Employing direct care workers through public and private funding: a scoping review of the literature

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Executive summary

This report informs a major study of Direct Care Workers being commissioned by Skills for Care from the perspective of the people employing them and the workers themselves. It is a review of the literature covering adults of all ages with disabilities and long-term health conditions who employ their own Direct Care Workers through public (state) and/or private (self and family resources). Published research and material relevant to this subject from consultations and reports are covered in this review.

The literature review investigated what is known about the dynamics of the employment relationship. The structure of the review covers the ‘career’ of this relationship, with the main findings covering ten interrelated areas:

1. Directly employed care workers’ previous employment; few studies have asked care workers about their previous jobs or indeed about other aspects of themselves.

2. Recruitment into directly employed care work; in the United Kingdom (UK) there is evidence that many people who are working as Directly Employed Care Workers were previously known to their employer; though family or social networks. We do not know if this generally applies.
3. The recruitment of family and friends; this is reported to be increasingly common; but again we do not know the extent of this practice.

4. Preparations for the work; there are many calls from groups of people using social care services or employing care workers directly that training, especially that provided by disabled people, is welcome. There are a few examples of the content of such training or its effects.

5. New demands and arrangements; there are suggestions that the work that people pay for may be more attuned to their needs and some small studies have evidence of this.

6. Regulation and legalities; some research covers issues of casual working, illegal working and regulatory frameworks but this is not extensive.

7. Choice and control; studies exploring aspirations for choice and control and the power relationships of direct employment highlight these as a positive matter for people receiving social care in many instances.

8. Managing risk; there are some examples of the ways in which risks might be assessed and managed but these are not generally explicit and we lack knowledge of the day to day practices around risk as well as overarching themes such as processes and feelings of accountability.

9. The use of intermediaries; these are often key to the relationships of direct care employment with family members in particular.
10. The termination of employment arrangements; there is little information about this activity and the steps leading up to the cessation of employment on behalf of either party.

The review concludes with an overview of some international literature that appears to have relevance to the UK context. In contrast to the UK there have been large studies in the United States (US) of direct employers and employees, although some of these studies rely on proxy or surrogate respondents. These studies confirm the popularity of employing relatives and the value of the flexibility of such work among staff. In mainland Europe, there is very substantial use of migrant labour as direct employees. Some of this is legal but much is unregulated.

The importance of direct employment in social care takes place in the context of national traditions of social care provision, local and national labour markets and in individual households. The employment relationship and dynamics are surprisingly little explored and generally unobserved.
Introduction

Internationally there is strong endorsement for the principles of consumer-directed support (OPM, 2007; NDS, 2009; Alzheimer’s Australia, 2007). This may take the form of a Home Care Grant (Ireland), Service Vouchers (Finland), or a Personal Budget (The Netherlands) (Timonen et al, 2006). In England, while a variety of terms is used, including consumer or self-directed support, these funds are often referred to as personal budgets or Direct Payments (and in a minority of local authorities as individual budgets). Direct Payments, or their equivalents, are seen as a way of empowering disabled people from all backgrounds and ages to get support that is tailored to their needs (CSCI, 2009).

This report was commissioned to inform a major study of Direct Care Workers from the perspective of the people employing them and the workers themselves. It draws on a review of the literature covering adults of all ages with disabilities and long-term health conditions who employ their own Direct Care Workers through public (state) and/or private (self and family resources). The literature review investigated what is known about the dynamics of the employment relationship. The structure of the review covers the ‘career’ of this relationship, starting with care workers’ previous employment; their recruitment into direct care work; the possible recruitment of family and friends; preparations for the work; new demands and arrangements; regulation and legalities; choice and control, managing risk, the use of intermediaries, the termination of employment, and
concludes with some international experiences that have not been covered in the main body of the review.

A summary of the key terms and definitions is included in the Appendix.
Background

There have been long-standing concerns over the quality, ethos and flexibility of social care. Disabled people (adults of all ages) have therefore campaigned for user-held budgets to fund their care and support (Morris, 2006). Such approaches have been supported by older people’s groups as a means of addressing problems with home care in particular (Help the Aged, 2008). Using public funds, provided on a means tested basis or through assessment of whether a person meets eligibility criteria, cash or near-cash (such as vouchers) are reported to lead to greater choice and control (Clarke, 2005; Arksey & Kemp, 2008; Leadbeater et al, 2008). In addition to social security monies which are available to meet disabled people’s extra living expenses, Direct Payments were introduced in England from 1996, but their growth has been slow until recently - by 2006-07 just £2.50 in every £100 of social care spending was through Direct Payments (CSCI, 2009). However, the policy of personalisation (Department of Health (DH), 2007) has changed this and there are increasing numbers of people using Direct Payments (in 2008-9, nearly 114,500 adults and older people were receiving Direct Payments). Three quarters received these to pay for their own care and a quarter of them were carers (Eborall et al, 2010). It is estimated that about 15,000 people were receiving personal budgets in October 2009. The Department of Health has predicted that the number will rise to 200,000 by March 2010 (Bartlett, 2009). However, not all those eligible for a personal budget use this to employ their own Direct Care Workers so care needs to be taken if
equating numbers of people with a personal budget to the numbers of people employing Direct Care Workers.

Nonetheless, people eligible for publicly funded social care using Direct Payments, have, in the past, mostly elected to recruit care workers directly as Personal Assistants, rather than through a formal provider organisation (Davey et al, 2006). We do not know if this pattern will continue and whether people may choose instead to spend the money on a service, such as day care, or on equipment.

Other disabled people of all ages pay for their own support if they are not eligible for public funds or if they choose to supplement or replace public provision. They do not receive a personal budget from their local authority. Such individuals are often referred to as self-funders (Henwood and Hudson, 2008a). They may supplement publicly funded social care with extra care that they pay for out of income and benefits, or from family resources. Forder (2008) estimated that 145,000 older people (aged 65 years and over) in England were meeting their personal care needs by paying for domiciliary (home) care in 2006. This estimate was based on a narrow range of personal care needs (such as difficulty or inability to perform some activities of daily living - dressing, eating, washing, help with going to the toilet, and so on). There are no corresponding estimates for other people (aged 18-64) paying for their own care and support.
Method

In light of this policy background, in Summer 2010 researchers at King’s College London conducted a brief scoping survey (Davis et al, 2009) of the research literature covering adults of all ages with disabilities and long-term health conditions employing their own direct care workers through public (state) and private (self and family resources) with particular reference to the dynamics of the employment relationship. This work is intended to inform a major study of Direct Care Workers from the perspective of the people employing them and the workers themselves. In this context workers are generally described as people providing care and support, sometimes termed support workers or Personal Assistants. The variety of terms around such job roles is considerable (Manthorpe et al, 2010) and indeed they may be referred to as ‘carers’ providing considerable confusion with the frequent use of the term ‘carer’ to denote a non-paid caring relationship (as commonly used in statute and in policy). While the term ‘care’ may be used to describe the tasks undertaken, there is increased call for the term ‘support’ to be used to reflect a less passive relationship, and thus for the term care worker to be replaced by the term support worker or Personal Assistant (Hatton et al, 2008). This report uses the terms support and care as used in the material reviewed (the word care often predominating); generally there are few differences between the two and many overlaps.

The search strategy for the current review was designed to cover research literature, user experience reports, academic articles and commentaries
published mainly since 2000 on the subject of Direct Employment by adults (including older people) with disabilities and long-term health conditions of people to meet their social care needs. While there is a focus on social care much of this touches upon health care. However, the day-to-day support of many people with disabilities and long-term conditions is the task of people employed by social care providers and often family carers (combined with significant co-production or input from disabled people themselves). The impact of the implementation of the policy of personal health budgets upon social care employment will be important to identify and may emerge from the evaluation of the personal health budgets pilots (NHS, 2010); some early studies have already observed that Direct Payments provided to meet social care needs are sometimes used for health related activities (Glendinning, 2006).

Search terms used in this review included ‘personalisation’, ‘consumer directed care’, ‘individual budgets’, ‘personal budget’, ‘Direct Payments’, ‘flexible funding’, ‘self-directed care’, ‘self-directed support’, ‘self-managed care’, ‘self-managed support’, ‘user-directed care’, and ‘user-directed support’. We followed the example of Ottmann et al (2009) in seeking publications from the internet as well as commonly used data sources. Material published or commissioned by Skills for Care, at national or regional levels, was also scrutinised. Publications were accessed through searches of citation indexes: Medline, BioMed Central, Cinahl, Social Care Online, Social Sciences Citation Index, Sociological Abstracts, and Web of Science. In light of the rapidly changing policy and practice environment,
priority was given to articles and reports that reflected the context of personalisation in England and the commitment to rolling out personal budgets, later reinforced by HM Coalition Government (2010).

The search retrieved a large number of publications that were then investigated to see if they covered features of the employment relationship. Many were small-scale studies or accounts, examining or reporting experiences of Direct Payments. Others were reviews or developmental materials related to the implementation of the policy document *Putting People First* (DH, 2007) or contained reflections on the role of personal budgets or, their predecessor, individual budgets. As expected, the investigations of the implications for employment practice and relationships in relation to these studies were thin. At best, employment relationships and the significance of them were marginal considerations in many studies and reports; others had small samples or were unclear about their sources of evidence. Furthermore, as noted, there is some difficulty in establishing whether some authors mean family members or paid care workers when using the term ‘carer’.

Building on this exploration of the literature we devised a series of questions for exploration in the study of Direct Care Workers being undertaken for Skills for Care (provided separately). These may be considered in the design of this study and wider discussions or in future research.
First, we summarise some of the findings from the studies we located and their consideration of Direct Care employment relationships in order to set the background. We took a ‘chronological’ approach, starting at the beginning of the relationship and finishing at its end. A subsequent section looks at the comparable international material to consider if there is relevant material from such studies.
Findings

Previous employment

There are mixed pictures of the Direct Care workforce in England in terms of whether they are directly employed by disabled people (of all ages and including their proxies) or are self-employed (other status is touched upon in later sections). There seems little evidence about care workers’ choices and options around this status. Some early evidence from a small number (9) of disabled people (Leece, 2000) suggested that they prefer that their care workers are self-employed, for reasons of wanting not to manage the ‘paperwork’, presumably connected with completing tax, insurance and other formalities, and wishing to minimise contact with officialdom. This suggests that while researchers may talk about people ‘employing’ care workers, this may not be the contractual relationship in force.

Five of the 12 businesses providing home care interviewed in the IBSEN (Individual Budgets Evaluation Network) study had already experienced individuals cancelling their service to employ a Personal Assistant instead (Wilberforce et al, in press). The managers of these businesses were frustrated, because they had usually provided training, support and Criminal Record Bureau (CRB) checks for the care worker and this investment was then lost to them. One provider thought that it was impossible to compete with Personal Assistants who did not incur the costs of overheads and training that an agency must cover. Reports of such ‘poaching’ are long-standing, if anecdotal (Leece, 2003). In an
exploration of the implications of personal budgets on providers of ‘housing with care’ (eg extra care), Housing 21 commented that there were mixed views about employment contracts that often forbade care staff to work independently for clients and the potential for such relationships to be to the providers’ advantage by establishing a link with possible customers (Vallelly and Manthorpe, 2009). The views of individuals about this dual status of care workers (working for an individual directly and for an agency) have not been established but there have long been suggestions that local authority ‘home helps’ often also worked independently for current and previous clients.

**Getting together – how employers find an employee**

There is evidence that recruitment relies heavily on personal contacts or social networks. Reid Howie’s (2010) review of the literature noted that few self-directed support clients have had previous experience of recruiting staff in any respect. Clark et al (2004), in one of the larger earlier studies of older people using Direct Payments in England, found that people preferred to recruit on personal recommendation – ranging from community networks to ‘poaching’ existing care workers. More recently, OPM (2010) found that disabled people in Essex sometimes initially knew whom they wanted to employ but others spread their enquiries among extended social networks. People with strong support networks appeared better placed than those with weaker networks to get more out of the money that was part of their personal budgets and were less reliant on ‘unproven’ Personal Assistants. Early in the development of personal budgets,
Baxter et al. (2008) found that a third of the home care agency managers they interviewed reported staff leaving to their agencies to work privately for Direct Payment funded clients because this offered more hours of work; however, in most cases the managers said that the workers concerned had returned to agency employment at a later date.

Carers UK’s (2008) survey of carers of people receiving Direct Payments found that carers were often managing the Direct Payment on behalf of the relative in terms of doing the administration and saw this as their responsibility. This is not new; parents played significant roles as initiators, managers and supporters of Direct Payments for their adult disabled son or daughter in the study conducted by Williams et al (2003). Parents often recruited Personal Assistants and managed the paperwork. In terms of outcomes, care arrangements were generally better and carers felt they were able to take more breaks from direct care giving.

In a paper considering the possible employment challenges of greater demand for Personal Assistants, Scourfield (2005) pointed to the possible restricted supply of this workforce. Some of the disabled people contributing to the CSCI (2004) consultation reported difficulties with recruitment both directly (eg through advertising or word of mouth) or through recruitment agencies. A seminar report (ESRC, 2009) provided an example of social care providers charging a ‘finder’s
fee' if a client took over a member of their staff. We do not know if this applies more generally.

The first major study of Direct Payment users exploring workforce implications (IFF, 2008) found that in many cases recruitment processes did not cover job descriptions. There seemed various interpretations of what a ‘formal’ job description might mean and what might be construed as an employment contract. Other studies do not appear to have shed any greater light on these matters.

**Employing relatives and close friends**

Many commentators (e.g., Henwood and Hudson, 2007a) have predicted that self-directed support will rely less on outside or formal recruitment because disabled people will make use of family, neighbours and friends as care workers. Poole (2006) suggested that this could lead to the creation of a hybrid; a ‘quasi informal’ or a ‘paid informal’ worker. From the perspective of social care arrangements in the UK and The Netherlands, Arksey and Moree (2009) have suggested that paying family carers runs the risk of them being financially dependent on their disabled relative and that this will negatively affect family relationships and dynamics. In the Netherlands, about a third of budget-holders employ their relatives to provide care; while a third purchase care from formal service agencies and a third use a combination (cited in Glendinning, 2010).
The IFF study (2008) for Skills for Care interviewed 526 Direct Payment employers and found that about half had recruited care workers from family or friends (at a time when there was less flexibility on whether this was permitted among local authorities). In Leece’s early study (2000) disabled people reported being refused permission to employ close family as care workers, which she found was unpopular particularly among minority ethnic communities (Leece, 2002). However, Clarke et al (2004) encountered mixed views about employing relatives - with older people expressing fears that boundaries and relationships would be jeopardised by financial exchange but also positive experiences of this being convenient. Dittrich (2008a) later noted varying approaches to agreeing the employment of relatives among local authorities; with some considering that this places undue strain on family relationships and increases the risk to the disabled person; accompanied by wider concerns that paying relatives for care work will entail greater public expenditure because previously they would have undertaken such support unpaid.

Times have changed in respect of earlier prohibitions of paying carers and it is now more common that local authorities do not see employing relatives as only permissible in exceptional circumstances. Nonetheless, there are likely to be uncertainties, and the sister study of the IBSEN research (Glendinning et al, 2009) found a lack of clear guidance for carers who took responsibility for managing an individual budget (particularly when in the form of Direct Payments) on how and on what it can be used for. They pointed to local and even client
group inconsistency on how far carers may be paid from the Direct Payment (individual budget as then was) of their disabled relative; whether the local authority set any conditions (such as employment contracts) that should be attached to such payments to relatives, and who would work out any interactions between Direct Payments and carers’ entitlements to social security and other benefits. The researchers noted that little is known of the possible implications of personal budgets on other parts of the family income, such as (un)employment and welfare benefits. In November 2009, Regulations changed in respect of Direct Payments and people lacking mental capacity to agree to and manage such decisions. There is not yet research about the ways in which such new arrangements are affecting employment relationships in the UK. The developmental project being undertaken by the Mental Health Foundation (Dementia Choices) is likely to provide some indications of this in practice. (http://www.mentalhealth.org.uk/our-work/older-people/dementia-choices/).

**Preparation for employment**

There are several accounts of people who employ care workers expressing a wish for training in how to manage employment relationships (Clayton, 2009; ARC, 2008 various) (which may be presented as quite complex tasks, see Box 1). However, there are few evaluations of the training on offer that appear to use pre and post test methods, for example, or to consider what works for whom. There appear to be no long-term studies covering the impact of training or its cost-effectiveness. Most of the ARC consultations reported people wanting such
training to be funded by public services. Cloverleaf Advocacy (2008) is among a number of authors that have reported disabled people keen to deliver training to others. Its typology of potential training programme contents divided them into three main areas: core values, core skills and specialist skills. One exception is the user-led programme of training devised by Connect in the North (2009) that was developed on the premise that service user-led training is preferable, popular and addresses disabled people’s concerns (this training was in the context of people with a learning disability). As Mansell (2010) noted, providing personal assistance to adults with profound intellectual and multiple disabilities is not an unskilled job and may involve quite high level skills.

Flynn’s (2005) small scale study of Personal Assistants and their employers noted that many of the Personal Assistants possessed social care employment backgrounds and had undertaken training. This was confirmed by the IFF study (2008) which found that as many as 87 percent of Personal Assistants had care work experience. This suggests the importance of enquiring about career history and not seeing directly employed care workers as inevitably lacking training or experience. Half the 17 Direct Payments employers in Policyworks’ (2009) consultation reported that their Personal Assistants possessed a social care qualification, and a third had a degree. The training employers wished for centred training on matters such as lifting. This was confirmed in the WECIL (2009) consultation on training for Personal Assistants although this consultation found it difficult to engage with Personal Assistants, possibly because employers would
have to deal with unfamiliar replacement staff if their Personal Assistants were undertaking training. In contrast, from the United States (US), Simon-Rusinowitz et al (2001) found that when people with developmental disabilities (learning disabilities) were asked whether they would want help or training with various cash option tasks, the great majority who were interested in this option wanted such support, and the researchers noted that the state of Florida required all consumers and surrogates/proxies to participate in some training. Their survey is one of the few that has sought the views of large numbers of people with developmental disabilities, obtaining a response rate to their telephone survey of 53 percent (378 respondents, of whom 100 were responding on their own behalf with the majority being surrogates, mainly relatives).
Guidance from Care Learning (2007) identified the need for disabled people considering employing a Personal Assistant to have:

- familiarity with the requirement for registration with the Inland Revenue; awareness of National Insurance and tax requirements, employees’ entitlements such as maternity and sick pay and of the National Minimum Wage
- knowledge of payroll schemes and possibly payroll providers
- awareness of Health and Safety responsibilities, carrying out risk assessments and knowledge of the responsibilities regarding safety belonging to the proposed worker
- awareness of the need for insurance against accidents, injury to staff as well as potential damage to property and its contents
- the ability to deal with conflicts, disputes and disciplinary procedures
- appropriate levels of control for the working relationship.

To employ a Personal Assistant, the individual must be familiar with aspects of recruitment such as:
- discrimination laws, CRB checks,
- writing a job description (which requires knowledge of the service user’s needs), devising application forms, advertising and interviewing
- employment contracts, pay rates.

On employment of the Personal Assistant the employer must then:
- be able to carry out appropriate employee induction
- ascertain any training needs of the employee and find out what training is available from which providers and at what cost
- keep accounts and audits of direct payments as they are monitored by local social services
New demands and arrangements

The IBSEN study of businesses or providers of social care (Wilberforce et al, in press) reported examples of people with an individual budget (using it as a Direct Payment) purchasing new types of activity, mostly from homecare providers, particularly cleaning and domestic assistance; gardening; transport and shopping. Likewise, Leece (2008b) observed that the boundaries of Direct Payment relationships were more blurred than in her sample of people working for a home care agency. She found Personal Assistants undertaking tasks such as: decorating, cleaning, gardening, pet care, companionship, and chauffeuring, whilst home care agency workers mainly undertook personal care.

The practice of ‘banking’ hours was more common in the individual budget pilots (IBSEN study) whereby users took up fewer hours of support over the course of several weeks to “save-up” for a special activity (previously it has been reported as difficult to achieve such flexibility, Newman and Hughes, 2007). There were also reports of more frequent demands for short-notice care in the IBSEN study, with people asking for more or less support on the same day, and also for care at specific times (especially “peak” hours around lunchtime). Home care agencies interviewed in another study predicted that personal budget users would expect and want help with a wider range of activities than the personal care currently arranged on their behalf by local authority care managers (Baxter et al 2008).

Difficulties over supply not meeting demand have been predicted as likely to occur in rural areas (Manthorpe and Stevens, 2008) and different practices are
reported about paying workers’ for their travel to work time. Carers UK (2008) found that 53 percent of their respondents (total unknown) reported problems with finding people to employ as care workers, especially those they considered to be suitably qualified. As noted, many people make use of social and family networks but this may leave people without such networks further excluded unless there are user-led organisations (voluntary sector) offering recruitment and payroll services, for example.

Earle (1999) explored the particular question of the boundaries of the employment relationship in the context of a small group of disabled people’s requests for what was described as ‘facilitated sex’ (help with sexual activity) from their Personal Assistants, and raised this as an example of the differences that may arise in defining needs and the limits of work relationships. Other research (Ponting et al, 2009) has reported people with learning disabilities being interested in employing people who have a more equal relationship with them (than traditional staff), are those who share interests and are willing to blur boundaries. There seems to be room to explore the capacity for employment to merge into friendship and affective, rather than instrumental, relationships to emerge.

Few studies have explored such boundary issues, although they are mentioned as possibly problematic. Likewise, there is little evidence of support for directly employed care workers in terms of regular supervision or mentoring, or in their
access to such opportunities at times when their work may be stressful or
distressing. James (2008), for example, suggested that directly employed care
workers may lack such support. Relationships with employers were sometimes
described as family-like, even by non–kin (Leece, 2006), indicating the fluidity of
relationships. However, Leece (2008a) further identified a small number of Direct
Payment employers who made efforts to avoid this sort of relationship and the
consequent blurring of boundaries. Later, Leece and Peace (2009)
conceptualised Direct Payment employers as experiencing ‘enhanced autonomy’
from the type of supportive care they received from the workers they directly
employed. However, they suggested that this might be at the expense of their
workers’ feelings of dignity because the workers were required to provide support
in unobtrusive ways, rendering them ‘invisible’.

Other features that have arisen in consultations include concerns among
employers about ‘juggling’ or employing multiple care workers (CSCI, 2004);
managing staff sickness and other absences; recruiting staff to work outside
normal working hours, and not being able to afford a Criminal Record Bureau
(CRB) check. Eborall and Griffiths (2008) noted that Personal Assistants may be
particularly likely to work for more than one employer (average number of jobs
being 1.64). Little is known about how such workers manage multiple employers.
Likewise, little is known about the welfare of care workers in terms, for example,
of their potential for being exploited (Henwood and Hudson, 2007b) or the long-
term effects of them being self-employed, or working casually, and possibly not contributing to pension and other schemes.

**Regulation and lack of regulation (grey or illegal working)**

There are reported to be concerns about the ‘grey economy’ whereby people are working directly for individuals (see Carr and Robbins, 2009) but in unofficial ways. However, there is little specificity of what is meant by this. Are workers not paying tax and national insurance (working cash in hand)? Are they claiming unemployment or disability benefits while working? Are they working without permission from immigration authorities? Are they relatives who are working as part of family feelings or obligations? Are their payments or wages less than the minimum wage? Are they working ‘extra’ hours for cash in hand? Are they undertaking other non-care activities for ‘cash’ or in kind? There is little information from the UK on these matters although the IFF study (2008) identified a minority of people working without contracts and for less than the minimum wage. Similarly, a recent qualitative study of people and proxy respondents (relatives) receiving a social security benefit (Attendance Allowance or Disabled Living Allowance) noted that some people used this to pay for care workers in the form of ‘gifts’ to helpful relatives, neighbours and friends (Corden et al, 2010). The term ‘casualisation’ is also widely used when referring to the risk of poor working conditions, insufficient employment protection and resultant insecurity, and a lack of revenue for the Exchequer (see Dittrich, 2008a). In Leece’s small study (2006) of eight directly employed care workers and eight Direct Payments
users, half of the workers did not receive sick pay (a further two were unsure about this), most were not paid for travelling time and none were members of pension schemes or trade unions (see also Leece, 2007).

In one of the few studies touching on this area in the UK (see later section covering the considerable international literature), Gordolan and Lalani (2009) made observations about migrant workers who were employed by individuals and their families (often in private arrangements) and by care providers. They interviewed 50 migrant workers, most of whom were from South Asian (22) and Filipino (17) backgrounds and had been recruited as domestic workers and whose tasks now encompassed some care work. Common among many of these workers was their lack of settled immigration status. Those who were directly employed reported feeling isolated; lacked training; felt exploited and insecure. The researchers recommended greater regulation of domestic work (on the basis that it was overlapping with care work), a maximum working week and compulsory recompense for overtime.

Choice and Control

Two examples from the IBSEN study (Wilberforce et al., in press) illustrate some of the dynamics of the relationship between a disabled person and a directly employed care worker:

We’ve got a guy whose main companion is his dog, but he can’t get out and walk the dog. So he’s assessed to having four half hour calls a
day so we go in and walk his dog for him ... who are we to argue if that’s what he wants, it’s his choice, isn’t it? [Provider 1, Wilberforce et al., in press]

I still wouldn’t provide a different service. I mean, at the end of the day this is about the care … obviously there will be things that you would have to explain [to IB holders], ‘I’m really sorry … if you want your loft cleared out, well then you’re going to have to get somebody that can do that task’. I’m not going to change my goalposts. [Provider 2, Wilberforce et al., in press]

Nonetheless, people using Direct Payments or having a personal budget in a large study in Northamptonshire (repeating some of the IBSEN measures) (Woolham and Benton, 2009) found that they accessed more forms of support than people using ‘traditional’ social services care packages. The former were more likely to employ Personal Assistants and to pay other people to help them at home, and less likely to access support from family and friends, use day care services or to take short-term breaks in residential care.

Other items that have emerged from consultations with Direct Payment employers are the importance of care workers guaranteeing confidentiality (ARC 2008a; 2008c; 2008d; 2008e; 2008f). There is little investigating the parameters of this, and one emerging question might be the way in which workers perceive that they have to operate under a duty of care or any code of practice. Not all
people using Direct Payments give confidentiality such importance. In one ARC consultation (2008b) participants placed much lower value on confidentiality; prioritising knowledge of how to meet health needs.

Given the importance of the relationship with those providing support, particularly intimate personal care, choosing who undertakes these tasks emerged as of prime importance in some studies:

[I] will have one or two carers providing care rather than lots of different ones provided by previous care agency to cover care hours.

[Person with learning disability, quoted by Glendinning et al., 2008: 54]

From Sweden, Ahlstrom and Wadenstern (2010) noted that ‘personal chemistry’ between employer and employee was important. Others have commented on the importance of having back-up or emergency assistance, and found having multiple care workers helped in this regard (Grossman et al, 2007). However, in its survey of carers who supported a person using Direct Payments – often to a considerable extent – Carers UK (2008) reported that 79 percent lacked a contingency plan for what might happen if they (the carers) were ill or not available to provide the support needed.

Managing risk

Care workers may encounter new, unanticipated risks as people using Direct Payments may wish for new flexibilities on a day-to-day basis (Wilberforce et al.,
Training may be needed around making home environments safe workplaces (Lightbown et al, 2008). Carr and Robbins (2009) in a summary of the findings of the individual budget pilots identified tensions in the balancing of safeguarding with aspirations for greater choice and control. In this context there are mixed views about whether the whole nature of consumer directed support and employment should be regulated (OPM, 2007). Nonetheless, large-scale studies from the US have countered earlier fears (Simon-Rusinowitz et al, 2000) that consumer directed support places people at greater risk of poorer health outcomes, or enhances risks of neglect, disrespect, or theft (Robert Wood Johnson Foundation, 2007; and see later section on international experiences).

There is little description on the assessment and management of risk as part of the dynamics of directly employment of care workers and consequently little about their practice and decision making, shared or otherwise. Subjects such as accountability are not yet widely covered.

**Using intermediaries**

The prospect of providing more Personal Assistant management services (eg help with recruitment, payroll, and so on) may prove attractive: in the Netherlands a third of personal budget holders have outsourced these tasks (Kremer, 2006, cited in Wilberforce et al, in press). Guidance for people using Direct Payments in the UK (Care Learning, 2007) highlighted the potential abilities of local support services to assist individuals in meeting the legal obligations of being an employer. These were identified as setting out the boundaries of the
employer/employee relationship; taxation responsibilities; risk assessments; insurance; managing conflict, and contracts. As Gillinson et al (2005) pointed out, becoming an employer is not something that most people are equipped to do. Indeed, many voluntary sector groups are reported to require investment in their own development around personalisation (Volition Leeds, 2008). Of course, many care providers may be familiar with self-funders as their customers and Nicholls (2007) reported that some early users of individual budgets (not employing staff themselves) appreciated the ability to negotiate with home care providers on the same basis as self-funders, for example, being able to arrange care worker visits when they wanted.

Terminating employment

There is little written about the end of employment relationship, whether by mutual agreement or by one party. Reid Howie’s (2010) review of the literature reported that some people employing their own workers find the overall management of performance gives rise to concern. Flynn (2005) found that disabled people, especially women, feared the subject of workplace discipline and contractual arrangements, characterising this as a ‘minefield’. Her study of 16 people using Direct Payments is one of the few to identify experiences of broken trust, dishonest, discourtesy, incompetence and even abuse – reported by half of those participating; none of whom had raised formal complaints. Her findings are echoed by Grossman et al (2007) whose interviews with 24 disabled
people employing support workers thorough Personal Assistance schemes in the US reported dismissing staff as difficult and distressing.

Aside from concerns about abuse or poor care, Leece (2004) suggested that some care workers may not wish to move jobs because they feel obliged to work for their employer on the basis of affective relationships. The implications of this are unknown.

Finally there is some report that it may be particularly difficult to ‘fire’ family members working as care workers for their relatives (Moullin, 2008). There does not seem to be any evidence of this from practice.

**International experiences**

Cash for care schemes in three European social insurance countries (France, Italy and Austria) were compared by Da Roit et al (2007). In France cash entitlements for frail older people had been introduced in 1997. Key points relevant to the themes addressed above are summarised below.

In France: the greater regulation of specific care packages for older people has made the development of a grey economy difficult; in France there was initial employment of relatives but a trend has been reported of more frequent employment of care workers who have received training; together with the development of a qualification framework for Personal Assistants. Cash
entitlements initially led to a significant contraction of formal services as older people initially opted for (lower-paid) unskilled carers and relatives, though this trend may be reversing (Da Riot et al., 2007).

In contrast, in Italy and Austria there has developed a substantial ‘grey market’ outside labour regulation and often reliant on migrant workers (from Eastern Europe but also from South America). This may use public funds but it is also common among people paying for their own care or care paid for by families. This is of policy concern in respect of the national economy and the quality of care. Ungerson (2006) further observed that many migrant care workers live with the disabled person (co-resident with their remuneration including accommodation but possibly necessitating being on duty round the clock). One Italian commentary (Pavolini and Ranci, 2008) referred to the notion of ‘a migrant in the family’ model of care; such is the prevalence of unregulated migrant workers, often termed private aides in the research literature, directly employed to provide care for older people. A study by Bilotta and Vergani (2008) found that good language skills and non-distressing life conditions among private aides appeared to be correlated with optimal quality of care for older people but that these were not common.

There are wider variations in approach and conditions internationally. For example, Arksey and Kemp (2008) noted that all cash for care schemes allow disabled people to employ close relatives as Personal Assistants: in France people could only employ non-relatives, but in Austria, Italy and the Netherlands
there is no restriction on the employment of close relatives. Moreover, social care is increasing a global phenomenon (Hussein et al, 2009; Yeates, 2009) and the use of migrants as directly employed care workers has been reported in a number of studies. However, some of the observations internationally are predictive rather than evidence based. Timonen et al (2006), for example described cash for care schemes as potentially increasing the number of jobs in social care. From the evidence, Wilberforce et al (in press) have summarised a range of experiences internationally which are briefly summarised here. First, experience in the Netherlands (which has a proportionately greater personal budget system than in the UK) has been that people do not yet have extensive choice of care workers or agencies and possibly, as a result, the majority of budget holders employ their relatives (Kremer, 2006: p392).

The German and Austrian Pflegegeld allowances have had little impact on the formal social care sector; though in Flanders businesses have developed as ‘temping’ agencies for Personal Assistants (Waterplas & Samoy, 2005; SCIE, 2007).

Lastly, from mainland Europe, one study that is of particular interest in focusing on the experiences of 32 Personal Assistants observed that they felt Personal Assistants needed empathy and sympathy; they needed to be aware of the general and specific situation of the employer/disabled person; they needed to be able to enter the other’s world; they should experience a degree of mutuality in
the relationship; they should be able to handle the relationship including with the employer/disabled person’s family, and should be able to negotiate difficulties around blurred boundaries and possible boredom or feeling of being used. Many of the workers in this study held qualifications and were providing support to younger adults (not older people) which may have affected some of their responses (Ahlstrom and Wadenstern, 2010).

There is mixed evidence from the United States (US). Directly hired workers in the Arkansas site of the national demonstration projects (a programme known as Cash and Counselling) were generally the family members or close friends of the disabled person (Dale et al, 2003). Many worked for free beyond their contracted hours and had been family carers prior to the scheme. Many saw no problems with undertaking health and social support roles. While wages were not high, they were comparable to the earning power of many of the workers. There was satisfaction on both sides – employer and employee – though risks of injury and lack of training were more common among directly employed staff than agency care workers.

In contrast, in another US state, Connecticut, Gruman et al. (undated) found that only 20 percent of Personal Assistants in their survey were related to their employers. Most of the 616 responding to the survey reported enjoying their work; held another job; felt taken advantage of if they did not have an employment contract, but appreciated the flexibility of the job, for example, being
able to take young children to their work. Of the 195 employers, most kept a worker for 1-2 years, and felt it took about 1-6 days to train one to their liking.

One large study describing the experiences of ‘directly hired workers’ in the US though telephone interviewing. In total 1,293 directly employed workers and 1,005 agency employed workers were interviewed (Foster et al, 2007) with 3,500 family caregivers also interviewed. Directly employed care workers in this study were more likely than agency workers to hold other jobs outside care work; they were far more likely to be the adult children (both sons and daughters) of the disabled older person; not surprisingly in the cases of family relationships they knew the care recipient well; but they were also paid for less time than they actually worked, and were more satisfied with their work than agency workers. Unrelated care workers were more likely to be better paid; to be trained and to work fewer hours.

A further large-scale US study of 2,260 workers providing consumer directed home care in California, found that the workers valued their relationship with their employer but also the flexibility of this work (Howes, 2008). For many having health insurance coverage was an important motivation to stay in this work.

In a study of consumer satisfaction with consumer directed support, Matthias and Benjamin (2003) reported being unable to interview the potentially most vulnerable older people employing direct care workers, for example those with
severe cognitive impairment. They also suggested that participants may be reluctant to complain about family members, even in a confidential research context. Benjamin and Matthias’ (2004) further studies illustrated the advantages of large-scale telephone surveys in terms of accessing sizeable data. Interviewing a large random sample of 253 consumer-directed (directly employed) workers and 365 agency workers and stratifying these samples by service model or type (agency employed versus directly employed worker) and age of disabled person (adults but excluding people with cognitive impairment), they established 10 worker-outcome dimensions for stress and satisfaction. These included stress dimensions of: concern about client safety; issues/problems with client's family; problems with client behaviour; getting along with client; worker's emotional state, and clarity of work roles. Satisfaction dimensions comprised five items:

- work role satisfaction;
- performance self-assessment;
- career advancement;
- independence, and
- flexibility.

There is potential to investigate these areas in other jurisdictions, mindful of the exclusions of people with cognitive impairment from this wider study who may be challenging for families/care workers to support.
Earlier, a review of self-determination schemes in eight US states concluded that provider agencies believed that the quality of their service, coupled with the administrative difficulties of recruiting care workers, meant that older people were likely to prefer formal agency-care to the opportunities of a consumer directed model (Tilly & Wiener, 2001). Interviews with providers in the Californian self-determination sites found that budget holders feared that individuals would poach staff and employ them directly as carers/care workers (Conroy et al, 2000). These misgivings are not borne out by the long term evaluations of consumer directed support in the US, as noted above (Robert Wood Johnson Foundation, 2007) that seemed to confirm the interest in consumer directed support as evidenced by a large-scale (493 interviews of 2,181 eligible for interview) telephone survey of disabled people in New York prior to the introduction of the programme (response rate of 23 percent) (Mahoney et al, 1998).

Nonetheless, a Canadian study found carers at risk of stress when responsible for care management, such as the administration surrounding employment matters (Rosenthal et al, 2007). In Australia and New Zealand, personalised budgets or consumer-directed support are a policy goal (Alzheimer’s Australia, 2007; Allen Consulting, 2007; ACAS, 2008; NDS, 2009). These have noted the fears among providers about their financial viability; of chasing ‘bad debts’ and managing unpredictable demand, and that staff training may suffer. In New Zealand the government is proposing to expand individualised funding but is also encouraging providers to offer a greater range of flexible support options, in
addition to expanding the number of agencies that provide support to budget holders (New Zealand Office for Disability Issues, 2009).
Conclusion

This review of the literature focusing on the employment relationship of Directly Employed Care Workers has revealed little evidence of the nature and dynamics of this important relationship in the UK. There is emerging interest in this relationship but little research as yet exploring in detail of many of its facets. Interest has been prompted by the policy of personalisation but there is surprisingly little about the relationships between the very large numbers of people who employ their own care workers using their own resources and the people they employ. It is likely that more people will need to pay for their own care and if they are in receipt of public funds that the care they receive may be more open to their own control or that of their families or proxies.

This review is designed to underpin and inform a national research study for Skills for Care, the main objectives of the research are to provide new information on: 1) the numbers of adults and older people employing care and support workers, either directly or indirectly, and to estimate the type, funding base, and scale of this work; 2) the numbers providing this care, with details of their skills, qualifications, experience, training, job roles, pay and terms of employment, and any other jobs; and 3) to set this in the context of unpaid care from family and friends. However, this research will also investigate aspects of the contractual, recruitment, training and resource implications of these employment relationships.
This review has broken new ground by looking at the ‘chronology’ of the employment relationship in the context of personalization. While there is not much evidence from UK studies, there is more on recruitment, training, and choice and control, than on other areas covering employment agreements, behaviour and management of day to day interactions. Care work is a complex mix of instrumental and emotional labour and this review exposes the paucity of scientific exploration of this subject at a time when there is unprecedented and growing demand for care.
References


Yorkshire and Humber Joint Improvement Partnership.


Leece, J. (2006) "It's not like being at work": a study to investigate stress and job satisfaction in employees of direct payments users. In J. Bornat and J. Leece (Eds.), *Developments in Direct Payments* (pp. 189-204). Bristol: The Policy Press.


Policyworks (2009) I'm safe because I've been trained correctly: Exploring the attitudes of direct payment employers in the West Midlands towards training and development for Personal Assistants. Birmingham: Policyworks Associates Ltd, for Skills for Care West Midlands and the Learning and Skills Council.


WECIL (West of England Centre for Inclusive Living) (2009) *Right Skills, Right Practice: Transforming the Adult Social Care Workforce for the Personalisation of Care Services: A pilot project delivering training to Personal Assistants and Social Workers*. Bristol: WECIL with City of Bristol College.


Appendix

Summary of key definitions used in this review (glossary)

Disabled person: This review uses this term to refer to disabled adults of all ages and does not use the term to only mean adults of working age or people aged less than 60/65 years. Not all disabled people refer to themselves in this way; they may describe themselves as long-term sick, having long-term health conditions, such as HIV/AIDS, or with mental health or addiction problems.

Care workers: This term is used to refer to a person employed to provide face to face care and support for a disabled person. Professionals such as social workers or community nurses are not covered by this term. In this review the term is used to mean people providing care in community settings, such as people’s own homes, accompanying them outside the home, or going outside the home on their behalf, such as when shopping.

Personal Assistant: This term is used by some people to describe people whose work involves care and support for a disabled person. The term ‘support worker’ may be used, or care worker, care assistant, or carer (see below). The term Personal Assistant may be more commonly used by younger people with physical disabilities than older people.

Direct employment: In this context this term is used to refer to the situation where a disabled person of any age employs an individual to provide them with social care or support with activities of daily living. The employment relationship
may be under a formal contract or otherwise, the worker may be a relative or friend or otherwise, and the worker may work full or part time, or irregularly. The worker may hold other employment, be working casually or illegally, or in self-employment. The person may also be directly employing people to do other tasks, such as gardening, housework or transport assistance.

**Indirect employment:** This means that the worker providing social care may be employed by a business specialising in social care or for a temporary employment agency. The care provider may be in the voluntary or private sector. The contract is between the disabled person or their proxy (such as a relative) and the agency; the disabled person may have a great deal of say in whom the agency sends, or they may have or want little. The worker may work full or part time or intermittently.

**Public funding** of social care: This means money or its equivalent provided by local authority adult services departments to an individual who is eligible for social care services, for which they may be asked to pay a part or full contribution on a means tested basis. Three particular types of public funding are referred to in this report (these are in addition to care that is commissioned by the local authority and provided by an in-house service, or an care provider from the voluntary or private sector): 1) Direct Payment (cash through payment to bank or third party/proxy, less frequently by payment card or voucher payment); 2) personal budget (an umbrella term including Direct Payment but can also be paid to care provider); 3) individual budget (a term used initially for combined funding
streams in a set of pilot local authorities but used currently in some areas to mean personal budget). The Department of Health (2007) committed English local authorities, to the goal of ensuring that people eligible for publicly funded adult social care would have a personal budget (excluding emergency access to care) by April 2011. While this does not mean that everyone will have Direct Payments, access to a personal budget and knowledge of its amount may encourage more people to take up this option. Changes to Regulations in 2009 now enable others (eg relatives) to use Direct Payments on behalf of someone if the eligible person is not able to do so (for example, if they have dementia).

**Private funding of social care (or self funding):** This means that a person pays for social care from their own money (or that of their family). This may be from earnings, savings or monies from pensions or social security benefits (the latter are, of course, in some instances publicly funded).

**Carer:** This term is often used in professional and policy circles to mean a family member (or friend) who is providing care and support to a relative or friend. Confusingly, it is sometimes used to refer to a person whose job is a care assistant in a care home or a home care worker. In this review it is used to mean family, friend or neighbour.