access direct payments when supported by
ULOs than by LAs. However, Gramlich et al (2002) report some DPOs
considering it wrong to give 'too much' support, perhaps because of bias
towards the needs and preference of people with physical rather than cognitive
impairments.

Some of these types of support may mitigate the issues which led Anne (at the
start of this chapter) to feel that disabled people should not themselves be the
legal employers of their PAs; however, they do not necessarily address (what
Anne saw as) the core issue, as no matter what external support direct
employers may have access to, as long as they are legally classed as
employers they have legal liabilities which they may not wish to have. One of
her reasons for this was that she considered it unfair and dangerous for
individuals in the case of unethical behaviour by PAs:

"What are you going to do if the day dawns when you're employing a carer who turns out to be abusive or who turns out to steal from you, or any other of all sorts of potential horrendous terrible things that might happen - who are you supposed to turn to for help if you are legally responsible as the employer? I guarantee you that if I contact [my LA], they'd say 'it's nothing to do with me because you're the employer'."

This issue has been raised by other direct employers; for example, Vogelmann (2016, no page number) describes her experience of threats and emotional abuse from a PA with a work-related grievance, which she was told by her employment insurance company was not covered by current UK law. Vogelmann therefore argues:

"The councils cannot simply make someone an employer, save lots of money and then wash their hands of any responsibility. There needs to be a restructure to the budgets to provide adequate support for the disabled employer who relies on personal and life dependent care... I accept we have responsibilities as employers and we can't ignore them, but we need more support and recognition in the eyes of the law."

Vogelmann, like Anne, argues that direct employers are not, and should not be treated legally as, in the same power position relative to PAs as corporate employers are to their employees:

"How can we be held to the same employment standards as John Lewis [a large department store] when we neither have their resources such as a HR department nor do we have any of the workplace remedies? When you work 1 on 1 with your carer, there isn't the option to transfer them to another department or have them work with someone else who they get along with."

Thus, there is a need to consider alternative models in which disabled

individuals who employ PAs do not have the same legal status as corporate employers. These possibilities will be dealt with in the next chapter.

Conclusions

The direct employment model of personal assistance is highly valued by disabled people who use it, and those interviewed in this study largely did not want to change it fundamentally, with the one potential exception being Anne, who did not want to be the legally recognised 'employer' of her PAs. However, nor was it regarded as perfectly functional, and interviewees were keen to talk about its flaws and difficulties. Many of these are not necessarily inherent in the direct employment model itself, but instead can be attributed to insufficient funding and/or unhelpful bureaucratic cultures that prevent the model from functioning as it was designed to. Thus an argument can be made that many criticisms that have been made of the direct employment model, particularly those focusing on the exploitation, low pay and poor working conditions of PAs (e.g. Guldvik et al 2014; Rivas 2002; see also Chapter 6) are in fact critiques of the imperfect implementation of the model rather than of the model itself.

Some of the problems in implementation may, however, derive from the conflicting 'social justice' and 'market' discourses within the direct employment model (Pearson 2000; Spandler 2004); as Barnes (2007a, p.349) argues, "the concept of independent living... appeals directly to advocates of the politics of the right and of the left". Where the appeal to authorities of providing direct payments rather than traditional 'care' services to disabled people is because of cost-efficiency rather than emancipatory principles, it is likely that levels of funding provided will not be sufficient to achieve true community inclusion, and that support services necessary for disabled people to effectively use their assistance funding will not be prioritised. It can therefore be argued that campaign arguments for direct payments which focused on cost-efficiency (e.g. Zarb & Nadash 1994) may have backfired against disabled people.

This research project has been undertaken at a time when not only personal assistance, but all of the provisions needed for disabled people in the UK to

achieve 'independent living' as defined in the Disabled People's Movement (Barnes 2007b), are under threat from a politics and economics of austerity. Disabled people are disproportionately victimised by this economic regime (Dodd 2016; Duffy 2013), and its ideological foundations are in a fundamentally disabling capitalist paradigm of market economics and individual (rather than collective) responsibility (McRuer 2018). Dodd (2016) argues that, while 'marketisation' and 'social protection' can be opposed to one another, movements for emancipation must oppose elements of domination that occur within both. Independent living and the direct employment model of personal assistance can be seen as a reaction against oppressively paternalist forms of social protection; however, "as domination through social protection is rightly attacked, forces of marketisation, which are far from benign, seize the opportunity to create new forms of marketised domination" (Dodd 2016, p.161).

At the time that the participants in this study were interviewed, many of the cuts to benefits and public services that have most severely affected disabled people with personal assistance needs in the UK had not yet been implemented or were only starting to take effect. Things are only likely to have got worse for many of the direct employers interviewed since 2015; indeed, some of those who I have remained in touch with, either due to existing friendships or mutual involvement in DPM and/or Disability Studies circles (see Chapter 3) have experienced either losses of personal assistance funding, or intensified struggles to keep the funding they have, between 2016 and 2018. A particularly worrying development for many is the financial crisis of local government which is making news headlines as I write this (Graby & Homayoun 2019).

The direct employers interviewed for this study are also likely to be relatively privileged among disabled people with similarly extensive personal assistance needs. Most, if not all, were relatively well-educated and politicised about their needs and rights to assistance through involvement in the DPM and associated communities, both of which factors are likely to give advantages in persuading local authority 'gatekeepers' to recognise assistance needs and award adequate levels of funding. Most also had supportive non-disabled family members who were able either to advocate on their behalf when necessary in

dealings with local authorities, and/or to provide emergency financial and/or practical support. Therefore, it is very possible that many other disabled people with comparable assistance needs may either not get direct payments to employ PAs at all, or receive much more inadequate provision. In particular, members of impairment groups not adequately covered by this study (such as those with mental health needs and/or learning difficulties) may struggle to get their assistance needs recognised within a culture of scarcity and rationing of funding provision.

Increases in funding, relaxation of bureaucratic restrictions and/or provision of additional support services by LAs and/or DPOs and other organisations may all help the direct employment model of personal assistance to function more effectively, and potentially make it more accessible to a wider range of disabled people. However, the direct employment model is not necessarily the only way for disabled people with assistance needs to achieve autonomy in everyday life, and the desire of some disabled people, such as Anne in this research, not to have the legal responsibilities of employers means that there is a need to examine possible alternative ways of organising personal assistance. This will be the focus of the next chapter.

Chapter 8: Alternative possibilities for personal assistance: beyond direct employment

Direct employment of PAs by individual disabled people is not the only possible way to arrange personal assistance. As mentioned in Chapter 7, one employer, Anne, was insistent that the legal responsibility of employing PAs should not be placed on the individual disabled person, and therefore wanted it transferred to LAs. This can be seen as a separation of the concept of 'boss' (in the sense of having authority over a worker) from that of 'employer', in the sense of legal and financial responsibility. These positions are often conflated, as with the frequent use in the Independent Living movement of the phrase "hire and fire" (see e.g. DeJong & Wenker 1983; Priestley 1999; Ratzka 1986) to invoke the control that disabled people should have over their PAs, not only in recruitment and dismissal but also with regard to their day-to-day tasks and activities. However, it has been argued that positioning the individual disabled person as an employer is not the only way to achieve control over the delivery of assistance and a 'boss' position with regard to PAs (Shakespeare 2014; Yamaki & Yamazaki 2004).

Other possible employment models

As discussed in Chapter 7, support for direct employers from CILs or other DPOs may mitigate some of the administrative barriers faced by disabled people placed in the role of employer. However, even with these types of support, disabled people would remain in a legally risky position in the case of serious conflict with, or unethical behaviour by, PAs (Vogelmann 2016). One potential solution to this problem could be, as Anne suggests, making LAs rather than disabled individuals the legal employers of PAs, while still assigning day-to-day managerial control over PAs and their tasks to disabled people as individuals. This is possible in some other countries, such as Sweden and Norway (Askheim et al 2014). However, at least in the UK, it is unlikely that a proposal to do this would be well received by the DPM, as despite the potential advantages such as not having to take individual responsibility for all the legal

aspects of employing, it could too easily be perceived as relinquishing choice and control over personal assistance to LAs whose attitudes towards disabled people are likely to be paternalistic and lacking in understanding of key concepts like independent living and the social model (Glasby & Littlechild 2016; Spandler 2004).

Another possibility could be changing laws to make the employment of PAs by individuals exempt from some aspects of employment regulation, or to give PAs a unique legal status distinct from both ordinary employees and the self-employed; for example, PAs could be exempted from paying income tax or National Insurance contributions. This could recognise that the relationship between PA and disabled individual employer is, in economic terms, not necessarily like that between most employees and their employers. This is reminiscent of recent debates around workers in the 'gig economy', resulting in the emergence in several jurisdictions of intermediate employment status categories between employment and self-employment such as 'dependent contractors' or 'subordinate workers' (Cherry & Aloisi 2016; Huws et al 2017). In the UK, the status of 'worker' exists as "a catch-all category to provide those who would otherwise be self-employed, but who have some employee characteristics (such as a degree of control by the business), with meaningful legal rights" (Mann & Suff 2018, no page number); this is mentioned, alongside 'employed' and 'self-employed', as a possible status for PAs by Skills for Care (2017).

The work of PAs already has some similarities to that of many 'gig economy' workers in that PAs are frequently isolated from other workers and lack colleagues or a traditional 'workplace', thus making them difficult to connect with for traditional labour unions (Cranford 2005; Webster 2016). Encouraging such a legal status for PAs as workers would be likely to increase the precarity of PAs' work (see Chapter 6). It would also be likely to entrench the conflict between the material interests of PAs and direct employers, as employers and PAs would be unlikely to agree on what differences from standard employment this status should have; for example, direct employers would benefit from not being required to give PAs sick pay while simultaneously having to pay a cover

PA, but PAs would be directly financially harmed by this. A likely result would thus be to make recruitment and retention of PAs harder by making the job less appealing to potential applicants.

DPOs as employers of PAs

A third possibility could be for a DPO, rather than the individual or local authority, to be the direct employer of PAs. In the UK, this was one way that user-controlled personal assistance was made possible before the passing of the Community Care (Direct Payments Act) 1996, which made it legal for LAs in England and Wales to make direct payments to individuals. This had previously been illegal under the 1948 National Assistance Act, meaning that where LAs had been persuaded to let disabled people employ their own PAs, the funding for this had to be routed through organisations as 'indirect payments'; these organisations varied between DPOs, non-disabled-led voluntary sector organisations, and trusts created explicitly for the purpose (Pearson et al 2005; Priestley 1999; Zarb & Nadash 1994). Luckhurst (2006) categorises these as one form of 'intensive support schemes', and reports users of such schemes benefiting from increased flexibility of support and experiencing them as "enabling the advantages of direct payments without the administrative disadvantages" (p.233). Areas in which these schemes existed also had higher rates of take-up of direct payments by older disabled people and people with learning difficulties, considered 'marginalised groups' with regard to 'typical' direct payments.

Some, though not all, of these intermediary organisations were the legal employer of PAs rather than the disabled individual (Luckhurst 2006; Priestley 1999). In the late 1990s, Derbyshire CIL's 'Personal Support Scheme' was an example of the latter which continued to offer this option after the passing of the Community Care (Direct Payments) Act; however, they still followed the "guiding principle... that the individual disabled person should exercise control over who is employed to provide their personal assistance" (Priestley 1999, p.99). Thus disabled people could still recruit and interview PAs on an individual basis, with optional support from DCIL with the interviewing process. While the provision of

support by DCIL was clearly appreciated by individual direct employers, Priestley draws attention to the risk that "the buffer of a third-party employer can sometimes mask the central role of the service user" and thus disabled people, particularly those with past experiences of disempowering paternalistic support provision, may "defer to peer support workers and scheme managers as 'authority figures'" (p.101). Thus it is necessary for an organisation taking on this role to have a strong ethos of control by disabled people and commitment to their liberation both as individuals and collectively.

Organisations with this ethos no longer exist in many parts of the UK due to the same political and economic forces that have impacted personal assistance provision. While there has been little or no published research on this since the 'Creating Independent Futures' project in the early 2000s (Barnes et al 2000; Morgan et al 2001), anecdotal evidence within the DPM suggests that many DPOs have been forced to shut down due to loss of funding from LAs or other sources, while many of those that still exist are struggling to survive and have had to reduce the scope of their activities or accept contracts for service provision which restrict their ability to represent the interests of disabled people rather than government, LAs or other funders (Alliance for Inclusive Education et al 2018; Pring 2018b, 2019). Others have ceased to be run and controlled by disabled people and are thus effectively no longer DPOs (see for example Pring 2016). Notably, the National Centre for Independent Living (NCIL) merged in 2012 with the charity RADAR (Royal Association for Disability and Rehabilitation) and the Disability Alliance to form Disability Rights UK. Neither RADAR nor the Disability Alliance were run and controlled by disabled people, and the status of DRUK is thus ambiguous, representing a blurring of the distinction between DPOs and organisations 'for' disabled people (Barnes 2013).

Oliver and Barnes (2012) argue that there has been a "gradual downgrading of the role of organisations controlled and run by disabled people at the local, national and international levels" since the mid-1990s, connected to a "growing professionalisation of disability politics" (p.155). This has involved co-optation of the ideas and language of the DPM by government and by non-disabled-led

organisations such as large charities, including a co-optation of the concept of 'independent living' into the traditional, individualistic definition of 'independence' as self-sufficiency, and specifically as the antithesis of financial 'dependence' on the welfare state (see for example the 2005 'Improving the Life Chances of Disabled People' report (PMSU 2005), which argued that independent living was being held back by a "culture of care and dependency within health and social care structures", one component of which was "higher than necessary expenditure on social security benefits" (p.73)). This interpretation of 'independent living' is in contradiction with Article 19 of the UN CRPD (Alliance for Inclusive Education et al 2018), as well as at odds with the established usage of the phrase within the international DPM (see chapter 2). There is also evidence of a lack of meaningful engagement by the UK government with DPOs in policy planning and implementation and prioritisation of engagement with non-disabled-led charities (Alliance for Inclusive Education et al 2018). Due to all these factors, DPOs taking on the direct employment of PAs on the behalf of individuals with assistance needs, or even playing a significant support role in the employment relationship, is not currently likely to be a realistic prospect in much of the UK.

Personal assistance co-operatives

A related but distinct approach, which may potentially be able to bypass some of the barriers to 'traditional' DPOs becoming 'third-party' employers, is the formation of personal assistance co-operatives. This has been done in some other European countries, particularly the 'Scandinavian welfare states' (Askheim et al 2014). In Sweden, for example, disabled people who receive support under terms in specific laws can choose between taking on the responsibility of employing PAs directly or having LAs, private agencies or co-operatives take on the role of employer (Askheim 2005); it is also possible for disabled people to use a combination of these options or to 'buy' assistance services from a PA acting as a 'sole trader' (Westberg 2010). The first PA co-operative in Sweden, the Stockholm Co-operative for Independent Living (STIL), was founded in 1984 by a group of disabled people, including Adolf Ratzka, affiliated with the international IL movement (Roulstone & Hwang 2013;

Westberg 2010); it and other co-operatives which have since been developed on its model can thus be considered the Swedish equivalent of CILs in the UK and US (and like them are also campaigning organisations).

In this model, disabled members of the co-operative pool their direct payments (in Sweden from a combination of municipal and national funding sources) to fund the co-operative, which then is the legal employer of the PAs managed by individual members. The co-operative is controlled by an elected board who are all personal assistance users (Bowman 2001; Ratzka 2015). STIL takes care of administrative aspects of managing direct payments, such as tax and payroll, but recruitment remains the responsibility of the individual disabled member; thus the one-to-one relationship between disabled person and PA is maintained as if they were an individual employer (Roulstone & Hwang 2013, 2015). STIL provides mandatory introductory training on the role of 'boss' or 'supervisor' to its members (Bowman 2001) and provides further optional training on specific aspects of the management relationship, as well as some training for PAs (Roulstone & Hwang 2013; Westberg 2010).

STIL allows the appointment of a 'vice supervisor', whose role is to manage PAs on the member's behalf, for those who find self-management difficult, although all disabled members are meant to "take on as much of the supervision as possible" (Westberg 2010, p.63). Another Swedish co-operative, JAG, was specifically established for people with "multiple extensive disabilities, one of these being an intellectual disability" (Westberg 2010, p.42). Every member of JAG, which was founded by a group of parents of disabled children inspired by the example of STIL (Tengström n.d.) has a 'service guarantor', often a family member, who is responsible for "recruiting, instructing, supervising and scheduling the assistants in accordance with the user's preferences" (Tengström n.d., no page number) and has a duty to "make sure the member receives personal assistance", meaning that if the service guarantor cannot find a substitute PA, for example to cover illness, they must work as a substitute PA themselves (Westberg 2010, p.62). Members of JAG also typically have legal guardians as adults, who represent them on the co-operative's board of directors (Tengström n.d.). Perhaps because of the availability of these

services, Sweden has a high proportion of people with cognitive impairments accessing user-controlled personal assistance compared to many other countries, although this may also be related to the fact that "persons with learning disabilities, people with autism or conditions similar to autism" are specifically guaranteed eligibility for personal assistance under Swedish laws (Askheim et al 2014, p.6).

While most PA co-operatives in Sweden, other than JAG, are local to cities or municipal areas in a similar way to DPOs in the UK, in Norway there is a single nationwide PA co-operative, Uloba, which was founded in 1991 and in 2013 was running 27% of all personal assistance programmes in Norway (Roulstone & Hwang 2013). Similarly to STIL, Uloba is also a campaigning DPO and involved in 'marketing' personal assistance to disabled people (Andersen et al 2014); it also offers peer support for disabled members as a core service (Roulstone & Hwang 2013). In Norway disabled people who are eligible for personal assistance services can also choose between joining Uloba, employing their own PAs directly, or having the municipality as legal employer. This latter is actually the most popular arrangement, but Uloba has a substantial 'market share' (33% of personal assistance users in 2010, up from 25% in 2007) (Askheim et al 2014; Christensen 2010). In Denmark there is similarly a nationwide PA user co-operative called LOBPA with the "double function" of co-operative and campaigning organisation. The latter function is perhaps even more explicitly articulated in LOBPA, as (unlike Uloba and the Swedish co-operatives) LOBPA also allows PA users who do not use its employment services (e.g. those who employ their own PAs directly; in Denmark, unlike Sweden and Norway, local authority responsibility for employment of PAs is not possible) to be members (Andersen et al 2014; Askheim et al 2014).

All of these 'Scandinavian model PA co-operatives' centre the empowerment of disabled people as a core value (in contrast to both for-profit agencies and traditional state-provided 'care' models) and are aligned with, or even effectively constitute, the independent living movements in their native countries. In this model, the roles of (legal/financial) employer and of 'boss/manager' are clearly distinguished from one another. STIL, for example, "distinguishes between a

'leader' and an employer", defining a 'leader' as "a disabled person who decides on the key questions of who, what and when of personal assistance" (Roulstone & Hwang 2013, p.30). Uloba similarly uses the phrase "work leaders" (in the English-language pages on its website) to describe its disabled members, as opposed to Uloba itself as the "employer" of PAs (Uloba n.d.).

To date in the UK there has not been a large-scale personal assistance co-operative comparable to the Scandinavian examples. A number of smaller-scale co-operatives in the field of 'social care' do exist; however, unlike the Scandinavian co-operatives, most of those in the UK are either workers' co-operatives of PAs/'care workers' or 'multi-stakeholder' co-operatives (Bibby 2015), whose membership includes more than one group, for example disabled people and PAs, and in some cases also family members who provide informal care and/or volunteers or 'community supporters' (Conaty 2014; Roper 2017; Roulstone & Hwang 2015).

Examples of the workers' co-operative approach include small local co-operatives such as Sunshine Care in Rochdale (Fisher et al 2011), and the somewhat larger franchise Care and Share Associates, which operates in a range of urban and rural localities across the North of England, but began as an offshoot of Sunderland Home Care Associates (Conaty 2014; Roulstone & Hwang 2013; Smith 2016). In Suffolk the co-operative Leading Lives was created from the former 'in-house' learning disability service of the county council when it moved from providing services directly to commissioning them from the private sector (Brindle 2016). All of these are employee-owned (although with a variety of legal structures) and function effectively as care agencies, with which service users engage as individuals, using direct payments to buy their services. While worker-owned agencies such as these may have a more mutual ethos and a greater commitment to the rights and self-determination of service users than traditional 'care' agencies run for profit, they do not necessarily have any connection to the DPM or 'independent living' principles, and are still likely to describe their services in terms of 'care' rather than 'personal assistance'.

Examples of the multi-stakeholder approach are more varied. One of the largest is Cartrefi Cymru, which operates across Wales and was originally a charity founded by parents of people with learning difficulties, but became a multi-stakeholder co-operative in 2016 (Roper 2017). Cartrefi has both disabled people and support workers as members and has recently introduced 'community supporters' as a third category of membership. Cartrefi defines its purpose as "to enable the people we support (mainly but not exclusively people with learning disabilities) to live a good life" (Roper 2017, p.52), and as well as providing direct support with daily living, collectively involves itself in voluntary action in wider local communities, decided on by its members. This and other social care co-operatives in Wales have been supported by the Social Services and Well-Being (Wales) Act 2014, which places a duty on Welsh LAs to promote "user-led services, co-operatives, social enterprises, and the third sector" (p.53). Other examples include Caring Support in Croydon, which was founded by a disabled person, has a board of directors including service users, informal carers and care workers and operates a 'cluster model' in which workers support both disabled people and informal carers (Fisher et al 2011; Roulstone & Hwang 2013), and Oxfordshire Wheel, whose board of directors includes individual service users and local user-led organisations, which gives training for PAs and employers as well as providing advice and support to disabled people about claiming benefits and finding paid work (Conaty 2014).

The term 'co-operative' seems to be used somewhat loosely in case studies of many of these small organisations, and sometimes seemingly interchangeably with 'social enterprise', an even less well-defined term (e.g. Smith 2016). Some also describe themselves as charities, meaning it is sometimes unclear which organisations are and are not technically co-operatives. There is no precise definition of a co-operative in British law (Footprint 2016); however, Restakis (2010, p.3) defines co-operatives as "enterprises that are collectively owned and democratically controlled by their members for their mutual benefit". Internal democracy is generally regarded as a core value and characteristic of co-operatives, distinguishing them from other types of social enterprise (Atxabal Rada 2016; De Peuter & Dyer-Witheford 2010; Gradin 2015).

Co-operatives in the UK adhere to the 'Seven Co-operative Principles' of 'voluntary and open membership', 'democratic member control', 'member economic participation', 'autonomy and independence', 'education, training and information', 'co-operation among co-operatives', and 'concern for community' (Scott 2016, pp.6-7). Co-operatives have been argued to be potentially very appropriate for organising personal assistance because of the resonance between these principles and those of the Disabled People's Movement; for example, Roulstone and Hwang (2015, p.861) argue:

> "there is a powerful affinity between cooperative principles, direct payments and disabled people's organisations. Shared ownership, user control, a concern to ameliorate provider and market-led 'solutions' and a belief that people are experts in their own life characterise both cooperatives and disabled people's organisations."

Similarly, Bowman (2001, p.51) describes the "fit between user-directed personal assistance and co-operation" as "logical", especially in the Scandinavian context, and Beresford (2016, p.255) argues that both DPOs and 'micro employers' (as he categorises direct employers of PAs) continue the "socially committed legacy" of the co-operative movements of the 1970s-80s in the UK. Co-operatives can be contrasted with both the paternalism and managerialism of the post-war welfare state tradition and the 'free market' values of neoliberalism (Beresford 2016; Restakis 2010), against both of which the emancipatory project of the DPM can also be positioned (Dodd 2016). Co-operatives "socialize individuals without extinguishing their individualism" (Restakis 2010, p.237), just as the DPM has emphasised both collective social responsibility for the social inclusion of people with impairments and individual self-determination.

Co-operatives also share with the DPM a core value of what Gordon (2018, p.209) calls 'subsidiarity', or "the principle that people should have power over an issue in proportion to their stake in it". This principle is exemplified in the DPM by the international slogan "nothing about us without us", which Charlton (1998, p.17) characterises as "a demand for self-determination and a necessary

precedent to liberation". In the case of both workers' co-operatives and DPOs, this principle has led to refusal to accept charitable status; as stated in a handbook for setting up workers' co-operatives produced by the UK-wide co-operative network Radical Routes (Footprint 2016, p.65):

> "Workers' co-operatives can't register as charities, because charity law says that those benefiting from the organisation can't be the ones making decisions – which of course goes against the whole idea of co-operatives, which are set up to benefit and be run by the members!"

Similarly the DPM opposes charity because of its paternalism, collusion with economic injustice and individualistic portrayal of disabled people as objects of pity (Drake 1996; Russell 1998) and emphasises the difference between organisations 'for' disabled people and organisations 'of' disabled people, or DPOs, only the latter of which are considered part of the movement because they are run and controlled by disabled people (Barnes & Mercer 2006; Beresford 2016).

Sandoval (2016a, p.109) calls for alliances between co-operatives and "other radical and progressive organisations" - which, while she does not explicitly mention disability, could include the DPM - "in order to formulate joint demands" as part of a wider political movement and critique of capitalism. Co-operatives may also provide a way around tensions between individualism and collectivism within the DPM and discourses of 'independent living', as they both have autonomy and self-determination as a central principle and are inherently collective and aligned with a concept of common (rather than state or private) ownership of resources (De Peuter & Dyer-Witheford 2010). Notably, in Sweden the co-operative form, with its history of connection to labour movements, was specifically chosen by the DPM there to alleviate opposition from left-wing parties and trade unions who saw user-controlled personal assistance as a form of privatisation and feared it would lead to increased exploitation of workers (Bowman 2001; Westberg 2010) (for more on trade unions and personal assistance see Chapter 6); the success of STIL in fact influenced the passing of

laws which allowed direct employment of PAs by individuals (Bowman 2001). Spandler (2004, p.205) also argues that co-operatives which are "sensitive to, and vigilant about, the power dynamics between recipients and PAs" could provide a means of organising the interests of PAs as workers which is not in opposition to those of disabled people.

However, while co-operatives and the DPM both centrally value autonomy as self-determination, an important question is whose self-determination. Here we return to the question of the potential contradiction between the autonomy of disabled people and that of assistance workers. All co-operatives aim to increase the self-determination of their members, but there are several possibilities for who could constitute the members of a co-operative operating in the field of social care. Roulstone and Hwang (2015, p.852) identify three potential models: service user co-operatives (such as the 'Scandinavian model' personal assistance user co-operatives), employee-owned (or workers') co-operatives, and multi-stakeholder co-operatives, in which both service users and PAs could be members.

Workers' co-operatives "reject the hierarchies of owner and non-owner, employer and employee, manager and worker" (Sandoval 2016a, p.103). The Radical Routes handbook on setting up a workers' co-operative (Footprint 2016) emphasises workers' control over decision-making in the workplace, as opposed to control by business owners or managers, as an advantage of forming a workers' co-operative over working for a non-employee-owned company, and says that "in contrast to traditional workplaces, a workers' co-operative tries to be a fair and empowering environment where everyone – and no-one – is the boss" (p.10). For disabled people who employ PAs, this principle of workers' co-operatives arguably contradicts the central independent living principle of choice and control over when, how and by whom assistance with daily living tasks is provided. It is precisely being able to legitimately be the 'boss' (or 'work leader', as Uloba terms it) of one's PAs that makes directly employing them appealing despite the administrative difficulties. Disabled people for whom this is the primary motivation for employing PAs thus may well view purchasing the services of a workers' co-operative as just as bad or even

worse for their personal autonomy than purchasing those of a more traditionally structured agency.

The concerns expressed by direct employers about PAs organising together, as discussed in Chapter 6, could be assumed to apply even more acutely to the formation of a worker-owned business than to forms of organisation, such as trade unions, which assume that workers will remain in a relationship, albeit potentially an oppositional one, with an external employer. Worker ownership of personal assistance services could easily be seen as relegating disabled people to a status of 'clients' without meaningful control over the services they 'purchase'. This potential conflict was recognised by one PA, Phoebe:

> "it would be potentially possible [to set up] some sort of workers co-operative... with PAs mutually co-ordinating between themselves, but for the most part it has to be subject to your employer's needs, so the employer's needs are paramount, and that's - the whole point of the job is satisfying their needs for assistance in independent living, so it would be very difficult for workers to be in control of that, per se."

Conversely, service user co-operatives on the Scandinavian model satisfy the demands of disabled people for choice and control over assistance while mitigating the isolation and administrative barriers, and thus could be seen as the 'best of both worlds' for PA users, but the advantages over being directly employed by an individual are not necessarily obvious for PAs as workers. However, it is possible that support services that would benefit PAs could be provided by a service user co-operative. Christensen (2010), for example, describes "regular meetings... between personal assistants working for the same disabled person, controlled by the disabled person, thus creating a forum in which reflections can be exchanged" organised by Uloba (p.249). Some direct employers may still have concerns about PAs having contact with one another because of the risk of undermining the control of the employer, but if this was done in the context of an organisation run and controlled by disabled people, it could potentially help to allay these fears.

If PAs employed by the co-operative would have the option of working for multiple individual 'work leaders', a service user co-operative might also be able to provide more consistent working hours than working directly for individuals would. For many PAs this could be a real material improvement of working conditions, but it would still not necessarily give them more direct control or autonomy. PAs might also have reason to suspect that a service user co-operative would inevitably prioritise the interests of its members over those of its non-member employees. Therefore it can be argued that a multi-stakeholder co-operative, in which PAs and personal assistance users form the two primary 'stakeholder' groups, would be best able to represent the interests of, and potentially provide the best outcomes for, both employers and PAs. This model is advocated by the Co-operative Party in the UK (Scott 2016), while multi-stakeholder social care co-operatives exist in Italy (Bland 2011; Restakis 2010) and Japan (Marshall 2013), though they are not based on a concept of personal assistance as understood in the UK or the Scandinavian countries.

Multi-stakeholder personal assistance co-operatives could help to establish solidarity between direct employers and PAs, enabling them to join together to "maximize the pressure for adequate resources" (Spandler 2004, p.205). However, some direct employers may have concerns about an organisation which would arguably assume a "symmetrical relationship between users and assistants" (Guldvik et al 2014, p.59), given that the relationship between disabled person and PA is in some respects necessarily asymmetrical. Ratzka (2015, no page numbers), for example, expresses scepticism about the idea that "assistance users, their relatives and assistants can be members with equal rights" in PA co-operatives, arguing that disabled people and PAs are not in comparable positions with regard to their stake in the issue:

"My background in residential institutions and living with local government community-based services has made me very sensitive to having my life controlled and restricted by structures that I cannot impact directly and by people who are not in the same boat as I am. I am dependent on personal assistance almost 24/7. My assistants work part-time. Personal Assistance is the foundation on which I built

my life, my family, my work, my lifestyle. For my assistants it's just a job. In my cooperative [STIL] with roughly 200 members and 1200 assistants, assistance users would never be able to get their positions through, if assistants had equal voting rights. Assistants as equal members may look politically correct but will not be conducive to self-determination of assistance users."

This argument would likely be echoed by many, if not all, of the pioneers of independent living in the UK. However, it is based on the assumption that in a multi-stakeholder co-operative, 'work leaders' and PAs would be equal members in a single decision-making body. This would not necessarily be the case depending on how the co-operative is organised; for example, in a multi-stakeholder personal assistance co-operative, PA and employer members could have different jurisdictions of decision-making. Somerville (2007, p.6) suggests that the principle of 'one member one vote' could be modified for multi-stakeholder co-operatives "to fit the context of an institution with different categories of membership", so that "where one category of stakeholder... is more deeply affected by the outcomes of the enterprise than another... it would follow that the votes of the former should count for more than the votes of the latter", which could prevent the 'outnumbering' situation that Ratzka describes.

Co-operatives may solve many of the problems with personal assistance, as it currently exists in the UK, which were identified by PAs and direct employers; in particular those around the administrative burdens and some of the relational tensions of individual direct employment. However, co-operatives are not a solution to every barrier mentioned by participants; in particular, there is no realistic way for them to address the issues mentioned above that result from insufficient funding for personal assistance from local and/or national government, as they do not generate income for PAs in themselves, but still rely on the funding awarded to individual disabled members from LAs or other sources. While the increase in flexibility that may be achieved by co-operative approaches may in some cases partially mitigate some financial difficulties by allowing individuals to share costs, the scope of this is inevitably limited. Roper (2017, p.52) argues that, while co-operatives "may not be able to increase

wages beyond the funding we receive from local authority commissioners", the "elevation of status and voice of employee members" may still have advantages for workers, particularly in comparison to those in privately owned agencies. Therefore, co-operatives should be seen as complementary to, rather than substituting for, public services (Restakis 2010; Roulstone and Hwang 2015).

There is also a danger in using cost-based arguments in favour of co-operative approaches, as these may then be used by local and/or national government as an excuse to cut budgets if co-operatives are considered to be a cheaper option. Parallels can be drawn here with the cost-based arguments used by the DPM in the 1990s for the legalisation of direct payments on the grounds that they would be cheaper than traditional 'care' services (Zarb & Nadash 1994); while this argument was successful, it contributed to the tensions between social justice and market discourses in the implementation of direct payments (Pearson 2000; Spandler 2004). This arguably led to the failure to implement the movement's original vision of independent living, as it resulted in cost-cutting assessment cultures which easily incorporated ideological discourses of independence as self-sufficiency, and can fit into austerity agendas of delegitimising support needs.

Similarly, Sandoval (2016b, p.58) argues that the co-operative concept "can... be integrated into neoliberal discourses of entrepreneurship and individual responsibility"; for example, co-operative business models were endorsed by Conservative prime minister David Cameron as fitting into his ideal of a 'Big Society' replacing state-funded services. Beresford (2016, p.256) argues that appropriation of self-organised initiatives with emancipatory aspirations into reactionary 'cost-cutting' policy "has been a major feature of modern public policy generally and social policy specifically"; this has frequently taken the form of deliberate confusion between the concept of 'independence' as autonomy promoted by the DPM (and other radical service-user-led movements) and that of 'independence' as self-sufficiency that characterises neoliberal and more broadly capitalist ideology. Therefore, co-operative approaches must be considered to be a partial rather than a complete solution to the barriers to day-to-day autonomy and full social participation faced by disabled people with

significant personal assistance needs.

Alternative care and support models

There is also a need to consider other alternative approaches to personal assistance that are not dependent on state funding for two other principal reasons. Firstly, funding for 'social care' in all its forms is increasingly under threat from austerity policies, and is already inadequate to provide for the needs of many disabled people (Dodd 2016; Duffy 2013). Thus it is not only necessary to campaign for increased funding, but also to find pragmatic solutions to immediate problems. Secondly, on a more abstract and utopian level of imagination, the analysis by foundational Disability Studies theorists (e.g. Finkelstein 1980; Gleeson 1999; Oliver 1990; Russell 1998) of wage labour as a fundamental root of the exclusion and oppression of disabled people in modern societies points to the necessity to consider possible ways to organise personal assistance for those disabled people who need it that do not rest on a foundation of wage labour. This was difficult for participants to envisage. Grenville, for example, replied when asked whether he felt that his ability to pay his PAs a wage affected the power relations between them:

> "if it wasn't in a wage market, if it wasn't a job but nevertheless that was somebody's role if you like, or something within a community or something... it just feels to me like it would be really really different, but it's difficult to say, everything would be different... when I start to imagine a situation in which there's a capitalist economy and people pay for labour, but for whatever reason I'm not, but it's within a capitalist framework - and of course the more radical scenario is one in which it just isn't one, and at that point I'd start to just lose my grip on what things would be like"

Other participants similarly found the question of what personal assistance relationships would look like in a post-capitalist society difficult to answer, so much so that after the first few interviews I abandoned the question (see Chapter 3). Some of their difficulty with this may have been due to the fact that

utopian imaginings were far from people's minds as things like funding and obstructive administration were much more immediate concerns, but another possible reason for this is the complex power relations surrounding concepts of voluntarism, gifts and gratitude. I have previously argued (Graby 2015), as have other authors (e.g. Taylor 2004; Withers 2012), that due to the fundamentally disabling nature of the capitalist system of wage labour and its attendant ideologies of 'productivity' and 'contribution' (Abberley 2002), a jobless and moneyless 'gift economy', based on a principle of 'from each according to their ability, to each according to their needs', is the only form of society in which disabled people could achieve full inclusion and liberation. However, disabled people have good reason to be suspicious of notions of the 'free gift', both due to oppressive experiences of charity in organised forms (see e.g. Drake 1996; Russell 1998; Withers 2012) and to the damaging emotional effects of the felt requirement for 'gratitude' in informal care relationships, which Galvin (2004) documents as resulting in guilt, shame and feeling like a burden both on informal carers and on society in general, thus being a major contributor to psycho-emotional disablement (Thomas 1999; Reeve 2004).

Illustrating this, Slav, when asked if he could imagine a means of organising personal assistance outside of a capitalist framework, replied:

> "It's not something I've ever considered. I think, you know, ultimately, I want, whatever system we have, in terms of living a life, and having means to live a life, I want to ensure that the PA is rewarded for that, whatever the mechanism is, the PA is rewarded for that job... I'm dreading the day, I'm waiting for the day when the Conservative government will say, 'Here's a great idea, people who don't work, let's bus them on to being PAs!'... So I'm not entirely sure what I'd say is an alternative to rewarding people for their labour, but... I just don't want us to fall into the trap of a gift model, because if we do that, it automatically removes the individual's role and contribution to their community, because it focuses their existence on having their support needs met."

When asked how they thought they (or their employers) might meet their personal assistance needs if direct payments did not exist, some participants thought that some form of non-monetary exchange economy or 'community currency' (Seyfang 2003) might be possible; however, all those who mentioned this were sceptical about some aspects of it. For example, Carol said:

> "I mean there are ideas about skill swapping and things like that - I'll just pimp out my mobility car, you know, in return for personal support… which I think would be a really interesting thing for disabled people to tap into - or there was that scheme about banking, you do a good job for someone, and you - is it time banking? But I don't know how that would work for disabled people…"

Shakespeare (2000, p.70), discussing alternatives to traditional paternalistic models of delivering 'care' to disabled people, mentions (in addition to the direct employment model of personal assistance) various forms of 'low-intensity support', which he regards as potentially useful for people who need some assistance but either do not qualify for support packages from LAs "due to resource constraints" or are "not happy with the responsibility of managing their own care package". Among these are 'circles of support' and various 'housing and support' models. According to Shakespeare, all these alternative models of assistance "are based around a model of help, not care, and they seek to empower the user, not the helper or professional" (p.72); however, both the extent to which this is true and the definitions of 'empowerment' used in these support models may vary. In particular, the power dynamics within these models may vary significantly depending on whether they were originated by disabled people or by others (such as non-disabled parents or professionals).

Circles of support

The concept of 'circles of support' is generally associated with people with learning difficulties (Gold 1994; Wistow et al 2016), although it arguably originates from the struggle of Judith Snow, a Canadian woman with a physical impairment, to get out of an institution and get the support, including personal

assistance, that she needed to live in the community (Snow 2015; Wistow et al 2016). A circle typically involves a number of people close to a disabled person, potentially including family members, friends and people in professional support roles, meeting regularly with that person to plan ways to help the person achieve their goals, and in some cases to provide practical support at the person's request. The formation of circles of support is often initiated by parents or other family members who are worried about their continued ability to provide informal care for a family member with learning difficulties, rather than (as in Snow's case) by the person themselves (Hillman et al 2013; Wistow et al 2016). An important purpose of circles, in particular for young disabled people in education settings, can often be to achieve social inclusion for disabled people who may be isolated or lack significant informal personal relationships; however, this has been criticised for inhibiting the spontaneous development of 'real' friendships not based on assistance (Gold 1999; see also Chapter 4).

However, circles of support are not usually direct providers of assistance with daily living tasks; Wistow et al (2016, p.198) describe one of the key tasks of the circles in their study as "supporting the individual to live well in the local community and assisting the management of their care package", and all the disabled people whose circles they studied also received formal social care funded by social service departments or the ILF. Snow (2015) also describes PAs and a circle of support as having separate, complementary roles in her life, with members of her circle mediating between Snow herself and her PAs if problems occur between them. Therefore, circles of support should not be understood as an alternative to personal assistance so much as a complementary support system with a distinct function, which could potentially play a similar role to co-operatives or DPOs in removing administrative barriers, particularly for people who would find the administrative aspects of employing PAs difficult (Scourfield 2005). However, particularly where parents or other non-disabled family members are the originators of a circle, there may be ambiguities over whether disabled people retain genuine choice and control over the support provided by the circle and/or the direct daily assistance.

Co-housing and 'intentional community' models

Another model which, like 'circles of support', is primarily focused on the assistance needs of people with learning difficulties and could be regarded as an attempt to formalise practices of informal support, is that of 'shared lives' schemes (the term now preferred for what in the UK were formerly known as 'adult placements'). In these arrangements, a person with assistance needs, typically an adult with learning difficulties, is matched with an individual or family who has room for the person in their home and is able to provide them with day-to-day support (Shared Lives Plus n.d.a, n.d.b). This model can arguably be traced back to the tradition in the town of Geel in Belgium, going back to medieval times, of accommodating people with long-term mental health conditions, known as 'boarders', in the homes of unrelated families (Fernie 2010; McCrary 2017). In the UK, 'shared lives' schemes are run either by local authorities or by charities and social enterprises, and are regulated by Shared Lives Plus, formerly known as the National Association of Adult Placement Schemes (Shared Lives Plus n.d.a). While Shared Lives arrangements are covered by similar regulatory requirements to more formal domiciliary care services, they are distinct from these in that Shared Lives carers "do not employ staff to provide care to the people placed with them" but "carry out their support in much the same way that a natural family member may provide that support" (Shared Lives Plus n.d.b).

Shared Lives Plus also administers 'Homeshare' schemes, a similar but inverse arrangement in which a person in need of accommodation, who is willing to provide some assistance with daily living tasks in exchange for free or cheaper rent, moves into the home of a person in need of assistance who has a spare room, typically an older person with a relatively low level of assistance needs (Fox 2010; Homeshare UK n.d.). This is also a partial formalisation of forms of informal support that may also occur spontaneously, described by Fox (2010, p.21) as "an attempt to take a naturally occurring, mutually beneficial relationship and to facilitate it in a way that makes it safer and accessible to a wider range of people". However, unlike Shared Lives, Homeshare schemes are not formally regulated. Because of this, they "cannot include provision of

personal care" (Fox 2010, p.22), meaning that their usefulness is limited for people with greater levels of assistance needs.

There are also other home-sharing schemes outside of the Homeshare UK network, such as 'Howzahelpa', a website founded by a disabled woman who needed assistance with housework and childcare (Davison 2017), which charges only for advertising and facilitates independent arrangements between 'Howzas' and 'Helpas' (or 'householders' and 'homesharers' in Homeshare UK's terms). Ada had previously used a similar arrangement as a source of assistance:

> "When I first started work I wasn't a PA user. I needed some help when I moved away from home so what I did - and this is because I have enough money to do this - I bought a flat and I 'let', in inverted commas, some of the rooms. So people got the room for free and paid for board and lodging and contribution to bills, but they got the room for free in return for getting me in and out of the car, which is one of the things I needed, getting the ironing board out, hanging my washing up, the very few things that I needed doing. But all my personal care stuff I could do for myself."

However, Ada's increasing assistance needs, in particular with 'personal care', due to having a progressive physical condition meant that at the time of interview this was no longer an option that she considered viable. As Ada's mention of her financial privilege suggests, another limitation of home-sharing arrangements is that they are also only accessible to disabled people who have stable housing with enough room for a 'homesharer' to live in.

Coele (2014) discusses the possibility of 'co-housing' communities (in which housing for individuals or families is clustered around shared facilities for both practical needs such as laundry and for communal social space (Brenton 2013)), as a potential solution for meeting the assistance and accommodation needs of older and younger generations respectively, which would alleviate some of the difficulties of home-sharing, such as tensions around the

boundaries between 'private' and 'shared' space (a problem shared by direct employers of PAs, especially those using 'live-in' arrangements (Woodin 2006)). While Coele's focus is primarily on older people with age-related impairments, she acknowledges that younger disabled people may also be interested in co-housing as an option. Her proposal that, to remain accessible to people with increasing assistance needs, co-housing communities "will need a certain proportion of accommodation to be available for people working full or part-time as overnight helpers for members who develop that level of need" (2014, p.77) has similarities with some early experiments in independent living by disabled people in the UK, notably the Grove Road housing project in Derbyshire (Davis 1981, 1990; Priestley 1999).

This project, set up in the late 1970s by a group of people with physical impairments seeking to get out of residential care (Davis 1990), consisted of a block of flats, built and owned by a local housing association, in which the ground floor flats were designed for disabled tenants and those above for non-disabled co-tenants, who agreed to provide "a background of personal help" (Davis 1981, p.322) in exchange for reduced rent. However, the non-disabled co-tenants were not expected to meet all the personal assistance needs of the disabled tenants, as they also made use of services provided by the LA and voluntary organisations (Davis 1981). The Grove Road project inspired other similar small-scale projects (some of which involved collective employment of PAs), was influential on deinstitutionalisation efforts by disabled people's organisations around the UK, and led to the formation of the pioneering Derbyshire CIL (see above and Chapter 2) (Davis 1990; Morris 1993; Priestley 1999). However, its founders Ken and Maggie Davis "soon found that they wanted more independence and moved on into ordinary housing" (Morris 1993, p.19), in which they presumably employed PAs directly as individuals, perhaps highlighting limitations of the co-housing model.

Another form of 'co-housing' for disabled and non-disabled people are the 'village' communities run by organisations such as Camphill and L'Arche, in which disabled people (typically people with cognitive rather than physical impairments) live and work alongside non-disabled people in 'family-like'

households (Lyons 2015; Randell & Cumella 2009). These communities tend to have strongly specific counter-cultural value systems, sometimes religious or 'spiritual' and often challenging fundamental values of 'mainstream' Western society, including the organisation of resources on the basis of wage labour (Cushing & Lewis 2002; Lyons 2015; Randell & Cumella 2009; Rhodes & Davis 2014). Their philosophies of support tend to emphasise mutuality and friendship (Cushing & Lewis 2002), long-term commitment (Felt & Walker 2000) and interdependence rather than independence (Kelly 2010b; Rhodes & Davis 2014). Some of these communities, such as the Camphill 'villages' in the UK, were traditionally financially self-sufficient through farming and selling of produce and small-scale craft industries, in which work (to the extent of one's capacity and with support where necessary) was treated as a community obligation for all, but no one, whether disabled or non-disabled, received a direct wage (Randell & Cumella 2009); however, they are now often financially supported by the LA-funded 'care packages' of the disabled residents (Rhodes & Davis 2014).

These communities are not led or controlled by disabled people, but by organisations that can be considered to fall within a paternalistic or charitable model of support provision. They are often referred to as 'intentional communities' (Lyons 2015; Randell & Cumella 2009; Rhodes & Davis 2014), but the extent to which they are truly 'intentional' in the sense of everyone involved actively deciding to join them, as opposed to being 'placed' there, has been questioned (Baggs 2009; Rhodes & Davis 2014), and they have been criticised as segregating disabled people from the wider community (Autistic Self Advocacy Network 2011; Greig 2015). In this there is arguably a continuity with the tradition of locating institutions for disabled people in rural areas (Ellis 2015). Disabled people who have lived in such communities have also reported oppressive treatment similar to that found in more typical closed institutions, including both specific instances of physical violence and routine denial of choice and control over day-to-day activities, including 'policing' of personal relationships between disabled residents (Baggs 2009; Lindsey-Halls 2014).

Village communities share with circles of support and 'shared lives' schemes several common features which contrast with the direct employment model of personal assistance: they tend to be based primarily around the assistance needs typical of people with learning difficulties or other types of cognitive impairments, as opposed to those of people with physical impairments; they tend to focus on the establishment or maintenance of personal relationships as primary needs that they are designed to meet (whereas these are enabled only secondarily by the direct employment model; see Chapter 4); and they tend towards emulating the family as an ideal structure for meeting care needs (McCrary 2017; Randell & Cumella 2009; Rhodes & Davis 2014; Hillman et al 2013). Many of these perspectives have similarities to the feminist ethic of care (on which see also Chapter 2) (Kelly 2010b; McCrary 2017), and similar arguments can be made in response to them to those that disabled people have made in response to some feminist care theorists (e.g. Silvers 1995; Morris 2001). In particular, these conflations neglect the importance of disabled people's consent to and control over the assistance they receive, which is profoundly essential to their achievement of (relational) autonomy (Graby & Greenstein 2016). McCrary (2017, p.297) critiques the 'family' ideal of the Geel 'boarder' system in terms also applicable to 'shared lives' schemes and 'village' communities:

> "inherent in the foster family system, modeling the parent–child relationship for which it is named, is a hierarchical organization. While the mutuality of care in Geel moderates its paternalism, the parent–child relationship remains."

This relational structure arguably positions disabled people as incapable of achieving the social status of 'true' adulthood, which is frequently equated with 'independence', particularly from one's family of origin (Ferguson & Ferguson 2001; Slater 2015), and thus implicitly treats assistance needs, particularly those typical of people with cognitive impairments, as mutually exclusive with the possibility of self-determination.

These models also often feature an ideological valorisation of informal community and deprecation of formalised services; for example, proponents of circles of support often regard 'natural' or 'friend-like' relationships as inherently preferable to 'paid support relationships' (Gold 1994, 1999; Worth 1999), a category in which staff working for LAs or agencies and directly employed PAs are placed without distinction. Similarly, the Shared Lives Plus organisation claims that it "aims to enable people to experience ordinary life, with real relationships, rather than to provide a service" (Shared Lives Plus n.d.b, no page number). The Camphill communities in the UK have recently been divided over plans to end the system of disabled 'villagers' sharing houses with non-disabled 'co-workers' and to require the 'co-workers' to become paid employees, which was regarded by many co-workers as fundamentally counter to the values of the community (Fearn 2014; Rhodes & Davis 2014).

Informal care collectives

Another alternative approach to meeting the day-to-day assistance needs of disabled people - distinct from most of the above in that it was originated by disabled people and in that it centres, at least in rhetoric, consent and relational autonomy - is the idea of informal 'care collectives', which has been developed in recent years by disabled activists in radical queer and anti-capitalist communities, particularly in North America. These collectives, of which the US-born and Canadian-based queer disabled scholar and activist Loree Erickson is a well-documented pioneer (Erickson 2008, 2015; Hande 2017; Hande & Kelly 2015; Hande & Mire 2013; Rainey 2011), typically consist of unpaid volunteers from within personal and/or political communities, and are associated with the intersectional activist framework of 'disability justice' (Hande & Kelly 2015; Hande & Mire 2013). This is often contrasted with older frameworks of 'disability rights' and independent living, which are seen from the disability justice standpoint as 'single issue' or lacking in intersectionality and focused primarily on the needs and experiences of the most privileged disabled people, typically white men with physical impairments (Berne 2015; Mingus 2011), and sometimes connected with a 'radical model' of disability seen as superseding the social model (Withers 2012).

Erickson, who has a physical impairment and extensive personal assistance needs, originally established a 'care collective' to meet those of her needs that were not met by inadequate funding for formal personal assistance, and also because she experienced homophobic attitudes from paid PAs (Erickson 2008; Rainey 2011), something that was also a concern for several employers who I interviewed with LGBT+ identities. Since moving to Canada, where she was not eligible for state-funded personal assistance at all due to her immigration status, Erickson has used care collectives, with a fluctuating membership of up to 50 people, to meet all of her personal assistance needs (Hande 2017; Hande & Kelly 2015). Anita, who had both worked as a PA (before acquiring a physical impairment) and employed PAs, was at the time of interview developing a similar collective, influenced by her experiences on both sides of the PA relationship:

"I've kind of set up something like a system of mutual exchange, where lots of people who need support and lots of people who can give support - not necessarily those people being separate people - kind of come together and kind of share resources between each other and find ways to kind of support each other, and most of these people that I've involved in that are friends, or people who I knew already, and I've kind of asked them to become involved because [of] shared politics… around disability, and race, and sexuality, gender"

While at the time of interview Anita was in the process of moving from a more typical model of recruiting and employing PAs to this system, and was paying all her PAs (including the friends and political comrades she had recruited) hourly wages from direct payments, she was considering different financial arrangements:

"What I had been thinking about is maybe having like a pot of money that lots of people put into, and then kind of distribute more fairly, according to who needs it, because a lot of people are interested in doing it as volunteers [because] as my friends they don't feel that

comfortable being paid to [do] stuff they would do for me anyway, and… some people are on benefits and they can't earn too much, and so that's something we need to kind of keep negotiating thinking about."

These ideas of informal, unpaid collective care, within a framework of egalitarian personal communities whose ethical model of care is based on the mutuality of friendship rather than on the hierarchical structures of the nuclear family unit, can arguably be traced back to LGBT community responses to the HIV/AIDS crisis of the 1980s-90s (Hande 2017; Hines 2007; Weeks et al 2001). Weeks et al (2001) document gay men taking friends with AIDS into their homes in what could be seen as informal 'homeshare' arrangements and an older lesbian arranging a rota of friends to assist her while recovering from surgery. In the present-day context, Hande (2017) similarly documents care collectives providing support for transgender people recovering from transition surgery, as well as many people with fluctuating impairments whose assistance needs may be intermittent and/or go unrecognised by authorities responsible for funding for formal personal assistance.

These care practices, because they are undertaken out of necessity by "marginalized groups who, due to social exclusion and a lack of resources, have found it necessary to build their own social networks and practices of care" (Hines 2007, p.467), are explicitly positioned outside of the social institutions of both the state and the nuclear family, which Hande and Kelly (2015, p.971) argue "are no longer predominately organized in ways that they will, or can, take on the care needs of most disabled and ill people". They can be regarded as attempts to prefiguratively build communities based on principles of mutual aid, which are capable of surviving without state services which are both unreliable and potentially more harmful than helpful due to being built on oppressive assumptions about those groups of people. This can be seen in Loree Erickson's care collective, which was established to meet her own immediate assistance needs, but was also conceived as a political project and has provided opportunities for consciousness-raising about disability and influenced activist organising in Toronto (Hande 2017). Anita similarly saw her

collective as having a potential broader political role in terms of mutual aid between disabled people:

> "I think I like this new idea, because what it does is not put the disabled person as always receiving, and actually the disabled community is really full of resources that can be shared with other people... there are some disabled people who have got direct payments, and have got DLA, and have had to fight for years to get those things in place, and there are other people who haven't got that support, and some way of like pulling together to make sure that everyone can receive some of the support, and also we can help people fight to get the resources they need from the state… even if you don't have a profession, or you haven't had an education, if you're a disabled people who employs PAs… you've got a real expertise, in terms of teaching other people how to get those resources and know how to use them"

Care collectives are, according to Hande (2017, p.74), "about forming new kinds of relationships that emphasized mutuality and reciprocity, rather than competition, charity and independence", which Hande associates with anarchist concepts of mutual aid (Kropotkin 2009; McKay 2010) and prefigurative politics (Gordon 2008). These relationships are seen by proponents of care collectives as forming the foundation of a "culture of care or interdependency" (Hande & Mire 2013, p.11) that radically rejects patriarchal and capitalist concepts of individual self-sufficiency. The critique of 'independent living' and the direct employment model of personal assistance made from a 'disability justice' viewpoint (e.g. by Loree Erickson and AJ Withers as quoted by Hande (2017, pp.72-3)) associates them with such "masculine" and "mechanistic" (p.73) ideas of 'independence', contrasted with interdependence and mutuality, and regards the view of PAs as the 'arms and legs' of direct employers as exploitative and dehumanising to PAs as workers.

Care collectives thus present a powerful challenge to elements of disabled people's movements that arguably uncritically accept narrow definitions of

'independent living' and neglect intersectional solidarity (including with the marginalized and precariously positioned people who often work as PAs; see Chapter 6); however, as a pragmatic means of organising the work necessary to meet disabled people's day-to-day assistance needs, they have limitations. If a care collective is to be organised by the person with assistance needs at its centre, large amounts of both organising work and emotion work by that person are needed to maintain it (Hande 2017; Hande & Kelly 2015); for example, Hande (2017, p.78) documents Erickson as "invest[ing] a huge amount of emotional energy into being warm, up-beat and inviting with the collective members that come for care shifts to give them something in return and ensure they keep coming". This may limit care collectives' efficacy as a political project by drawing time and energy away from other activities (Hande 2017), and it also means that they are more, arguably even only, an accessible option for those disabled people who have the social capital to easily recruit people to join their collective and the cognitive and emotional capacity to maintain the many and potentially complex relationships involved. Therefore care collectives may be inaccessible to many disabled people, perhaps particularly those with cognitive impairments, for some of the same reasons as being an employer of paid PAs.

Relations within a care collective may also be asymmetrical; non-disabled (or 'less severely impaired' in terms of assistance needs) collective members may not 'need' the collective in the same way as the person whose needs it is centred on, and may remain in it more out of a feeling of obligation than genuine commitment. This may result in exploitation of the unpaid labour of collective members, which may not be recognised as such because it is seen as outside the exploitative exchange relations of capitalism. Therefore, Hande (2017, p.77) argues that it is "important to emphasize that these radical forms of care alternatives are not solutions in and of themselves". Care collectives are thus perhaps better viewed as complementary to, rather than substituting for, direct employment of PAs (as Shakespeare (2000) argues about 'low-intensity support'). Supporting this, Anita saw her collective system not as an alternative to receiving direct payments to employ PAs, but as an alternative and potentially better way to use the resources that she had access to, saying that if she did not get direct payments:

"I would try and do this collective thing, but I don't really believe in like a big society answer to things, I kind of believe in the state, that the state should have - that as a society we should be collectively supporting people, through our taxes, which then goes into things like this."

This is reminiscent of the critique by Beresford (2016) of the voluntarism of models such as 'circles of support' *(which Hande (2017) seems at times to conflate care collectives with)*. Beresford argues that the idealistic rejection of all paid support relationships in favour of informal and voluntary ones "does not provide an adequate or reliable support system for everyone needing it" (2016, p.318), and easily fits into the conservative 'Big Society' agenda of replacing state-funded provision with voluntary action by and within communities, currently being revived in response to the crisis of local authority funding (Ryan 2018b).

While it superficially invokes values of empowerment and self-determination, the concept of the 'Big Society' is based on capitalist values of individual responsibility and is unlikely to have improved social inclusion for disabled people (Goodley & Runswick-Cole 2014; Greig 2015). Similarly, Hande and Kelly (2015, p.970) argue that care collectives, like other forms of 'DIY culture' created in response to the withdrawal of state-funded services and/or as prefiguration of a post-capitalist society, "can be neatly co-opted into the systemic, neoliberal austerity agenda as this informal care work is removed from the paid labour sector". For Beresford, a user-controlled system of formal, paid support, such as the direct employment model of personal assistance as it was originally envisaged, is ethically and pragmatically preferable to informal, unpaid support models because it "builds on the reality of a wage-based economy, while seeking to transform the nature of its relationships" (2016, p.319).

Conclusions

This chapter has overviewed a number of possibilities for arranging personal assistance outside of the direct employment model, with varying degrees of variance from it (though doubtless many other possibilities exist). All of these alternative models have both advantages and drawbacks in comparison to the direct employment model as currently practiced. Some, such as making DPOs or co-operatives rather than individuals the direct employers of PAs, do not fundamentally alter the core concept of the payment of PAs as waged workers who are answerable to the authority of the disabled person 'employing' them, and could be implemented within essentially the same funding system as exists today, though arguably additional funding might be needed for the administrative costs of the intermediary organisations. Conversely, while these models may help to overcome some of the administrative barriers faced by disabled people in employing PAs as individuals (see Chapter 7), they do not directly address the arguably greatest barrier of insufficient funding to employ PAs for enough hours and give them desirable working conditions.

Other alternative models, such as care collectives, 'circles of support' and some 'co-housing' models, challenge the direct employment model more fundamentally, by problematising waged employment itself as a means of delivering assistance. While this is usually motivated by one form or another of opposition to capitalism and its impact on human relationships, paradoxically the attempted separation of 'caring' labour from monetary exchange can result in it being deemed not worthy of payment. Some of these models, particularly care collectives and 'village' communities, can be regarded as attempts to prefigure an ideal non- or post-capitalist society (based on varying critiques of capitalism). In such societies, attitudes to disability and dependence would also be radically transformed, albeit in widely divergent ways; however, this prefiguration is necessarily small-scale and may not necessarily accurately represent what relationships of assistance might be like in a large-scale society based on the same principles. Some others, such as 'circles of support', can perhaps best be viewed as complementary rather than alternative to the direct employment of PAs.

Within each of these categories, there are examples of alternative personal assistance models which both are and are not run and controlled by disabled people (e.g. LAs as employers or workers' co-operatives of PAs versus DPOs or 'consumer' co-operatives as employers, and 'Shared Lives' schemes or 'village' communities versus radical care collectives); notably, it is those alternative models that are originated and controlled by disabled people that prioritise disabled people's choice and control over how, when and by whom assistance is delivered. This principle can thus be separated, conceptually and practically, from the direct employment model of personal assistance; the latter can thus be understood not as the universal answer to all barriers experienced by disabled people to maximising the autonomy of their daily lives, but as one part of a broad 'landscape' of support options. In this view, the extent to which a particular disabled person might use directly employed PAs or other options to meet their assistance needs could depend on that person's individual circumstances and preferences.

This is supported by the fact that, while aspects of some of these alternative models appealed to some interviewees, all of them (including Anne, who did not think disabled people should be the direct employers of PAs as individuals) wanted to defend the provision of public funding for personal assistance. In particular, Anita's plans for her in-development care collective show that tactics developed for survival in the absence of funding for personal assistance can also be used to organise the provision of assistance in a more collective and convivial way within the space of opportunity enabled by that funding. All alternatives to direct employment of PAs have the potential to be co-opted into establishment agendas that are ultimately hostile to the self-determination of disabled people; however, this can also be said of the direct employment model itself, which was successfully established in part because of its convergence with capitalist discourses of cost-efficiency (Pearson 2000; Spandler 2004).

It is, therefore, tactically necessary to avoid both uncritical defence of the currently existing direct employment model of personal assistance (which, as discussed in Chapter 7, has arguably never been fully implemented as it was originally intended) and dismissal of it as only and hopelessly capitalist. Both

the direct employment model and the possible alternatives to it occupy ambiguous positions between the emancipation of disabled people and the forces of capitalism and paternalism which, while both are opposed to emancipation, may also oppose one another (Dodd 2016). These ambiguities, arguably key to the whole issue of 'independent living', will be more fully explored in the concluding chapter of this thesis.

Chapter 9: Conclusions

The material presented in Chapters 4 to 8 represents only a small part of the data gained from my interviews. Many other aspects of personal assistance as a job and as a relationship were discussed by my participants and could not be included in this thesis due to length and time constraints. I hope to cover at least some of this unexplored material in additional publications in the future. However, the themes which have been showcased in this thesis were among the major concerns of the PAs and direct employers who were interviewed, and all can be related to the central concept of autonomy and its potential contradictions. In this concluding chapter, I summarise my findings, synthesizing the themes explored in Chapters 4 to 8 and connecting them back to the initial research questions set out in Chapter 1 and to the background concepts introduced in Chapter 2. I then end with recommendations for public policy, for future research and for activist practice in the Disabled People's Movement.

Summary of key themes and findings

Autonomy was a core theme of the entire thesis. **Chapters 5 and 6** both focused on aspects of the occupational status of PAs' work which, in different ways, connect to autonomy. In examining the discursive uses of the word 'professional(ism)' in reference to the appropriate role of PAs, **Chapter 5** revealed complex connections to concepts of autonomy within work and associated dynamics of power and authority. The positively normative use of the word tended to refer to norms of conduct appropriate to the role of PA, such as confidentiality or not volunteering opinions unless asked for them, in contradiction with the traditional meaning of 'professional' as possessing expertise and authority, associated with the 'professions allied to medicine' (Finkelstein 1999a, b), which was generally used negatively to refer to an undesirable quality. PAs were contrasted to members of 'helping professions' within this paradigm as having a fundamentally opposite power relationship with disabled people receiving their services. Traditional professions are characterised by a higher degree of autonomy over decision-making within work

than other occupations (Freidson 2001; Witz 1992), which in the case of those providing necessary services can translate to the authoritarian exercise of power over service users which denies their autonomy in daily life decisions (Davis 1993; McKnight 1977). In contrast, in the direct employment model of personal assistance, it is the disabled person receiving assistance services who is given the authority of an employer over employees, reversing the power relationship. In this case norms of 'professional' conduct by PAs correspond to the aims of the direct employment model and refer to behaviour that maximises the autonomy of direct employers in their daily living activities. Thus whether PAs can be considered to be a 'profession allied to the community', as Finkelstein sought to establish, depends on the meaning of 'profession' being used.

The desire of some PAs for their work to be seen as a 'profession' (rather than as a casual or trivial job) can be viewed in several ways (all of which are interconnected and not mutually exclusive): as a desire for more autonomy or control over their own work (arguably at the expense of direct employers), as a desire for more recognition of their work as skilled and socially important (and connectedly for it to be rewarded with better pay and conditions), and/or as a desire for formal training, qualifications and a structure of career progression. The latter would arguably make the job more appealing both to potential applicants and to existing PAs as a long-term option, consequently improving stability for direct employers and reducing the need for continual recruitment of new PAs. Some direct employers could, however, perceive this as a threat to their own autonomy, arguably in part due to cultural associations with professions allied to medicine and professional authority.

PAs' desires for 'professionalisation' are obviously related to the low status and lack of social recognition given to their work, which was the focus of **Chapter 6**. This manifests both in low rates of pay and precarious material conditions and in PAs' work being perceived as 'dirty' and demeaning, meaning that elements of both maldistribution and misrecognition (Dodd 2016; Fraser 1995) are present. This bivalent devaluation can be directly connected to the similarly bivalent oppression of disabled people, which was recognised by participants,

as for example when Anita said that PA work was "seen as a rubbish job because disabled people are seen as kind of rubbish people". In the material (distribution) dimension, the low rates of pay for PAs derive directly from the inadequate provision of financial support given to disabled people, exacerbated by disabling cultures of distrust and paternalism within assessments of needs. This is rapidly worsening due to the political economy of austerity that has been pursued by governments in the UK since 2010, as discussed in **Chapter 7**.

In the cultural (recognition) dimension, the lack of understanding by the general public of the role of a PA or what distinguishes a PA from a 'carer' can be related to the conflation between decisional autonomy and 'independence' (perceived in terms of self-sufficiency) discussed in Chapter 2. The role of a PA in supporting the 'independent' (defined as autonomous) life of a person perceived as essentially 'dependent' due to their impairments being incompatible with self-performance of daily living tasks that it is culturally normative to do for oneself (such as eating, dressing or using the toilet) can only be understood as distinct from the paternalistic role of an institutional 'carer' if the distinction between these meanings of 'independence' is understood. Without such an understanding, 'dependency' is assumed to be an individual characteristic and a negative thing to be avoided because it is seen as incompatible with self-determination (an assumption which is bound up with the fundamentally disablist values of capitalism and patriarchy). Work associated with such a 'self-evidently' undesirable condition is then easily perceived as itself necessarily unpleasant and degrading. These two dimensions of devaluation are of course interconnected, meaning that strategies to overcome them must necessarily also be so (Dodd 2016).

The mutual impact of scarcity of funding (and of other forms of administrative supports) directly connects the precarity of PAs' work to the precarity of direct employers' (and all disabled people's) daily lives (Bates et al 2017). Together with the bidirectional dependence in the PA/employer relationship (direct employers depending on PAs for assistance with daily living needs, while PAs depend on direct employers for income), this reveals a key difference between directly employed personal assistance work and many, if not all, other forms of

waged labour. The power relations between waged workers and employers are generally assumed to be unidirectional, with employers having structural power over workers. While anti-capitalist activist rhetoric frequently focuses on the potential power of workers (particularly in the context of exercising power through the refusal of work, such as in a strike) and the dependence of employers on their labour, this potential power is not typically realised in the contemporary context, and realising it requires large-scale collective action. In contrast, PAs have very significant power over their direct employers on an individual level, which is mitigated both by the wage relationship making dependence mutual and by ethical norms of the occupation (derived from the social model of disability and 'independent living' principles) giving the direct employer authority on the basis of a right to self-determination. Additionally, both PAs and direct employers typically occupy social locations which are marginalized in capitalist society (Cranford & Miller 2013).

As a result of this, while some of the interests of PAs and direct employers remain potentially antagonistic towards one another (such as when a PA wants to work shorter shifts but their employer needs them to work for longer), this is often due to conditions of scarcity which are neither desired by nor under the control of either employer or PA. Both parties in the personal assistance relationship are often positioned in struggle not against one another but jointly against state funding structures which have power over both of them. There is therefore the potential for genuine solidarity between direct employers and PAs which is unlikely to exist between employers and employees in most other contexts, something which both PAs and direct employers among my interviewees experienced and recognised (for examples see the final section of Chapter 6). This is arguably reflected by the mutually supportive and sometimes emotionally significant relationships which can exist between direct employers and PAs, which were the subject of **Chapter 4**.

In this chapter I examined the effect of the direct employment model of personal assistance on relationships, including the relationship between PAs and direct employers as well as the other relationships of direct employers and, to a somewhat lesser extent, PAs. A key concept here was that of friendship, in

particular the framework of 'paid friendship' developed by Woodin (2006). The importance of friendship has arguably been overlooked in comparison to sexual and nuclear family relationships (M. Barnes 2012; Shakespeare 2014); however, it is frequently of central importance in disabled people's lives (Shakespeare 2014; Worth 1999), perhaps even more so because disabled people may less easily fit into the normative frameworks of other relationships. Friendship has also been argued to be a potential source of resistance against capitalism and other oppressive social systems because it "can provide certain thematic elements necessary for a politics of solidarity" (May 2012, p.124), including space to confront entrenched social norms and a model of egalitarian, non-hierarchical political relations, in contrast to both traditional family relationships and many forms of formal 'care' (M. Barnes 2012). The lack of access to friendships experienced by many disabled people, who are frequently socially isolated (Shakespeare 2014; Welsby & Horsfall 2011), can thus also be seen as exclusion from political participation.

PAs may help to overcome these barriers in two significant ways: firstly, the provision of personal assistance can remove unequal burdens of 'caring' labour placed on friends, partners and family members of disabled people (Keith 1992; Morris 1993), meaning that direct employers are enabled to participate reciprocally in relationships on an equal basis with people who do not need the same types of assistance with daily living activities. This can also enable them to become (or remain) 'givers' as well as 'receivers' of 'caring' labour, whether as parents or in other relationships. However, there are also situations in which the presence of PAs may inhibit the development or maintenance of direct employers' other relationships; thus there may be complex interpersonal dynamics to negotiate for both parties. In particular, it is often counter-intuitive, and may be disturbing, for others when a PA is physically present but a 'non-participant' in social interactions. Secondly, relationships with PAs may themselves be emotionally significant for some disabled people, perhaps particularly those who are lacking in other close relationships and/or those whose assistance needs are cognitive rather than physical in nature (Callus 2017; Williams et al 2010). However, this may be problematic if perceptions of the nature of the relationship do not match between employer and PA.

Paid friendship is distinct from typical 'social' friendship (Woodin 2006), and arguably does not possess the features of 'true' friendship that May (2012) argues give it its potential as a basis of radically transformative social values, such as reciprocal openness to constructive challenge of decisions and opinions. However, the friendship-like qualities of the personal assistance relationship, in comparison to both other employer-employee relationships in the world of waged work and to other means of meeting the 'dependency' needs of disabled people, arguably contribute to its potential for mutual aid and solidarity. The paid friendship aspect of personal assistance work thus arguably troubles normative assumptions about employment as a transactional relationship in which one party temporarily sells their autonomy to another in exchange for payment, adding another dimension to the unusual possibility for solidarity between employers and employees found in personal assistance work.

Woodin (2006, p.256) argues that taking a paid friendship stance may be "associated with increasing personal control and autonomy" on the part of direct employers. Many critiques of the direct employment model of personal assistance (e.g. Rivas 2002; Twigg 2000; Ungerson 1999) have started from the assumption that directly employed PAs are likely to be particularly acutely lacking in autonomy, even among waged workers (and relatedly that there is a zero-sum relationship between the autonomy of the providers and recipients of 'caring' labour). However, this is directly contradicted by the assertion of many PAs interviewed in my research that they perceived their work as PAs as subjectively more autonomous than other waged work they had done, to the extent that for some it did not 'feel like work' at all ('work' here being implicitly defined as work that is only done for payment, without intrinsic motivation). While this can be related to emotional labour (Hochschild 1983) being performed by PAs, as described in **Chapter 5** (arguably representing a form of 'false consciousness' in which PAs identify more with their employers' needs, desires and emotions than with their own), there is a significant difference between personal assistance and other occupations involving emotional labour, which is the bidirectional rather than unidirectional nature of that emotion work

(which thus may not accurately constitute 'emotional labour' in Hochschild's sense of emotion work performed for a wage). This reflects the similarly bidirectional relations of power and dependence within personal assistance, as compared to other waged work.

This can be connected back to the feminist concept of relational autonomy, as discussed in Chapter 2. In this reconceptualisation of autonomy, dependence on others is not incompatible with autonomy, but indeed in stronger versions of the argument is a necessary precondition for it (Arneil 2008; Nedelsky 1989). Autonomy is thus achieved within supportive relationships which are mutually consented to (Graby & Greenstein 2016). Viewed through this lens, the subjectively felt greater autonomy of directly employed PAs than workers in other sectors of employment (such as shops or restaurants) or in other jobs within the 'care sector' (such as nursing homes or care agencies), as strongly expressed by those PAs who had also done such other jobs, arguably derives from the mutually supportive relationships which often existed between PAs and direct employers (perhaps particularly those who took more of a 'paid friendship' approach to their employment of PAs). As described in Chapter 4 and also reported in other research (e.g. Browne & Russell 2005; Shakespeare et al 2017), direct employers sometimes provided significant practical and emotional support to PAs. Thus it is not necessarily paradoxical that the direct employment model of personal assistance can increase the subjective autonomy of both PAs and employers.

This is not to say that the direct employment model of personal assistance is perfectly liberating for both disabled people and PAs. Both direct employers and PAs among my interviewees reported controlling and abusive behaviour from PAs and direct employers respectively, as well as more general frustration and dissatisfaction with personal assistance relationships. However, as argued in **Chapter 7**, many of the problems experienced by both PAs and direct employers are arguably not inherent in the direct employment model itself (as envisaged by the DPM activists who developed and originally promoted it), but are caused by failures in its implementation, which in turn are largely the result of the cultural and material devaluation of disabled people and work connected

with them. For example, restrictions on the hours and/or tasks that people could employ PAs for, due to inadequate funding and/or attitudinal barriers in the assessment of assistance needs, frequently resulted in the effective loss of the day-to-day autonomy that personal assistance was intended to provide. Struggles to maintain levels of funding and fears of losing it also inhibited direct employers' ability to feel secure and plan for the future, while also putting PAs at risk of redundancy or insufficient income to viably stay in the job. For some direct employers, differences in provision between local authority areas meant that their freedom of movement was restricted because they did not consider it safe or viable to leave their current home LAs for fear of losing funding. The lack of adequate support with administrative aspects of employing PAs, such as taxes or insurance, was also a serious concern for many direct employers.

Thus it was difficult for many participants to think in terms of critiques of or potential alternatives to the direct employment model, because insufficient funding and other barriers to the day-to-day functioning of that model were much more pressing concerns. Answers to the question of "what could be changed about personal assistance?", rather than speculation about alternative models, thus generally took the form of requests for greater and more secure funding or the provision of support for direct employers with management of funding, recruitment of PAs or other administrative aspects of being an employer. As with many other issues affecting disabled people in the contemporary political and economic climate (such as cuts to 'income-replacement' benefits or the lack of accessible social housing), there was a perception that so much energy had to be invested in fighting losing battles against the removal of necessary, if flawed, existing provision that there was little or none left over for looking beyond that to an 'ideal world' situation. Austerity, and in particular the escalating crisis of local government funding (Graby & Homayoun 2019), are therefore necessary context for any critical discussion of personal assistance and/or 'independent living' in the present-day UK, and scholars examining it must balance critique with defence of critically (in the other sense of the word) endangered services.

Nonetheless, the direct employment model of personal assistance does have some problematic or paradoxical aspects when viewed through an anti-capitalist lens, which cannot easily be reduced to barriers to its 'proper' implementation. Foremost among these is the deeply ambiguous position of waged employment within analysis of disabled people's oppression and social exclusion and in strategies for achieving their inclusion and/or liberation (Abberley 1996; Graby 2015, 2016). The establishment, during the transition in the Global North from agrarian feudal societies to industrial capitalist ones, of a standardised relation of waged workers to employers, accompanied by normative assumptions about the capacity for labour of the 'standard' (assumed male and 'able-bodied') person, is regarded by many authors as the foundation of the disablement of people with impairments, at least in its modern form (Davis 1995; Finkelstein 1980; Gleeson 1999; Oliver 1990). It has also been argued to have been influential on the social construction of 'independence' as a positive value and the devaluation of 'caring' labour and the women who typically perform it (Federici 2004; Fraser & Gordon 1994). (The connections of these processes with racialisation and imperialism (Erevelles 2011; Federici 2004), though requiring acknowledgement, are regrettably beyond the scope of this thesis.) Responses to this from the DPM have ranged from calls for the inclusion of disabled people in the mainstream labour market through the use of assistive technology (Gibbs 2005; UPIAS 1976) - and implicitly also personal assistance - to arguments that a society that genuinely includes disabled people must fundamentally refuse the valorisation of work as an ethical necessity (Abberley 1996; Graby 2015; Richter 2017; Taylor 2004).

However, by advocating the direct employment model of personal assistance, the DPM embraces waged employment, albeit with disabled people as employers rather than as employees, as a means to disabled people's emancipation. It has been argued that the employment of PAs by disabled people can be characterised as an alternative form of contribution to the 'work economy' rather than as dependence on the state (C. Barnes 2012; Prideaux et al 2009); however, this still represents an acceptance of the wage labour economy as a system that disabled people must find a place in, despite its responsibility for their oppression. This leaves a dilemma for disabled people

and allies whose desired social transformation is the abolition of capitalism rather than inclusion within it (particularly if their political philosophy is anti-hierarchical and/or anti-authoritarian as well as anti-capitalist): if an employer-employee relationship with PAs is necessary for the realisation of autonomy in everyday life for disabled people with significant assistance needs, how can this be reconciled with ultimate opposition to waged employment as a whole on the basis that it denies autonomy to both those exploited and those excluded by it?

Thus in **Chapter 8** I examined alternative models of meeting disabled people's assistance needs, some of which may be seen as more fitting with an anti-capitalist conception of relational autonomy than the direct employment model of personal assistance. All these alternative models, however, have their own flaws and ambiguities. Some, such as the potential use of DPOs or co-operatives (instead of individuals with assistance needs) as the formal employers of PAs, do not directly challenge the waged employment economy or the positioning of PAs as employees, though they may at least partially resolve some of the practical and relational difficulties faced by disabled people as individual direct employers. Others, such as some forms of 'intentional communities' and 'care collectives', appear to more explicitly challenge capitalist relations of exchange and employment, though arguably from idealist rather than materialist perspectives (Hande 2017). Communities such as Camphill and L'Arche, while ostensibly based on principles of equality and rejection of social hierarchies of disabled and non-disabled or 'giver' and 'receiver' of services, in practice tend to work according to paternalistic ethics of care which do not prioritise choice and control for disabled people over their daily lives, and to remain controlled by non-disabled people. They also share with other non-employment-based support models, such as 'circles of support' and 'shared lives' placements, a valorisation of the voluntary which is easily co-opted into neoconservative and individualistic cost-cutting agendas (Beresford 2016).

The 'care collectives' developed in radical 'disability justice' communities in North America share some aspects with these models, such as an intentional use of voluntary rather than paid support because it is seen as less dehumanising and exploitative (Hande 2017). However, they differ in that they

were created by disabled people within the context of a disabled people's movement, with an intersectional and explicitly anti-capitalist anti-oppression politics. Care collectives arguably take the political ethics of friendship and the ideas of relational autonomy and interdependence which I have argued are latent in personal assistance to their logical conclusion, entirely displacing the capitalist logic of waged employment which arguably exists in dialectical tension with them in the direct employment model. While one direct employer who I interviewed, Anita, was exploring the potential of this model for meeting her own assistance needs, her views on it were ambiguous, as she felt that it was not a viable replacement for state funding for personal assistance. This highlights ambiguities around the role of the state in relation to disabled people's oppression and potential liberation, which has been under-theorised in Disability Studies (Hande 2017), but which there is regrettably not space to fully consider here. However, it is worth acknowledging that the assumption made in much of Disability Studies and DPM politics, in the UK and elsewhere in the Global North, that the state can be reclaimed as a benevolent provider of services rather than a fundamentally capitalist and imperialist vehicle of exclusion reflects white privilege and 'Northern' citizen bias (Berne 2015; Gorman 2016).

Another ambiguity is around the concept of the freely given gift, which is central to many anti-capitalist, in particular feminist, visions of alternative economies (Vaughan 2007), but which, particularly in the context of assistance with essential daily living needs, may justifiably be viewed by disabled people with suspicion due to the history of segregation and misrepresentation in the name of 'charity' (Drake 1996; Withers 2012). For people with either direct lived experience or political consciousness of these histories (and continuing realities) of paternalistic treatment of disability as an 'individual tragedy' (resistance to which was a major element of the development of the DPM in the UK), the mutual dependence of PAs on direct employers for income may be seen as a necessary element in the shift in the power balance between disabled person and 'carer'. This can be viewed as the strategic use of one hierarchical and inegalitarian element of capitalist society to counter another. A move towards a voluntary or fully friendship-based model could thus be viewed as a step backwards into non-autonomous dependence on the benevolence of non-

disabled people. A care collective model based on mutually supportive friendships and voluntary networks of solidarity also requires disabled people to have such friendships and networks, which is problematic given that social isolation is a well-documented aspect of disablement (Shakespeare 2014; Welsby & Horsfall 2011). The organising and emotion work needed to establish and maintain such a collective may also be impossible for people with some types of impairments.

While it does not necessarily resolve these tensions, it is arguably useful in pragmatic terms to view 'care collectives' and similar voluntaristic forms of support as complementary, rather than alternative, to the direct employment model of personal assistance (Hande 2017). In this framing different approaches to meeting assistance needs are not necessarily antagonistic to each other, but can coexist in a pragmatic pluralism, much as potentially contradictory models of disability, such as the social model and the affirmation model, have been argued to instead be complementary to one another as 'tools' appropriate for different tasks in the struggle for liberation (Cameron 2008). Both the direct employment model and the possible alternatives to it thus occupy ambiguous positions between the emancipation of disabled people and various disabling societal systems, with each having its own risks of co-optation which may be mitigated by the use of complementary strategies.

In(ter)dependent living revisited

Proponents of care collectives and associated ideas such as 'disability justice' criticise the older DPM concept of 'independent living' as lacking in intersectionality, stemming from the particular experiences of white, primarily male disabled activists with a narrow range of impairments, and erasing the providers of assistance, who are typically marginalised women, through the idea of PAs acting merely as the 'arms and legs' of disabled people (Hande 2017). This critique parallels that of some non-disabled feminists (e.g. Rivas 2002). As explored in Chapter 4, this philosophy of 'impersonal' assistance is in fact rejected by many direct employers who prefer a paid friendship approach, despite its perceived status as an orthodoxy of the DPM (Marfisi 2002; Vasey

1996). Hande (2017) cites Loree Erickson, a pioneer of care collectives, arguing that the 'arms and legs' approach was a reaction against previous dehumanising institutional models of 'care', which did not feel adequate for her present-day situation of having complex and often mutually supportive relationships with 'caregivers'. This same argument was made by Anne, a direct employer I interviewed who strongly embraced the paid friendship approach of relating to PAs, to differentiate her relationship with her PAs from that of many people in the DPM, whose experiences of struggling against segregation and institutional provision did not match with hers as someone with assistance needs acquired in adulthood through chronic illness.

This framing of 'independent living ideology' (Shakespeare 2014) as a (potentially over-) reaction against the most severe forms of paternalism can be connected to the arguments of Dodd (2016), building on Fraser's (2013) critique of Polanyi (1944), about the polarisation of 'marketisation' and 'social protection' as forces which sometimes oppose one another, but can both be opposed to emancipatory struggles against domination in both social and economic spheres. While Polanyi - writing at the time of the birth of the welfare state - identifies 'social protection' as a positive force opposed to the "ravages of the free market" (Dodd 2016, p.159), Dodd follows the argument of Fraser (2013, p.229) that this binary juxtaposition "tends to whitewash forms of social protection that are at the same time vehicles for domination", including the paternalistic oppression of disabled people by institutions within the welfare state. A truly emancipatory movement must thus be "against domination in both the market and society" (Dodd 2016, p.160), reflecting the bivalency of disabled people's oppression involving both economic and socio-cultural elements.

Through this lens it is possible to re-examine critiques of independent living and the direct employment model of personal assistance from 'left' or anti-marketisation perspectives (see also Chapter 2), for example Richter's (2017, p.160) argument that "instead of recognizing that disability, as a concept, requires interdependence, an ideology of independent living left the atomized capitalist notion of individualism stable" and Pearson's (2000) characterisation of direct payments as involving conflicting 'market' and 'social justice'

discourses. Independent living is undoubtedly, from the point of its proponents within the DPM, a movement for emancipation and social justice (see for example Morris's (1993) principles of independent living as quoted in Chapter 2). However, its invocation of 'independence' as a positive value has made it amenable as a concept to capitalist as well as socialist political tendencies (Barnes 2007b), especially when 'independence' in the sense of decisional autonomy has been insufficiently disambiguated from 'independence' in its more conventional meaning of self-sufficiency, thus allowing for the erasure and devaluation of the work of PAs and the illusion of complete 'authorship' by direct employers of tasks done by or in collaboration with PAs (Rivas 2002).

In the UK, it was Conservative-controlled councils which first embraced the possibility of giving disabled people money to directly employ their own PAs and a Conservative government which passed the Community Care (Direct Payments) Act in 1996, enabling the direct employment model to become part of the mainstream of UK disability policy (Pearson et al 2005). This was in part because of evidence that direct payments were cheaper than institutional provision (Zarb & Nadash 1994), but was also arguably because direct employment of PAs fitted well with conservative political rhetoric about individual responsibility and with moves away from direct state provision and towards the greater involvement of markets in social services (Finkelstein 2007; Pearson 2000). In contrast, Labour-controlled local authorities in the North of England and Scotland were more suspicious of direct payments, viewing them as "a means to further erode public sector provision of services" (Pearson 2000, p.463). Trade unions in countries including Sweden and Canada have similarly opposed moves towards direct employment of PAs because of fears that it would lead to increased exploitation and disempowerment of workers (Bowman 2001; Cranford 2005; Spandler 2004; see also Chapters 6 and 8).

Independent living ideology and the direct employment model of personal assistance can thus be seen as strategies for emancipation which are positioned against the oppressive aspects of paternalism and social protection, which were at the forefront of disabled people's experience at the time of the formation of disabled people's movements in the UK, US and other 'Global

North' countries. This was a period in which Fordist labour norms and the post-war welfare state consensus were still in operation (Beresford 2016; Neilson & Rossiter 2008). The domination of the economy by manual work meant that disabled people with physical impairments were those most obviously excluded from it, and thus it was people with physical impairments and the types of assistance needs associated with them who developed, through organisations such as UPIAS (the Union of the Physically Impaired Against Segregation), the political analysis and campaign goals of the nascent DPM. Therefore, movements for independent living, and the models of personal assistance that they developed, were centred around the particular assistance needs of people with severe physical (but no cognitive) impairments, and opposed to paternalistic forms of 'care' which they particularly wished to distance themselves from. This has sometimes resulted in the explicit or implicit exclusion of people with cognitive impairments from independent living movements (Kelly 2016; Montgomery 2001).

Changing political and economic conditions in recent decades have shifted the balance between marketization and social protection as the dominant opposing forces to disabled people's emancipation (Dodd 2016). As I have previously argued with regard to work and income-replacement benefits (Graby 2016), this has meant that the impairment demographics of disablement in the UK have shifted, with people with cognitive, 'hidden' and/or fluctuating impairments among those most severely affected by disablist austerity policies, but frequently among the least represented in traditional DPOs. Attitudes towards impairment and its place in the social model, as well as towards formal services (which many of the aforementioned people are either unable to access or do not view as appropriate or relevant to their needs), have thus diverged between older and newer generations of disabled activists, which can be connected with the development of ideas like care collectives as forms of mutual aid developed without expectation of state-provided assistance. It is notable here that an impetus for the development of Loree Erickson's care collective was the unavailability of formal personal assistance services to her as an immigrant in Canada (Erickson 2008; Hande 2017).

The problem with 'independent living' in current political and economic conditions is that its emphasis on opposition to paternalism can easily be recuperated by capitalism. While the coincidence of market and social justice discourses described by Pearson (2000), or of marketization and emancipation in Dodd's (2016) terms, was useful to the DPM as an alliance against a joint enemy of authoritarian and paternalist welfare state institutions, it has arguably diminished the ability of the DPM to respond effectively to new conditions of disablement which are characterised primarily by extremes of marketization. Indeed it is notable here that much of the most visible opposition to disablist austerity on its introduction to the UK came from charities typically opposed by the DPM on grounds of their association with paternalistic social protectionism. There have also been notable examples of disabled people campaigning, largely outside established DPOs, to oppose the closure of segregated provision (such as 'care homes' and day centres) that would previously have been campaigned against, because they were not being replaced with more inclusive and autonomy-supporting provision, but simply removed to leave disabled people in isolation with no formal support (Brindle 2018; Elkes 2018).

There is therefore a need to re-articulate the concept of 'independent living' so that it explicitly embraces interdependence and acknowledges the labour and the personhood of PAs (and others who provide support to disabled people out of solidarity or mutual benefit rather than out of pity or paternalism), while refusing to abandon the value of autonomy and consent in daily living. This rearticulation needs to avoid two pitfalls: firstly, the history of movements for independent living must not be written off as merely an individualistic, patriarchal and/or capitalist movement (though its biases and implicit exclusions must be acknowledged); critique must be constructive rather than destructive, and should seek to expand independent living to live up to its principles (Morris 1993) and genuinely include disabled people of all impairment groups and intersectional social locations, rather than abandoning it as the preserve only of relatively privileged disabled people (i.e. white men with stable physical impairments). Secondly, the movement must openly acknowledge that autonomy is necessarily relational (whether for disabled or non-disabled people), and thus must not portray 'independence' as equating to self-

sufficiency in either physical, cognitive or emotional resources, or imply that only a purely instrumental relationship with PAs is compatible with independent living.

It may or may not be preferable to retain the phrase 'independent living' itself. It is noteworthy that in the UK those CILs with more socialist foundations in local politics defined themselves as Centres for 'Integrated' or 'Inclusive', rather than 'Independent Living', although in practice these were often conflated due to the identical acronym. To return to the frequently made point emphasised in Chapter 2, 'independence' in the sense of self-sufficiency is impossible for anyone, and the illusion that anyone has it is only made possible by a distinction between 'normal' and 'abnormal' dependencies which categorises only the latter as dependence and erases the former (Erevelles 2005; Finkelstein 1980; Montgomery 2001; Morris 1991; Withers 2012). Interdependence is therefore a universal condition of humanity. Thus it can be argued that 'interdependent living' could be a better term than 'independent living'.

Interdependence has been championed as a value that could or should replace 'independence' by some proponents of the feminist ethics of care (e.g. Kittay 1999; Sevenhuijsen 1998) and by some post-structuralist authors within Disability Studies (e.g. Gibson 2006; Hughes et al 2005; Shildrick 2009). However, this is also problematic, because such framings tend either to ignore the oppression both of disabled people and of 'care' workers that is often a component of such dependency relations, or to conflate it into a single effect on both parties without distinction, and because without a clear assertion of the value of autonomy, the importance of choice and consent in the receipt of assistance can be lost (Graby & Greenstein 2016; Hande 2017). This is arguably the same conflation as that of 'independence' with self-sufficiency, but from an opposite ethical perspective. It is therefore necessary to clearly distinguish autonomy from independence, so that (rightly) rejecting the latter as impossible does not abandon the former.

Thomas (1999) disambiguated the 'true' social model definition of disability, described more accurately as a 'social relational definition of disability', from the

misleading 'property' definition which conflates incompatible social and individual model understandings of what 'disability' is. Similarly, the 'true' value of 'independent living' can be better defined as 'autonomously interdependent living', disambiguated from misleading understandings that conflate two contradictory understandings of 'independence'. As with the social model, 'independent living' is arguably a term too entrenched within the DPM to be easily replaced; however, it may be possible for it to be clarified. An understanding of 'independent living' as 'autonomously interdependent' living can accommodate preferences for more friendship-like relationships with PAs without contradiction, as 'true' friendships can also be characterised as both interdependent and autonomously or consensually chosen relationships. Autonomously interdependent living can also be viewed as the basis of a potential future society without capitalism or social hierarchies, while still being applicable to both activist organising and daily survival within presently-existing capitalist society.

Automation, robotics and artificial intelligence in personal assistance

An issue which has not been covered in this thesis is the possibility of automation of personal assistance work. This was not explicitly discussed in any of my research interviews, but it is worth briefly engaging with as it is connected to themes of autonomy and independent living as covered in Chapter 2, to themes of 'care' and relationships as covered in Chapter 4 and to themes of precarious work as covered in Chapter 6. As discussed in Chapter 2, assistive technology and personal assistance can and should be seen as complementary rather than opposed to one another, despite the fact that reliance on technology rather than on assistance from other people can be perceived and promoted as a greater degree of 'independence' (French 1993; Sheldon 2001). Some assistive technologies have been developed with the explicit aim of reducing disabled people's 'dependence' on human assistance (see for example Hari Krishnan & Pugazhenthi 2017). However, technological developments in more recent years have raised the potential of (at least some of) the tasks typically performed by PAs instead being carried out by robots or other technologically advanced devices. So-called 'social robots' have already

been developed to carry out tasks such as household cleaning, lifting and carrying people, and monitoring accidents and medical issues, particularly for elderly people in residential settings, but have not yet become widely available (Kantorovitch et al 2014; Wolbring & Yumakulov 2014).

These developments may be seen in the context of a broader trend towards automation of tasks currently or formerly requiring human labour which has, since at least the early 1980s, been connected to the precaritisation of work and potential 'post-work' futures (Frase 2016; Gorz 1982). Concerns have been raised about the potential for paternalistic coercion of the use of robotics and other forms of 'intelligent' technology in social care (Wolbring & Yumakulov 2014). Advanced technology is thus neither necessarily good nor necessarily bad for disabled people; it has the potential to contribute either to their liberation or their oppression. This parallels Frase's argument that the automation or 'robotization' of much existing 'unskilled' labour is neither inherently good nor bad for workers, but whether it has positive or negative effects depends on the ownership and control of it.

The use of robots to carry out personal assistance tasks could be seen as potentially resolving the dilemmas around the autonomy of disabled people being in conflict with that of PAs as workers (as discussed in Chapter 2), as robots do not have human emotions or 'free will' (Wolbring & Yumakulov 2014). This is arguably supported by accounts of direct employers treating PAs, or desiring them to act, 'like robots' (Guldvik et al 2014) or using similarly instrumental or 'mechanical' terms to describe their preferred relationship with PAs (Shakespeare et al 2018; Yamaki & Yamazaki 2004). However, as seen in Chapter 4, this attitude is by no means universal among direct employers. Pols and Moser (2009) argue that, despite the commonplace opposition of 'cold' technology to 'warm', caring human support, users of assistive technologies may in fact have a wide variety of emotional relationships with such devices, with 'social robots' functioning as 'pets' or 'companions' for some people as much as doing practical 'care' tasks. These differences in attitudes and relationships parallel the range of stances taken by direct employers towards PAs (Woodin 2006).

Anecdotally, some disabled people may prefer some of their assistance needs to be met by a machine rather than by a person because of issues such as social anxiety making continual interaction with multiple people exhausting or feelings of shame, guilt or embarrassment about receiving help with specific tasks from another person. This suggests that automation of personal assistance could reduce the level of emotion work needing to be done by direct employers (Cranford & Miller 2013; Shakespeare et al 2017). However, in a conversation some time after the interviews for this research were conducted, one friend who I previously interviewed as a direct employer told me that they would prefer this if it were possible, but any robot with complex enough artificial intelligence to do everything they required PAs to do would have to have essentially all the cognitive capacities of a human. While such robots do not currently exist outside of science fiction, this raises the speculative consideration that if they did exist they would arguably deserve the same rights and freedoms as 'real' persons, and thus their use would not in fact resolve the tensions between the autonomy of disabled people and that of PAs, and might indeed exacerbate them.

Relationality, as opposed to simple instrumentality, is arguably a necessary core of personal assistance (Kelly 2016; Shakespeare et al 2017). Therefore, whether the tasks are carried out by human PAs or by hypothetical autonomously intelligent robots, personal assistance, like many other forms of 'caring' labour, is arguably part of the "irreducible core of heteronomous activities" which Gorz (1982, pp.94-95) argues will remain even in a maximally autonomous society, as it requires a being capable of mental self-determination to compromise that self-determination by carrying out tasks at the direction and discretion of another (the person with assistance needs). However, automation and advanced technologies can be used to reduce the amount of heteronomous work involved in personal assistance, even if they cannot eliminate it; this is consistent with both personal assistance and 'technical aids' being among the 'Seven Needs for Independent Living' (Davis 1990), and can be another component of 'autonomously interdependent living'.

Recommendations for policy

The research that this thesis is based on is not 'policy research' as such; while national and local government policies in the UK are important parts of its background context, they have not been its central object. Thus a detailed analysis of policy concerning personal assistance is outside its scope. However, some recommendations for policy can be made on the basis of its findings, particularly those presented in Chapter 7. These recommendations are admittedly unlikely to be taken up by a Conservative government which seems to be ideologically committed to austerity policies which disproportionately impact on disabled people, regardless of either the financial or the social cost. They are thus perhaps better seen as recommendations for policy-related demands, and therefore overlap with recommendations for the DPM (as presented below), but I have chosen to present them separately because of the conceptual distinction between actions that can be taken by the movement itself and those that can be demanded, but require government agreement to be actually implemented.

The most obvious of these recommendations is for greatly increased funding for personal assistance services (including both the funding given directly to disabled people for employing PAs and associated support services). Insufficient funding was by a significant margin the most frequently mentioned barrier to personal assistance functioning 'well' for direct employers. Higher rates of pay for PAs would not only give their work the recognition it deserves as skilled and at times both physically and relationally difficult, but would also have a great impact on recruitment and retention of PAs, which was a serious problem for many employers, particularly those with complex support needs (see also Glendinning et al 2000b; Graby & Homayoun 2019). Direct employers of PAs must also be sufficiently funded for them to offer more attractive pay and working conditions than institutional settings or care agencies.

The inconsistency between different local authorities in funding levels (including numbers of hours of personal assistance funded for individual direct employers and hourly rates of pay for PAs) is also a serious concern, creating a 'postcode

lottery' which denies many direct employers the right to move to where they want to live. Therefore a change from local to national government funding of personal assistance, accompanied by legislation guaranteeing it as a right for all disabled people with personal assistance needs, is a strong recommendation from this research (see also Barnes 2007b; Beresford & Harrison 2017; Graby & Homayoun 2019). However, there is still a need for locally provided support services, for example with recruitment of PAs or with employers' responsibilities such as payroll, tax and insurance. These support services are arguably best performed by organisations run and controlled by disabled people, but their availability is arguably more important on an immediate level than who they are provided by. Thus these services should also be funded on a national level regardless of who is the local provider.

National and local government should also support initiatives by disabled people to set up new support services, for example personal assistance co-operatives either on the model of those that exist in other countries such as Norway and Sweden or on newly developed multi-stakeholder models. Consideration should also be given to funding DPOs, co-operatives or other local organisations to provide training for PAs and direct employers which is based on the principles of independent living and the social model of disability (in their expansive rather than simplistic definitions). Funding for DPOs, however, must not have conditions attached which prevent them from also campaigning against government policy or advocating for disabled people to challenge individual funding decisions when necessary. The related risk of DPOs losing their social model principles and/or ceasing to function in their other important capacities (such as campaigning, peer education or providing social space for disabled people) through shifting focus to become 'service providers' must also be considered (see for example Inclusion London 2014; Morgan et al 2001); it may therefore be pragmatic to separate direct payment support services into their own organisations.

A change in the culture of assessment of personal assistance needs is also urgently necessary. Several direct employers reported anxiety at losing funding in annual reassessments, and described social services departments as

obstructive or unhelpful. Additionally, several mentioned that they felt lucky to have been awarded personal assistance funding before the onset of really severe austerity policies, as they were anecdotally aware of other disabled people with comparable but more recently acquired assistance needs getting far lower levels of funding or being unable to get direct payments at all (see for example Ryan 2016, 2017). Assessment of personal assistance needs must therefore move from a suspicious and distrustful attitude which seeks to minimise expenditure by questioning the validity of disabled people's claimed needs to affirmation and acceptance of their self-assessment of need and respecting disabled people's own suggested solutions rather than being inflexibly prescriptive about which assistance tasks may be funded.

Another policy area which is of crucial importance to disabled people with personal assistance needs is immigration policy. Many of the PAs interviewed for this research were migrants from other European countries, and most of the direct employers interviewed had employed migrant workers, either from within Europe or from the 'Global South'. The social care sector in general relies heavily on migrant labour (Christensen & Guldvik 2013; Erevelles 2011). Therefore, policies restricting immigration could have a disastrous impact on disabled people who rely on migrant workers as PAs (Lawson & Sayce 2017; Pepper 2017). Personal assistance must have the status of a job which people can migrate to the UK to do without fear of refusal or deportation. The vital contribution of immigrants as PAs must also be publicly recognised in the face of growing racism and xenophobia, particularly in the context of Britain's impending exit from the European Union.

Recommendations for further research

The research that this thesis is based in was in many ways a starting point for much broader and deeper potential research about personal assistance. Many areas that were touched on in passing could be explored more thoroughly by further research, using either similar or different methods. There is arguably a need for systematic quantitative research about the numbers of PAs and direct employers in the UK and associated statistics such as how many PAs, on

average, are employed by each direct employer and for how many hours, whether PAs frequently work for more than one direct employer, which tasks typically take up what proportion of PAs' working time, etc. This could help to build a more comprehensive picture of the social and economic significance of personal assistance in the UK. Research about unmet personal assistance needs is also crucial. In particular, given the anecdotal evidence about the impact of austerity policies on personal assistance provision, quantitative research on how personal assistance provision has changed over the past decade (for example, whether the amount of personal assistance funding granted to disabled people newly presenting to local authorities with comparable impairments and needs has changed) is urgently needed to reveal a fuller picture of the impact of austerity on disabled people with assistance needs.

More in-depth qualitative research (either using interviews or perhaps other methods, such as longitudinal observation) is also needed about aspects of the personal assistance relationship which this research touched on but was not able to deal with in sufficient depth. This would require more focused attention on narrower topics of investigation. These could include, for example, PAs' feelings about whether their work as PAs is more or less autonomous than other work they have done, interactions between PAs and other people in their employers' personal communities, or employers' preferences with regard to how much discretion or initiative PAs should exercise in carrying out the variety of tasks within their overall work. Another potentially fruitful avenue of investigation could be research involving 'matched pairs' of PAs and direct employers to find out how perceptions of the same personal assistance relationship differ from each side, as the scope of this research to examine both sides of the dialectic was limited by only being able to hear one side of each PA/employer relationship examined.

Further research is also needed on the potential of personal assistance co-operatives in the UK. In particular, there is scope for a pilot project involving the establishment of a local co-operative along similar lines to the Scandinavian personal assistance user co-ops, involving participatory action research to

document its development and impact. This could be done in collaboration with one or more DPOs as a base from which to launch the co-operative project, and/or with national co-operative support organisations. If the co-operative was successful and benefited direct employers and/or PAs, the research could establish a precedent for larger-scale implementation of similar co-operatives and/or provide evidence to support funding of personal assistance co-ops by government or other funding bodies. Conversely, if the co-operative model did not prove to have significant advantages over traditional direct employment of PAs by individuals, further research could examine what differences in policy, economic or cultural conditions resulted in different outcomes in the UK than in the Scandinavian countries.

Further investigation, though perhaps not necessarily in the form of primary research, is also needed into issues around work, autonomy and disablement. In other writings (Graby 2015, 2016; Graby & Greenstein 2016) I have begun to explore these issues, building on the foundations laid by other authors (e.g. Abberley 1996, 2002; Gleeson 1999; Russell 1998, 2002; Taylor 2004). The tension between the identification of wage labour as a source of disabled people's oppression (Finkelstein 1980; Gleeson 1999) and as a system for distribution of resources from which many disabled people are inevitably excluded (Abberley 1996, 2002) and the use of wage labour to emancipate disabled people through personal assistance is only one of the potential contradictions in approaching work and employment that remain unresolved within Disability Studies and the DPM. The shift away from Fordist labour patterns and the dominance of manual labour towards a precarious work economy increasingly dominated by cognitive and emotional labour is likely to have significant impacts on the economic and social inclusion/exclusion of different groups of disabled people, and therefore needs to be a focus of future analytical attention in Disability Studies.

Finally, the process of conducting this research has showed that most research and analysis of personal assistance has focused on the needs, experiences and personal assistance relationships of a relatively narrow demographic of disabled people, namely those with physical (and to some degree sensory, particularly

visual, but not cognitive) impairments, and that special effort is required to capture the experiences and viewpoints of disabled people outside this category. The typical assistance needs of this group of disabled people - which has historically dominated the DPM in general, and campaigns for personal assistance provision in particular (Hall 2009; Kelly 2016) - arguably predispose personal assistance relationships to take certain forms rather than others. Research done on the personal assistance relationships of other groups of disabled people, for example people with learning difficulties (e.g. Gramlich et al 2002; Williams et al 2009a, 2009b, 2010), has shown that there may be significant differences in the relationship dynamics that develop based on the difference in assistance needs. However, that research has tended to exist separately from research on personal assistance for people with physical impairments and there has been little direct comparison. Therefore research has produced partial and contradictory pictures of personal assistance as a phenomenon ranging across the spectrum of disabled people and their assistance needs.

While my intention was not to focus particularly on any one impairment group, and my call for participants only specified that they directly employed PAs or worked as directly employed PAs, all the direct employers who responded fit within the narrow demographic of physical and/or visual impairments (there was more diversity in the disabled people who the PAs I interviewed had worked for, but the same demographic still dominated). Therefore, an explicitly pan-impairment research project on personal assistance which intentionally sought to purposively sample a range of disabled people with many different types of access needs (and perhaps put particular effort into seeking participants with cognitive impairments and/or 'non-physical' assistance needs) could potentially produce new and important insights which this research was not able to.

Recommendations for the Disabled People's Movement

A major goal of this research project was to produce knowledge and ideas that would be of use to the Disabled People's Movement, both in the UK and internationally, for advancing the cause of disabled people's liberation. In

addition to the recommendations for policy demands as outlined above, there are a number of 'internal' recommendations for the DPM which I believe can be derived from my research findings. While some of these encourage intellectual questioning, they are distinct from recommendations for further research because they are concerned not so much with factual knowledge as with the ethical and theoretical basis for action.

One practical recommendation is for the movement, and particularly for local DPOs, to consider personal assistance co-operatives as a strategy to explore with regard to solving the immediate difficulties facing many direct employers in recruiting and managing PAs and meeting the obligations of an employer. Co-operatives could be formed within, and practically and/or financially supported by, existing DPOs. The services potentially provided by personal assistance co-ops, including the legal employment of PAs on the behalf of disabled individuals, resemble those that were at various times provided by CILs and other DPOs in the UK (Barnes & Mercer 2006; Priestley 1999); thus it may be questioned whether new co-operative models have advantages over reviving previous practices. One possibility is that co-operatives, like trade unions or care agencies in different contexts, may be able (after initial investment) to sustain themselves financially by using a small proportion of the money paid by 'employer' members (which would have been profit in a private-sector agency) for administrative costs, thus potentially bypassing the problem of the financial precarity and dependence on public-sector funding of many existing DPOs.

The DPM should also pay critical attention to other alternative models of personal assistance, including both those developed from within disabled communities elsewhere (such as 'care collectives') and those with other origins (such as various 'homesharing' and 'intentional community' models). These models should be analysed to determine how they do or do not fit in with the values and principles of the DPM, and whether there are practical lessons that the DPM can learn from them about current conditions of disablement and how to overcome them. Some 'intentional community' models have been promoted in recent years by allies of the DPM (see for example Rhodes & Davis 2014); however, there is a need to be aware of the dangers of reintroducing

institutional segregation and paternalistic denial of autonomy through an insufficiently critical embrace of community values which, while counter to the capitalist mainstream, are also conservative in their social protectionism.

Care collectives, while they are (unlike many other alternative models) originated by disabled people and connected to grass-roots activist organising, should also be analysed critically. As a model of collective survival and resistance developed in North American communities, there may be differences in their applicability to the UK context (though conversely, as policies of austerity and marketisation move the UK away from European social democracy and closer to the extreme capitalist individualism of the US, they may become more tactically relevant). Issues that they raise for the British DPM include problematising orthodoxies around 'independent living', intersectionality (particularly involving the marginalised people who frequently provide 'caring' labour, both formally and informally) and the difficult dilemma of 'DIY culture' activist self-organisation versus making demands of the state for publicly funded services.

Connected to this, it is imperative for the DPM to question its assumptions about the benevolence of the (welfare) state. Much recent activism by the DPM and its allies in the UK has focused on calls for the restoration of welfare state provisions that have been cut or restricted. This has arguably ignored the broader political, historical and economic context of the state as an institution functioning primarily to defend capitalism and 'Global North' imperialism. It has also meant that nuance has been lost and the 'status quo ante' has been defended uncritically, leading to potential alienation of people who did not experience previous provisions (such as the Independent Living Fund) as unqualifiedly positive. The DPM needs to recognise that many of its collective positions were developed by a relatively narrow demographic of disabled people and in resistance to forms of disablement which have changed over time. Therefore, it is necessary to re-evaluate 'traditional' positions (such as the 'received wisdom' that relationships between disabled people and PAs should be purely instrumental) and consider whether or not they fit with the current lived experiences of disablement of the full spectrum of disabled people,

including all impairment groups and those who experience other forms of marginalisation.

It is also important for the DPM to make intersectional connections and seek alliance with other social movements against capitalism and paternalism and for autonomy and equality. This must be done without losing the principle of subsidiarity, or 'nothing about us without us' (Charlton 1998; Gordon 2018), that centres those most affected by specific forms of oppression in the struggle against them. However, it is also necessary to resist isolationism or presumptions of a zero-sum relationship between the interests of different oppressed groups, or for example between disabled people and PAs (which are in any case not mutually exclusive categories, as many PAs themselves have impairments). Disabled people and PAs have significant common interests, for example in increased funding and support with administrative aspects of employment or with conflict resolution between PAs and direct employers. However, it must be acknowledged that their different standpoints on the personal assistance relationship mean that their interests are not identical and may sometimes require balancing with one another. Therefore a joint movement of disabled people and PAs for better pay and conditions should be recognised not as a homogeneous movement but as an alliance of distinct groups in practical solidarity with one another.

None of this means that the principles of independent living, as articulated by the DPM in the UK and elsewhere since the late 1970s (see for example Morris 1993), and as prescribed in Article 19 of the UN CRPD, should be abandoned as demands. However, as discussed above, these principles must not be misinterpreted as referring to self-sufficiency or opposed to 'dependence' on other people. Disabled people and DPOs must be vigilant to co-optation of the rhetoric of 'independent living' by government to justify cuts to benefits and/or services, as seen for example in the influential 'Improving the Life Chances of Disabled People' report (PMSU 2005), and care must be taken to avoid arguments for user-controlled personal assistance services on the grounds of them being cheaper than more paternalistic services (see for example Zarb & Nadash 1994). Such arguments should instead be based on the principles of

self-determination (within a necessarily interdependent society) as an ethical right regardless of cost. Demands for a nationally funded independent living service have a long history within the DPM (Barnes 2007b; Beresford & Harrison 2017; Graby & Homayoun 2019; Inclusion London 2014) and should continue; however, these demands must be made while recognising that nation and state are arbitrary and problematic entities, and thus that focusing demands at the 'national' level is a tactical choice rather than an implicit acceptance that rights to enabling support should be limited by national borders or legal status.

Finishing thoughts, no final answers

This research set out to address several (interconnected) major questions about personal assistance. These included whether and how the direct employment model of personal assistance differs from other waged labour and from other means of meeting disabled people's assistance needs, what kind of power relations exist between PAs and direct employers, whether the direct employment model actually emancipates disabled people in the way that it was intended to, and how to resolve the tensions between the DPM's critiques of waged employment as a source of oppression for disabled people and its use of waged employment, in the form of personal assistance, as a means to disabled people's liberation. My original intent was also to attempt to establish how disabled people could get the assistance they need in everyday living without denying either their own autonomy or that of those who provide that assistance, and to suggest ways that disabled people with personal assistance needs could be given control over their daily lives in a society that was not based on capitalist concepts of waged labour and exchange value. I cannot claim that this thesis provides definitive answers to any of these questions. However, my hope is that it has laid a foundation for further research and debate on them, and introduced some new insights on them to the DPM and Disability Studies communities.

This thesis is also not a comprehensive work on personal assistance in all its aspects. Many important areas were not covered in my research interviews to an extent that allowed anything to be meaningfully written about them based on

the data gathered (for example the gender demographics of PA recruitment and employment, or questions around the limits of employers' responsibility for or 'authorship' of their PAs' actions). More research is needed on these issues and how they impact on the themes and questions of this thesis. I hope that the research findings presented in this thesis (and hopefully also in future publications) can form part of a foundation on which to build such further research by others. Many areas that were covered in the interviews could also not be presented in this thesis due to the inevitable constraints of time and length. Life circumstances allowing, I hope to present at least some of this as yet unexamined data in future publications which will complement what is presented here.

The 'original contribution' of my research is thus not to provide a new resolution to old dilemmas, but to consider perspectives from both sides of the personal assistance relationship in such a way as to display, in more detail than has been done previously, the challenges that relationship presents both to the norms of currently existing capitalist society and to movements attempting to create something better. It thus may point towards further questions that need to be asked and answered by other researchers, writers and activists, both within Disability Studies and beyond, as part of a greater project of seeking autonomy and liberation for all.

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Appendix A: Information sent to participants before interviews

Dear participant

My name is Steve Graby. I am a PhD student in Disability Studies at the University of Leeds and I am inviting you to take part in a research project. Please take time to read the following information carefully. You may discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please ask me (see contact details below).

What research is this?

This research is about personal assistance for disabled people. I am interested in the relationship between disabled people who employ personal assistants (PAs) and the people they employ. I hope to find out:
- what is good and bad about the way personal assistance works now;
- whether PAs give disabled people real choice and control over their everyday lives, and;
- if and how you think personal assistance should be changed.

I hope that the information that I find through this research will be useful to both disabled people and PAs, by improving understanding of the ways that they relate to and work with each other, and by suggesting ways that personal assistance could be changed to work better.

Why are you asking me to take part?

I am inviting you to take part in this research because you have already expressed an interest in what I am doing, and you are in one of the two groups of people I want to interview:
- Disabled people who employ, or have employed, PAs; or
- People who work, or have worked, as PAs for disabled people.

Do I have to take part in this research?

It is up to you whether or not you want to take part in this research. If you do not want to take part, you do not have to do anything. You do not have to give a reason why you do or do not want to take part.

If you do want to take part in this research, you will need to fill in your details on the consent form attached to this information sheet and send it back to me (either by post or email). Even after signing the consent form, you can change your mind and decide not to be part of the research.

If I do this, what will I have to do?

If you decide to take part in this research, I will arrange to interview you, either face to face in a place of your choice or by phone, Skype or email, according to your preferences. The interview will probably take around 1-2 hours, but it can

be split into shorter parts. I will contact you by the end of February 2015. The interview can be at a date and time of your choice, but will probably be between March and June 2015.

In the interview, I will ask you questions about:
- your experiences of and opinions about employing PAs, or working as a PA;
- what choice and control over your life means to you as a PA or as a disabled person who employs PAs;
- whether and how you think the system of employing PAs could be changed for the better.

If you have accessibility needs that would make it difficult for you to do this kind of interview, but you are still interested in taking part in this research, please contact me so that we can work out a different way to interview you that works for you.

Will you pay me?

I cannot afford to pay you for taking part in this research, but I can pay for reasonable travel and access-related expenses. Please contact me if you may need this.

What will happen to the information I give you?

I will use the information I get from the interviews to inform what I write about in my PhD thesis, and possibly other publications (e.g. journal papers or book chapters). I may or may not use direct quotes from your interview in my thesis or other publications - if I do, I will ask you for permission first.

Where appropriate, you can choose whether or not you want your real name to be used in the thesis or any other publication based on this research. If you do not want to use your real name, you can choose another name which I will use when quoting you or writing about what you have told me, and I will make sure that no one will be able to identify who you, or other people, really are from your information.

The audio recording of your interview and the full transcript of it, as well as any other information that I have about you (for example, your contact details) will not be accessible to anyone other than you and me unless:
- a) you request for it to be shared, or
- b) I am compelled by law to reveal information (for example, about an immediate risk to someone's safety).

It is very unlikely that b) will happen. If I am forced to disclose any information, I will tell you about this before I do so.

What if I want to know more?

Thank you for taking the time to read this information! If you would like to know anything else about this research, you can either contact me:

- by email at **ss10sdg@leeds.ac.uk**
- by phone or text on **07539 754529**
- by post c/o the **School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.**

or if you are worried or unsure about anything you have read here, you can contact my supervisors, Dr Alison Sheldon and Dr Simon Prideaux:
- by email at **a.sheldon@leeds.ac.uk** and **s.j.prideaux@leeds.ac.uk**
- by phone or text on **0113 3434715** and **0113 343442**3
- by post c/o the **School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT.**

(the consent form is presented on the next page as an image to preserve formatting; apologies for the small font size)

[School of Sociology and Social Policy]

UNIVERSITY OF LEEDS

Consent to take part in my PhD research:
'Personal Assistance - The Challenge of Autonomy'

	Add your initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 18th December 2014 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. (If you choose to withdraw from the study after having already participated, any data relating to you will be destroyed and not used in any publications.)	
I understand that my name will not be linked with the research materials unless I want it to be, and I will not be identified or identifiable in the PhD thesis or other publications that result from the research, unless I request to be. I understand that my responses will be kept strictly confidential unless I request otherwise.	
I agree for the data collected from me to be used in relevant future research in an anonymised form.	
I agree to take part in the above research project and will inform the researcher should my contact details change.	

Name of participant	
Participant's signature	
Date	
Name of researcher	
Signature	
Date*	

*To be signed and dated in the presence of the participant.

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, the letter/ pre-written script/ information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be kept with the project's main documents which must be kept in a secure location.

Researcher contact details: email ss10sdg@leeds.ac.uk, phone 07539754529

Appendix B: Question guide for use in my interviews with participants

A) for disabled employers:

1) factual/contextual questions about employment of PAs - e.g. how many PAs do you employ? for how many hours a week? how long have you been employing PAs? what tasks do you use your PAs for? (etc.)

2) questions about the interviewee's relationship with their PAs:

- what kind of relationship do you have with your PAs?

- who (from your perspective as employer) has the most power in the relationship, you or your PAs?

- how do you think being able to pay/employ your own PAs makes your situation different from if they were not employed by you? (e.g. if they were volunteers? if they were employed by an agency or other organisation?)

- do you feel that employing PAs meets your needs? if not, why not? what would need to be changed for it to meet the needs that are not met?

- have you had conflicts with your PAs? if so, how were they resolved?

3) questions about personal assistance more broadly:

- how and why did you start employing PAs (as opposed to getting assistance in other ways)?

- (if you have also received other types of assistance) what are the advantages and disadvantages for you of using PAs compared to other options?

- how does employing PAs affect the way you feel about yourself (empowered? disempowered? etc.) - or 'how you see your life'?

4) more normative and/or theoretical questions:

- what would your ideal world look like (in broad political/economic terms)? would it still have money, would people still work for a wage?

- how do you think you would get your PA needs met if you lived in your ideal world?

- what does autonomy/independence/choice and control(?) mean to you?

- what do you think the relationship between disabled employers and PAs should be like? (how) do you think the reality differs from this?

- what do you think the balance should be between the rights (needs? decisions?) of disabled employers and of PAs as workers?

5) is there anything else you would like to say on the subject of personal assistance that has not already been covered?

B) for (current or former) PAs:

1) factual/contextual questions about working as a PA - e.g. how many employers do/did you work for? how long have you worked/did you work as a PA for? what do/did you do for your employer(s)? (etc.)

2) questions about the interviewee's relationship with their employer(s):

- what is/was your relationship like with your employer(s)? (if you work(ed) for more than one employer, was it different for each of them?)

- have you had conflicts with your employer(s)? if so, how were they resolved?

- who (from your perspective as PA) has the most power in the relationship, you or your employer(s)?

3) questions more generally about "being a PA" as a job/career:

- how and why did you start working as a PA?

- do you think the employment relationship is similar or different between working as a PA and other kinds of work?

- (if you have also worked in other types of jobs) what are the advantages and disadvantages for you of PA work compared to other jobs?

- how does/did working as a PA affect the way you feel about yourself/view your own life? (empowered? disempowered? etc.)

4) more normative and/or theoretical questions:

- what would your ideal world look like (in broad political/economic terms)? would it still have money, would people still work for a wage?

- in your ideal world, would you still want to assist disabled people as a 'job'?

- what does autonomy/independence/choice and control mean to you?

- do you think it is possible for workers to have control over your type of work? (and why/why not?)

- what do you think the relationship between disabled employers and PAs should be like? how do you think the reality differs from this?

- what do you think the balance should be between the rights (needs, decisions, etc) of disabled employers and of PAs as workers?

5) is there anything else you would like to say on the subject of personal assistance that has not already been covered?