SOCIAL CARE FOR OLDER PEOPLE: THE ROLE AND FUNCTION OF DIRECT PAYMENTS

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Abstract

“Direct payments” (DPs) are now a core route for publicly funded social care provision in the UK. DPs are allocated to meet needs of social care recipients in lieu of community-managed social care services. DP recipients must organize their own care even if external support is usually available for some tasks.

There are long-standing concerns about the benefits of direct payments for older people. Perceived risk factors include frailty, limited social networks, a lack of information technology skills, spouse co-morbidity, overburdened unpaid carers.

Little is known about how direct payments actually work for older people. This thesis investigates direct payments practice, analyzing newly collected and previous data from a variety of perspectives.

First, a general view on policy and practice developments is obtained by tracing the evolution of DP support in the past decade. A bottom-up perspective follows, analyzing interviews with 82 older people receiving DPs. The unprecedented detail given by this data permits the identification of factors associated with greater gain from DPs and exploration of how DP-care fits within pre-existing patterns of care, both formal and informal.

Two particular phenomena highlight the unique role of DPs. The first is the role of husband and wife teams. In these husbands, affected by chronic physical illness, provide very substantial levels of unpaid care. As the term suggests, the couples operated DPs as a team: a mechanism which enhanced their ability to manage. Direct payments were critical to increase these couples’ health and social capital.

The second explores the circumstances of working unpaid carers managing DPs for older people. Overstretched and overburdened, these carers still found multiple benefits from DPs, not least the ability to coordinate care with their employment, ensuring the quality of services and with it their peace of mind.

The work contributes to understanding how directing care through DPs fits in a continuum in which unpaid carers interact with formal care in any caregiving scenario. Directing care represents an additional phase in adaptation to dependence. Resilience is viewed as a confluence of individual, social, physical and environmental factors. For those with the most complex or precarious caregiving role, increased control may have the greatest benefits.

Declaration of Authorship

I, Vanessa Davey, hereby declare that this thesis and the work presented in it is entirely my own.

The analyses presented in chapter 3 were completed with the assistance of Dr. Francesco D’Amico at the London School of Economics. The analyses presented in chapter 4 were assisted by Dr. Roshni Mangalore (formerly of the London School of Economics).

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Signed:____________________________________

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I would also like to thank other members of the Personal Social Services Research Unit at the LSE who have provided comments and feedback including Dr. Nicola Brimblecombe, Klara Lorenz and Dr. Juliette Malley. I would especially like to thank Margaret Perkins for helping to conduct the interviews with older people receiving direct payments as part of the Department of Health funded project we were engaged with, and for her willingness to adapt beyond the immediate goals of the funded work to support the objectives of my thesis, and to fill in any gaps at various points in time when I was analysing the data. My warmest thanks also go to Dr. Francesco D’Amico for his support with the analyses of data on Direct Payments Support Schemes which required a good deal of ingenuity and perseverance.

This research would not have been possible without the many individuals and families who not only agreed to be interviewed but subsequently shared the intimate dynamics of living with disability, frailty and precarious health, alone or as a couple, to demonstrate what using direct payments meant to them. The results are also a product of the generosity of sons and daughters organizing direct payments care for family members unable to do so themselves, who ‘found the time’ to take part. This meant dedicating the best part of a morning or afternoon, more often than not, taking time off work, in the hope that others might benefit from their experiences. Some of the families interviewed did not speak English as a first language and their willingness to take part and share their lives was especially valued.

Aside from the individuals and families who took part, this research also relies on data from Direct Payments Support Schemes who took part in a national survey. Although the follow-up data presented here relies was predominantly obtained online, many contacts from the field helped to develop the research by providing additional information and through discussions that helped to put the results into context.

Last but definitely not least, I would never have completed this without the support from my family and husband, although my motivation was especially boosted by my daughter who, when asked in school at Christmas to write a request to the three kings for *something to do with her family, friends or the world*, asked not for world peace, nor even for snow at Christmas but, “for Mummy to finish her work on her computer.” Thank you, Jimena.

Contents

1. Introduction

Direct payments are funds allocated to older people in lieu of community-based social services. Direct Payments (DPs), once a marginal service option, are now a core route through which individuals can choose to take their personal budget (PB). Although still only a small proportion of older people today receive their PB in the form of a DP, they are at the centre of the social care policy debate.

Controversy surrounds the implementation of direct payments (DPs) for older people. This derives from the contradiction between positive (early) user-level data which suggested that DPs to older people were beneficial versus (current) council-level data which suggests that DPs offer no greater benefits to older people than managed budgets.

Whether managed by the service user or a suitable person, DP management requires completion of core administrative tasks and other skills related to securing and supervising care. Since DPs were first introduced, external direct payments support (DPS) has been an integral part of the model, provided by entities referred to collectively as Direct Payments Support Schemes (DPSS).

A decade ago, when this policy instrument was still in its infancy, two major data gathering efforts related to DP were conducted from PSSRU. In the first one, a cross-sectional sample of 81 older people in ten local authority areas between 2005 and 2007 in receipt of DP were interviewed in depth. In the second a systematic survey of DPSS in England was conducted. In both studies the author was the lead researcher.

This thesis set out to re-examine in depth that historical dataset to obtain responses to some questions about self-directed care for older people that are still topical. The critique of such schemes has been generally based on two lines of argument. One is the charge of inappropriateness: self-managing care adds complexity to an already fragile situation. The other is an underlying suspicion of austerity considerations as the main policy driver.

The data gathered one decade ago is still unsurpassed in terms of scope and depth. Chapter 2 outlines the mixed-method approach that was devised to exploit the data and made the answers obtained relevant for today. The following chapters, present studies focusing on specific questions related to DP and DPSS.

The characteristics of DPSS providers have undergone substantial change in the last decade. In 2007 they were very heterogeneous in size and capabilities, dominated by voluntary organizations and ideological centered around User-Led Organisations (ULOs) and Centres for Independent Living (CILs). By 2010, significant turnover in DPSS was being reported. Concerned service users, DPSS staff and members of the independent living movement suggested that DPSS run by CILs and other ULOs were increasingly being decommissioned, whilst other organisations were growing, offering lower-priced services but less direct contact with service users.

In Chapter 3, I use the database of organisations responding to the PSSRU national Direct Payments Survey as a starting point to study the evolution of DPSS providers and identify its drivers. To do so I first identify service patterns within the DPSS providers that participated in the original survey. Five distinct profiles emerged which could be linked to organisational characteristics.

The work then analyzes and presents data from follow-up studies (performed in 2011, 2014 and 2016) of the original sample, registering organizational turnover and changes in patterns of provision. The observed evolution is related to organizational typologies. The results provide insight into the evolution of this market over the past decade, demonstrating the influence of local authority preferences on the delivery of DPS and the impacts of service viability, revealing a hidden face of DP with significant implications for service users.

In chapter 4 data from the interviews with older people using DPs is quantitatively analysed to evaluate the policy as practiced in 2007. What made the exercise promising was the unprecedented (and still unequaled) detail that such data offered about key variables. These include individual characteristics and circumstances, care packages and the types and quantities of care purchased. DP outcomes were also measured. In chapter 4 this data is gathered together and analyzed to assess the effect of various explanatory variables on the marginal gain derived from DPs based on a conceptual framework described in chapter 2. The findings are presented taking into account the current, changed, context for DP use.

DP outcomes were high and participants reported significantly higher levels of safety and control over daily living than the general population of community care recipients aged 65 and above – yet they were more limited with respect to the home environment and social participation. Service users who received support from unpaid carers achieved significantly greater gains from DPs. Unpaid care boosted outcome gain by complementing DPs and through the function of managerial care. Greater outcome gains were also linked to recruitment support and receiving flexible care inputs (typically from a PA). In contrast, large discrepancies between total care input and DP-funded support reduced outcome gains, irrespective of the value of allocated care.

The importance of unpaid care to DP outcomes is further explored in Chapter 5. A large majority (89%) of the respondents to the PSSRU DP survey received some degree of regular unpaid care. However receipt of unpaid care varied significantly among the sample and with it the balance between formal and unpaid care. A further factor was the use of supplementary self-funded care, which although minimal, did contribute to total care input for some of the sample. There was also a large proportion (79%) which received unpaid care support to manage their direct payment. Again, the intensity of that support was highly variable, ranging from minimal to full control of the DP by the unpaid care (46%). Yet further important distinctions were found according to the caregiving circumstances: whether care was provided by a son, daughter, husband or wife; whether they worked or not and whether they were supported by another unpaid carer.

These variations are examined in detail to determine if there was any evidence that receiving DPs altered the balance between unpaid and formal care. In doing so, the significance of caregiving contexts to patterns of unpaid caregiving emerges as a major guiding factor. This idea is put to test in the next two chapters.

The DPSS survey identified a significant sub-group of couples where both husband and wife had chronic illnesses, but where the main caregiver was the husband. These caregiving husbands appeared to be a particularly vulnerable group considering on the one hand, that receipt of DPs may increase the isolation for unpaid carers and / or the intensity of unpaid care of care they provide – and on the other –that male carers are generally reluctant to seek help. Chapter 5 already confirmed that these were the most burdened of all unpaid carers in the study, according to the hours of support they provided – and they were also the most likely to provide support with activities of daily living.

This topic is analysed in detail in Chapter 6, where I quantify the role that these husbands played in supporting older women receiving DP and assess the impact of DPs on the dynamics of unpaid care among the couples. The study is novel in that in previous work on DP's, samples – where they relate to the over 65s - have mainly featured daughters (and sons) acting as unpaid carers.

It appears that these couples operated DPs as a team: a mechanism which enhanced their ability to manage, despite the dual demands of unpaid care and morbidity. The paper provides detailed information concerning the circumstances of these couples and how they managed, and the role and benefits of directing care. The findings highlight the importance of resources – conceived in the widest sense - and the capacity to manage those resources – to the outcomes of DPs, as first introduced in chapter 2. DPs were critical to sustaining these couples' daily lives and increasing their health and social capital.

Chapter 7 shifts the focus to another aspect illuminated by interview data: the experience of working carers managing DPs on behalf of their elderly mother or father. Their accounts capture the incentives that led them to take-on the task, despite their multiple roles and responsibilities. The analysis explores their circumstances, motivations and experiences of managing DPs.

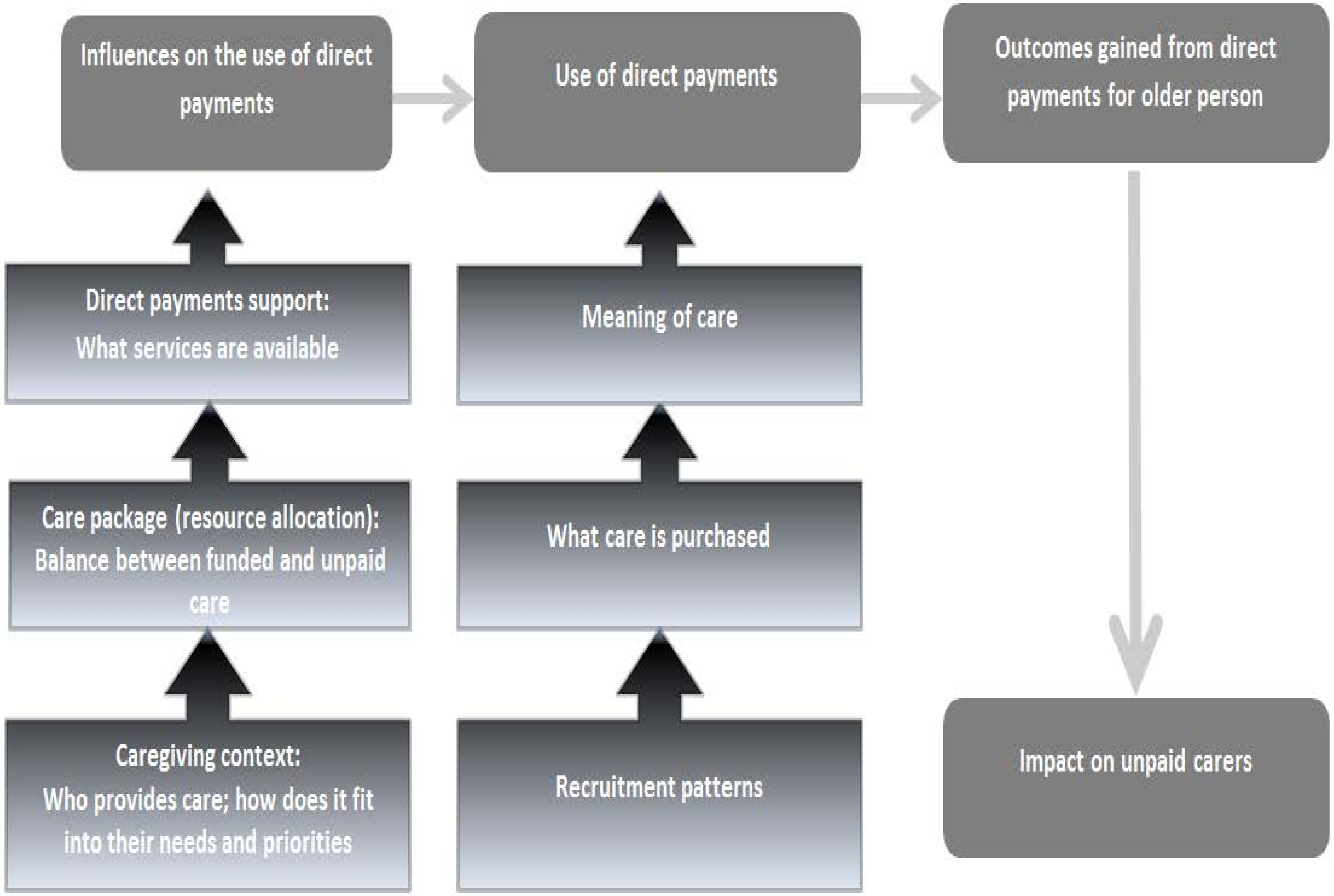
The research finds that working carers had been managing care well prior to DPs, as they strove to keep things in order in their absence. Their efforts were frequently frustrated by inflexibility, poor quality and poor communication systems over which they had little or no control. DPs by and large converted previously futile efforts to productive experiences. Undue burden from administrative responsibilities was avoided by the use of support services but the experience of recruitment was variable. The findings challenge previous suggestions that DPs are inevitably associated with an increase in managerial care, and they are discussed in relation to ongoing developments within the field.

2. Aims and Methods

My research is centred on direct payments (funds in lieu of community-based social services) for older people. Direct Payments (DPs), once a marginal service option, are now a core route through which individuals can choose to take their personal budget (PB), but only a small proportion of older people today receive their PB in the form of a DP. The main aim of the research is to understand and identify what factors influence the use of DPs by older people and how particular confluences of these may shape the experience of DPs, the benefit derived from them, and in doing so offer new insights into their impact on unpaid carers (Figure 2.1). The thesis includes five empirical chapters which comprise overlapping streams of quantitative and qualitative work which feed into two key inputs driving outcomes of DPs to older people: factors influencing the use of DPs and the nature of DPs use (as depicted by the rising arrows in Figure 2.1). The specific methods used for each section are described in detail in those chapters along with further detail on the aims of each chapter. Each chapter offers new findings which, chapter to chapter, create a whole picture of the nuances that underpin the extent to which older people may benefit from direct payments, and the reasons why direct payments might be a beneficial option for them and their families (or not). Each chapter offers new research insights relevant to the overarching aim of the thesis, but each also aims also to contribute to the knowledge base associated with each of the topics covered. In the interest of avoiding lengthy repetition with later sections of the thesis, what follows here is an overview of the approach taken in my research and the context in which it was conducted. Table 2.1 provides an at-a-glance summary of the empirical chapters and their aims.

Unusually for social policy, the work derives primarily from data that is primarily historic. Four out of the five chapters (chapters 4, 5, 6 and 7) are formed of new analyses of data collected from a cross-sectional sample of 82 older people in ten local authority areas between 2005 and 2007 conducted for a DH-funded project. These were face-to-face semi-structured interviews lasting between one-and-a-half and two-and-a-half hours with the older person alone or with them and their primary unpaid carer in

Figure 2.1: Overarching research design



participants' homes. Where the older person took an active role in managing their DP these were joint interviews. A number of these were dyadic interviews with husbands and wives (Koren 2011; Masters *et al* 2013; Racher *et al* 2000; Torgé 2014). In other cases the older person was limited in their capacity to participate and the interview was largely conducted with the person nominated to manage their DP (typically their primary unpaid carer) who acted as proxies, albeit in the presence of the subject.

A framework was used to ensure that specific detail on service users' caregiving arrangements was collected. Each service user (or their appointee) was asked to provide details of how their DPs care package was used throughout the week using a daily diary approach (Van De Berg & Spauwen 2006), and what additional inputs they received on a daily or weekly basis. This included additional input from unpaid carers, self-funded care or formal care that was commissioned directly by the local authority and did not form part of the DPs care package. Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) were recorded using standard tools (Collin *et al* 1988, Lawton & Brody 1969) and the empirical data used to group service users into dependency-level groups, using a classification system developed by Henderson (2006). It was anticipated that unpaid carers would occupy important roles (Glendinning *et al* 2008, Office for Public Management 2012) and with this in mind, detailed unpaid carer characteristics were noted. Other care recipient characteristics included whether they lived alone or cohabited, and the presence of an (observed) cognitive impairment. Aspects of the physical environment (equipment and accessibility) were also recorded.

The interviews also sought information on participants' means of securing care and managing DPs, including any support obtained, such as through a Direct Payment Support Scheme (DPSS) and how their experiences had altered over time. Interviewees were asked about their experiences of DP-funded care and previous non-DP experiences (where applicable), their motivations for taking up DPs and how they learnt of DPs, length of time using DP, recruitment experiences and how they had coped in response to changes in caregiving circumstances. Unpaid carer involvement in, and experience of managerial care was central to the interviews. Surprisingly, I think this early study still offers the largest and most diverse sample of interview data from unpaid carers supporting older people receiving DPs (cf. chapter 7).

The contribution of DPs to outcomes was measured using an adapted version of the Older People’s Utility Scale for Social Care (OPUS; Netten *et al* 2002), measuring expected outcomes along seven domains: food and nutrition; personal care; safety; social participation and involvement; control over daily living; control over home environment; leisure pursuits/social participation. The last two domains were added to the five-item OPUS; subsequently this tool was developed to incorporate these extra items and became ASCOT (Netten *et al* 2011). ASCOT is now used in national monitoring of service outcomes (DH 2014), and has been subjected to rigorous construct validity testing with older people, including proxies (Rand et al 2017; Malley *et al* 2012).

The interviews were both quantitative and qualitative, meaning that the answers to certain questions were entered on a coded schedule, although this occurred in the course of partially structured, fairly informal discussions. The objective was for interviews to be conducted in a manner which allowed participants ample “space” to describe in detail how they managed their daily lives and the role that DPs played without imposing any specific set of ideas onto the interview process (Charmaz 2013). To ensure that this worked in practice, the coded data was very specific and, if the interviews had been limited to only this part, they could have been completed in between 30 and 45 minutes. A further important factor was that the interviewers had the requisite skills to consistently gather detailed information from service users at their pace and tempo, and without the need to follow a linear schedule. This allowed participants to provide a complete account of their situations and explain how they managed their daily lives. Interviews were conducted primarily by me (as lead researcher) and a colleague, both experienced professionals with health and social care backgrounds.

Despite its age the data offers unprecedented detail with the possibility of exploring the following:

The empirical work reported in chapter 3 uses data derived from a survey of Direct Payments Support Schemes across England conducted in 2006 (Davey *et al* 2008), as well as follow-up longitudinal data from the original respondents that I collected in 2011, 2014 and 2016. Analysis of this information provides insight into the evolution of this DPSS market over a decade. DPSSs fulfil important roles in facilitating DPs, especially for older people.

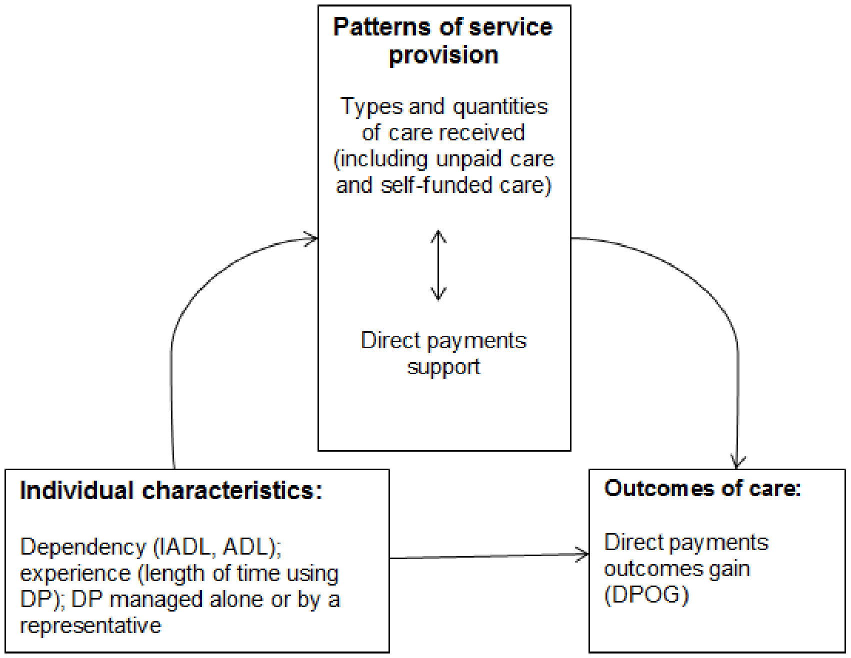
2.1. Historical function

Aside from the unique perspectives on the function of DPs to older people offered by the level of detail gathered, a notable feature of the data is that it was collected prior to the advent of PBs. The introduction of PBs has set off a cascade of changes to the context in which social care services are delivered, particularly DPs. There is now an important contradiction between (early) user-level and (current) authority-level data in investigations of the benefits of DPs. This is largely uncontested because early data is primarily qualitative – limited to small non-representative samples – while more recent research has been quantitative, involving much larger samples including comparisons with other service options. A potential limitation of research to date has been the automatic acceptance that these effects demonstrate how DPs fare against other service options when studied on a wider scale, without striving to understand if changes in the ways in which DPs are being delivered have affected the outcomes of DPs for older people. Mainly this is due to limits in the data collected or rather the requirement to focus on variables which can be easily measured according to the method chosen.

The work presented in this thesis stems from a basic conceptualisation of care outcomes in which the benefits derived from DP among older people are a product of individual characteristics of service users and the patterns of service provision (Fig 2.2).

My argument is that the benefits derived from DPs for any sample of individuals at any given time can only properly be understood by controlling for differences in the types and quantities of support received. The introduction of PBs has created a context in which these inputs are likely to have changed, although the major impediment for research is that it has led to extreme variations in practices which feed into this equation. These are discussed below.

Figure 2.2: Factors influencing outcomes from direct payments



Types and quantities of support received

The introduction of PBs has led to major changes in assessment and allocation of publicly funded social care through what is now referred to as Resource Allocation Systems (RAS). Above all, very little is known about what these changes mean in terms of how resources currently allocated versus resources previously made available through the community care assessment process which was in place at the time that data was collected.

Initial studies indicate broad differences in development of RAS by local authorities (Series & Clements 2013; Challis *et al* 2016). While local variations have always been a significant feature of social care allocation (Fernandez *et al* 2007), the early evaluations suggest that applications of RAS have resulted in less transparency, more complexity, less equity (for example between user groups), and even greater discretion from front-line staff than the traditional social work-led community care assessment process.

Such variation is at least partly fuelled by the divergent techniques for applying RAS. Some local authorities have invested in software to allocate resources according to algorithms developed through extensive examination of service users with similar needs; and working out a formula that predicted the cost of meeting those needs (Clifford *et al* 2013; Challis *et al* 2016). Other local authorities rely on the ´ready reckoner´ approach which formulates an indicative amount based on the number of hours of support an assessor estimates that a person needs – more or less along the lines of practice at the time of the research. Others employ a points-based system where points represent so many pounds per week. Further variations of this approach use points against scales or bands. All three methods rely on lengthy questionnaires to score points, a system highly vulnerable to gaming (Series & Clements 2013).

While social care has always been influenced by local priorities (Fernandez *et al* 2007), research where care managers were asked to provide (simplified) assessments on the basis of vignettes suggested considerable consistency in appraisals based on the approach used in former community-care assessments (Fernandez & Snell 2014).

A further impact of PB implementation has been a sharp rise in delays in allocating care. Despite staffing increases, the numbers of assessments, reviews and people supported by social workers has reduced in conjunction with the implementation of PBs (Slasberg 2013). Together these factors have led to increased anxieties for service users and the people caring for them, affecting the benefit derived from services (Hatton & Waters 2014; OPM 2012). It is impossible to infer what impact this may have had on the types and quantities of care being received, but it is well known that the quality of care depends much upon the subjective experience of the care relationship (Lewis & West 2010). For service users and their families, care does not begin and end with a specific care input, whether purchased via DPs or commissioned by the local authority. Instead, it starts with the first interactions within a chain of care provision (Kajonius & Ali 2015), typically social care departments and care managers (Willis *et al* 2016). Negative experiences early on in the process of receiving care can therefore shape later responses.

Finally, there are concerns in the way that direct payments have been promoted since PBs were introduced. Fierce efforts to control costs and recruitment and retention difficulties have combined to make it increasingly difficult if not impossible for local authorities to match available services to users´ needs, creating an incentive to promote direct payments where authority-commissioned care is considered poor quality, or where the choice of authority-commissioned providers is very limited (National Audit Office 2016). There are even reports of local authorities withdrawing from contracts due to the low rates paid for services (UKHCA 2016). Added to this, local authorities have been led to believe that a major shift towards DPs can result in significant cost savings (LGA 2014), leading to "practices to promote DPs which work against personalised care" (National Audit Office 2016: 7). This is likely to have altered the inputs available to DP users.

In contrast to this situation, the data I collected and analysed is from a period when the context in which DPs were being delivered was considerably more homogenous. This makes it easier to examine how individual characteristics and the types of quantities of care received may have shaped the benefits derived from DPs. The level of detail obtained is, I believe, one of the factors that ensures that these findings have practical relevance: it permits meaningful reflection on how the changing context of DPs may have altered experiences in reference to wider studies.

2.2. A mixed-methods approach

The framework for DP outcomes depicted in Figure 2 has its origins in the empirical examination of the production of welfare approach which, inter alia, uses regression models to explore the benefits of services after 'controlling' for the effects of factors not directly related to the service (Malley & Fernandez, 2010). Chapter 4 derives loosely from this approach by identifying factors influencing direct payments outcome gain among older people. A challenge to this approach is that it relies on capturing all relevant service and non-service inputs (Malley & Fernandez 2010; Knapp 1984), yet many aspects affecting outcomes cannot easily be measured.

For example, an important dimension of care is the nature of the interaction between service user and care worker: the care relationship (Lewis & West 2010). The interactions that form a care relationship are collaborative. Very often they involve not only the care worker(s) and the person receiving services, but also whoever provides unpaid care. The latter may actually be the person coordinating care where a service user is unable to do so themselves. Inevitably, service users and unpaid carers co-produce the services they receive, although not necessarily working in union. The collaboration of unpaid carers may be risk-averse, controlling or result in conflicts (RSA Action & Resource Centre 2012), undermining the resources available. On the other hand, service users and their families may act to employ the resources available to them to best use. In the case of DPs this role takes on greater importance and requires appraisal of the individual as a “suitable person”, implying that they have been assessed as being competent for the role.

Despite this collaborative potential, differing care worker approaches may foster this process or work against it (Kajonius & Ali 2015). These have been categorised as: task-orientated, person-focused, affect-orientated; cooperation-based and driven by time-use. What best suits the individual at any given moment may vary, but time and task-based support is often perceived as unhelpful. This is particularly highlighted in relation to the care of people with dementia (Pascoe 2011; Kajonius & Ali 2015). Still it has formed the dominant mode of commissioning care for more than twenty-years as it is easily defined and cheaper to provide (Lewis & West 2010). In contrast, DPs provide the opportunity to recruit a care worker whose basic approach is better suited to their needs. Additionally, they control the extent to which they invest in a care relationship with particular workers to foster the approach to care that they require (Cash, Moyle & O´Dwyer 2017). There is therefore a strong argument that any research that strives to understand the outcomes of DPs, accounts for such dynamics.

On the other hand, why should we presume that individuals (service users and their cares) will be automatically aware of the potential they have to collaborate in their care and be able to do so effectively? Is it not more realistic that they would engage in “an act of discovery” (Bianchi 1998) for which there is an initial “learning curve”? This may be applied to what may be considered to be the requisites for decision-making concerning factors such as what types of care to purchase and in what quantities, and according to what particular schedule. It is also relevant to the interactions with any given care worker. As such a likely crucial factor is the support available in establishing this role. This is shaped by formal and informal inputs. Specifically, direct payments support schemes (DPSS) are often commissioned as a minimum to support DP users when setting-up their direct payment and in many cases beyond this starting point

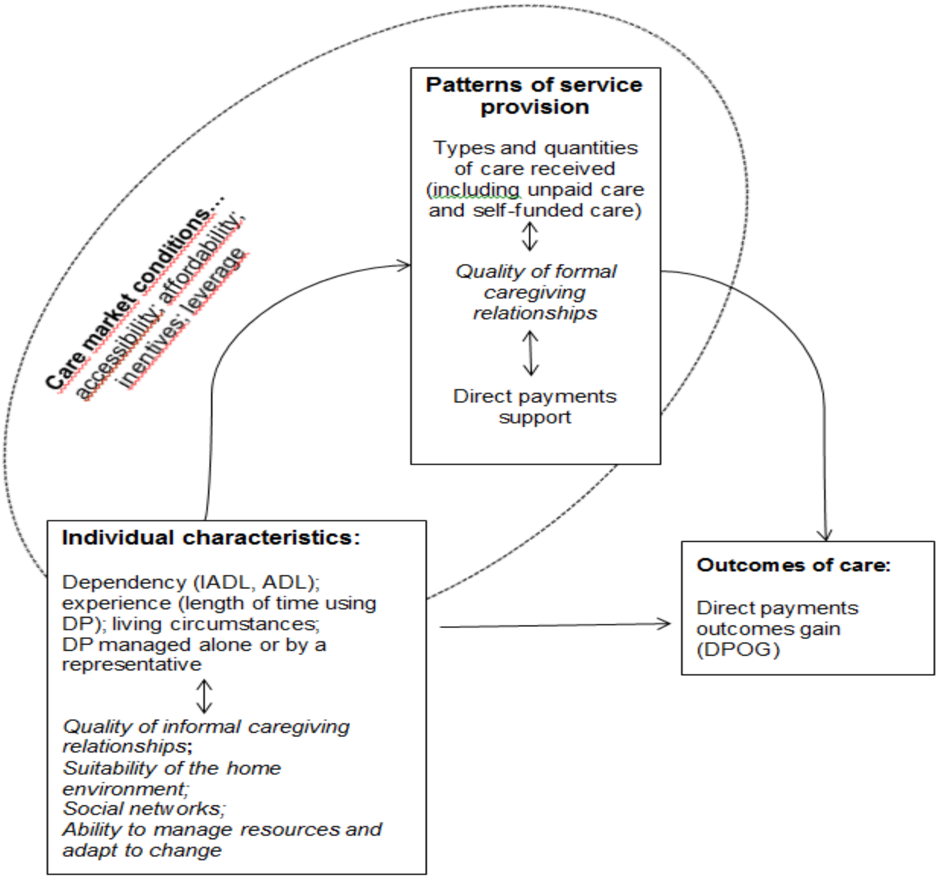
(Davey *et al* 2008). Hence a better understanding of the role of DPSS is also required (chapter 3). There is also a role for other organisations offering advice and input with what is now termed support planning and brokerage, as well as for other professionals that may feature along the chain of care provision (Wilder 2013).

Yet still there are many wider issues that may affect outcomes. Epsing Anderson (1999) highlighted the significance of resources in long-term care. Looking at work on adaptation to old age, we see that resources are often conceived in terms of material (e.g. income), health (e.g. ability to care for oneself) and caring (e.g. access to social support), each of which contributes positively or negatively to outcomes (Arber & Gin 1991 in Schmidt *et al* 2016). The concept of adaptation has parallels with the concept of resilience, described as “a confluence of individual, social, physical and environmental factors” (Otmman & Maragoudaki 2015). This suggests that a much wider range of factors need to be explored in relation to the characteristics of service users than envisaged in the initial conceptualization (Fig 2.2).

Finally, between the characteristics and circumstances of service users and the intermediate output (i.e. the types and quantities of care received) external factors are also at play, especially those relating to care market conditions. This might include accessibility of care (including information on available options cf. Turnpenny & Beadle-Brown 2015; Baxter 2012; Baxter & Glendinning 2011); their affordability, the underlying incentive structure (for care providers to respond to DP users) and the potential leverage of care purchasers. This leaves us with a far broader conceptualization of outcomes (Fig 2.3).

There are two possible ways of responding to the complexity of factors potentially impacting on the outcomes of DPs to older people. The first centres on measuring “outputs” as late in the process as possible in the production of welfare process (Davies & Knapp 1981). Chapter 4 therefore focuses on patterns of service provision on the understanding that these are the product of many wider factors. Likewise, while the range of individual characteristics controlled for is limited, the variables selected can predict differences which are less easily measured.

Figure 2.3: Wider conceptualisation of possible factors influencing outcomes from direct payments



In the field of social care research there is, however, growing recognition that a combination of qualitative and quantitative methods (so called mixed-methods) provides a better overall picture (Bryman & Becker 2012). By employing mixed methods, researchers can expand the scope and breadth of a study and explore different aspects of the phenomenon in ways that would be impossible by relying solely on either quantitative or qualitative methods alone (Miles & Huberman 1994). There are also crossover benefits where the quantitative parts of study enhance the qualitative aspects and vice-versa (*Ibid*.). For example, qualitative data can “supplement, validate, explain, illuminate or reinterpret quantitative data” (Miles & Huberman 1994: 10). To benefit in this way researchers need to consider their approach in combining methods, for example to determine how the work is sequenced. For this purpose I have drawn upon grounded theory methodology.

2.3. Organising the work: a grounded-theory approach

Grounded theory is principally an inductive methodology based on the principle of allowing the emergence of concepts from the data (Charmaz 2013). Essentially a form of qualitative analysis, it involves a couple of guiding principles: 1) moving back and forth between data and analysis from the start, and 2) conducting a literature review only once the first clear picture of themes emerges. These principles informed not only the analyses for the two qualitative chapters (chapters 6 & 7) but were applied as guiding principles to the evolution of the PhD as a whole and the combination of quantitative and qualitative elements.

How did this affect the form of enquiry?

Preliminary analyses of interview data were vital to the quantitative model developed to explore the influences of service characteristics and older people's attributes on outcome gain derived from DPs (chapter 4), and the interpretation of results. The results of chapter 4 then fuelled the design of chapter 5, and with it the evolution and interpretation of chapters 6 and7.

Chapters 6 and 7 present qualitative analyses, exploring the experience of direct payments among two sub-groups of older people: husband and wife teams, and older people whose DP was managed by an unpaid care who was employed (´working carers´). It was anticipated from the outset that two chapters would be developed from the qualitative data, but the initial expectation was that one would explore DP use among service users with an unpaid carer and one for those without, based on initial appraisal of my fieldwork notes, and also fuelled by the results of the quantitative model for chapter 4. Also influenced by chapter 4's findings on the significance of unpaid care to direct payments outcome gain (DPOG) it was felt that one chapter should focus on patterns of unpaid care, making use of the rich quantitative data obtained, although the format for analysis was undecided.

Instead of ploughing ahead with these sections one by one, I started by taking an overview of all the interview data, allowing the data to direct me. Initially one third of all the interviews were transcribed (n=81) – split randomly between participants with and without unpaid care. I first read all the transcribed interviews and then to listened to the recordings of all the non-transcribed interviews, and took notes on each. From this, unexpected sub-groups appeared and these were linked to common themes. This allowed me to break down the large and extremely diverse group of service users *with an unpaid carer* into meaningful groups (Box 1).

Box 1:

Sub-groups of older DP users

1. Husband and wife teams
2. Managed DP
    - Working carers
    - Non working carers
3. Self-managers

From this initial stage of the analysis (at this stage, qualitative), it appeared that each sub-group was clearly associated with particular traits in terms of the intensity of unpaid care provided and the dynamic between formal care, unpaid care and care funded out of-pocket (self-funded care); the tasks involved (IADLs vs. ADLs) and their wider circumstances (support networks; employment status). The data also revealed a greater participation by male unpaid carers than expected. Moreover this diversity appeared key to understanding what DPs were used for and *why*, how DPs were managed and the experiences of participants.

The most complex of the three groups was ‘managed DP’ (Box 1), which includes spouses, sons and daughters (many of whom worked full-time) who managed DPs on behalf of the service user. This was sub-divided into working carers and non-working carers. With these categories identified, two groups selected for qualitative analysis (chapters 6 and 7): husband and wife teams and working carers. This provided a rationale for a further round of interview transcription, to ensure that all interviews relating to each of the two sub-groups were included.

The identification of the sub-groups of older people also provided a compelling argument for exploring the descriptive data on care inputs by sub-group and comparing the results to averages for other (standard) categories of service user/unpaid carer combinations, such as by dependency level (in chapter 5). When designing the interview schedule (which dictated what data was coded for future quantitative analysis) the potential relevance of certain levels of detail on unpaid care characteristics had not been foreseen, yet the data was available within the interview recordings. This included their gender, relationship to the caregiver, employment status and whether the main caregiver performed ADL and/or IADL-related tasks as well as whether they were supported by other sources of unpaid care. Hence, the task of listening to all the interview recordings to develop an initial overview doubled as an opportunity to code this data which was subsequently included in the descriptive analyses for chapter 5. These quantitative findings corroborated the initial qualitative findings as to the relevance of the groups (Box 1) and in doing so, justified the choice of mixed-methods to look beyond what could be captured quantitatively.

Armed with the descriptive findings from chapter 5, the subject of the following two qualitative chapters was then narrowed down – to husband and wife teams (chapter 6) and working carers (chapter 7) – and the scope of literature being applied was driven into new (and emerging) fields and away from the field of research on choice in social care which was an important element of existing research (Arksey & Baxter 2012; Baxter & Glendinning 2013; Rabiee 2013). This reflected the underlying principles of grounded theory (Charmaz 2013), albeit through a novel approach which involved moving back and forth between quantitative and qualitative analyses. Subsequently, this method continued to influence the work such as in the identification of more interviews for transcription to ensure the best representation of the two sub-groups finally chosen for the work of chapters 6 and 7.

Finally, while the first empirical chapter (chapter 3) appears to stand alone in that it draws on data from a national survey of direct payments schemes and a follow-up of these organisations, this chapter was also part of the grounded theory approach. The analysis was informed by a variety of fieldwork activities with DPSS and local authorities undertaken for other research during the period of my PhD studies. These insights were vital to my understanding of the evolving treatment of older people receiving direct payments. Moreover, as demonstrated by the work, the development of DPSS over the past decade is a potent means of gauging the policy and practice developments in this field. These insights in conjunction with the overall body of work provide a rich and detailed basis for understanding how different tiers of the social care system may influence the outcomes of DPs users (Fig 2.3).

Table 2.1: The empirical chapters and their aims

Chapter	Title	Aims to:
3	Direct payments support schemes in England: exploring profiles of support across a decade of direct payments development	• Explore the provision of direct payments support (DPS) at the start of the decade (when the market for DPS expanded across England) and establish if particular services tended to be provided together. • Examine if such service profiles were linked to characteristics of DPSS. • Determine the extent of turnover in DPSS during the decade of direct payments development from 2006-2016 and identify trends in the development of DPS and their divergence from previous service profiles. • Explore how approximation to a service profile might 'impact' upon the tendency for DPSS to survive during the decade. • Examine the impact of service viability and other organisational factors on DPSS turnover. • Evaluate the evidence of transition in local authority preferences affecting what services are provided to direct payments users.
4	Influences of service characteristics and older people's attributes on outcomes from direct payments	• Identify associations between outcomes gained by direct payments and factors such as service users' characteristics and the types and quantities of care purchased. • Explore the relevance of changing structural factors affecting who receives DPs, the external support available to them and later recruitment patterns versus individual characteristics including the balance between DP funded care and unpaid care. • Discuss the implications of the findings for current practice.
5	Understanding the role of unpaid care in the provision of direct payments to older people	• Determine how unpaid care varied among older people receiving direct payments. • Identify who the unpaid carers supporting older people receiving direct payments were, and what kind of care they provided. • Explore if managing direct payments on behalf of the older person changed care patterns. • Search for evidence to suggest whether or not the use of DPs modified the balance between unpaid and state-funded care, and/or enabled unpaid carers to organize care that better suited them?
6	Husband and wife teams: a profile of older direct payment service users	• Quantify the role that husbands played in supporting older women receiving direct payments.

		• Assess the impact of direct payments on the dynamics of unpaid care among the couples and on their wellbeing. • Explore that factors that were instrumental in the success that they had with direct payments.
7	Working and managing care: exploring the experiences of working carers managing direct payments on behalf of an older person	• Explore the circumstances, motivations and experiences of working carers heavily involved in managing DPs for their father or mother. • Examine how "managerial care" as a key aspect of unpaid care compares when direct payments are used versus when being in receipt of council commissioned services. • Discuss the findings in relation to recent policy and practice advances including the advent of support planning and service brokerage to increase choice and control for people receiving council-managed personal budgets.

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3. Direct payments support schemes in England: exploring profiles of support across a decade of direct payments development

Background

- Direct payments support schemes (DPSS) are often commissioned by local authorities to support DP users when setting-up their direct payment an subsequently on an ongoing basis.
- Interaction with DPSS marks a critical starting point in the chain of care provision for people receiving DPs. The type, quantity and quality of support received may affect the benefit that individuals derive from DPs (cf. chapters 4 and 7).
- DPSS can support many aspects related to direct payment management (advocacy, accountancy, recruitment and employment services, support planning and brokerage) but availability varies widely.
- The composition of support services is poorly understood. No previous research has explored whether services provided by DPSS tend to cluster around particular aspects of support, or if they depend upon characteristics of the organisations providing the service.
- DPSS evolved from organisations run by disabled people campaigning for independent living. Government-led promotion of DPs targeted at improving access to DPS (2005-2007) widened the market for direct payments support (DPS). Subsequent mainstreaming of DPs through personalisation of social care, and austerity has altered demands placed on DPSS, the context in which DPs are provided and local authorities' priorities when commissioning DPS.
- From around 2010, major turnover in DPSS was being reported. Given the role that DPS plays in the production of welfare for DP users (cf. chapter 2, figure 2), it was important to explore its potential impact on service user outcomes.

Aims and Objectives

The work set out to pursue a number of aims:

1. To explore the provision of direct payments support (DPS) at the start of the decade (when the market for DPS expanded across England) and establish if particular services tended to be provided together.
2. To examine if such service profiles were linked to characteristics of DPSS.
3. To determine the extent of turnover in DPSS during the decade of direct payments development from 2006-2016 and identify trends in the development of DPS and their divergence from previous service profiles.
4. To explore how approximation to a service profile might 'impact' upon the tendency for DPSS to survive during the decade.

In accordance with the listed aims, the chapter offers insight into the evolution of DPS across a decade:

- The impact of service viability and other organisational factors on DPSS turnover.
- Evidence of transition in local authority preferences affecting what services are provided to direct payments users.

Key findings

- Five profiles of DPS existed in 2006 – each focused on a specific set of priorities but DPSS turnover in the period 2006-2016 was colossal and likely caused significant disruption to DP users.
- The most prominent profile in 2006 was 'fiscal moderators', focused on safeguarding adherence to statutory and fiscal responsibilities, recruitment support and employment law advice linked to larger organisations with fewer staff working as support workers and favourable contractual relationships. It was favoured between 2006 and 2011, with many local authorities switching to providers that fitted this profile in a wave of turnover that resulted in more

contracts going to branches of national voluntary organisations (BNVOs) and far fewer contracts with the local voluntary sectors.

- The remaining profiles focused on; employment management; recruitment advice; acting as recruitment agents, and enabling access to through advocacy, support and training for self-assessments and provision of indirect (third-party) payment schemes (the ‘enablers’).
- Employment managers were typically user-led micro organisations, with running costs dominated by direct contact with service users and questionable sustainability.
- When recruitment advice was the main service focus, providing organisations were generally well funded, user-led, both connected and established. Many organisations fitting this profile remained in contract throughout the decade.
- Those that acted as recruitment agents were often large Centres for Independent Living spanning two or more local authorities with supportive local authorities and likely contact with the (then) National Centre for Independent Living. These also tended to survive.
- Enablers were long-serving user-led organisations with many users but weak formal relations with their funding authority, and were mostly decommissioned early on.
- From around 2010 onwards, priorities changed: between 2011 and 2014 many (but not all) local authorities opting for a fiscal moderator profile switched practices, if not once, often twice. Many moved to systems of recommended providers: requiring services users to purchase DPS themselves, paying directly out of their DP shifting greater responsibility on individuals. This often occurred in tandem with the introduction of pre-paid card schemes and is likely to have been driven by the priority of controlling costs.
- Support with recruitment support and employee management moved away from face to face interactions in favour of online platforms and sign-posting service user to other organisations (such as Skills for Care, or private home care agencies), not necessarily the best means of support for some users such as older people.

- Despite such trends, not all local authorities that decommissioned original DPSS went down this path: a significant proportion opted for an in-house solution taking responsibility for DP users but potentially disempowering users.
- Of the original DPSS that did remain, most were among those which originally offered services on a par with the fiscal moderators or recruitment advice profiles. Clearly this was influenced by more than the profile of support offered: to survive each of these organisations had to adapt and grow – impossible without active support from the commissioning local authorities. The question is why some local authorities chose to invest in such long-standing relationships?

3.1. Introduction

The Direct Payments Act 1996 gave local authorities the powers to allocate money in lieu of services to people with a physical disability of working age, assessed as needing support. As is well documented, the legislation followed what were previously isolated practices dating back to the mid1980s of providing indirect payments to service users through a third party, predominantly Centres for Independent Living (CILs) and other disability-led organisations (Davey *et al* 2007). The direct payments movement gained momentum with the introduction of the Independent Living Fund (ILF) in 1988 by the Department for Work and Pensions (DWP) for disabled people with 24-hour care needs. Eligible individuals were given monetary payments to help them achieve higher standards of independent living. Notwithstanding the fact that the ILF was established under pressure to compensate for ongoing social security reforms, it marked a landmark for the disability movement as well as important impetus to emerging CILs offering fledgling direct payments support (DPS), securing a historical legacy in the provision of DPS. Over time, DPS became associated with various services including advocacy, accountancy, recruitment and employment services, support planning and brokerage (DH 2010b). Above all, an effective direct payments support scheme was accepted as crucial in the provision of DPs with government guidance emphasizing how such support helps “improve outcomes for both individuals and councils” (DH 2009a: 15).

Much has changed in the context of DPS since the advent of direct payments: the availability of DP to all social care user groups: among other things, exponential increases in client numbers; the introduction of personal budgets and related changes to social care provision (Slasberg 2013; Slasberg *et al* 2014). While central government policies continue to favour the use of DPs, very little attention is given to the organisations that help to secure positive outcomes – namely Direct Payments Support Schemes (DPSS). This chapter charts the evolution of DPSS in England in a follow-up to the first (and so far only) major survey of DPSS (Davey et al 2008) to explore how changes in the context in which direct payments are provided have affected DPS provision.

3.1.1. A decade of direct payments support

DP management requires completion of core administrative tasks and other skills related to securing and supervising care either by the service users or by an agreed “suitable person”. Since DPs were first introduced, external direct payments support (DPS) has been an integral part of the model, provided by entities referred to collectively as Direct Payments Support Schemes (DPSS). A decade ago, amidst a major policy drive to promote DPs, the sector expanded significantly. As a result, by 2007 almost every council in England had a contractual agreement with a DPSS provider. Despite the historical legacy of the independent living movement, this provider group was surprisingly heterogeneous, ideologically centered on User-Led Organisations (ULOs) and Centres for Independent Living (CILs), but actually composed of a variety of organisations ranging widely in their size and scope of services, albeit mainly voluntary organisations (Davey *et al* 2008).

A key vehicle in the development of DPS was the Direct Payments Development Fund (DPDF) (2004-2006), which allocated £9 million between 90 different partnerships in England between local authorities and voluntary organisations (Davey *et al* 2008). Although priority was given to develop provision of DPS in areas where none was available, it mostly went towards extending existing schemes. The National Centre for Independent Living (NCIL) was tasked to support and evaluate DPDF-funded schemes. The implicit message was that DPS was *best provided* by a CIL (where disabled people constituted at least 75% of committee members), or a user-led organisation (ULO) (where at least 51% of the organisation’s board and senior management team were disabled). Not long afterwards, the User-led Organisations Development Fund (2007-

2010) was made available on the back of a commitment to ensure that every local authority had a user-led organisation modeled on existing CILs by 2010 (Cabinet Office 2005; DH 2008c). Nevertheless government guidance on DPS, while attempting to steer local authority commissioners and providers towards certain *combinations* of services, repeatedly encouraged authorities to commission services with a view to local circumstances (DH 2009a, 2003). Above all, this recognized that the number of CILs remained limited while direct payments numbers were growing steadily.

As take-up of DPs grew, pressure mounted on local authorities to support an increasing user-base, both in number and in diversity. By 2010, significant turnover in DPSS was being reported (Williams 2008; Ivory 2008). Concerned service users, DPSS staff and members of the independent living movement suggested that DPSS run by CILs and other ULOs were increasingly being decommissioned, whilst other organisations were growing, offering lower-priced services but less direct contact with service users.

Yet the context for DPS was rapidly overshadowed by the introduction of Personal Budgets (PBs) in 2007 (and in some authorities previous to this with the pilot of their forerunner, Individual Budgets) (DH 2007). PBs are simply statements of the “cost” to the local authority of meeting a service users´ needs considered eligible for support by social services. They detail the amount that the local authority must pay towards the care and support needs, and the amount that the service user must pay towards that cost themselves (on the basis of their financial assessment). A service user may deploy his/her PB in a number of ways to secure services: 1) as a direct payment, 2) as an Individual Service Fund (ISF) (where there service user´ chooses an independent provider to manage the funds and offer a personalized service), 3) as a managed budget (MB) or council-managed service[1]. On the face of things, the shift to PBs appeared to offer unbridled opportunities to strengthen the implementation of DP (and the centrality of DPSS) raising it as a priority for local authorities, yet a closer look revealed potential threats.

PBs differ fundamentally from former arrangements in their requirement for hypothecated funding - a revolution for local authorities (and providers) after years of

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[1] Options 2 and 3 are interchangeably referred to as managed budgets although government has tried to encourage differentiation between the two terms (House of Commons 2016).

block funding or variations of (Wilberforce *et al* 2012; Knapp *et al* 2001). Until now, the only service users in receipt of a hypothecated budget were those receiving DP, which despite year-by-year increases in uptake, remained marginal, thus impacting minimally on LA financial flows and commissioning practices. With PBs, the impact on financial flows and commissioning became unavoidable, creating new complexities and difficulties for LAs that could potentially threaten the commitment to the implementation of DP as a result of competing priorities. At the same time, PBs offered direct competition to the DP paradigm since MBs were designed to provide some service user choice over certain aspects of day-to-day support (timings, care worker, tasks), without the responsibilities of a DP.

Notwithstanding the likely impact of these shifts, PBs were introduced in tandem with an added raft of new policies and processes. Among other things these required local authorities to develop revised resource allocation systems (RASs) – typically points-based systems to aggregate aspects of need severity (Forder & Fernandez 2015). Also, written statements for service users were to be supplied *prior* to support planning detailing a) the outcome of their needs assessment and b) their eligibility position according to service allocation principles. Care planning was transformed to outcomes-focused support plans in which a) a wider range of means of support were to be acceptable, and b) local authorities were obliged to ensure that support should be available for designing the support plan from various sources (including external sources) such an independent organisation or significant others (family, friends, carers, work colleagues or neighbours). This both legitimized and prioritized the role of third-party support in balancing the dynamic between service users and local authorities - already a common feature of DPS. However all of these changes occurred during a period of unprecedented funding cuts across social services (NAO 2016).

Initially, the role of existing DPSS remained largely unchanged by PBs, owing to the continuity with existing practice. Yet it was quickly marked by ambitious targets for implementation. In 2010, the adult social care strategy stipulated that all ongoing users of community-based services should receive a personal budget by April 2013, *preferably* as a direct payment. This target was highly controversial and ultimately recalibrated, but it still created a frenzy of activity within local authorities and a significant leap in DP use which DPSS had to keep pace with. People who already managed their care through DPs were also ‘transitioned’ onto PBs that were set through new RASs. DPSS were called upon in waves by previously stable clients as transitions sometimes resulted in funding reductions (Birnie, Hyslop & Lockwood 2014) in a process where austerity cuts were, for some, masked by new assessment and allocation systems. Even a report by the House of Commons in 2016 flagged that the Department of Health should keep under review whether cost-cutting is negatively affecting users with a reported 84% of directors of adult social services expecting personalisation to be an area of savings in 2016–17.

Meanwhile, with PB processes beset by excessive bureaucracy (Hatton & Waters 2013) – and the threat of reductions – DPSS also became engaged with PB clients for longer periods, increasing workloads and capacity to respond to new clients. Then the government announced the closure of the ILF, where funding would be subsumed by local authorities from late 2010 onwards. This was a response to wide-ranging criticisms of the ILF[2], yet the closure caused widespread concerns due to the fact that funding would no longer be ring-fenced, and also that there were no guarantees that equivalent allocations would be maintained at the individual level. This created further demands on DPSSs already concerned about the impact of the abolishment of the Individual Living Fund on their care arrangements. There were growing tensions, with some DPSS participating in campaigns against the closure of the ILF as well as individual appeals.

Finally, in 2011, Think Local Act Personal (TLAP) released the report “Best Practice in Direct Payments Support” acting in response to a growing mismatch between the capacity of existing DPSS and the demands of policy implementation (Bennett & Stockton 2012). This served to shift local authorities’ perspective on commissioning DPS, advising that “in future, single service solutions are not likely to be adequate and commissioners should look to develop a mixed market of direct payments support” (*Ibid*: 1), whilst maintaining that “there should always be a role for local ULOs in a mixed model of support also encompassing larger providers with the capacity and infrastructure to meet significant growth in demand” (*Ibid*: 1). A further development

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[2] Duplication of functions between the ILF and social services was a recognized impediment to accessibility (Henwood & Hudson 2007), while certain aspects of fund rules challenged the very principles of independent living, such as the fact that financial eligibility criteria effectively created “a barrier to married life” (Hunt 2015).

took place in the marketing of prepaid card schemes which also attracted attention as an example of evolving “best practice”. These schemes were developed to simplify the payment processes promoting a “light touch” approach to monitoring DPs in line with the Care Act Guidance and promote trusting relationships between DP users and LAs (TLAP no date). In practical terms they leave an audit trail that enables local authorities to track DP spending in real time. Some areas have interpreted this service as a means to bypass DPS (particularly if care is purchased via an agency). There have also been concerns that they create a disincentive to hire a PA (the process is simplest when used to pay staff from a homecare agency), leading the DH to stipulate that local authorities employing prepaid cared schemes must ensure that service users are enabled to employ PAs should they wish to (DH 2012). Others have raised concerns about blanket restrictions on cash spending (In Control 2017). They appeal to local authorities wishing to ensure a tight control on spending but they are far from cost-neutral. A recent report estimates that local authorities implementing them spent £1.5m on introducing them, and a similar amount per year on associated costs and fees (In Control 2017).

In short, the context for DPS was now a world away from where it had been in the early days of DPs and at the time of the PSSRU national survey of DPSS, while concerns about the impact of these combined influences on the sustainability of DPSS were growing. The question was *how* to explore how changes in the context in which direct payments are provided may have affected DPS provision. As a starting point, the PSSRU national survey of DPSS offered rich data on DPSS at the time of the first major policy push on direct payments implementation (2004-2006). We set out to determine the extent of turnover from a database of organisations responding to a national Direct Payments Survey (Davey *et al* 2008). We started by exploring the original data to establish if the variation in services provided was patterned and if it was linked to characteristics of organisations. Five profiles emerged offering very distinct models of DPS. We then explored how close association to a particular profile of DPS affected organisations’ *subsequent* contractual status in the period. Alongside this process we charted if, and when, further changes in DPS took place, thus establishing a picture of turnover in DPS generally, as well as an understanding of how affinity to a certain service profile affected organisations’ staying power within the evolving market context.

The results provide insight into the evolution of this market over the past decade, demonstrating the influence of local authority preferences on the delivery of DPS and the impacts of service viability, revealing a hidden face of DP with significant implications for service users.

3.2. Methods

3.2.1. Data collection

The first (and only) major national survey of DPSS (Davey *et al* 2008) was used as the core database for the study. This offered a source of systematic data on DPSS structure and function across the UK. All DPSS in existence at the time (2006) were surveyed through postal questionnaires sent to DPSS coordinators. Most DPSS were limited to one area, although some long-serving schemes were operating across two or more authorities. Each scheme completed a questionnaire for each local authority area they were working in, and data were linked to local authorities. Aside from the core survey data we used some data collected immediately post survey by telephone, in response to feedback from participating organisations; this identified if survey respondents were (or had been) user-led (including those conforming to the more rigorous CIL definition).

The original survey sought to sample all DPSS across the UK. Owing to the diverging policy and practice contexts across the UK, I concentrate here solely on respondents from England.

Follow-up of the original survey respondents took place in three successive rounds (2011, 2014 and 2016). At each point in time we identified:

a) If the original (or current) provider was still contracted to provide DPS;
b) If not, which category of provider had replaced it (user-led, CIL, any other form of local charity, for-profit, in-house, national voluntary, or none). A further category, “spot” represented cases where provision had been replaced by a new *form* of purchasing where service users were required to individually contract DPS from a selection of available providers paying directly from their DP funds

for services. Finally, a category of “introduced prepaid card scheme” was included.

The category of ´none´ was only applied if no DPSS was contracted at the time: during the course of the work, some local authorities initially reduced from two or three DPSS, to one. This was partly due to the fact that some DPS at the time of the survey were only commissioned as part of a pilot funded by DPDF. We also recorded where there had been repeated de/recommissions.

Information was obtained through internet searches, telephone and/or e-mail contact, until all organisations had been accounted for.

3.2.2. Analysis Methods

Part 1

The first step was to establish a baseline of how services were patterned in 2006.
We used data from the original survey on services provided to people receiving DPs per DPSS, under the categories of accountancy, advocacy, recruitment and employment services that were in use at the time. The survey listed 38 possible services (Table 3.1). Amongst those some were highly correlated and some were not. Direct examination of the 35x35 correlation matrix between services to detect patterns of grouped services is impractical so exploratory factor analysis (EPA) was used. This is a well-established technique to make sense of data collected through questionnaires in social and health sciences (Pett *et al* 2003; Williams *et al* 2010) as it enables researchers to reduce a large number of items from a questionnaire to a smaller number of components (termed *factors*) which reflect underlying shared variance between the original variables (services in this case) (DiStefano, Zhu & Mîndrilă 2009).

Factors are selected through a statistical procedure that operates on the original correlation matrix[3]. Standard algorithms are applied to ensure that different factors are

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[3] EPA was conducted using STATA® set up to apply EPA to the original correlation matrix and a orthogonal varimax rotation technique to optimize factor loadings.

as distinct as possible and that they are ordered by explanatory power. Explanatory power in this context means the ability to classify respondents by their similitude to the ideal types embodied in factors. Variability in responses is optimally reduced when similitude to the first factor is accounted for. The second factor accounts for the larger fraction of the remaining variability (after discounting variability due to larger or smaller similitude to the first factor). The third factor does the same with variability remaining after discounting that due to the first and second factor etc. This property permits the selection of a few factors which together account for the majority of variance in the input variables (the services being provided).

After several trials, only *five* factors were retained using the Kaiser criterion which requires that only factors with eigenvalues[4] equal or higher than 1 are retained, which typically account for between 70-80% of the variance (Koostra 2004). These five factors accounted for 75% of observed variance in DPSS services.

The emergent factors represent five separate ideal profiles of support provision. For each factor, a value termed a *factor load* is given for each variable included in the analysis. Each *factor load* expresses the correlations between each of the of the original variables (services provided) and each factor (Kim & Mueller 1978) – factor loads therefore express the probability of a service being provided by the ideal (unobserved) profile represented by that factor. Interpretation of each factor is driven by the variables which are most highly loaded for the factor (see Table 3.1). Subsequent labelling of the factors is a, “subjective, theoretical and inductive process” (Williams *et al* 2010).

For EPA to have further practical application, it is necessary to determine the relationship between the factors and the responses from the individual sample members from which the original variables were drawn. A separate process is undertaken to determine where each sample member (in this case each individual DPSS) is placed in relation to each of the ideal factor profiles – in this case the regression method was used which is the default function in STATA®[5]. The analysis derives a *factor score* for each individual DPSS. This score indicates how close that particular service provider is to the

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[4] Distefano *et al* (2009) describe eigenvalues as “scalars (i.e., one number) that show the proportion of variance accounted for by each factor”.

[5] See Distefano *et al* (2009), p. 4 for a full explanation on how regression factor scores are calculated,

Table 3.1: Rotated factor loadings for the five factors

		Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Advocacy services	General advice and support*	0.61	0.11	0.43	0.34	0.28
	Support with applying for DPs	0.63	0.10	0.39	0.31	0.35
	Training in self-assessments	-0.03	0.21	0.27	0.20	0.65
	Support with self-assessments	0.09	0.18	0.16	0.15	0.82
	Advocacy for statutory assessments	0.06	0.33	0.05	0.12	0.72
	Assistance with indirect payments schemes	0.31	0.33	0.03	0.10	0.61
	Financial advice (general)*	0.74	0.01	0.22	-0.01	0.27
	Peer support*	0.52	-0.09	0.51	0.31	0.07
Recruitment services	Lists of personal assistants	0.11	0.11	0.16	0.78	0.21
	Lists of local agencies*	0.52	0.16	0.61	0.03	0.30
	Bank of emergency staff	0.12	0.31	-0.10	0.85	0.08
	Assistance with interviews*	0.62	0.16	0.54	0.19	0.33
	Assistance with training	0.37	0.12	0.19	0.59	0.35
	PA training	0.55	0.14	0.34	0.55	0.05
	Employment law advice*	0.78	0.15	0.24	0.26	0.26
	Recruitment support*	0.80	0.14	0.31	0.26	0.29
	PA management advice*	0.63	0.27	0.49	-0.11	0.28
	Assistance compiling job descriptions*	0.49	0.02	0.71	0.18	0.09
	Assistance compiling contracts*	0.45	0.04	0.81	-0.05	0.19
	Any other backup service*	0.26	0.15	0.72	0.02	-0.11
Accountancy services	Help setting up bank accounts	0.70	0.25	0.44	-0.06	0.24
	Issuing cheques	0.51	0.25	-0.12	0.50	-0.07
	Assistance with tax*	0.94	-0.04	0.13	0.11	-0.02
	Assistance with National Insurance*	0.94	-0.02	0.16	0.09	-0.06
	Accountancy service*	0.92	-0.02	0.06	0.12	-0.07
	Assistance with payroll*	0.90	>-0.01	0.14	-0.04	0.02
	Payroll service*	0.85	0.08	0.14	-0.06	-0.18
	Training in budgeting*	0.77	0.21	0.21	0.23	0.16
	Completing monitoring forms*	0.78	0.20	0.21	0.27	0.16
	Help to organize employer's liability insurance	0.75	-0.02	0.37	0.05	0.23
Employment agency services	Care worker introduction scheme	-0.14	0.66	0.13	0.38	0.14
	Employee scheduling/rotation service	0.23	0.69	0.19	-0.03	0.14
	Finance and insurance management service	0.09	0.65	-0.11	0.36	0.10
Employment business services	Contract care workers	0.03	0.81	0.07	0.11	0.20
	Organisation of payment to care workers	0.04	0.88	0.10	0.20	0.14
	Finance and insurance management	0.13	0.81	0.04	0.04	0.14

*DPS referred to in official guidance on direct payments (DH 2003).

ideal provision profile represented by a factor, given the sub-set of services they provide. For practical purposes, DPSS most likely to provide the services linked to any given profile are those in 'close proximity' to it (high scores), while DPSS with negative values are correspondingly associated extremely unlikely to provide the set of services highly associated with a factor. A table of factor scores for each DPSS provider cannot be listed to respect the confidentiality of the respondents. However, factor scores can be exploited to investigate further possible causes of variations in services offered such as size, scope, structure, governance and ideology of organisations providing DPS.

Part 2

Once DPSS profiles were established, the factor score for each organisation was used as the dependent variable in multivariate regression analyses using ordinary least squares methods (OLS) to explore *how proximity to a service profile might be associated with other DPSS characteristics*. The following macro-categories were included among the covariates: organisation type, roles, size (measured by income, FTE staff numbers, user-base); receipt of DPDF and some aiding/hindering factors reported as relevant by the DPSS. Identical explanatory variables were initially examined for each profile, but only indicators with statistically significant association to each profile were included in final models to simplify interpretation, minimize multicollinearity risk and maintain estimate precision. Consequently, the five models (see Tables 3.3-3.7) include different combinations of explanatory factors, and some of the variables explored do not appear at all. All models were estimated using robust standard errors when the Breusch-Pagan test rejected the hypothesis of homescedasticity.

Part 3

In separate analyses, I examined the relationship between individual DPSS factor scores in 2006 and data collected in the three follow-up rounds (2011, 2014 and 2016). Such data described the evolving status of the original DPSS organisations', as well as subsequent commissioning patterns (where original DPSS had been decommissioned). Evolution was characterised first by noting if the original DPSS was still contracted, or had lost its contract. In the second case the outcome was also noted with possibilities including; replaced by a mix of providers (spot-contracts); replaced by an in-house provider; replaced by a for-profit provider; replaced by a user-led organisation (ULO); replaced by a local voluntary organisation; not replaced (no DPSS). Other changes noted were the possible introduction of pre-paid card schemes as well as repeated changes in provider.

Having follow-up results at three moments in time (2011, 2014, 2016) it was possible to examine the incremental changes in organisation status for three separate periods (2006-2011; 2011-2014; 2014-2016). The correlation between 2006 factor scores and those incremental changes was evaluated – again with STATA® 14 – by using marginal effects models with an OLS estimator with errors clustered around the DPSS identifier (a standard procedure when estimating regressions that have more than one observation per unit, in this case more than one year for each unit).

It some cases it was more interesting to look at cumulative change in the overall intervening period (i.e. 2006-2016), which was done when examining the possible effect of original DPSS traits, such as if the original DPSS was funded solely by DPDF funding and whether it was disability-led, on overall DPSS continuity.

3.3. Results

3.3.1. Sample Characteristics

Response rates to the original survey varied by country; highest rates were in Wales and England (Davey *et al* 2008). An initial challenge was to distinguish between organisations that were actually providing any services of DPS defined by the research (Table 3.1), and those that were not. Of the 147 confirmed DPSS in England, 109 responded (74%). This represented 66% of all local authorities as a few local authorities had more than one DPSS and some replies were from second schemes (while some other authorities actually had none). All DPSS that responded were tracked across the ensuing decade. Once the original DPSS was decommissioned we continued to track the relevant local authority area (LAA). This meant that we monitored not only changes to the original provider from the time of the survey, but also subsequent providers, generating substantial data on turnover.

Turnover in DPSS: 2004-2016

Considerable change had taken place among established DPSS (Table 3.2). In 2004, the market was divided almost equally between strictly *local* voluntary organisations, and local branches of *national* voluntary organisations (BNVOs; e.g. Rowan, Penderels, Age Concern, Shaw Trust). Some local voluntary organisations fitted the strict NCIL definition of CIL, some were more loosely defined ‘user-led’ organisations (ULOs) and others included cooperatives. A few well-established DPSS were run by local councils.

By 2011, 39 had lost their contract (equal to 39 LAAs), 75% of which were replaced by other providers. Among the eleven that were *not* replaced all were second (often pilot) schemes, set up with DPDF monies where the main DPSS within the LAA prevailed. Aside from these, a further seven schemes established only on the back of DPDF investment were replaced by alternative providers –in local authorities where there had been no DPSS prior to the DPDF.

Table 3.2: DPSS by type: 2004-2014.

Year	*n*	Local voluntary (all)	Branch of national provider organisation	In-house	For-profit organisation/ community interest companies	Spot contracts to a mix providers	No provider at present
2006	109	53%[1]	30%	16%	-	-	-
2011	99	30%[2]	33%	24%	12%	-	-
2014	99	23%[3]	25%	7%	7%	12%	6%
2016	99	24%[4]	30%	23%	1%	19%	2%

[1] 69% ULOs (of which 29% were CILs); 31% other local charities. [2] 80% ULOs (of which 47% were CILs); 20% other local charities. [3] 82% ULOs (of which 52% were CILs); 17% other local charities. [4]79% ULOs (of which 50% were CILs); 21% other local charities.

Turnover between 2006 and 2011 mostly took place at two points of time: immediately after the expiry of the DPDF (2007/8); or in 2010, coinciding with the directive that all adult social care users should receive a personal budget, preferably as a direct payment, by 2013 (DH 2010a). The wave of decommissions-recommissions in this period resulted in a significant shift in the market share of different types of provider. Most significant was ULO replacement by for-profit organisations or community interest companies, followed by a slight increase in in-house schemes (Table 3.2), which together reduced the local voluntary sector from 53% to 30% (Table 3.2). In contrast, the share of DPSS provided by BNVOs rose by two percentage points.

Between 2011 and 2014, a further 35 DPSSs were decommissioned. Just over a third (n=14) were repeated recommissions. Among these some were contracts with for-profit providers which survived only the minimum contract period (usually a year). Such services offered only a telephone service (no face-to-face contact with clients) and in all cases were terminated due to dissatisfied clients, local authority concerns or, in one case, a major data protection breach. Yet the most striking change in this period was the relinquishment of contracts with some exiting DPSSs in favour of a system of spot-purchasing. –This transformed access to DPS from a service to which service users were automatically referred and were offered support mostly free at the point of use (Davey *et al* 2008), to one where service users were being advised to commission their own DPS (using a portion of their direct payments funds), from one or more, "recommended" providers offering various support options: these now could include homecare agencies and accountancy firms as well as ´traditional' DPSS, such as those formerly contracted. From zero, spot contracts, rose as a form of providing DPS to 14%, reducing the local voluntary sector and BNVOs. At the same time, 7% of LAAs had no provider – underlying the instability affecting the sector.

By 2016 we see further contraction in the share of provision occupied by the local voluntary sector as a whole (comprising ULOs; both CILs and disability-led organisations, as well as other local charities), but a boost in the coverage of BNVOs returning to 2006 levels (Table 3.2). This shift was partly fueled by more local authorities shifting to spot contracts – representing 19% of LAAs covered by the survey - and partly by a return in confidence in BNVOs which appears in tandem with the decline of for-profit companies between 2011 and 2016.

The follow-up survey also charted the introduction of pre-paid card schemes. In 2011, none existed; in 2014 12% (n=12) had introduced them. By 2016 this had risen to 19% (n=19).

Overall, only one third of original respondents from England were still contracted by 2016. Predictably the least fall out among provider type has occurred among in-house schemes but beyond this, subtler differences between schemes have impacted on their staying power. Given that there were 104 lost contracts during the period, the remainder clearly fared well. On the other hand, with 27% of contract changes representing repeated recommissions, clients in a sizeable portion of LAs faced multiple upheavals. What characterized organisations that remained versus those that were replaced?

3.3.2. The Five Profiles

Only indicators with statistically significant associations to one or more of the DPSS profile(s) are shown.

Profile one: fiscal moderators

The first and most common profile of DPSS from 2006 is described as '*fiscal moderators*' since its most prominent drivers were activities such as assistance with tax, National Insurance and related accounting services, including provision of payroll services (Table 3.3). Yet it was also substantially linked to general recruitment support, including employment law advice, help with organizing employers' liability insurance, training in budgeting and completing monetary forms, but *unlikely* to provide advocacy services or training for self-assessments. Of all the profiles which emerged, this is the only one which offered a broad profile of accountancy and recruitment services (Table 3.3) and, despite its clear fiscal focus, it may be viewed as the generic profile of DPSS in 2006. Indeed, it accounted for the greatest share of variation in DPS, equal to almost half of total variation.

Fiscal moderators were most likely to be BNVOs, dominated by organisations such as Penderels or The Rowan Organisation, although associated with *all* types of organisation participating in the survey, albeit unequally (Table 3.3). For instance, they were unlikely to be disability-led (Table 3.8).

Fiscal moderators had a lower ratio of staff dedicated to direct client work suggesting that they were either larger and/or had more complicated organisational structures. They also worked in environments with more favourable contractual relationships; they were likely to have discussed the implications of local demand for DPs exceeding contractual expectations with their local authority and they did not depend upon soft money in the form of DPDF as their funding basis (Table 3.9). They tended to view 'inspection and regulation of local authority services' and, 'the priority of DP development within the local authority' as having assisted the development of DP. The inclusion of DP targets in Local Public Service Agreements, a feature of inspection and regulation at the time, led in many authorities to increased funding for DP development (Vick *et al* 2006).

Table 3.3: Characteristics of DPSS associated with the fiscal moderators profile (N= 126)

Factor 1: Fiscal moderators profile	**Coeff**	**P-value**
Branch or affiliate of national provider - all user groups	1.88	0.000
Local organisation supporting one LA	1.01	0.000
In-house scheme	0.85	0.005
Local organisation supporting neighboring local authorities	0.72	0.014
Inspection and regulation of LA services*	-0.54	0.012
DP demand exceeded expectations	0.40	0.012
Ratio of staff involved in DP related services	-0.58	0.097
Constant	-0.18	0.598
Adjusted R^2	0.42	

* As a positive aiding factor in implementation of direct payments

Accounting for the largest share of variation in DPS, fiscal moderators were the most widespread in 2006. Despite this, the profile exhibited significant staying power in the years following the survey (Table 3.10) although this diminished (Table 3.11). There was a specific peak in the replacement of fiscal moderators by 2014, but this was the result of divergent objectives. Fiscal moderators were linked to a switch to spot-contracts from a mix of providers (2014), replacement by a ULO (2014), replacement by an in-house scheme (2014) and the likelihood of no DPSS being in place in 2016. Of note, where fiscal moderators were replaced by a switch to a mix of providers, this was frequently in tandem with the introduction of a prepaid card scheme (Table 3.10)[6] and this was the *only* profile with statistical links to this phenomena.

With such variety, what can this tell us? Firstly, we understand that a statistically significant proportion of LAs attracted to the comprehensive model of DPS offered by fiscal moderators circa 2006 were susceptible to the changing discourse on best practice in DPS (cf. Bennett & Stockton 2012), were market-orientated (in their approach to commissioning DPSS and implementing DP), and driven by perceived potential

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[6] Moving to a mix of providers was statistically associated with the introduction of a prepaid care scheme (0.126**)

efficiency gains from a) switching to a mix of providers[7] funded exclusively via service users PBs and/or b) introducing payment cards to ensure a tight rein on use of funds (this may be referred to as Type A). This approach, while “innovative”, would suggest a certain amount of lip-service being paid to the relationships between service users and DPSS – and to their expertise. An extreme extension of this is revealed by the prevalence of LAs formerly commissioning fiscal moderators who had either repeatedly recommissioned DPS and/or had no DPSS in place in 2016 (Type B).

In an almost opposite interpretation of how best to mainstream DP – but a common drive to innovate and respond to external directives - a significant share switched to in-house support (Type C). These may have been more paternalistic authorities; seeking to protect social work roles (Leece & Leece 2011), although reports suggest that there were positive benefits to bringing DPS in-house. In a best practice review by Edwards (2008), the decision by one LA to take over responsibility for support and monitoring of direct payments from a local charitable organisation was highlighted. According to the evaluator, “this allowed more effective links to develop between the DP support service [in-house] and the social work personnel who advised service users about direct payments during assessments” (Edwards 2008: 5).

Finally, a further significant share of authorities formerly attracted by schemes offering a fiscal moderators profile reacted to the need to improve services by commissioning a user-led organisation (Type D). Again, this was consistent with best-practice messages[8] but represents a very different interpretation of them more in line with the early values around DPS that were prominent in 2006. Finally, a significant proportion of LAs contracting fiscal moderators in 2006 maintained long-standing contractual relationships with these original DPSS commissioned to provide a broad and comprehensive service of basic DPS (Type E). Notably types C, D and E have continued to provide DPS which is free at the point of use, in sharp contrast to the ideology of Type A.

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[7] One London council was cited in the Local Government Association Adult Social Care Efficiency report (2014) as having made savings of £0.9 million as a result of a significant intake in the uptake of DPs (to 66% of customers) partly through switching to a mix of providers which ensured that all DP support costs were being met by the individual with no “*additional costs*” from a contract with a DPSS.

[8] Bennet & Stockton (2012) advised local authorities that, “there should always be a role for a local ULO in a ***mixed model of support*** (emphasis mine) **also** encompassing larger providers with the capacity and infrastructure to meet significant growth in demand.

Profile two: Employment managers

The second cluster that emerged among the 2006 sample of DPSS was driven by provision of services associated with an employment agency (Table 3.1) or business (care worker introduction, employee-scheduling/rotation services). The latter requires registration with the Care Quality Commission (CQC) as a homecare agency (CQC 2012). As such, they can be called *employment managers*. As there were few DPSS registered as employment businesses at the time, it was thought that employment management services represented the absolute margin of DPS provision. Yet this emerged as the second most important profile, accounting for the second largest share of variation in services provided by DPSS (14%). DPSS that fitted closely with this profile were highly specific and negatively associated with provision of some other forms of DPS, including peer-support.

The most notable factor associated with this group was their very low annual income, often below £20.000[9] (Table 3.4); they were mainly funded solely from the DPDF in 2006, suggesting they were newcomers to DPS provision (Table 3.9). However they tended to report high user numbers.

The profile was also linked to spending less on management and administration, suggesting that they were schemes with simple organisational structures, and a large proportion of their resources was dedicated to direct staff costs, consistent with their low income-base.

Table 3.4: Characteristics of DPSS associated with the employment managers profile (N= 118)

Factor 2: Employment managers profile	**Coeff**	**P-value**
Prop. of expenditure used for management & admin.	-2.20	0.016
Income (extra small size)	1.67	0.000
Support from the NCIL*	-0.62	0.032
Inspection and regulation of LA services*	0.58	0.060
Availability to work as personal assistants*	0.56	0.003
Average number of home visits per month per user	0.19	0.024
Number of service users	0.01	0.043
Constant	-0.92	0.018

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[9] Income categories: extra small (<£20,000 pa); small (£20,000 - £50,000 pa); medium (£50,000 - £99,999 pa); large (£100,000 - £199,999 pa); extra-large (> £200,000 pa).

Adjusted R^2	0.38

* As a positive aiding factor in implementation of direct payments

Some indications of the local environment in which they operated were also revealed. They tended to consider the availability of people to work as personal assistants as a factor promoting DPs, but were unlikely to note support from the NCIL as an aiding factor. They saw inspection and regulation of local authority services as an aiding factor of some impact.

Most employment managers lost their contracts (Table 3.8). This must have been early on (and probably following expiry of the DPDF) and replacements hastily appointed, because by 2014, areas with former employment manager schemes were very likely to have experienced a repeated change on provider (Table 3.11). They were then unlikely to be replaced by a mix of providers but by a local voluntary (but not user-led) organisation (Table 3.10).

Profile Three: Recruitment Advisors

Accounting for 6% of total variation in DPS provision in 2006, '*recruitment advisors'* offered a highly specific service: providing assistance with recruitment (e.g. compiling contracts and job descriptions and support with interviews), a list of local agencies and back-up support (Table 3.1). This group tended *not* to: issue cheques for payment of personal assistants, provide a bank of emergency staff, or provide finance and insurance management services. In direct contrast to employment managers, these DPSS had above-average income levels (£100-200K per year), and received greater DPDF support than other groups (Table 3.5), but surprisingly were extremely unlikely to be operating services set up solely through DPDF funding (Table 3.10). This suggests that that they were established organisations and that DPDF funding was providing a short-term substitute for LA funding. They were likely to be 'user-led' but did not campaign, nor did they charge users for services. Unsurprisingly, they viewed central government stewarding as positive in aiding DPs implementation locally, but did not feel that NCIL support was helpful (despite their role in supporting DPDF funded projects). They cited the benefit of accessible information for potential service users.

In terms of their staying power, of the three recruitment-focused profiles, recruitment advisors were very likely to have remained in contract with their local authority during the period 2006-2016 (Table 3.8)

Table 3.5: Characteristics of DPSS associated with the recruitment advisors profile (N= 118)

Factor 3: Recruitment advisors profile	**Coeff**	**P-value**
Central government stewarding*	0.68	0.002
Access to accessible information for potential service users*	0.59	0.002
Income (Large)	0.53	0.017
Support from NCIL	-0.69	0.024
Users being charged	-0.39	0.060
Campaigning	-0.36	0.056
DPDF funding (in thousands)	1.81	0.072
Constant	0.12	0.530
Adjusted R^2	0.20	

* As a positive aiding factor in implementation of direct payments

Profile Four: Recruitment Agents

The fourth profile reflects a set of DPSS which operated as '*recruitment agents*' by offering a bank of emergency staff and a list of personal assistants, but *not* employee scheduling/rotation (Table 3.1). They represented a further 5% of variation in services provided. They were linked to assistance with training, PA training and issuing cheques, for which factor loadings were greater than 0.50. Surprisingly, the profile of recruitment agents was negatively associated with provision of a payroll service, assistance with payroll, assistance in compiling contracts, PA management advice and help setting up a bank account.

These DPSS tended to offer support in neighbouring authorities (Table 3.6) and were associated with being a CIL and campaigning for DPs use, suggesting that they had substantial legacies in DPS. Surprisingly, they tended to serve fewer users and they were very likely to be solely funded by DPDF. These characteristics suggest that these were branches of CILs that were commissioned in one LA but served a handful of users in neighboring authorities. DPDF offered an opportunity to persuade a neighbouring LA for then to extend their services in the area. The fact that services on offer in 2006 were circumspect is also consistent with their operation as an “add-on” service. This opportunity seems to have paid off because recruitment agents were unlikely to have lost their contract in 2011, 2014 and 2016 (Table 3.11) meaning that they were successful in securing local authority funding after the DPDF expired.

Table 3.6: Characteristics of DPSS associated with the recruitment agents profile (N= 115)

Factor 4: Recruitment agents profile	Coeff	P-value
Proportion of exp. for management & admin.	-2.36	0.009
Local organisation supporting neighboring LAs	1.24	0.000
Support from the NCIL	1.01	0.001
Concern about managing DP among users and carers	-0.82	0.004
CIL	0.75	0.005
Residential, domiciliary or day-care services	-0.43	0.064
Demand from service users and carers for DP	-0.35	0.101
Number of WTE staff working as DP support workers	0.11	0.062
Number of users	-0.04	0.000
Constant	0.79	0.001
Adjusted R^2	0.38	

Consistent with their CIL slant, they were unlikely to offer residential, domiciliary or day care services. They were neutral in their views of factors that may have helped or hindered DP development locally. Of note, they were likely to have a greater proportion of their staff dedicated to DP support, and spent a lower proportion of their expenditure on management and administration. This suggests high-intensity services focused on direct contact with users (Davey *et al* 2009) – in keeping with their CIL values.

Profile Five: Enablers

The final profile of DPSS are *enablers*, associated with services such as provision of general advocacy, support and training for self-assessments and provision of indirect (third-party) payment schemes (Table 3.1). This factor accounted for the remaining 4% of variation observed in services provided by DPSS in 2006. Operating at the opposite end of the spectrum from fiscal moderators, enablers were negatively associated with accounting services, including assistance with tax, National Insurance and provision of payroll support. As may be expected, DPSS scoring highest for this profile were unlikely to be run by a BNVO (Table 3.7) but rather were user-led voluntary organisations (Table 3.8) offering individual advocacy outside the realm of DPs (Table 3.7).

Table 3.7: Characteristics of DPSS associated with the enablers profile (N= 115)

Factor 5: Enablers profile	**Coeff**	**P-value**
Branch or a national organisation serving all user groups	-0.82	0.001
Individual advocacy	0.61	0.003
DP demand exceeded expectations	-0.52	0.013
Availability to work as personal assistants	2.20	0.043
Voluntary	0.51	0.041
Users being charged	0.44	0.045
Years of support	0.05	0.068
DPDF (amount)	0.01	0.012
Constant	-0.73	0.019
Adjusted R^2	0.35	

Unlike any other group, enablers tended to charge individuals for services provided, despite the fact that many received DPDF funding (Table 3.7). They had weaker formal relations with their funding authority, and were unlikely to have discussed the implications of DPs demand exceeding expectations. The only factor considered by this group to be aiding DP development was availability of people to work as personal assistants, reflecting the fact that they tended not to provide recruitment support.

Of the five profiles, the enablers were the only ones associated with a sizeable length of service, having provided DP support for much longer than other DPSS. However, they were later among those most likely to have lost their contracts by 2011. The lack of any positive association with any other provider types that may have replaced the original enablers (Tables 3.10, 3.11), is likely due to the limited variation accounted for by this marginal profile. Of note, LAAs formerly commissioning an enabler were among those least likely to have moved to an in-house scheme (Table 3.10) or to have implemented a pre-paid card scheme (Table 3.11), possibly as a result of residual collective service user voice in these areas.

Table 3.8: Regression results for the post survey analyses of association between factor profiles, user-led status and having remained in contract across the period 2006-2016 (N=198)

	Factor 1: Fiscal moderators profile	**Factor 2: Employment managers profile**	**Factor 3: Recruitment advisors profile**	**Factor 4: Recruitment agents profile**	**Factor 5: Enablers profile**
User-led (2006)	**-0.304***	0.164	0.053	**0.476*****	**0.828*****
Original DPSS still contacted (2006-2016)	**0.509*****	**-0.492****	**0.474*****	-0.041	-0.124
Constant					
N	309	309	309	309	309
r2	**0.080**	0.046	0.064	0.063	0.136

Table 3.9: Regression results for the post survey analyses of association between factor profiles, having been funded exclusively by DPDF in 2006 and having lost contract between 2006-2016 (N=198)

	Factor 1: Fiscal moderators profile	**Factor 2: Employment managers profile**	**Factor 3: Recruitment advisors profile**	**Factor 4: Recruitment agents profile**	**Factor 5: Enablers**
Lost contract since survey	-0.066	-0.03	**-0.199***	-0.115	-0.028
DPDF only (2006)	**-1.629*****	**1.100***	-0.4	**-0.773*****	0.18
Constant	0.841***	-0.085	0.718***	-0.108	0.175
N	198	198	198	198	198
r2	0.374	0.103	0.058	0.115	0.004

Table 3.10: Regression results for the post survey analyses of association between factor profiles and subsequent DPSS status (a): 2011, 2014 and 2016 (N=198)

		Factor 1: Fiscal moderators profile	**Factor 2: Employment managers profile**	**Factor 3: Recruitment advisors profile**	**Factor 4: Recruitment agents profile**	**Factor 5: Enablers profile**
Moved to mix of providers	2011	-	-	-	-	-
	2014	**0.901****	-0.389	**0.712****	0.186	-0.297
	2016	0.53	**-0.530****	**-0.514****	-0.22	0.916
Gone in-house	2011	0.126	0.213	-0.308	-0.16	-0.608
	2014	**1.090*****	0.512	0.538	0.085	-0.481
	2016	0.186	0.632	0.378	**0.778***	**-0.846*****
Gone to for-profit company	2011	0.47	-0.563	-0.748	-0.614	-0.217
	2014	0.814	-0.009	-0.488	**-0.593****	0.526
	2016	-	-	-	-	-
Gone to ULO	2011	-	-	-	-	-
	2014	**1.079****	-0.203	0.098	**-0.628****	0.427
	2016	-0.562	-0.025	0.575*	0.21	**-0.801****
Gone to branch of NPO	2011	0.268	-0.543	-0.787	0.105	**-0.953***
	2014	0.144	-0.4	0.651	0.024	-0.139
	2016	0.22	-0.193	0.194	0.074	**-0.658*****
Gone to local voluntary org	2011	-	-	-	-	-
	2014	0.288	-0.587	0.502	**0.983****	0.313
	2016	-0.155	**1.180***	**-0.734***	**-0.844****	-0.092
No DPSS	2011	-	-	-	-	-
	2014	0.627	0.708	0.83	-0.261	-0.345
	2016	**1.030****	-0.31	**-0.615****	**-0.791****	1.222
Original DPSS still contracted	2011	**0.944****	-0.363	0.165	-0.159	**-0.807***
	2014	**0.989*****	-0.332	**0.749*****	0.004	-0.176
	2016	0.291	-0.251	**0.413***	0.119	-0.17

Table 3.11: Regression results for the post survey analyses **of factor profiles, subsequent DPSS status, the introduction of a prepaid care scheme and the incidence of repeated change in provider: 2011, 2014 and 2016 (N=198)**

		Factor 1: Fiscal moderators profile	**Factor 2: Employment managers profile**	**Factor 3: Recruitment advisors profile**	**Factor 4: Recruitment agents profile**	**Factor 5: Enablers**
Original DPSS lost contract	2011	-0.237	-0.649	**-0.708*** **	**-0.371***	0.14
	2014	-0.235	-0.135	-0.206	**-0.516****	-0.045
	2016	0.271	-0.466	**-0.450****	**-0.612*** **	0.049
Prepaid card scheme introduced	2011	-	-	-	-	-
	2014	**0.645*** **	-0.092	-0.381	0.069	0.198
	2016	**-1.139****	>-0.001	0.008	0.549	**-0.590****
Repeated change in provider	2011	-	-	-	-	-
	2014	**0.609****	**-0.937*** **	-0.269	0.175	-0.039
	2016	**-0.658***	0.567	0.28	0.374	0.056

3.4. Discussion

Key aims of the study were to examine DPSS profiles and to explore associations between them and the survival of DPSS. This study has revealed key data on how the market for DPS has evolved over the past decade (Table 3.2). It has also explored how local authority priorities may have merged with DPSS organisational characteristics (and other factors) to create five distinct profiles of support in 2006. The insights from this exploration cut across many of the basic generalisations about DPSS that have been prevalent (i.e. user-led versus non user-led) which offer only a limited perspective on the dynamics and evolution of DPSS and fail to account for important differences in DPSS, such as size and services available. It additionally provides a glimpse at how local authority priorities have evolved in relation to the implementation of DP. By not only charting the survival of the original survey sample, but also following commissioning patterns subsequent to termination of a contract in each LAA represented by the original sample of DPSS, the research casts light on how local authority priorities have evolved across a period of unprecedented change in the prioritization of direct payments as a service option.

3.4.1. Direct Payments Support: the emergence of a core profile of support and its subsequent demise

The profile of fiscal moderators emerged as the closest representation of a generic profile of DPS, focused on safeguarding adherence to statutory and fiscal responsibilities, and offering recruitment support and employment law advice.

The convergence of DPS in the UK to fiscal moderation was unsurprising given international experience (Scherzer, Wong & Newcomer 2007). UK research has demonstrated how access to DPs is blocked by care managers' lack of confidence in handling them, combined with concerns about risk and professional responsibility (Ellis 2007; Mitchell & Glendinning 2007). As a result, a system which truly supports self-directed care must incorporate robust protocols for abuse detection and prevention (Carr 2010, DH 2010b; Manthorpe *et al* 2009), although such safeguarding may eclipse efforts to enable and empower service users to make informed and creative choices (Carr 2010). Recent evidence suggests that a coordinated yet proportionate focus on safeguarding is justified (Ismail *et al* 2017).

Another major strength of fiscal moderators was their emphasis on managing PAs. In the USA, fiscal intermediary organisations have been criticized for failing to safeguard the position of personal assistants, or improve worker training, safety, wages, benefits and retention (Scherzer, Wong & Newcomer 2007). Unlike the fiscal intermediaries in the USA, fiscal moderators in the UK scored highly for services related to PA management and support, including employment law advice; indeed they scored highest for these services of all the profiles.

This profile was unequivocally favoured by commissioners: many DPSS of this type remained under contract for at least the first half of the decade 2006-2016 but the profile diminished between 2014 and 2016. Given the alignment of the fiscal moderator profile with local authority priorities it is surprising yet it is symptomatic of the shifting yet highly divergent priorities that have emerged with the implementation of personalisation.

Fiscal moderators suited local authorities in the early implementation of direct payments but for different reasons. LAAs that were attracted to this profile seem to be divided into followers and implementers.

For the followers the broad model of support offered little more than a tick-box list of requisites at the right price at the right time only to be traded in for the next best offer. It was recognised early on that BNVOs were at an advantage when responding to invitations to tender due to their infrastructure (Reynolds 2006). This makes it unsurprising that this fiscal moderators profile was the most closely linked to BNVOs of all the provider types. What the results show is that this advantage did not reward them with stability in the market.

The second group of LAAs attracted to this profile may be described as implementers in that they were linked in their post-survey commissioning by purposeful attempts to develop DPS with a view to implementing central government directives, according to their interpretation of the best path – this contrasts with the behaviour of LAAs linked to the other profiles. Of these, there were three kinds. The first formed longstanding relationships with fiscal moderators. This would have necessitated working with them to adapt to the increasing demand for services and changing resource and policy context. Others shifted DPS in-house in an effort to ensure the principles of DPS were built into social services and delivered consistently. The final and probably largest group shifted towards a mix of providers (purchased individually by DP users), often in tandem with the introduction of pre-paid card schemes.

These three different responses – the partnership response; the protectionist response and the cost-control response underline the extreme differences in the implementation of personalisation. Most significant is that this represents the response of LAAs that formerly commissioned the broadest form of support.

3.4.2. Intensive support for recruiting

Supply of PAs has long been perceived as a major issue in securing access to DPs. Support provided for recruiting can significantly affect success of DPs and influence working conditions experienced by employed workers (Baxter *et al* 2008a). Three support profiles centered on recruitment (employment managers, recruitment advisors, and recruitment agents), reflecting what was then growing interest in developing services to meet recruitment needs. Perceived challenges included: potential vulnerability of DP users when recruiting; recruitment difficulties in areas of high housing costs and rural areas; delays in setting up DP packages (NCIL 2006).

The notable feature of the three recruitment profiles that existed in 2006 is that none provided more standard DP support services, akin to those mentioned in the official guidance on DPs: their prime ‘business’ was recruitment support. This was most surprising for recruitment agents, positively linked to CILs, and generally presumed to provide a more generic model of DPS. Despite their shared focus on the business of recruitment, each of the three profiles was distinct in its service scope.

The most prevalent of these three profiles was employment managers, akin to registered care agencies, but very different in approach and scale. These were micro-providers without previous experience in delivering conventional homecare, set up to recruit, manage and match PAs on behalf of DP users. Despite their forward-thinking approach, employment managers had little staying power. Many were pilot schemes, funded solely for the period of DPDF funding. DPDF projects fitting the profile of employment managers reported difficulties with registration, due to conflicting information from CSCI (Commission for Social Care Inspectorate, now CQC) and excessive costs relative to income potential and organisational capacity (NCIL 2006). This, combined with DP rates lower than the average cost of contracted care, resulted in dependence on local authority or self-funded top-ups to meet running costs (Cooperatives 2010).

Financial unviability may also have been stoked by operating factors: employment managers engaged in high levels of direct support to users which may have been unsustainable within their funding and staffing limits. Similarly, conventional homecare agencies newly serving DP users reported that they spent, “more time in discussion with service users resolving problems and adapting services” with DP users than with standard clients (Wilberforce *et al* 2011: 607) leading to the prediction that allocative efficiency would raise increased costs (Rodrigues & Glendinning 2015).

However, some of the fault for the instability of employment managers would seem to relate to the local authorities that agreed to commission them. Reports from the time suggest a lack of commitment to support – evident from their lack of LA funding. This appears to continue over time as areas where employment managers were decommissioned were likely to have experienced two changes in DPS provider by 2014.

In contrast to the precarious position of employment managers, recruitment advisors (profile 3) offered a more general service along the lines of the recruitment services offered by *fiscal moderators* without the payroll support. Many circumvented this disadvantage by referring their users to payroll organisations – thus focusing their service on direct service user contact. These were primarily established ULOs both connected and well-funded. These have tended to survive, probably more because of these characteristics rather than the sub-set of services on offer. They have a common link with fiscal moderators that survived in that they appear to have operated within supportive LA environments.

Finally recruitment agents offered a restricted but high-intensity service focused on direct client contact consistent with models of support for independent living. They offered lists of PAs and a bank of emergency staff (to meet short-term needs if PAs became ill), but did not provide payroll (a function which requires more investment of resources in administrative staff). They were also well-established organisations, including large CILs but featuring here at a point in which they were developing in neighbouring authorities - a situation promoted by the DPDF. DPSS linked to this secured their position by these means and survived in their expanded positions. This may be influenced by recognition of their expertise, obvious economies of scale (for example in staff training) and the particular slant of their services - the provision of a list of PAs continues to feature as an example of best practice (cf. TLAP 2015, Skills for Care 2014) and has been developed across the country since the time of the survey. PA lists have however evolved: while the presence of services that LA boundaries is common, these registers are now predominantly online – *North West Personal Assistance* being a prominent early example.

Clearly there has been much evolution in services focused on supporting recruitment, yet the challenges that drove these developments remain. The follow-up work strongly suggests that services that are currently *directly funded* by local authorities offer *low-intensity service*s. In addition to online PA matching, many LAs have developed lists of local accredited providers by specialty/geographical area (Brookes *et al* 2015; Hunt 2010).

Furthermore, local authorities seem to be taking the view that if service users require ongoing intensive support, it should be funded directly from personal budgets. Thus increasingly, DPSS are not commissioned to provide ongoing employment support. In contrast, conventional homecare agencies are being *encouraged* to target service users with intensive employment support needs and/or third party management of funds (DH 2012), effectively taking on roles previously occupied by employment managers. It is now common for conventional homecare providers to advertise PA recruitment and management. The pace of change is noteworthy. Until relatively recently, homecare providers had little interest in serving DP users (Baxter *et al* 2008b), linked to perceptions of increased risk and limited financial return (Sawyer 2008). The experience of employment managers suggests that these fears may be well-founded, and their new found willingness to occupy this role is symptomatic of wider changes in the way homecare agencies are commissioned, combined with greater competition and wider market uncertainty (Rodrigues & Glendinning 2015).

A crucial issue is that the shifts in recruitment support for direct payments are likely to have significant impacts on how direct payments are employed. This is already underway: DPs are now increasingly used to purchase care from conventional homecare providers, with recent data showing that only 33% of DP users employed a PA in 2014, compared to 52% in 2013 (Fenton 2014 in Slasberg *et al* 2014/5), even though outcomes may be better when DP service users hire PAs (Slasberg *et al* 2013). This shift is increasingly evidenced as a dilution of the social model of disability in the implementation of direct payments (Pearson & Ridley 2017).

3.4.3. Enabling and empowering service users

Supported self-assessment, advocacy and brokerage are now cornerstones of self-directed care policy, yet these services only reached the mainstream relatively recently (DH 2010a; 2010b). The minority of DPS that represented *enablers* at the time of survey were ahead of the trend by providing support, training and advocacy for self-assessment. Coupled with being associated with long lengths of service and being user-led, it would be reasonable to assume that the enablers would have flourished. On the contrary, the results clearly indicate marginalization of the enablers of 2006 as providers of DPS. Early indications of their fate were present at the time of the survey. They tended not to have discussed the implications of demand exceeding expectations with their local authority. They lacked resources for management functions, did not provide many functions associated with mainstream DP support, were unlikely to have received DPDF funding (which required partnership with their local authority) and relied to some extent on co-payments by service users. By 2011 DPSS driving the enablers profile were largely out of contract.

Why should DPSS focused heavily on advocacy have fallen into this position, given regular acknowledgement of the need for user-led services (see DH 2009b)? Enablers were clearly more vulnerable due to their limited profile of services, yet a key factor is likely to have been the nature of their relationships with their funding authorities. There have been recognized tensions between some CIL-run DPSS and authorities (Bennett & Stockton 2012), reports that some had funding revoked for various reasons (Priestly *et al* 2010), including tensions between reconciling user-controlled principles with the harsh reality of securing finances (Barnes & Mercer 2006) . Such decisions have been partially legitimized by guidance suggesting that advocacy services for self-directed care may be best served by organisations other than those providing DPS, due to potential conflicts of interest (DH 2009a). The possibility of a residual collective service user voice in areas where enablers were previously commissioned is raised by the discovery that these LAs were very unlikely to have implemented a prepaid card scheme or switched to in-house support – both viewed as controversial in terms of supporting service user empowerment.

There is however a much bigger picture in the realm of self-assessment, advocacy and brokerage service, in terms of everything that has been developed since the time of the survey (see chapter 7 for further discussion).

3.4.4. CILs and direct payments support

As in the USA, DPs were first pioneered in the UK in conjunction with local CILs (Barnes & Mercer 2006). As CILs proliferated, a common approach to DP support was supposedly developed through the emergence of the NCIL, which established overarching principles and rules on governance and a strict definition of CIL, to which a growing number of 'user-led' organisations do not conform. It was therefore assumed that a profile of support may have existed closely associated with CILs. The results show that the only profile statistically linked to CILs at the time was recruitment agents, a minor profile linked to high levels of DPDF funding. This almost certainly does not account for all CIL provision of DPS at the time, and the main conclusion is that CILs were far more heterogeneous in their supply of services than assumed. This is an obvious weakness, given the tendency of local authorities to demand a particular composition of services, as evidenced by the dominant fiscal moderators' profile. Nonetheless, 66% of CILs covered by the survey maintained their contracts to provide DPS over the subsequent decade. This figure compares favourably with the equivalent one (30%) for non-CIL ULOs. Thus, the position of CILs as providers of DPS might has been less fragile than other ULOs, possibly as a result of the scale and prominence of well-established CILs versus other ULOs. On the other hand, of the CILs that were no longer commissioned to provide DPS many where previously cited as examples of best practice. Moreover, their total lack of growth across a decade driven by policies emanating from the independent living movement raises questions about representation of disabled people at local level and the conditions necessary to promote CILs, not least given successive commitments by governments to promote them.

A related development is the merger of NCIL with Disability Alliance and Radar in 2012, creating Disability Rights UK. While it upholds the vision of a society where everyone with lived experience of disability or health conditions can participate equally as full citizens, unlike NCIL it serves no role in championing the specific place of CILs. Its member organisations (paying) range from CILs and other disabled-led organisations, to health service trusts, national voluntary organisations and local councils, suggesting a move towards mainstreaming its focus.

3.5. Conclusion

This study has revealed much about the shape of DPS at the time of the national survey of DPSS (2004) and, by tracking respondents, provides insight into the evolution of this market over the past decade. For much of the period there was convergence towards a generic profile of support, as a result of local authority commissioning practices, a process which led to considerable turnover in DPS provision, with only 33% of original responders surviving. The dominant model of DPS that emerged from this process focused on safeguarding statutory and fiscal responsibilities, and provision of services supporting relational aspects of PA management, including employment law advice. On the face of things, early market losses centered on organisations that were not closely aligned to this generic profile, yet there are other characteristics that can be attributed to DPSS that floundered by 2011. These included (a) newly established organisations funded exclusively or largely by DPDF funding (monies which, ironically, were aimed at *building* capacity of the voluntary sector to meet DP users' needs); (b) those with minimal managerial capacity directing most of their resources to direct contact with users, regardless of length of service or user-base; (c) organisations that provided services that may have caused conflicts of interest with their funding local authority and (d) defined as user-led. In other words, market losses between 2004 and 2011 were not evenly distributed between those more distant from the generic profile of DPS, but were positively skewed towards organisations on very limited incomes that tried to offer highly personal styles of support but were unable to do so sustainably. Moreover, they disproportionately featured small local voluntary organisations and ULOs, effectively halving the share of DPS provided by local voluntary organisations from 2004 to 2011.

However, things changed substantially from around 2012 onwards with the advent of prepaid card schemes and the suggestion that DPS should be funded directly from PBs, relieving local authorities of block commissions and opening up user choice to a mix of providers. This prompted a very different wave of change by local authorities taking the lead in personaliation - impacting on organisations which previously appeared to have a competitive advantage in tendering. Yet this period also marked a turning point in interpretations of DPS with LAs that had developed a more mainstream approach dividing into those that were more market-driven (and seeking immediate cost-savings), those that sought in-house solutions and those that stuck to their original path and their longstanding relationships with providers (many of whom are user-led). The analyses here are therefore unique in their ability to quantify the wide differences in the evolution of DPS across the decade. The market-driven approach creates an environment where even more responsibility is placed on the service user while an in-house focus takes responsibility for them but in doing so potentially disempowers users.

The period between 2012 and 2016 has also been marked by substantial disruption for service users, with 44% of total turnover recorded in 2014 represented by repeated decommissions. While turnover is inevitable, the experience of being transferred from one DPSS to another can be very disruptive (Williams *et al* 2014). At best, authorities ensure a period of contract overlap to allow transfer of client data from one DPSS to another. At worse, contracts are ended abruptly, and there is a gap between termination of a contract with one DPSS and start of the replacement service.

A further consideration is the shift away from intensive recruitment support which appears to be changing how DPs are employed with many service users moving away from hiring PAs and towards conventional homecare providers. This shift potentially dilutes the model of independent living on which direct payments was based. According to work on the outcomes of DPs for older people, it may also be affecting outcomes (cf. chapter 4). An added concern is the limited extent to which user-led organisations are now engaged to provide support planning and brokerage (cf. chapter 7) despite their early developments in this field - as in the *enablers*.

Many questions need to be asked about the *carte blanche* with which local authorities have engineered DPS, the backbone of direct payments, to suit their priorities. Given that some have consciously fostered long-term relationships with providers, why have they chosen to and how do service users' experiences differ according to these different options available? Also what is the viability of maintaining a mix of providers funded solely through individual commissions from DP users? For example, can it work if providers offer services to both state-funded and self-funded social care recipients? There is mounting evidence that outcomes for personal budgets are better among authorities that offer services that "support the principles of self-directed care" (Hatton & Waters 2013; Forder *et al* 2012) and with receiving support from ULOs (Williams *et al* 2014), while user-group-specific ULOs can increase uptake among under-represented groups (SCIE 2014). How does this translate if the responsibility to commission DPS is left in the hands of the user?

With so much unknown in this new world of supporting DP users it is worth concluding on a note about what *is* known. Research underlines that self-directed care is a dynamic process, with decisions constantly reviewed and renegotiated. DP support workers' ongoing relationships with service users and their attention and intuition in providing support in the right amounts at the right time through regular contact are considered especially pertinent to safeguarding and securing successful outcomes, and highly valued by users and carers (Williams *et al* 2014; Newbronner *et al* 2011; Blyth & Gardener 2007; Schore, Foster & Phillips 2007). Good quality DPS is claimed to potentially reduce widespread differences in access to personal, material and social resources to help them make choices, thus reducing inequalities in outcomes (Arksey & Baxter 2012), and may help to balance the mental effort associated with decision-making with the potential benefits of a DP (Rabiee & Glendinning 2010). It may also serve as a firewall where family members or friends are supporting DP users, balancing the preferences of service users and carers (Newbronner *et al* 2011). In many of these contexts, it is difficult to see how service users are best placed to pick their own support from a list of available options. Policy-makers should focus on the outcomes of local authorities' DPS commissioning in the same way that they are focusing on the way that DPs are being offered. Ongoing DPS is not required by all service users, and as the user-base increases it is important that funds are not tied up in DPS where it is not needed. Earlier models of support that emerged were designed to provide equal opportunities for access to DP and ensure that service users did not fall through organisational gaps. A radical shift away from this approach may result in a major shift in the way DPs are employed and leave some service users vulnerable to unwanted outcomes.

3.6. References

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4. Influences of service characteristics and older people’s attributes on outcomes from direct payments

Background

- Direct payments for care remain a cornerstone of personalisation of adult social care in England yet there is controversy about their suitability for older people. Relevant evidence appears contradictory: positive results of early qualitative studies versus less positive findings from recent survey data.

- Outcomes data specific to older people in receipt of DPs are extremely limited due to the conflation of outcomes of direct payments with those of individual budgets and personal budgets. Individual budgets and personal budgets feature major changes in assessment and allocation of publicly funded social care which make it difficult to separate the impact of actual services received from the impact of how funds are allocated, and how assessment and support planning are handled.

- The context in which DPs are supplied has changed dramatically in the past decade, particularly because of the personalisation agenda reform and government concomitant austerity policies. This has had a particular impact on the model of support for direct payment users and on the provision of direct payments support services, as shown in chapter 3. There are also concerns that local authorities may have reduced allocations of care to people who take-up a direct payment as a means of managing budget pressures – or else, that they offer direct payments as the default option because of severe supply constraints in council-managed services.

- Interviews with older people using DPs (and proxy respondents) were conducted as part of a project funded by the Department of Health a decade ago. At the time direct payments had become more widely available, but personal budgets had not been implemented. The data obtained in these face-to-face interviews offers unprecedented level of detail on the use of direct payments among older people. Both its detail and its timing allow me to explore the relevance of changing structural factors (affecting who receives direct payments, what external support they have available, what are the subsequent recruitment patterns, and so on) versus individual characteristics, such as the balance between DP-funded care and unpaid care.

Aims & Objectives

The chapter sets out to:

- Identify associations between outcomes gained by direct payments and factors such as service users' characteristics and the types and quantities of care purchased.

- Explore the relevance of changing structural factors affecting who receives direct payments, the external support available to them and later recruitment patterns versus individual characteristics, including the balance between DP-funded care and unpaid care.

- Discuss the implications of the findings for current practice.

Key findings

- Direct payment contribution to outcomes was high. Participants reported significantly higher levels of safety and control over daily living than the general population of community care recipients aged 65 and above. The contribution was also positive, even if more limited, with respect to the home environment and social participation.

- Service users who received substantial support from unpaid carers achieved significantly greater gains from DPs. Unpaid care boosted outcome gain by complementing DPs and through the function of managerial care. This required significant input from unpaid carers. The extra work that this implies for carers needs to be balanced against the benefits they may derive from the arrangement. This topic is explored further in chapters 6 and 7.

- Greater outcome gains were also linked to recruitment support and receiving flexible care inputs (typically from a personal assistant). Purchasing care that deviated from standard personal care inputs improved service benefits. Qualitative insights on these findings are laid out in chapters 6 and 7.

- The freedom to combine care packages with self-funded care enhanced the impact of direct payments (cf. chapter 7 for qualitative case examples).

- Large discrepancies between total care input and DP-funded support were associated with lower outcome gains, irrespective of the value of allocated care. This was often due to care allocations that were unable to include health funding, resulting in a greater share of care being delivered by unpaid carer(s). This raises two important issues: the continued underuse of health funds within current direct payment care allocations; and the risk associated with shifting the balance between formal care and unpaid care.

4.1. Introduction

Social care in England has changed substantially as a result of “personalisation” policies, such that Direct Payments (DPs; cash payments) are now core routes through which individuals can take their personal budget (PB), with third-party management arrangements also possible. Successive governments have attempted to steer implementation, placing particular emphasis on DPs to older people, both directly through numerous publications and via sub-contracting (Department of Health 2008; 2010; Carr 2013; Newbronner *et al* 2011; Routledge *et al* 2015). Acceptance of DPs by older people has been slow. Home care[10] remains the mainstay of support for

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[10] Home care (also often termed ‘domiciliary care’) is care provided at home. Where home care is state-funded care, it is arranged through the local authority and usually provided by private home care

community-dwelling older people, with only 13% of over 65s receiving a direct payment versus 48% of younger people[11] whose primary support reason is physical disability (HSCIC 2016a). Yet these figures cover a broad range: the top 5% of councils provide DPs to one third of over 65s (Ibid). A further sign of progress is that average weekly expenditure for a DP to older people is now similar to average weekly expenditure on home care, in sharp contrast to earlier practices (Davey *et al* 2007) and contrary to expectations given recent deep expenditure cuts (HSCIC 2016b). In fact, one quarter of councils[12] now spend more per year on DPs to older people than on homecare (HSCIC 2016b).

These developments emerge in tandem with research evidence that the priority to implement DPs among older people goes against what may be best practice. Woolham *et al* (2016: 20) recently challenged the sustained promotion of DPs to older people, stating that current policies fail to recognize or acknowledge that “older people may want different things from personal budgets and direct payments to younger people”, although this fails to acknowledge that it is often the families of older people who recognize the possible advantages of DPs.

This attack is fueled by studies in which the suitability of “self-directed care” for older people is questioned. The IBSEN study of individual budgets (IB), forerunner to PBs, reported lower psychological wellbeing in older people receiving IBs compared to those receiving standard care and compared to younger IB holders, although there were no differences in social care need-related outcomes between older and younger participants (Glendinning *et al* 2008). Further analysis found no differences in psychological wellbeing between older and younger recipients when proxy responses were excluded (Moran *et al* 2013); psychological wellbeing followed a U-shaped curve by age, with wellbeing highest in young adults and older people, and lowest for the middle-aged (Netten *et al* 2012).

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agencies. These agencies recruit and train individuals to provide care per the service users’ support (or ‘care’) plan according to eligible assessed needs. This may include support with personal care, such as washing or dressing; cooking or preparing meals and/ or housekeeping or domestic work, such as vacuuming. Priority is given to personal care, nutrition and safety needs.

[11] Figures are for under 65´s and over 65´s in the community with a primary support reason relating to physical disability.

[12] The pattern of local government in England is complex, with the distribution of functions varying according to the local arrangements. ‘Council’ refers to a council with social services responsibilities which include: London boroughs, Unitary authorities, Shire authorities and Metropolitan councils.

The conflation of PB/IB/DP, grouped together under the umbrella term “self-directed care”, is problematic (FitzGerald Murphy & Kelly 2018; Ottman *et al* 2013). IBs and PBs feature major changes in assessment and allocation of publicly funded social care, including introduction of supported self-assessment and notional budgets. Amidst these evolving processes, it is difficult to extrapolate the impact of actual services received from the impact of how funds are allocated, and particularly how assessment and support planning are handled. PB implementation has created significant delays in such processes, increasing service users’ anxieties and impacting on results, particularly among older people (Hatton & Waters 2014; OPM 2012).

Existing research is also limited by amalgamation of data on older people taking their PB (or IB) as a council-managed budget, provider-managed budget or DP, despite differences between them (Glendinning et al 2008, Netten *et al* 2012; Hatton & Waters 2014). PBs managed by local authorities (where the personal budget is “paid to” the council) offer limited participation for recipients in services they receive (Rabiee & Glendinning 2014), while data on provider-managed budgets (Individual Service Funds) are also limited (National Audit Office 2016; Rabiee & Glendinning 2014). Consequently, outcomes data specific to older people in receipt of DPs are extremely limited.

Attempting to address these issues, Woolham *et al* (2016a) compared the outcomes of DPs to managed budgets (MBs) among older people. Their findings suggest no significant differences in social care outcomes between the service types, although DP recipients scored higher for process outcomes (timing of care and satisfaction with services). Their findings are in line with official data covering all English councils, available since 2016 following changes to the range of data collected as part of the Adult Social Care Survey (National Audit Office 2016). These results seem to suggest that there is a growing mismatch between the Department of Health’s assertion that research shows that “direct payments... lead to a higher quality experience for *appropriate* users” and the growing evidence base (House of Commons 2016: 11). An obvious question is why there is so much disparity between studies, particularly early qualitative studies (Clark, Gough & Macfarlane 2004; Glendinning *et al* 2000) versus more recent quantitative studies.

Some may argue that DPs were initially offered to those most likely to benefit and as the user base grew those with less to gain were drawn into the pool, thus reducing average benefits. Indeed, in early studies of DPs to older people, almost all participants knew about DPs before applying for them and purposefully requested a direct payment service (Clark, Gough & Macfarlane 2004; Glendinning *et al* 2008). Yet there is an important distinction between this and DP use, where there is no obvious potential gain to the service user – an issue raising increasing concern. The incentives for councils to increase uptake of DPs to older people are now such that “practices to promote DPs which work against personalised care” are recognised (National Audit Office 2016: 7). This hints at the use of DPs primarily for council interests, particularly “in areas where authority-commissioned care is considered poor quality, or where the choice of authority-commissioned providers is very limited, [where] users may feel pushed to take a direct payment, leading to relatively high rates of take-up” (National Audit Office 2016: 34). Much of this stems from fierce efforts to control costs: between 2006 and 2016 the average unit cost for local authority-commissioned home care rose only 21% (Curtis & Netten 2006; HSCIC 2016b), leaving many providers struggling financially with knock-on effects for recruitment and retention of staff, combined with a switch from cost and volume contacts to ‘framework agreements’ for approved providers which secure potential services at a given cost but do not guarantee service volume to providers (Baxter 2018; Glendinning 2017). The latter was developed as a means of allowing more user choice over provider but paradoxically has reduced it by creating such risk to providers that many are opting out of council-commissioned care (Baxter 2018). Reduced supply has led to DPs becoming the last available option.

Concern about the benefit of DPs to older people has heightened the priority placed on outcomes data, but this comes with some drawbacks. Survey data trades off the benefits of greater sample size with the depth of information collected. It also excludes proxy responses (Malley & Fernandez 2012), thereby excluding older people who have their DP managed by an appointee, an important subsection of this user group. The desire to quantify whether DPs offer an greater benefits than alternatives such as MBs has also shifted attention from factors that cannot be readily quantified, such as those described in best practice reports which identify “the barriers and facilitators to older people benefitting from DPs” (Carr, 2013: 1).

Qualitative evaluations have concluded, among other things, that local authorities can improve outcomes through the provision of DP support; by facilitating more creative use of funds and improving responsiveness to fluctuations in need (Carr 2013). However, major changes in the provision of DP support have occurred over the past few years, with many local authorities pursuing a mixed market of direct payments support where service users are required to individually contract DP support - paying directly from their DP funds for services from a selection of available providers (including standard home care agencies) (cf. chapter 3). Individuals can now be expected to choose between service options including “assisting service users to obtain most benefit from their direct payment” priced at £20.00 per hour and “support with paperwork” also at £20.00 per hour. This contrasts sharply with the model of generic support prevalent at the time of the study, where service users were in principle, if not always in practice, automatically referred to a DPSS which was usually free at the point of use with the exception of some ongoing functions such as payroll (*Ibid.*).

The pursuit of DPs to older people at the local level is intertwined with local authority priorities, as shown in earlier research (Fernández *et al* 2007), but these priorities have evolved in line with the changing policy context. One London council was cited in the Local Government Association Adult Social Care Efficiency report (2014) as having made savings of £0.9 million as a result of a significant increase in the uptake of DPs (to 66% of customers). This was attributed to two factors: the use of PAs (which was cheaper than in-house domiciliary care), and the fact that all DP support costs were being met by the individual from their PB with no additional costs from a contract with a DPSS (with the exception of a three-year contract with an online ‘PA Finder’ service). Despite this ‘best practice’ approach, multiple sources of data report that far more current DP users purchasing care from a home care agency than previously (when contracting a personal assistant or PA was the preferred option) (Fenton 2014). This is influenced by various factors: Conventional homecare agencies are now *encouraged* to target service users with intensive employment support needs and/or third party management of funds (cf. chapter 3), while there are reports of continued overemphasis of the potential problems of hiring a PA (Glasby & Littlechild 2016). Also some local authorities have sought to reduce their spend on DPSS by introducing pre-paid card schemes which offer local authorities real-time auditing of spending: these are interpreted as circumventing the “need” for DP support (cf. chapter 3).

In the face of so much change in the context in which DPs are being provided, here is a pressing need to unpick the “apparent contradiction between [early] user-level and [recent] authority-level data” (National Audit Office 2016: 7). To do so requires exploring how outcomes are influenced by individual characteristics, circumstances and care packages (not just the amount but also *what* is purchased and with what support). Little data has been collected which offers this potential, although material from interviews undertaken as part of an early Department of Health-funded study of DPs to older people offers such detail from face-to-face interviews with 81 older people immediately prior to the introduction of PBs. These data, newly analysed, give unprecedented depth of analysis, while their historical nature provides distance from the complex currents in which DPs are now provided, allowing us to examine possible reasons for the contradiction between (early) user-level and (current) authority-level data.

4.2. Methods

4.2.1. Recruitment

Older people receiving DPs were recruited from ten councils and interviewed between 2005 and 2007 as part of a wider national evaluation on DPs to older people conducted for the Department of Health, England. Councils were selected to represent a spread of DP take-up rates. The top and lowest performing councils were excluded.[13] Participating councils were from the first, second and fourth quartiles for take-up. Selected councils were dotted across the whole of England, and were split equally between high and low population-density areas.

All older people (of pensionable age and above) in receipt of a DP in each council were contacted via a letter, distributed by councils to ensure anonymity. Individuals received information on the study and a freepost envelope to return if they wanted to participate. Eight service users were sought per council, roughly half the national average of older

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[13] The top performing councils for DP take-up were excluded as many had already been involved in research of some kind. The lowest performing councils were excluded as DP numbers were too low to recruit the desired sample.

people receiving DPs per council in 2007 (Davey *et al* 2007). In areas with more positive responses than required, individuals were chosen to give the widest geographical spread within each council. Recipients were chosen irrespective of whether or not they had an unpaid carer.

Participants had a wide range of circumstances and socio-economic characteristics (Table 4.1). In contrast to previous studies where older people receiving DPs had been introduced to them via direct payments support schemes or disability groups (Clarke 2004), or at the direct request of family members (Laybourne *et al* 2016; Jepson *et al* 2016; Glendinning *et al* 2007; Mitchell *et al* 2014), two-thirds of the sample had only found out about DPs through social or health service sources (Table 4.2).

Table 4.1: Sample characteristics

Variable	***n***	**Sample all**	**Moderate dependency**	**Moderate-high dependency**	**High dependency**	**Highest dependency**
n		***81***	***10***	***13***	***32***	***26***
(%)		100	12	16	39	44
Socio-economic characteristics						
		%	**%**	**%**	**%**	**%**
Age (years)						
< 70	***25***	31	20	31	28	39
71-85	***40***	49	50	8	41	23
86+	***16***	20	30	62	31	39
Gender						
Male	***30***	37	50	38	22	50
Female	***51***	63	50	62	78	50
Lives alone	***38***	47	50	62	53	31
Cognitive impairment$^+$	***24***	42	40	15	34	65
Interviewed by proxy	***23***	28	30	23	22	38
Unpaid carer helps to manage DP	***53***	75	60	62	75	89
Ethnicity: BME	***17***	21	30	23	19	21
Care package values						
Hourly DP rate **(£)**	***81***	9.46	7.65	11.04	8.06	11.12
Weekly allocation **(hours)**	***81***	20	20	11	19	30
Weekly care package value **(£)**	***81***	189	153	121	153	333
Unpaid care **(hours)**	***70***	33	19	26	30	45
Care suppliers						
Unpaid carer	***70***	86	70	85	87	92
Personal assistant(s)	***64***	86	100	82	80	84
Home care agency	***18***	22	-	31	25	23
Self-funded care	***20***	25	-	31	21	35
Level of met needs						
Food and nutrition	79	93	90	100	92	90
Personal care	79	92	90	100	93	85
Safety	***79***	76	90	77	70	65
Social participation	***79***	70	80	62	60	77
Control over daily living	***79***	83	80	84	93	73
Home environment	***79***	85	100	77	83	80
Social and leisure	***79***	65	70	62	66	61
Other outcomes						
Feels confident in the event of an emergency	***81***	71	70	85	56	73
Feels more confident in event of an emergency than when using standard services	***48***	95	100	100	85	95
Hospitalised unexpectedly in previous 12 months	***81***	40	30	38	50	42

$^+$ Suspected or diagnosed

Table 4.2: How service users were introduced to direct payments

How aware of DPs	N	Percentage (%)
Social Worker	46	57
Friend	8	10
Publicity (National or local)	5	6
NHS worker (nurse, GP…)	5	6
Not known	4	5
Disability group	3	4
Direct Payments Support Service (DPSS)	3	4
Relation	3	4
Older people’s advisory service	2	3
Domiciliary care agency	1	1
Housing warden	1	1
TOTAL	81	100

4.2.2. Ethical considerations

The research was undertaken before implementation of the Research Governance Framework (2005-2007). Its design and methods were reviewed by the LSE Research Ethics board, as per guidance at the time. As interviews were conducted face-to-face we were able to include older people with cognitive impairment (42% of the sample). All but one of the interviews for these people was conducted by proxy with their main representative (usually the person managing the DP on their behalf) in the presence of the service user. In all cases, service users were addressed in so far as they were able to participate in the interview.

Proxies were the people managing direct payments, as there was usually no other person available with sufficient knowledge of the circumstances to complete the interview. This approach is consistent with other studies (Coles, 2016; Glendinning *et al* 2008; Laybourne *et al* 2016; Jepson *et al* 2016).

For ethical reasons it was stipulated that the main interviewee could not be an unpaid carer remunerated through DP to provide care; in the only instance of this in the sample, a representative from the local Direct Payments Support Services[14] (DPSS) was called

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[14] Direct payment support schemes provide support to people receiving direct payments. Services available may include support with: devising a support plan; budgeting; accountancy (and payroll of hiring a personal assistant), recruitment, employee responsibilities. DPSS also offer information on local homecare providers for service users who wish to purchase from a homecare agency, rather than recruit a personal assistant (Davey *et al* 2008). Services vary considerably (*Ibid*).

upon. A DPSS representative was also present in two other interviews with service users who lived alone, at their request.

The research was undertaken prior to implementation of the Health and Social Care Act 2008 which extended the scope of DPs to people who lacked capacity to consent and legitimised the practice of employing a ‘person’ to act on their behalf and prior to the implementation of the 2005 Mental Capacity Act (DCA 2007). Where carers acted for service users unable to express their views, the assumption of responsibility to manage the DP took place under the auspice of lasting power of attorney.

4.2.3. Measures

All data were obtained during face-to-face semi-structured interviews lasting between 1.5 and 2.5 hours in length. The contribution of DPs to outcomes was measured using an adapted version of the Older People’s Utility Scale for Social Care (OPUS; Netten *et al* 2002), measuring expected outcomes along seven domains: food and nutrition; personal care; safety; social participation and involvement; control over daily living; control over home environment; leisure pursuits/social participation. The last two domains were added to the five-item OPUS; subsequently this tool was developed to incorporate these extra items (ASCOT; Netten *et al* 2011). ASCOT is now used in national monitoring of service outcomes (DH 2014), and has been subjected to rigorous construct validity testing with older people, including proxies (Rand *et al* 2017; Malley *et al* 2012).

The interviewer asked service users (or proxies) to evaluate expected level of need (no, low-level or high-level) in each domain *in the absence of* publicly funded social care (but not excluding freely provided unpaid care) to determine baseline need. As all individuals were receiving a service at time of interview, evaluation was based either on experiences directly prior to receiving the service or, where they had received services for some time, on experiences of short-term breakdown in care support.

A second need measure for each domain *in the presence of* publicly funded social care input was recorded, related to net outcome of all care inputs (Table 4.1). Our analyses focus on the *difference* between baseline and service impact assessments: hereafter the DP outcome gain (DPOG).

Other data obtained through the interviews covered: DP management reliance on DP support services and/or unpaid carers; how their DP-supported care package was used throughout the week (based on diaries; cf. Van De Berg & Spauwen 2006); total care input (including from unpaid carers); self-funded care or formal care commissioned directly by the council and not part of the DP-supported package; and activities of daily living (ADL) and instrumental activities of daily living (IADL) using standard tools (Collin *et al* 1988, Lawton & Brody 1969); dependency categorised as low, moderate, moderate-high (2-4 personal activities of daily living (PADLs)), high (5 PADLs) or highest dependency on the basis of ADL/IADL item scores and observation during interview (Henderson 2006).

4.2.4. Analysis

Individual-level analysis of DPOG was conducted using multiple regression analysis. Outcome gain scores had a low mean and were positively skewed; we therefore used the Poisson log-functional form (Colin, Cameron & Trivedi 2010).

The model was developed in line with a conceptual framework that was drawn up at an early stage of the work prior to developing the interview schedule. This conceptual framework hypothesized that outcomes would be influenced by a mixture of individual characteristics (dependency, informal support) and patterns of service provision (types of care purchased, direct payments support). Given the relatively small sample size, the model was conceived for explanatory purposes (Shmueli 2010).

Explanatory variables included individuals' characteristics, needs (IADL, ADL), dependency and services used. Information on types of support purchased, total care input and proportion contributed to total care input by each support type were included. Total care input was defined as weekly sum of hours of DP support allocated per individual, hours of privately purchased care and unpaid care input. Hours of care were generally recorded as per the care plan/DP records, but if these differed from the daily diary, the latter took precedence, although the ‘official’ care package amount was recorded separately.

Although data on cognitive impairment was collected (by observation), I did not include this as a variable in the model, as it was outside the capacity of the research to include a formal assessment of cognitive impairment, and because of its potential impact on other variables.

A number of variables were initially included in the model that were later discarded as they were not statistically significant. These included age >80, PA turnover, IADL score, individual scores for the following IADL items: telephone, household tasks, use of and significance of accountancy service. The final set of variables included was a result of a step-wise process through which careful attention was paid to the impact of collinearity. Risks of overfitting were reduced due to the fact that there were almost no missing data points (Santos Silva & Tenreyo 2010). Overdispersion was discounted performing the likelihood ratio test of the over-dispersion parameter alpha using a negative binominal distribution.

All measures used in the model are described in Tables 9.1 and 9.2 of Appendix 1.

4.3. Results

4.3.1. Sample

A third of the sample of 81 people were aged under 71, half 71-85, and 19% over 85 (Table 4.1); 46% lived alone and 63% were female. Approximately 73% of the sample received unpaid care support to manage their DP to varying degrees, while 43% had their DP fully controlled by an unpaid carer owing to their inability to do so (advanced frailty, limited speech and/or cognitive impairment)

Most individuals exhibited significant levels of disability: one-third were immobile or chair-bound, two-fifths required assistance with five PADLs and either used a wheelchair or were unable to walk >2 metres (Table 4.1). Approximately 85% (n=69) of sample members were unable to bath alone, 32% could not use the toilet independently (n=26), and 21% (n=17) and 30% (n=24) were regularly incontinent of faeces and urine, respectively. More than three-fifths were unable to manage finances on their own (n=49), and so were particularly likely to require support with DP management. Around 30% had some degree of cognitive impairment as a result of dementia or stroke (Table 4.1); of these, half had severe cognitive impairment, relying entirely on unpaid care for DP management. Many individuals were in the so-called “grey area” for continuing care funding. However, to receive a DP they had to be solely funded by social care, a situation now altered by availability of personal health budgets (PHB) (Care Act 2014).

Although the high dependency of sample members reflected the increasing dependency of older people in receipt of state-funded social care, the sample was particularly skewed towards the very dependent. In a 2005 home care sample of 365 people, highest dependency service users comprised 10% of the sample, versus 44% in the current sample of older DP users (Darton *et al* 2006). According to social workers interviewed as part of the wider study, this was a reflection of the composition of older DP users at the time which tended towards very complex cases.

Unsurprisingly, DP care packages significantly exceeded ten hours support per week, the threshold used by DH to define intensive community care. Levels of care were particularly intense for the most dependent users, averaging 30 hours per week of support (Table 4.1).

Unpaid care inputs were positively associated with dependency, and varied with nature of relationship between carer and service user: spouses of individuals with high or highest dependency typically provided >20 hours support per week (DH threshold for intensive unpaid care) and often >40 hours (Table 4.1). Spouses (both male and female) represented one third of unpaid carers present (n=27); others were daughters (24%, n= 20) and sons (22%, n= 20).

4.3.2. Outcomes

Net outcomes of all care inputs were generally high, varying by domain (Table 4.1). Levels of met need were greatest for domains prioritised by state-funded social care (food/nutrition) and personal care outcomes were significantly higher than "supplementary" domains such as social participation and leisure activities, yet still compared favourably to average outcomes for adult social care (only 30% of the sample had some unmet needs for social participation, versus 55% nationally) (PHE 2017). DPs also contributed significantly to needs associated with the home environment (lower-priority domain). Outcomes for the safety domain were especially affected by dependency level, with 28% of the most dependent reporting some unmet need, versus only 10% among the moderately dependent (Table 4.1) – however these were substantially better than national averages published every year since 2010/11 when national outcome data was first collected (Table 10.1, Appendix 2). According to recent national figures, 31% of older service users report that they "do not feel as safe as they would want", or worse (HSCIC 2016c). Levels of met needs among the sample of DP users for the domain of *control over daily living* were also well above the nationally recorded averages across the entire time period. Since 2010/11 the percentage of older adults receiving state-funded social care across England who have reported that they have as much control over daily living as they would like has been virtually unchanged – most recently recorded at 74% (HSCIC 2014; NHS Digital 2016), versus 83% among the DP sample.

Alongside these results, 83% of the sample with previous experience of standard services felt that services received through DP were *much better* (Table 4.1), and 91% felt more confident in the event of an emergency since using DP. For those purchasing care from a home care agency, 87% felt the agency responded better to their needs as a result of being the direct purchaser (Table 4.1). Rates of hospital admission in the preceding 12 months were similar to the *general* population of older people, rather than those with chronic health problems, for whom rates are usually much higher (Purdy 2010) (Table 4.1). This figure alongside qualitative data suggested care purchased with DPs may have helped to prevent unplanned admissions.

4.3.3. Factors contributing to outcomes

Service user characteristics

We looked at factors associated with DPOG (Table 4.3). A strongly significant factor was dependency, consistent with previous findings: those with the greatest need derive less benefit from the same amount of service than those with lower needs (Malley & Netten 2009). Older people living alone reported outcome gains 23% lower than older people living with others (Table 4.3). Living alone is frequently referred to by care managers as a factor limiting potential benefits of DPs (Glendinning *et al* 2008). Living alone and having sufficient ADL difficulties to receive state-funded care can cause social isolation. Older adults living alone are also more likely to have limited access to unpaid care.

Alongside dependency level, we included single IADL items. A standard IADL score of 4 and above is a reliable predictor of 1-year incidence of dementia (Barberger-Gateau *et al* 1993). Scores for each item were adapted so that being autonomous for medication was scored lowest and incapacity for medication scored highest (range 1-5) (cf. Table 9.1, Appendix 1). Individuals with largest adapted IADL scores were more likely to achieve greater outcome gains from DPs. This finding was counter-intuitive: cognitive impairment is a risk factor for package breakdown (Rowlett & Deighton 2007). Our finding probably reflects how individuals lacking these capacities received support by unpaid carers in planning and coordinating support arrangements, which may therefore indicate the added value associated with ‘managerial care’ performed by unpaid carers (Rosenthal *et al* 2007).

Care packages

National statistics show that DPs to older people are less generous than packages to younger adults with physical or learning disabilities, raising concerns about potential

Table 4.3: Factors associated with direct payments outcome gain scores among older people

	Coeff	Prob	95% CI lower limit	95% CI upper limit
Highest Dependency	-0.75	0.00	-0.93	-0.55
High Dependency	-0.58	0.00	-0.71	-0.45
Moderate- high Dependency	-0.27	0.00	-0.40	-0.15
Lives alone	-0.22	0.00	-0.29	-0.15
Adapted IADL: medication use	0.13	0.00	0.08	0.18
Unpaid carer helps to manage DP	0.13	0.00	0.04	0.21
Chose & received recruitment support service(s)	0.07	0.00	0.05	0.09
Adapted IADL: handling finances	0.08	>0.01	0.03	0.13
Activities of Daily Living Score	-0.06	0.00	-0.08	-0.05
Significance of recruitment support (critical)	0.017	0.01	0.004	0.03
Length of time using direct payments	0.003	0.00	0.002	0.0045
Difference between package size and total care input	-0.004	0.00	-0.005	-0.002
Percentage of total care input composed of self-funded care	0.003	>0.01	>0.001	0.005
Percentage of total care input composed of unpaid care	0.006	0.00	0.004	0.008
Percentage of package spent on combination household care/ personal care	0.002	0.00	0.001	0.003
Percentage of package spent on combination household care/ social and leisure care	0.004	0.00	0.002	0.007
Percentage of package spent on therapeutic management	-0.003	<0.01	-0.005	-0.001
Constant	4.62	0.00	4.30	4.95

Observations=79 Pseudo R^2 *=30%*

GLM model; Link function: Log, Variance function: Poisson benefit of DPs for older people (Moran *et al* 2013). Package size was close to significance but exerted little influence relative to other variables and was therefore excluded. However, there was a significant negative association between package size and total care input, which may point to a negative impact where there is inequity in social care provision relative to unpaid care input, usually in cases of cognitive impairment and/or extreme dependency (Table 4.3). At the time, such individuals were unable to receive health funds as cash payments, a situation now reversed by the 2014 Care Act which permits contribution from NHS continuing care funding to DPs (Care Act 2014).

Experience with DPs

Deriving greater outcome gain from DPs was linked to time using the service (Table 4.3). Using an agency to purchase care was not statistically significant (possibly due to low uptake– only 22% (n =18) of service users purchased care from an agency).

Impacts of care worker characteristics were investigated qualitatively (First author et al 2007): individuals were asked about continuity, flexibility, reliability, communication, staff attitudes, staff skills and knowledge. Attitudes were particularly important, as they were considered to influence flexibility, reliability and continuity. Individuals with longest experience using DPs had, for obvious reasons, greatest experience and competence in finding staff. Staff turnover was not relevant to outcome gain (hence excluded from the model). When individual users were sufficiently assertive to take tough decisions about unsuitable staff, they improved their quality of care, but when individuals were afraid of the consequences of taking decisions, they had less control over quality.

Types of care received

Compared to other factors, the types of care received had less impact on outcome gains, as was expected, although there were some notable findings.

Of all care inputs explored, the input of a DPSS was the most influential on outcome gain. Of the two forms of DP support explored (accountancy services and recruitment services) only recruitment services were significantly associated with greater DPOG (Table 4.3) despite the fact that receipt of such services was fairly widespread: 69% (n=56) of the sample received ongoing DP support. Of these, 41% (n=23) received both accountancy support and recruitment support, while 36% (n=20) opted for accountancy support only; the remainder relied solely on recruitment support (23% n=13). These services were mainly free at the point of use: only 12% (n=10) of those who used ongoing DPSS support paid towards the cost of the service, mostly for payroll services. Service users were typically referred to the service by the local authority. It was notable that referral to DP support was high among the sample. In other research it has been found that only around one–third of DP users ever had contact with a DPSS due to poor referral rates (Newbronner *et al* 2011):

Of the purchasing choices made, using funds to purchase "therapeutic care" (n=5) was associated with lower outcome gains possibly due to the incidence of cognitive impairment among those purchasing care for this purpose (100%).

In contrast, paying for care defined as "combination of personal care and home (household) care". The former was relatively common (42% of sample, n= 34), while the latter was rare (6%, n=5). Such combinations represented flexible care and contrasted with purchasing care which was solely for home (household) care which was not associated with improved outcome gains. Purchasing a combination of personal care and home (household) care was linked to hiring a PA: 84% of individuals who received combined personal/ household care hired a PA (n=32); versus only 5% of those that recruited via a home care agency (n=44). A high proportion of service users who recruited a PA had received some form of DP support (76%, n=48), with 60% of this group (n= 29) receiving recruitment support. Service users who viewed recruitment support as critical also achieved better outcomes (Table 4.3). Surprisingly, 50% of those who did not recruit a PA also used recruitment support (n=6). In these cases, DPSS acted as brokers for individuals purchasing care from home care agencies. These findings help to better understand the role of DP support as an 'intermediate output' in the production of DPOGs (Knapp 1984). Previous research has noted that 'third-party organisation' support improves outcomes for individuals with and without unpaid care (Forder *et al* 2012; Hatton & Waters 2013) in the absence of further detail on what services were provided of what type of organisations were involved. Backed by qualitative research, it has been widely accepted that DP support is critical to take-up of DPs (Arksey & Glendinning 2012; Hasler & Marshall 2013), that absence of payroll support can put people off using DPs (Clark, 2004) and that DP support can ease the burden felt by unpaid carers (Larkin 2015; Woolham *et al* 20178).

Last but not least, individuals receiving self-funded care (25% of sample) had better outcomes. Overall self-funded care was marginal to total care input received but exceeded 25% of total care input in the following subgroups: highly-dependent users who either lived alone (regardless of whether or not they had some form of unpaid care); people who did not live alone but self-managed their DP, and people who received no unpaid care. In essence, self-funded care offered a substitute to unpaid care. Despite the term, ‘self-funded care’ was predominantly publicly funded, albeit indirectly by service users employing their Attendance Allowance to purchase extra care.

4.4. Discussion

4.4.1. Importance of unpaid care

A major thread running through our results is the positive influence of unpaid care on DPOG. While this corroborates the views of care managers (Glendinning *et al* 2008, OPM 2012b), these statistical effects are important in identifying how and why unpaid care is so influential. The impact appears at different levels which we now examine in turn.

Unpaid care as a function of total care

While it may seem unsurprising to find a positive association between DPOG and receiving a higher fraction of total care input from unpaid care, this assumption needs unpacking. Unpaid care as a fraction of total care can limit potential outcome gain from state-funded care, as need in the absence of a service may be relative rather than absolute.

There is a longstanding debate as to whether unpaid care complements or substitutes for formal care (Pickard 2012). There are particular concerns about impacts of cash payments on unpaid caregiving, centering on the concern that unpaid care may decrease if families have greater license to organize care to suit their priorities[15]. Our results challenge these concerns: the way DPs are organised in England ensures that unpaid care not only complements formal care, but promotes its efficacy. This is largely due to the rigorous limitations on funding relative to need and consideration of available unpaid care prior to allocation of funds. This finding begs the question whether it is appropriate that a service promotes unpaid care as a function of support for older people, given that the Care Act (2014) expressly aims to reduce carer burden, and given recent increases in intensive caregiving among over 65s (Carers UK 2015). Unpaid care contributed on average 42% of the total care input received by people with an unpaid carer (cf. chapter 4). A recent study comparing unpaid carers for older people receiving DP and MBs found that those supporting DP users provided more hours of care (Woolham *et al* 2017). Setting aside macro viewpoints, at the individual level it is likely that much depends upon whether or not DPs offer what carers are lacking, such as the ability to coordinate care to fit in with their other responsibilities, or the ability to assure the quality of services being received, as well as whether they are compensated by access to their own packages of care as they should. Brooks *et al* (2016) point out that assessment for personal budgets should only take place *after a carer assessment has been conducted* so that the budget takes full account of carers´ actual willingness and ability to provide support, something that has been routinely lacking in practice. On the positive side, there is consensus in existing research that DPs to the person being cared for can assist unpaid carers in gaining more control over their time and daily lives and improve their quality of life (Larkin 2015; Moran *et al* 2012; Woolham *et al* 2016b). Moreover a recent study by Rand *et al* (2017a) also showed that carer' and care recipients rating of *control over daily living* are mutually interdependent.

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[15] This was observed in Holland until reforms were undertaken to adjust the extent of eligible needs, and the way in which the potential contribution of unpaid care was taken into consideration (Shut & Van der Berg 2012).

Dependency on an unpaid carer to manage the DP

Those who were dependent upon an unpaid carer to manage their DP were likely to reap greater benefits from their DP. Many of these were service users for whom their unpaid carer acted through power of attorney as a “suitable person”. Wider research has begun to explore how such indirect payments evolve (Jepson *et al* 2016; Laybourne *et al* 2016: Mitchell *et al* 2014), but has not associated the actions of an appointed person who manages care on that person’s behalf with DPOG for the cared-for person.

The impact of these “actions” was most likely related to “managerial/orchestral care” which includes discussing care arrangements, obtaining information, organising services and managing finances (Rosenthal *et al* 1998). An obvious risk of unpaid carers managing care is that care packages become ‘carer-centred’ (Manthorpe & Samsi 2012). Carer-orientation appeared merely to reflect that many care packages were only sustained by unpaid care and thus needed to fit with their availability. The multiple positive influences of unpaid care on outcomes further suggest that any degree of carer-orientation did not detract from the benefits from DPs. There is anyway often considerable overlap between the needs and goals of the cared-for and the carer (Jones *et al* 2012), with official guidance recognizing that support for carers may be provided in the form of services or support to the service user (Brooks *et al* 2016).

It is widely accepted that situations where the unpaid carer makes proxy decisions require greater transparency when appointing a suitable person. They also need ongoing assessment to ensure that an appropriate balance is achieved between the needs/goals of the cared-for and carer. To date, there is little evidence that practitioners have developed confidence in these areas (Jepson *et al* 2016; Laybourne *et al* 2016). This coincides with a period in which the so-called productivity of social work teams (numbers of assessments, reviews and people supported by social workers) has reduced, despite staffing increases, a factor which has been linked to the bureaucratic burden of implementing personalisation (Slasberg 2013). Added delays associated with setting-up DPs for those who require an indirect payment, lead to greater likelihood to take up a managed budget, potentially denying access to the very service users who may have more to gain from a DP. The Alzheimer’s Society (2016) has recently argued that fewer than 20% of older people receiving social care in the community for memory and cognition problems are receiving DPs, while national figures suggest an even lower figure (HSCIC 2016a).

A further impediment derives from practitioners reacting to concerns that responsibility for managing care will overburden already stretched caregivers: “the almost simultaneous introduction of austerity measures and the roll out of personal budgets have amplified the expectation… that carers are expected to take on additional roles” (Milne & Larkin 2014: 7). This fails to recognize the evidence which suggests that attributes such as ‘control over the caring’, ‘fulfillment’ (Al Janabi *et al* 2008), and “a sense of control and mastery” (Muratore & Earl 2014) have the potential to promote carer wellbeing. Brouwer *et al* (2014) found that involvement in coordinating care (facilitated by availability of DPs) may increase the ‘process utility’ of caregiving, while Andrén & Elmståhl (2005) found that unpaid carers could simultaneously perceive both moderate burden and great satisfaction. These studies would suggest that the rewards, risks and costs of practical unpaid care differ from those of delivering managerial care (Glendinning *et al* 2009).

The role of unpaid care: benefits versus risks

Concerns surrounding the benefits versus risks of DPs for older people for those heavily reliant on unpaid care are multifaceted and multidirectional; oscillating between concerns for unpaid carers and for service users.

Research suggests that carers’ experiences are shaped by many situational and structural factors (Milne & Larkin 2014). Aspects such as the ability to control care can have positive benefits for carer wellbeing but the downside is that if goals and expectations are not achieved, adverse effects could jeopardize carer wellbeing, hence the need for sources of external support through DPSS or carers’ organisations. Also the reasons for providing care need to be considered, as this affects care-related quality of life and carer strain (Rand *et al* 2018).Councils need to monitor carers’ experiences and wellbeing both as a right and in recognition of their role in the productivity of DP to older people, but most research suggests this is not happening (Woolham *et al* 2016b).

4.4.2. Flexible care arrangements

Regardless of access to unpaid care, other factors stood out as significant. Individuals, who purchased care that was flexible, in that it deviated marginally from standard home care, achieved greater gains. Purchasing this type of care was most prevalent among service users who used a PA and the majority of those who recruited a PA had done so with some form of support from a DPSS. Innovation typically required minor deviation from the authorised care plan which was typically discussed with a DPSS.

These results underline the importance of external mechanisms on DP outcomes: a reminder to councils that support structures for DPs directly influence the benefits of receipt. Research continues to report narrow interpretations of what would be “appropriate use of funds” and over-emphasis on the potential difficulties associated with contracting PAs (Glasby & Littlechild 2016). What lacks recognition is that the support structure for DPs has undergone radical change as result of the personalisation policy push. This includes significant shifts in access to DPSSs in recent years, with extremely high turnover in services, particularly in recruitment support where low-intensity (low-cost) services such as online PA registries are increasingly favoured over contracts with organisations that offer direct contact with service users (cf. chapter 3). Home care agencies also now visibly target their services to DP users (*Ibid*).

In an increasing number of councils, service users are expected to make a choice about whether they should dedicate a portion of their DP to paying for a service that will assist them to obtain most benefit from their direct payment, without knowing in advance what that might mean for them. This scenario contrasts with the access to DP support that many of the service users in this sample had - which was free at the point of use, one-to-one and allowed service users to explore the options available to them regardless of the means by which they eventually recruited care.

At the same time there has been a decrease in the use of PAs (Fenton 2014). Although not directly linked to outcome gain in the model, the use of a PA was indirectly associated in so far as flexible care (which was linked) was much more common among those employing a PA.

What the results provide evidence for is that using DPs to purchase support closely aligned with "mainstream" support will negatively influence the outcome gain. Hence the kinds of changes that have occurred in recent years in the implementation of DPs for local authority interests, including changes in DP support, may offer an explanation for reducing benefits from DPs – much as has been argued by some commentators (Slasberg 2012), but unfortunately with little impact on practice.

4.4.3. Financing DPs: sufficient?

For some time researchers have argued that DPs to older people may be of insufficient value to achieve optimal outcomes (Moran *et al* 2013). Our results begin to challenge this argument in that package size was close to, but not statistically linked to DPOG.

Our findings only have weight if the intensity of care packages for the sample was consistent with practices at the time, and comparable to recent levels of per capita expenditure. This is challenging to ascertain given wide variations in expenditure between councils, both then and now, but we observe that the sample tended towards high-intensity care packages, in response to high-level needs. This reflected the trend for DP users as well as recent trends across community services for all older people (Audit Commission 2013). The average weekly DP value for those of highest dependency was £333 (averaging at 30 hours of state-funded social care per week). This was consistent with the £11 average unit cost for independently provided home care at the time (Curtis & Netten 2006) but DP rates were lower in the sample among the less dependent. This was typical of DP unit costs at the time, which tended to be less than the relative value of home care packages (Davey *et al* 2006). Therefore the rates observed for the most dependent (44% of the sample) may have been inflated to be in line with independent home care costs, and/or reflect a greater dispersion of highly dependent users among the councils with more generous DP rates. A major principle of PBs is to ensure parity in community care funding allocations regardless of service supplied, so the situation of the highly dependent service users in the sample is aligned with current resource allocation principles and applicable to today's context.

In terms of the overall sample, we see that for 2015-2016, the average per capita expenditure on DP among the over 65s was equal to £248 (HSCIC 2016a, b), versus

£189 for the sample in 2006 (Table 4.1). Against current home care costs[16], this equates to roughly 18 hours of state-funded social care per week in 2015-2016, versus 17 hours a week for the sample based on average home care costs in 2006[17]. While this parity underlines the relevance of the results to current practice, it does not entirely rule out concern regarding today's funding levels. Average DP package values for older people have generally risen over the past four years, with a median increase of 19% but with large variance (±65%) (*Ibid*) within which there is ground for concern. It is also debatable whether the rise in funding is sufficient to fund sustainable care from the home care sector. Moreover, there is known resistance from home care services to apply the same economical rate to DP users that they charge councils (Rodrigues & Glendinning 2015), which makes it very difficult to estimate how much care is available to users given an increasing tendency for older DP users to purchase care from home care agencies (Fenton 2014).

Focusing on what can be asserted from the findings, it is evident that the sufficiency of the value of DP packages can only really be understood in relation to other factors. Whilst variations in outcome gain were close to but not significantly associated directly with DP package values (within the ranges observed in the study), outcome gains were significantly less where there was a larger *discrepancy* between the total care input (which could include unpaid care and/or self-funded care), and the funded package. Larger discrepancies were observed where service users' funds had been capped, as extra funding from health was then still not legally permitted, and in circumstances where service users who were physically able but cognitively impaired and required almost constant supervision for safety reasons (a scenario which fitted poorly into resource allocation priorities at the time). But this effect was not directly the result of shifting a greater burden of care onto unpaid carers (as one obvious possibility), or a greater responsibility to self-fund, as both service users for whom unpaid care represented a higher fraction of the total care input, and those for whom self-funded care represented a higher fraction of the total care input were associated with greater DP-related outcome gains. It appears from our results that they were less ineffective simply for being out of line with individuals' circumstances. The results suggest that DP

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[16] The national average unit cost for independent home care was £13.82 for 2015-16 (HSCIC 2016b).
[17] In 2006 the average unit cost for independent home care was £11:00 (Curtis & Netten 2006).

package values *do* influence outcomes, but the effect is weak against other factors, provided funding is set at an *appropriate* level.

The extent of current variation in per capita expenditure on DPs to older people therefore warrants attention as major (negative) deviations from benchmark values[18] would suggest that DP provisions in some councils are more likely to be misaligned with individuals' circumstances. There also appears to be significant potential for optimizing DPOG in mobilizing NHS contributions where applicable. There are no longer legal barriers to older people receiving extra funding from health towards their DP, but only 42% of councils are using this freedom[19], suggesting that other barriers still exist: this is clearly evidenced by the fact that only 30% of councils involved in the PHB pilots are receiving contributions from the NHS for expenditure on DP to older people. Among those receiving contributions from the NHS, this tends to comprise a small portion of expenditure (12%) but a few notable councils are receiving significant contributions of around 50%[20].

4.4.4. Living alone and "resource-poor"

As expected, living alone was associated with worse DPOG. The different mechanisms by which unpaid care influenced outcome gains show that those without a carer were resource-poor in various ways. The significance of social networks was also underlined in the PB survey which found that, for PB holders (of all ages) who chose a DP, the two factors associated with better outcomes were "friends" and "where and who they lived with" (Hatton & Waters 2014). This has led to arguments that some older people are "too vulnerable" or "too isolated" for DPs and would be better off with alternatives, but this risks denying choice to those who are already most excluded. Our research explores beyond this dichotomy to highlight the impact of inequalities between service users in the widest sense. The *flexibility* of DPs provides a platform from which those with greater resources can extract greater benefits from them, compared to other support arrangements. Those with care being performed from other sources reaped *greater*

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[18] Such as those in the current sample, uprated to current values.

[19] This relates to packages for over 65's for physical support (the category where NHS contribution to social care costs is most frequent) for the year 2015-2016 (Source: HSCIC 2016b).

[20] *Ibid.*

DPOG. This included self-funded care. Self-funded care was accessed equally among those with and without unpaid care. It is easy to argue that the use of self-funded care offers evidence of a two-tiered service, except that entitlement (and uptake) to Attendance Allowance was universal across the sample. The use of private care might be considered a reflection of purchasing power, a concept which clearly is affected by psychological vulnerability as recognised in EU commercial law (Van Boon, Garde & Askeli 2016). So those that used their Attendance Allowance to purchase a bit of extra care were likely to have been those that had greater confidence in the choices available to them and in their ability to reap worthwhile benefits from doing so (versus spending the money on housekeeping).

DPs had their limitations in outcomes for certain domains (Table 4.1). Qualitative interview data suggested that other issues were very relevant – such as inability to use transport, lack of interest in attending organised groups, lack of acceptable meeting places – coupled frequently with a general demotivation, related to the loss of siblings and peers. Also, there were significant needs in the domain of home environment, for basic decoration, house refurbishment and adaptations that social care funds would not meet. It is unlikely that these needs may have been met simply by access to more generous care packages, but might have been eased by other social care interventions (Mead *et al* 2010; Leeuwen *et al* 2014). Still there are now increased opportunities for using DPs as vehicles for tackling these issues: home equipment and adaptations now lie within the realm of DP, and outcomes-focused assessment could allow for neighbours or other social contacts to be paid to provide visits, offering support for social needs in conjunction with some practical support, replicating some of the input that others receive freely from their immediate kin.

4.5. Limitations

A limitation of this work is the lack of comparison of proxy versus non-proxy responses due to confounding factors that would need to be controlled for, requiring a much larger sample. This was not feasible within the resources available. Proxy responses were biased towards the most dependent, who were statistically associated with lower DP outcome gains, consistent with wider studies measuring the impact of social care services *(*cf. Malley *et al* 2012).

A further issue is that the potential influence of unpaid carers on outcomes scoring is not just limited to proxies. Just under a third of the interviews were conducted by proxy, but the majority of interviewees received some degree of support from an unpaid carer to manage their DP (73%) and in most of these cases their unpaid carer was also present in the interview. Rand *et al* (2017b: 2) underline how the use of proxies is both a widely used method for collecting data and “preferable to the systematic exclusion of individuals who are unable to self-report based primarily on the principles of equity and inclusion, as well as the potential methodological issues associated with missing data and bias” (Rand *et al* 2017b: 2). The strong positive impact on outcomes associated with the presence of an unpaid carer who helped to manage DPs clearly prompts reflection on the potential of *positive* bias linked to proxy responses. It should be noted that, “the majority of studies that directly compare self-report and proxy-report have found an **underestimation** of quality of life by proxy respondents compared to patient self-report” (Rand *et al* 2017b: 12). On this basis, it appears unlikely that proxies would have overestimated needs met by the service as a construction of the effectiveness of the support they provide. However, the context of DPs is distinct because managerial care is a more critical component of care: as such the efficacy of a service managed by an unpaid carer may be construed as a measure of self-efficacy. In other words, unpaid carers that take on management of a DP may be more sensitive to how the benefit of service received reflects on them. In defense of the results presented here, it should be remembered that proxy evaluation of DP outcomes was strengthened by independent observation and that the positive impact of unpaid care was consistent with the beliefs of social workers (Glendinning *et al* 2008).

4.6. Conclusion

The work presented has explored how outcomes are influenced by patterns of service provision and individual characteristics. Unlike previous survey data which excludes proxy responses (Woolham *et al* 2016; Hatton & Waters 2014), service users in the sample were skewed towards the most highly dependent. The sample therefore better reflects the profile of older people currently receiving publicly-funded social care. The payments received by the sample were also in line with current norms. Direct payments were effective in securing outcomes among this group – their results outperformed national average outcome scores at *any* time since data were first recorded, with the most important differences being in the extent to which DP recipients felt safe and in control of their lives.

These findings are historical – based on interviews conducted between 2005 and 2007. The revisiting of this data is justified on two counts. The data offered unprecedented detail – not offered by other studies - while the very fact that the collection predated the main wave of personalisation was an advantage. Personalisation has radically altered the context in which DP are used by older people and reports of decreasing success of DPs to older people coincide with the period associated both with the implementation of personalisation and radical austerity (Glendinning 2017). The richness of the data provides the opportunity to explore possible reasons for this.

There are many factors that cannot be taken into account in such an analysis, such as the vastly more precarious state of home care services brought about by a combination of restrictions of fee increases, rising wage costs and increased uncertainty and risk (Baxter 2018); or the extreme variation between councils in the average value of DPs to older people. Nevertheless the results offer a number of key messages to guide future service delivery within this context.

The sufficiency of DPs is a complex matter subject to local and individual variation. Responsibility lies in ensuring that DPs are adequate to support outcomes. My results show that particular attention needs to be paid to the *discrepancy* between total care input (which could include unpaid care and/or self-funded care) and DP-funded support. This information is not routinely collected but could be required as a means of monitoring – particularly given concerns that DPs offer a convenient route to councils to further shift caregiving costs to unpaid carers. Related to this, the findings support an increased role for funding from NHS continuing care, made legal as part of the Care Act (2014). Implementation of so-called “Personal Health Budgets” (PHB) has been marred by widespread criticism of personalisation as an attempt to privatize the NHS;

scepticism surrounding the suitability of DPs for older people affecting social workers willingness to promote them and the willingness of NHS commissioning groups to release funds to councils with social services responsibilities. As a result, service users at the high end of the need spectrum, as represented in the sample, are currently unlikely to access DPs.

Consistent with earlier qualitative studies, the work found positive impacts of unpaid care on older DP recipients, but this is the first study that quantifies this, and demonstrates separate effects for unpaid care as a function of the total care received, and unpaid care as managerial care. These findings support the hypothesis by Tanner *et al* (2018) that the experience of paying for care – be it through direct payments or as a self-funder – can helpfully be analysed using a capability approach, that addresses interactions between personal characteristics, available resources and environmental factors. This approach naturally separates unpaid care as a function of total care received as a commodity, from ‘capabilities’ that may include unpaid carers acting as agents. While Tanner *et al* (2018) apply the capability approach to explain why paying for care fails; in this study evidence is provided as to the circumstances in which it succeeds. Just having an unpaid carer is not necessarily sufficient: it is the time and effort that they invest in caring that is significant. This insight helps with the dilemma regarding over-reliance on unpaid carers. Unpaid carers’ commitment and capability can (and should) be readily observed at the outset. This should not be confused with an ability to go it alone, or suitability being dependent upon pre-established competencies. External support was also important to the outcomes of service users supported by unpaid carers as has been highlighted in other studies (Arksey & Baxter 2012; Woolham *et al* 2016; Glendinning *et al* 2009).

The findings also provide an incentive to recognise the impact of unpaid carers on the outcomes of DPs - often overlooked (Woolham *et al* 2018) - whilst demonstrating why assuming that “if the service user [is] unable to manage a DP, then the carer [will] be asked to manage it for them” (Mitchell *et al* 2014) is the wrong approach. This is not only because of its potentially negative impact on carer wellbeing but also because the benefits likely to be achieved by providing DPs will be less thereby indicating a need to consider alternative service options.

A major concern surrounding the uptake of DPs in the wave of personalisation and austerity is that current pressures and incentive structures promote the ‘easiest’ rather than the best route of care. This, for an increasing number of councils, equates to DPs being supplied as the ‘default’ option. Ironically, this often precludes access to DPs in so called ‘complex-cases’ due to the pressures on social work teams. These include: service users requiring indirect payments (managed by a nominated person). particularly people with dementia, individuals requiring health funding and people for whom including funds to purchase home equipment and adaptations may be beneficial, as each of these scenarios increases set-up times and requires skills that social workers continue to lack (Jepson *et al* 2016; Laybourne *et al* 2016).

The findings also highlight the influence of the type of inputs received. Recruitment support provided by Direct Payment Support Schemes significantly altered outcomes. Those that used recruitment support had better outcomes, while those for whom recruitment support was considered by them to be critical to their success – had better outcomes still. These findings are important given the way that recruitment support has been reconfigured in many areas, with reductions in the ‘associated expenditure’ on DPSS and a shift towards online platforms in lieu of the 1:1 support received by the sample. Related to this, receiving flexible care also led to greater outcome gains and this was also often brokered by DPSS support staff. My results suggest that these changes are likely to also be implicated in the increasing failure of DPs to achieve outcomes superior to standard services, and the lack of evaluation of their function for older people is a concern.

Finally this work demonstrates for the first time the benefits of the freedom to combine care package allocations with self-funding in achieving better outcomes. DPs remain the only mechanism by which service users and families can choose to add to their funded package, but in the past this has provoked heated debates about the risk of a two-tiered service (Leece & Leece 206). In this study, self-funded care was a small but pivotal factor in optimising outcomes, but was predominantly funded by the social security benefit Attendance Allowance. This benefit remains surrounded by controversy amidst discussions on the future funding of social care (Corden *et al* 2010). Its proponents point to its wide coverage; ability to compensate for unmet need among people who remain ineligible for social care funding and the value of it being centrally administered at set rates, thus offering some independence from the highly variable allocative practices of local councils.

The work presented provides an urgent reminder that it is not access to DPs *per se* that offer improved outcomes but *DPs with support* to identify and realise the potential they offer. It is said that personalisation has not worked for older people (Leahy 2018) while others argue that the suggestion that personal budgets are unsuitable for older people is in itself a form of ageism (Glasby & Littlechild 2016). This work offers insights into the tools at councils' disposal to improve the potential of DPs, as well as lessons for other countries implementing consumer-directed care.

4.7. Abbreviations

PB: Personal budget; DP: Direct payment; MB: Managed budget; DPSS: Direct payments support scheme; DPOG: Direct payment outcome gain; DH: Department of Health

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5. Understanding the role of unpaid care in the provision of direct payments to older people

Background

- Unpaid care is widely recognised as an “input” capable of limiting “demand” for formal care. Determining the optimal balance between formal and unpaid (informal) care is an issue that is both delicate and controversial for policy makers

- Direct payments in England allow the payment of relatives for care but within a strict framework; this is in contrast to some other countries. For a relative to be paid they must work as care provider (according to an agreed schedule and tasks), be registered for tax and national insurance and be subject to employment checks. Co-resident family members are only accepted in *exceptional* circumstances. These rules are set for the purpose of safeguarding service users and to reduce the possibility that care previously provided informally will be transformed into formal care, thus raising the costs of long-term care.

- In Chapter 4 we saw that unpaid care exerts a significant influence on the benefit gained from receiving direct payments among older people, suggesting that direct payments complemented unpaid care rather than crowded it out. Individuals that received a great amount of their total care from unpaid care gained higher benefit from direct payments. A separate indicator for service users who had support from an unpaid carer to manage their direct payment was also significant in direct payment gain.

- The results from chapter 4 provide insight into the importance of unpaid care but do not tell us how (if at all) direct payments transformed the way in which unpaid care was provided, or provide insight into the characteristics of the individuals that managed that managed the direct payment, or provided intensive unpaid care – or both.

Aims and Objectives

This chapter explores further the data obtained from interviews with older people and their unpaid carers which was used in chapter 4 to investigate factors influencing outcomes of direct payments, and sets out to answer the following questions:

- How did unpaid care vary among older people receiving direct payments?
- Who were the unpaid carers? What kind of care did they provide? Did managing direct payments on behalf of the older person change care patterns?
- Is there evidence that direct payments enabled unpaid carers to organize care that better suited them?
- Did use of direct payments modify the balance between unpaid and state-funded care?

Key findings

- Helping to manage a direct payment did not reduce the amount of hands-on care performed by unpaid carers. Furthermore, if the unpaid carer managed the direct payment less home care related to Instrumental Activities of Daily Living needs was funded through the direct payment.
- Direct payment recipients without support from an unpaid carer to manage their direct payment also purchased more ‘combined home and social and leisure care’(activities such as paying their personal assistant to accompany them shopping, rather than doing it for them) because they tended not to have this opportunity with an unpaid carer.
- Somewhat unexpectedly, the number of primary unpaid caregivers that were male was higher than the number of females in that role. The male subgroup was divided equally between sons and husbands.

- Female unpaid carers had greater support in their role as caregiver than male carers. More shared care with a secondary unpaid carer. Also, where direct payments users were supported by daughters and wives, allocations of funded care relative to dependency level were greater than when direct payments users were supported by husbands or sons.
- Filling the gap, sons sometimes purchased private care (or were left with less total are input) while husbands consistently provided greater amounts of unpaid care and more support with Activities of Daily Living than female spouses.
- Unpaid care amounts were greater when care was by a same sex child whether or not they were male or female.
- Based on hours of care provided, sons appeared to provide less unpaid care than daughters, although this was not always the case when expressed as a proportion of the total care input.
- Differences in absolute terms between sons and daughters appeared linked to other factors. Daughters were more often managing a direct payment for a parent with cognitive impairment than sons, a factor which was associated with greater levels of unpaid care. Also, service users supported by daughters more often had a second unpaid carer contributing such as a son-in-law or grandchild.
- Female spouses were also much more frequently acting as appointees to manage a direct payment on behalf of a husband with dementia than vice versa, possibly reflecting reluctance among social workers to appoint husbands to this role.
- The purchase of private care among service users with an unpaid carer appeared to be linked to the availability of a secondary caregiver and was much less frequent if a secondary unpaid carer was available, suggesting it was employed only when families exhausted their limits of funded and unpaid care.
- Primary caregivers were paid through direct payments much less frequently than secondary caregivers. Employing second-degree relatives as personal assistants helped to reduce the strain on primary caregivers. This was because availability of secondary carers widened, and secondary carers provided more unpaid care if also paid through direct payments.
- Beyond the dichotomies of male/ female, son/ daughter and husband/ wife, patterns of unpaid care were clustered by caregiving context. Four groups stood out through initial qualitative enquiry which was corroborated by the

quantitative data. These were; lone service users, self-managers, husband and wife teams (cf. chapter 6) and indirect payment receivers.

- Only 11 people in the sample had no access to unpaid care (the lone service users), while the ‘self-managers’ (a larger group of 20 people or one quarter of the sample) received little unpaid care and took full-control of their DP. Patterns of intensive caregiving were linked to two types of circumstance: unpaid carers managing a direct payment on behalf of the older person; and husband and wife teams. Among the group of indirect payment receivers, it was noticeable that many of them were working, but still provided a substantial amount of unpaid care. This group is studied in chapter 7.

5.1. Introduction

Unpaid care underpins a large proportion of state-funded social care, especially for service users aged 65 and older. It is said that, “policy makers tend to under-appreciate the interdependence of the formal and informal sectors of care and support” (Land 2002 in Sin 2006: 221). Above all, unpaid care is recognised as an input capable of limiting the demand for formal care. From this line of argument stems a wealth of studies aimed at determining the optimal balance between formal and unpaid (informal) care, to ensure that state provided formal social care does not crowd out unpaid care (UC) (Bolin *et al* 2008, Bonsang, 2009; Dunér & Nordström 2007, Litwin & Attias-Donfut 2009, McMaughan Moudouni et al 2012; Stabile *et al* 2006, White-Means & Rubin, 2004; Van Houtven & Norton 2007). This is combined with concern to create incentives to sustain UC (by compensation methods or benefits to unpaid carers) and mechanisms to protect unpaid carers (UCs) from the physical, psychological and social burden of caregiving as a means of increasing the viability and sustainability of unpaid care (Gervès-Pinquié *et al* 2014; Keefe & Rajonovich 2007; OECD 2011; Pickard 2004; Pickard 1999; Riedel & Kraus 2011).

Policy-makers have been particularly ill at ease with the relationship between direct payments (DPs) for care and unpaid care (Lundsgaard 2005). There are special concerns about their potential impact to the balance of informal and formal care owing to, a) the possibility of paying relatives and other unpaid carers for care received and b) the freedom to purchase care according to preferences. The first of these theoretically creates the possibility that care previously provided informally will be transformed into formal care, thus raising the costs of long-term care (Arntz & Thomsen, 2011). The second of these could result in tasks which were previously performed by an unpaid carer being performed by a formal care worker paid for by the state. On the other hand, there are concerns that DPs may lead to increased burden on unpaid carers and greater isolation due to the private and independent nature in which care arranged through DPs is managed (Mitchell *et al* 2014; Moran *et al* 2011; Manthorpe & Samsi 2013). These debates have fuelled research within a variety of Western countries operating or experimenting with cash payments or care in place of local authority-commissioned care (Schneider & Reyes 2007), albeit within varying contexts.

The study presented here was concerned with measuring the inputs of formal and unpaid care among a cross-sectional sample of 81 older people in ten English local authorities conducted as part of the evaluation of the Direct Payment Development Fund (Davey *et al* 2007), which took place immediately prior to the implementation of Personal Budgets (PBs). This study, while somewhat historic remains the only available source of detailed quantitative data on unpaid care among older people using DP. The vast majority of service users in the study (89%) received some degree of regular unpaid care although this varied significantly according to their circumstances, particularly levels of service user dependency (Baxx *et al* 2014). A similar proportion (79%) received support from an unpaid care to *manage* their direct payment, again to varying degrees. Some 43% of the sample had their direct payment fully controlled by an unpaid carer owing to their inability to do so themselves (due to advanced frailty, limited speech and/ or cognitive impairment), combined with the willingness of an unpaid carer(s) to take on the responsibility. Receipt of unpaid care varied significantly among the sample and with it the balance between formal and unpaid care. A further factor was the use of supplementary self-funded care, which although minimal, did contribute to total care input for some of the sample. This paper explores these variations to determine if there was any evidence that receiving DPs altered the balance between unpaid and formal care. In doing so, it provides a detailed description of the significance of caregiving contexts to patterns of unpaid caregiving.

5.2. Methods

5.2.1. Sampling

Older people receiving DPs were recruited from ten councils and interviewed between 2005 and 2007 as part of a wider national evaluation on DPs to older people conducted for the Department of Health, England. Councils were selected to represent a spread of DP take-up rates. The top and lowest performing councils were excluded.[21] Participating councils were from the first, second and fourth quartiles for take-up. Selected councils were dotted across the whole of England, and were split equally between high and low population-density areas were sampled.

All older people in receipt of a DP in each council were contacted via a letter, distributed by councils to ensure anonymity. Individuals received information on the study and a freepost envelope to return if they wanted to participate. Eight service users were sought per council, roughly half the national average of older people receiving DPs per council in 2007 (Davey *et al* 2007). In areas with more positive responses than required, individuals were chosen to give the widest geographical spread within each council.

As a result of the sampling strategy, participants were from wide range of circumstances and socio-economic characteristics and from a range of ethnic groups: 21% of the overall sample (and up to 67% in individual London boroughs) were from BME groups, above the English average (14%; ONS 2011).

5.2.2. Ethical considerations

The research was undertaken prior to implementation of the Research Governance Framework (2005-2007). Study design and methods were reviewed by the LSE Research Ethics board, as per guidance at the time. As interviews were conducted face-

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[21] The top performing councils for DP take-up were excluded as many had already been involved in research of some kind. The lowest performing councils were excluded as DP numbers were too low to recruit the desired sample.

to-face we were able to include older people with cognitive impairment (30% of the sample). All but one of the interviews for these people was conducted by proxy with their main representative (usually the person managing the DP on their behalf – who was also the person who responded to the request for interviewees), with a second representative was present, often a representative from the local Direct Payments Support Services (DPSS). Where carers acted for service users unable to express their views, the assumption of responsibility to manage the DP took place under the auspice of enduring power of attorney. Subsequently the Health and Social Care Act 2008 has extended the scope of DPs to people who lacked capacity to consent and legitimized the practice of employing a 'person' to act on behalf of them (DH 2008).

5.2.3. Measures

Data was obtained during face-to-face interviews with service users and their unpaid carers. Each service user (or their appointee) was asked to provide details of how their DPs care package was used throughout the week using a daily diary approach (Van De Berg & Spauwen 2006), and what additional inputs they received on a daily or weekly basis. This included additional input from informal carers, self-funded care or formal care that was commissioned directly by the local authority and did not form part of the DPs care package. Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) were recorded using standard tools (Collin *et al* 1988, Lawton & Brody 1969) and the results were used to group service users into dependency level groups, using a classification system developed by Henderson (2006) (Table 5.1). Data was analysed using IBM SPSS Statistics for Windows Version 19 (IBM Corp 2010).

5.2.4. Analysis

Data was analysed in a step-wise progression making use of quantitative and qualitative data. In Stage one, I compared the spending patterns of service users with support from an unpaid carer to manage their direct payment, versus service users who managed their DP alone. This focused specifically on *types of care* purchased. Qualitative findings from analyses for chapters 6 and 7 brought to light the importance of the caregiving context in understanding patterns of unpaid and the balance of formal and unpaid care. Responding to this, stage two of the analyses provided a series descriptive analyses comparing and contrasting *patterns of care* by caregiving context. Related to this I explored how caregiving contexts varied in a wider sense (stage 3). As part of this I looked for evidence of any transformation from unpaid to paid care as a result of DPs and examined how unpaid care may have altered: specifically with respect to management roles. The specific measures used are detailed below.

Table 5.1: Dependency classification

	Description of condition
Highest dependency: **chair-bound and dependent in transfer**	Immobile or chair-bound. Unable to transfer without the assistant of two carers. Requires a hoist for getting in and out of bed. May be incontinent or occasionally incontinent of faeces. May wear pads at night for urinary incontinence or be catheterised. May require assistance with feeding. Unable to do any IADLs.
High dependency I: **5 PADLs, can walk <2m**	Requires assistance to wash and dress. May be incontinent of urine or catheterised. Unable to walk outside, must therefore use be pushed in a wheelchair or use a power wheelchair or scooter. Unable to prepare meals. Unable to do housework or laundry. May be wheelchair independent in the home or using other aids, such as a stick or frame. Requires help and equipment to get into a bath, or alternatively a level-access shower.
High dependency II: **2 - 4 PADLs, can walk <10m**	Able to dress partly independently but requires assistance. Requires help and equipment to get into a bath, or alternatively a level-access shower. Unable to climb stairs. May have occasional urinary incontinence. Able to transfer independently indoors with the use of aids and grab rails. Either sleeps in the ground floor, uses a stairlift or lives on one level. Has difficulty preparing meals. Unable to carry shopping or do most housework except washing up. Unable to walk outside without considerable assistance, being pushed in a wheelchair, or using a power scooter or wheelchair.
Moderate dependency: **1 PADL in addition to bathing**	Experiences difficulty with washing body/ lower limbs at sink. Requires help getting into bath. May have difficulty transporting food around kitchen or to other rooms. Uses mobility aid outdoors. Unable to carry shopping or do heavy housework.
Low dependency	Experiences difficulty with washing lower body or back thoroughly, or with nothing generally. Has difficulty carrying shopping and doing general housework.

Source: Henderson (2006)

Stage One

Data from service users' daily diaries was used to generate, i. the weekly sum of each type of care input per individual (in hours, per week) and ii. the proportion that each type of support contributed to the total care input. From this, average values were derived for each type of care input for the independent groups, a) service users with an unpaid carer who supported them to manage their DP, and b) service users without this. To account for differences in patterns of support related to level of dependency, we generated sub-groups for each dependency level. The Mann-Whitney U test was then used to compare the means of the two groups and assess for statistical equality.

Stage Two

Data collected on unpaid care was used in the form of contingency tables to explore patterns of unpaid care by caregiving contexts. Data was included on: the average weekly hours of care fulfilled by the main unpaid carer; their gender and relationship to the caregiver. Related to the care recipients characteristics we included data on dependency level, whether they lived alone or cohabited and presence of a cognitive impairment.

Stage Three

Contingency tables were generated to explore how different caregiving contexts varied in a wider sense. Data was included on: whether the main caregiver performed ADL and/ or IADL related tasks; the availability of a second unpaid carer; whether they were in general employment and whether they were employed by DP and if they acted as an appointee or "suitable person" for managing the DP. Related to the care recipients characteristics I included data on dependency level, whether people lived alone and presence of a cognitive impairment. I then compared service users by "sub-group" using four categories which appeared in the process of qualitative analysis which were confirmed by descriptive quantitative analysis as representing substantially different types of service user, or service user/ unpaid carer combinations. Finally I examined how unpaid care might have changed in response to DPs from available qualitative and quantitative data.

5.3. Results

5.3.1. Purchasing differences between service users with and without unpaid care

The first part of the analysis compares how those with unpaid carers and those without used their DP allocations – specifically, what types of care they purchased. For this section I differentiate between those who had support from an unpaid carer to help them manage their DP (hereon referred to as “managerial carers”) versus those that did not (this essentially distinguishes between those with regular unpaid care and those for whom unpaid carer was either sporadic or not available). It also distinguishes between those for whom the unpaid carer had sufficient presence to influence patterns of spending and those that did not. This distinction is important because of the notion that payments for care (such as DPs), could offer unpaid carers greater license to organize care to suit their priorities (Shut & Van der Berg 2012). With respect to the types of care input received, there is no evidence for a substitution of unpaid informal care to formal (publicly funded) care. First and foremost, unpaid care accounted for a very significant share (42%) of the total level of support received by users for whom an unpaid carer helped with DP management, as shown in Table 5.2. Much of this care was of a practical nature: the significantly lower proportion of the care package and total care input consumed by publicly funded ‘home care’ amongst older people with managerial carers shown in Tables 5.2 and 5.3 is clearly related to the amount of domestic support provided by unpaid carers. Service users without managerial carers not only purchased greater levels of home care as part of their direct payment package but, where feasible, they were also more likely to purchase a “combination of home care and support with social and leisure pursuits”, as reflected in the category of “moderate dependency”. This underlines the role that unpaid care plays in the area of social needs.

Table 5.2: Proportion of total care input by service type (%)

	All users		Moderate dependency		High Dependency I (2-4 PADLs)		High Dependency II (5 PADLs)		Highest Dependency	
	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support
Rehabilitation / specialist counselling	0	0	0	0	0	0	0	0	0	0
Therapeutic management	1.9	0	11.2	0	1.2	0	2.0	0	0	0
Home care (HC)	11.3	26.1***	25.2	47.9	14.8	0	13.7	22.1	4.0	21.2**
Personal care (PC)	16.6	20.5	2.5	2.1	9.7	16.7	17.6	39.9	21.2	29.0
Health care (HLC)	0.4	0	0	0	0	0	0	0	1.0	0
Social and leisure pursuits (SLP)	0.7	4.5	0	11.1	1.5	0	1.0	3	0.1	0
Other	0.1	0	0	0	0	0	0.3	0	0	0
HC and PC combined	16.1	26.2	20	19.5	12.3	31.3	15.3	26.4	17.8	32.1
HLC and PC combined	1.0	0.4	0	0	0	0	1.7	1.5	0.7	0
PC and SLP combined	0.8	0	0	0	0	0	0.5	0	1.6	0
HC and SLP pursuits combined	0.9	8.1*	0	4.2	0	33.3*	1.9	0	0.3	0
Other care combinations	0	1.5**	0	4.4	0	0	0	0	0	0
Day care	1.0	3.6	0	10.7	0.7	0	0.6	0	1.9	0
Sitting service	1.6	0	0	0	0	0	3.4	0	0.3	0
Self-funded care	5.3	9.2	0	0	14.0	18.8	2.8	7.1	6.1	17.6
Informal care	42.3***	0	41.1*	0	45.8***	0	39.3***	0	44.9**	0
Valid number of cases (*n*)	65	15	5	5	9	3	28	4	23	3

WMW Significance levels: *=10% **=5% ***=1%

Table 5.3: Proportion of users receiving different types of care as part of their DP (%)

	All users		Moderate dependency		High Dependency I (2-4 PADLs)		High Dependency II (5 PADLs)		Highest Dependency	
	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support	With informal support	Without informal support
Rehabilitation / specialist counselling	0	0	0	0	0	0	0	0	0	0
Therapeutic management	4.9	0	32.8	0	9.1	0	2.6	0	0	0
Home care (HC)	17.6	26.1**	40	47.9	25.3	0	20.6	22.1	6.1	21.2*
Personal care (PC)	32.6	25.2	7.2	2.1	29.6	33.3	27.9	39.9	44.9	35.7
Health care (HLC)	0.4	0	0	0	0	0	0	0	1.1	0
Social and leisure pursuits (SLP)	3.5	4.5	0	11.1	4.3	0	6.5	3	0.3	0
Other	0.8	0	0	0	0	0	1.8	0	0	0
HC and PC combined	28.7	30.7	20	19.5	28.5	33.3	27.0	33.5	32.7	43.1
HLC and PC combined	1.6	0.4	0	0	0	0	3.1	1.5	0.7	0
PC and SLP combined	2.5	0	0	0	0	0	1.8	0	4.6	0
HC and SLP pursuits combined	1.1	8.1*	0	4.2	0	33.3	1.9	0	0.9	0
Other care combinations	0	1.5**	0	4.4	0	0	0	0	0	0
Day care	3.6	3.6	0	10.7	3.125	0	1.6	0	6.8	0
Sitting service	2.9	0	0	0	0	0	5.1	0	1.8	0
Valid number of cases (*n*)	64	15	5	5	8	3	28	4	23	3

WMW Significance levels: *=10% **=5% ***=1%

Managerial carers were also significantly involved in home care tasks. This was most significant for the sub-group of highest dependency users where the difference between the proportion of home care purchased by service users with and without informal carers was greatest (Table 5.3). Here informal care acted as a direct substitute for publicly funded home care that would have needed to have been in place in the absence of informal care support. Qualitative interviews indicated that managerial carers supporting service users within the highest dependency category provided support with a wide range of activities, including cleaning, cooking, doing the laundry and helping with self-care needs. As a result, proportionately more service users with managerial carers purchased personal care than those without (Table 5.2). In principle, focusing DP spending on personal care might help to retain privacy and reduce the emotional strain related to caregiving given the relationship between care giver burden and personal care (Bamford *et al* 2008), but in practice personal care use was actually greater for those without UCMS (Table 5.3). This was largely because unpaid carers also frequently provided support with ADLs - including personal care tasks - although this varied according to the relationship between the unpaid carer and the service user (see section below).

While there was no evidence to suggest that formal care was substituting unpaid care, qualitative data suggested that DPs offered managerial carers the freedom to build flexibility into the care package to support both the needs of the service user and the preferences of the unpaid carer. For example, instead of purchasing support to help with putting a spouse to bed, one managerial carer opted to do this alone with appropriate support (such as a mechanical hoist) which allowed them to extend the amount of time available for personal care in the mornings or at lunch times. In other cases, the extension of morning hours enabled some assistance with domestic chores such as washing soiled bed sheets or ironing although these tasks were always conducted in a context in which the care worker was providing mainly personal care such as assistance with washing, dressing, toileting or feeding. These were examples of small but significant practical assistance with a direct impact on unpaid carers – but overall amounted to a negligible proportion of total care input.

5.3.2. Patterns of unpaid care among older DP users

Unpaid care and relationship to service user

Gender balance

Generally, patterns in unpaid care were more clustered according to the relationship between the service user and the main unpaid carer rather than by gender, and ultimately the context in which unpaid care took place (Tables 5.4, 5.5, 5.6). One result of this was that patterns of unpaid care diverged to some extent from the typical gender patterns of informal care (Da Roit, Hoogenboom & Weicht 2015). This was evidenced in the unusually high share of service users for whom a son was their main unpaid carer (22%), combined with male spouses acting as main caregivers (also another 22% of the sample) (Table 5.4). Male unpaid carers represented just under half of all main unpaid carers supporting older people receiving DPs in the study. In addition, the vast majority of caregiving sons were in full-time employment (Table 5.7). The hours of unpaid care they provided tended to be just below the threshold of 20 hours, beyond which unpaid carers are known to be less likely to be employed than the general population (Pickard *et al* 2016), although research suggests that employment is also negatively affected at levels below this threshold (King & Pickard 2013).

In other respects the situation followed wider trends. For example, female caregivers were less isolated than male caregivers, while spouses were more isolated than adult children (Carmichael & Ercolani 2014) (Table 5.7). Daughters who operated as main carers shared caregiving with another unpaid carer in 67% of cases, and female spouses did so in 44% of cases. In contrast, less than one quarter of male spouses and only one third of sons benefitted from the input of another unpaid caregiver, as a potential buffer to the physical or psychological burden of caregiving (Bauer & Sousa-Poza 2015; Bamford *et al* 1998). These figures highlight the intense situation of male caregiving spouses.

Table 5.4: Average weekly hours of unpaid care by client characteristics.

Dependency level	ALL			Moderate dep			Moderate high dependency			High dependency			Moderate		
Care receipt characteristics	n	%	Average weekly hours of unpaid support (hrs/wk)	n	%	Average weekly hours of unpaid support (hrs/wk)	n	%	Average weekly hours of unpaid support (hrs/wk)	n	%	Average weekly hours of unpaid support (hrs/wk)	n	%	Average weekly hours of unpaid support (hrs/wk)
Lives alone	39	*47*	26	8	*10*	15	8	*10*	5	15	*18*	7	8	*10*	42
Cohabiting	42	*51*	51	2	*2*	35	5	*6*	59	17	*21*	51	18	*22*	51
UC: Male	37	*45*	33	4	*5*	23	4	*5*	23	19	*23*	36	10	*12*	34
UC: Female	33	*40*	44	3	*4*	32	7	*8*	35	9	*11*	31	14	*17*	59
Care by male spouse	18	*22*	52	0	-	-	2	*2*	33	12	*15*	51	4	*5*	61
Care by female spouse	9	*11*	41	0	-	-	0	-	-	2	*2*	30	6	*8*	51
Care by son	18	*22*	16	4	*5*	23	2	*2*	12	6	*8*	12	6	*8*	17
Care by daughter	20	*24*	49	2	*2*	45	4	*5*	39	6	*8*	35	8	*10*	66
Service user cognitive impairment[1]	34	*41*	47	4	*5*	26	2	*2*	74	11	*13*	38	17	*21*	54
“Husband & wife team”[2]	14	*17*	57	0	-	-	3	*4*	50	8	*10*	55	3	*4*	69
Indirect payment receivers[3]	36	*44*	48	5	*5*	35	2	*2*	74	12	*15*	38	17	*21*	55
“Self-managers”[4]	20	*24*	8	2	*2*	7	6	*8*	7	8	*10*	9	4	*5*	10
“Lone” DP user[5]	11	*13*	0	3	*4*	0	2	*2*	0	4	*5*	0	2	*2*	0
ALL	39	*47*	36	8	*10*	24	8	*10*	41	15	*18*	30	8	*10*	58

[1] Suspected or diagnosed cognitive impairment.
[2] “Husband & wife teams” are units where the DP was jointly managed by a team of cohabiting spouses.
[3] “Indirect payment receivers” refers to cases where the DP was managed by an unpaid carer(s).
[4] “Self –managers” are categorized as DP recipients that took full control of managing their DP but received some unpaid care.
[5] “Lone DP users” were those without any unpaid care. All users in this category lived alone.

Table 5.5: Average total of funded and unpaid care hours of care per week by client characteristics.

Dependency level	ALL			Moderate dependency			Moderate high dependency			High dependency			Highest dependency		
Care receipt characteristics	n	%	Average weekly hours of funded and unpaid support (hrs/wk)	n	%	Average weekly hours of funded and support (hrs/wk)	n	%	Average weekly hours of funded and unpaid support (hrs/wk)	n	%	Average weekly hours of funded and unpaid support (hrs/wk)	n	%	Average weekly hours of funded and unpaid support (hrs/wk)
Lives alone	39	*47*	38	8	*10*	33	8	*10*	14	15	*18*	26	8	*10*	78
Cohabiting	42	*51*	68	2	*2*	51	5	*6*	77	17	*21*	66	18	*22*	77
UC: Male	37	*45*	44	4	*5*	34	4	*5*	34	19	*23*	50	10	*12*	58
UC: Female	33	*40*	64	3	*4*	61	7	*8*	49	9	*11*	56	14	*17*	92
Care by male spouse	18	*22*	62	0	-	-	2	*2*	42	12	*15*	62	4	*5*	81
Care by female spouse	9	*11*	61	0	-	-	0	-	-	2	*2*	51	6	*8*	71
Care by son	18	*22*	34	4	*5*	34	2	*2*	26	6	*8*	31	6	*8*	44
Care by daughter	20	*24*	71	2	*2*	72	4	*5*	55	6	*8*	63	8	*10*	95
Service user cognitive impairment[1]	34	*41*	70	4	*5*	44	2	*2*	96	11	*13*	56	17	*21*	83
"Husband & wife team"[2]	14	*17*	72	0	-	-	3	*4*	64	8	*10*	65	3	*4*	86
Indirect payment receivers[3]	36	*44*	73	5	*5*	52	2	*2*	96	12	*15*	58	17	*21*	84
"Self-managers"[4]	20	*24*	26	2	*2*	25	6	*8*	17	8	*10*	29	4	*5*	31
"Lone" DP user[5]	11	*13*	27	3	*4*	19	2	*2*	16	4	*5*	14	2	*2*	60
ALL	39	*47*	55	8	*10*	43	8	*10*	46	15	*18*	48	8	*10*	72

[14]

[1] Suspected or diagnosed cognitive impairment.
[2] "Husband & wife teams" are units where the DP was jointly managed by a team of cohabiting spouses.
[3] "Indirect payment receivers" refers to cases where the DP was managed by an unpaid carer(s).
[4] "Self –managers" are categorized as DP recipients that took full control of managing their DP but received some unpaid care.
[5] "Lone DP users" were those without any unpaid care. All users in this category lived alone.

Table 5.6: Receipt of unpaid care by service users supported by sons and daughters

	Service user characteristics											
	Female			Male			Cognitive Impairment			No cognitive impairment		
	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input
Son	10	16	31	8	17	44	10	18	35	8	15	38
Daughter	13	52	41	7	44	34	12	59	51	8	9	21

	Unpaid carer circumstances																	
	Employed			Not employed			Other unpaid carer available			Sole unpaid carer			Private care purchased			No private care		
	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input	n	Unpaid care (hpw)	Unpaid care as % of total care input
Son	7	18	37	11	16	36	6	18	48	12	15	31	2	26	30	16	16	37
Daughter	6	52	46	14	33	35	13	60	53	7	28	11	7	34	29	9	41	43

Table 5.7: Caregiving circumstances by gender of main unpaid carer and relationship to care recipient

	Gender of main unpaid carer		Relationship of main unpaid carer to OP							
Caregiving context	Male	Female	Son	Daughter	Male spouse/ partner	Female spouse/partner	Brother	Sister	Granddaughter	Neighbour/ friend
n	37	34	18	21	18	9	1	1	1	2
	%	%	%	%	%	%	%	%	%	%
Shared care with other unpaid carer	27	59	33	67	22	44	0	0	100	50
Had carers' assessment	24	20	11	24	39	22	0	0	0	0
Used private care	19	33	11	35	28	22	0	0	0	0
Acts as appointee for indirect payments	38	52	44	52	33	78	0	0	0	0
Care recipient with cognitive impairment	38	52	55	57	22	66	0	0	0	0
Employed *	50	43	94	57	5	33	100	100	100	50
Employed by DP	11	18	6	10	17	11	0	100	100	50
Lives alone	38	44	66	52	0	0	100	100	100	100

*Employment rates were affected by the age of unpaid carers with 37% of male carers and 21% of female carers of retirement age.

Table 5.8: Contribution of main unpaid carer to IADL and ADL needs by gender of unpaid carer and relationship to care recipient

	Gender of main unpaid carer		Relationship of main unpaid carer to OP							
Contribution to IADL and ADL needs	Male	Female	Son	Daughter	Male spouse/ partner	Female spouse/partner	Brother	Sister	Granddaughter	Neighbour/ friend
n	37	34	18	21	18	9	1	1	1	2
	%	%	%	%	%	%	%	%	%	%
ADL	51	49	22	57	83	67	0	0	0	0
IADL	95	97	89	100	100	100	100	100	100	50

Unpaid carers of both sexes contributed regularly to IADLs, and unusually an equal proportion of male and female unpaid carers supported ADLs (including in many cases personal care tasks), although the distribution could be better understood in relation to other factors (Table 5.8). Help with ADLs was most likely to be provided by a male spouse or male partner (83%), a female spouse or partner (67%), or a daughter (57%). Less than one quarter of sons providing unpaid care gave support with ADLs and no siblings, grandchildren or friends.

Sons and daughters

Sons and daughters were caring for parents with a similar range of dependencies (Table 5.4) with almost equal shares supporting parents with a cognitive impairment (Table 5.7), a factor that on average was associated with significantly more hours of unpaid care (47 hours per week unpaid care, versus 23 hours among those without any cognitive impairment, p.0.003). However, sons appear to have provided considerably less intensive care than daughters, reflecting wider trends (Grigoryeva 2017) - in this sample, service users supported by sons received only one third the hours of unpaid care received by those supported by daughters, and they did not receive significantly greater support if their needs were greater (Table 5.4), a pattern also identified in wider studies (Grigoryeva 2017) Not only did service users relying on sons for unpaid support receive less unpaid care, they also received less funded care (Table 5.9). Excluding the most dependent service users, DP allocations of care were systematically lower for service users supported by sons, than for those supported by daughters. Such lower levels of care were generally not compensated by self-funded care[22] – as a result, for each level of dependency, service users reliant on sons received some of the lowest levels of care (Table 5.5). Only service users without an unpaid carer received lower levels of total support (Table 5.5), but unlike those dependent upon their son, service users without unpaid support received higher levels of DP funded care (Table 5.9). Among the most dependent, those *without* unpaid care actually received substantially greater support than those supported by sons due to more generous allocations of funded care which increased in response to greater needs (unlike the hours of care provided by sons) (Table 5.5).

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[22] With the exception of two older men who lived alone and had working sons where self-funded care compensated for the shortfall between the total funded and unpaid care and requirements for care.

Table 5.9: Average weekly hours of allocated social care support by client characteristics.

Dependency level	ALL			Moderate dependency			Moderate high dependency			High dependency			Highest dependency		
Care receipt characteristics	n	%	Average weekly hours of social care (hrs/wk)	n	%	Average weekly hours of social care (hrs/wk)	n	%	Average weekly hours of social care (hrs/wk)	n	%	Average weekly hours of social care (hrs/wk)	n	%	Average weekly hours of social care (hrs/wk)
Lives alone	39	*47*	21	8	*10*	18	8	*10*	9	15	*18*	19	8	*10*	36
Cohabiting	42	*51*	19	2	*2*	16	5	*6*	18	17	*21*	15	18	*22*	26
UC: Male	37	*45*	15	4	*5*	11	4	*5*	11	19	*23*	14	10	*12*	24
UC: Female	33	*40*	22	3	*4*	26	7	*8*	14	9	*11*	25	14	*17*	33
Care by male spouse	18	*22*	13	0	-	-	2	*2*	9	12	*15*	11	4	*5*	20
Care by female spouse	9	*11*	21	0	-	-	1	*1*	22	2	*2*	21	6	*8*	20
Care by son	18	*22*	18	4	*5*	11	2	*2*	14	6	*8*	19	6	*8*	27
Care by daughter	20	*24*	25	2	*2*	27	4	*5*	16	6	*8*	28	8	*10*	29
Service user cognitive impairment[1]	34	*41*	23	4	*5*	18	2	*2*	22	11	*13*	18	17	*21*	29
“Husband & wife team”[2]	14	*17*	14	0	-	-	3	*4*	14	8	*10*	10	3	*4*	17
Indirect payment receivers[3]	36	*44*	22	5	*5*	17	2	*2*	22	12	*15*	20	17	*21*	29
“Self-managers”[4]	20	*24*	17	2	*2*	18	6	*8*	10	8	*10*	20	4	*5*	21
“Lone” DP user[5]	11	*13*	26	3	*4*	19	2	*2*	10	4	*5*	14	2	*2*	60
ALL	39	*47*	20	8	*10*	18	8	*10*	14	15	*18*	18	8	*10*	29

[1] Suspected or diagnosed cognitive impairment.

[2] “Husband & wife teams” are units where the DP was jointly managed by a team of cohabiting spouses.

[3] “Indirect payment receivers” refers to cases where the DP was managed by an unpaid carer(s).

[4] “Self –managers” are categorized as DP recipients that took full control of managing their DP but received some unpaid care.

[5] “Lone DP users” were those without any unpaid care. All users in this category lived alone.

Service users reliant on daughters received in contrast some of the greatest levels of unpaid support (Table 5.4). Among the most dependent, unpaid care received was greater than for those supported by co-habiting female or male spouses, usually the most time-intensive unpaid carers (Bamford *et al* 1998). Added to this, service users relying on daughters for unpaid support were also more likely to receive supplementary self-funded care (35%) (Table 5.7). This did not appear to be related to daughters' employment rates as might have been expected (He & Mchenry 2016) - service users with daughters that *did not* work tended to receive more self-funded care (42%), than those with working daughters (16%) (Table 5.6). Nor was there any pattern with respect to service users' level of needs (although the dependency classification used does not account for the impact of cognitive impairment), or even whether or not the service user lived alone or cohabited (43% versus 27% among those that cohabited). Of greatest relevance, service users with daughters simultaneously received the *most generous* allocations of DP funded care (Tables 5.5 and 5.9).

So called 'structural theory' has offered an explanation for the difference in receipt of unpaid care between those reliant on sons or daughters. This centres on differences in societal expectations and labour market position between men and women (Kruijswijk *et al* 2015). Added substance is given to this argument in large longitudinal studies of unpaid caregiving which have found that sons reduce their input in response to the availability of female siblings (Grigoryeva 2017). In this small sample of DP users, we consider not only the hours of regular unpaid care but also the proportion of total care input derived from unpaid care. This paints a rather different picture as to the relative contribution of sons and daughters in this group. Mothers reliant on their daughters received considerably more hours per week than fathers (Table 5.6), a variation that was not apparent in the hours of unpaid support received by those reliant on sons, a finding consistent with wider research (Grigoryeva 2017). However as a proportion of total care input we see that the tendency to receive more care among those cared for by children of the same sex was equivalent for both sons and daughters (Table 5.6). We also see that when private care was purchased (or was not purchased), the share of unpaid care received by service users relying on sons and daughters was roughly equal (Table 5.6).

Equally, when considering variation in receipt of unpaid care between those where a further unpaid carer was on hand to share the burden, the proportion of unpaid care received for those for whom their daughter was their primary caregiver unpaid care equaled 53% of total care input, versus 48% for those for whom their son was their primary caregiver (Table 5.6). These findings suggest that in terms of their relative contribution to total care received, the responsiveness of sons and daughters was far more comparable than suggested by research that considers the differences in hours of unpaid care (Grigorveya 2017). This comes with some notable exceptions. Service users with a cognitive impairment who were reliant on daughters received far more unpaid care than those cared for by sons (despite the fact that sons also responded to this difficulty) (Table 5.6). Secondly, where the primary caregiver was a daughter who worked, service users received significantly more unpaid care than those with daughters that were not employed (where as for those cared for by sons whether they worked or not made little difference) (Table 5.6).

In terms of the differences between sons and daughters in the availability of secondary unpaid care to share the burden, the difference between sons and daughters in access to support from a wife/ husband or partner was limited (10% less for sons) but access to support from their children (the service users' grandchildren) was far less for sons than for daughters. One third of female spouses had support from a daughter but only one of the fourteen male spouses had support from a daughter.

Clearly there were important differences in the receipt of unpaid care between those cared for by sons and daughters, but the greatest disparity was found in the total weekly care input, the product of the allocated care package and unpaid care. Service users with primary support from a daughter received simultaneously the most generous allocations of DP funded care and the greatest intensity of unpaid care, across all dependency levels. Why should this be the case? One hypothesis is that daughters were more effective advocates than sons, resulting in more generous allocations of care but there are a number of reasons why the explanation is unlikely to be so straightforward. Brimeblecombe *et al* (2016) identify how carer burden (as indicated by poor health, providing long care hours and/ or subjectively rated burden) may affect unpaid carers' perceptions of the needs of the person they cared for. The fact that service users supported by daughters received simultaneously the most generous allocations of DP-funded care and the greatest intensity of unpaid care suggests that daughters' perceptions of the needs of those they cared for were different from sons. This is consistent with various studies reporting a gender imbalance in caregiving burden, with daughters experiencing significantly greater care burden than sons (Bamford *et al* 2008; Faison *et al* 1999; Friedemann & Buckwalter 2014).

A further factor is the possibility that social workers set their allocations in response to reports of how much unpaid care was being provided. The unexpected similarity between the share of overall care provided by sons and daughters can only mean that sons or daughters acted in response to allocations of funded care, or vice versa. On balance it seems far more likely that social care allocations were made in response to reports of unpaid care. Indeed, Mitchell & Glendinning (2016) have identified how points' based systems are used to identify allocated care to carers to meet their needs based on *hours spent caring*.

The findings provide some dilemmas for social care practice. Clearly something is wrong if by unquestionably responding to reports of unpaid care social workers are simultaneously reinforcing the excess burden that daughters place on themselves and contributing to the inequity in levels of care between service users cared for by sons and daughters.

Aside from this it was found that daughters reacted to a far greater extent if the person they cared for had a cognitive impairment, possibly due to heightened sense of concern for their safety - although wider research has found that sons are equally likely to worry about accidents when caring for elderly relatives in general (Bamford *et al* 1998). Also, if they were employed, they appear to have over-compensated by ensuring that the person being cared for received greater input (we cannot determine if this was as a result of extra unpaid care by them or care that was organized by them but provided by a secondary unpaid carer). These findings seem to suggest gender specific reactions. It is said that women differ from men as unpaid carers in that women perceive their work as an extension of their normal female role (Calasanti & King 2007 in Friedemann & Buckwalter 2014). Are these findings in any way *DP-specific*? On the face of things, there is no particular reason to believe that these findings were particular to the context of DPs, although a recent study comparing unpaid carers for older people receiving DP and managed budgets dominated by daughters (67% among the DP group) found that those supporting DP users provided more hours of care (Woolham *et al* 2017), a fact that was largely assumed to be related to added time spent setting-up, commissioning and managing care. Clearly the impact of gender on responses of unpaid carer to DPs warrants further attention.

Spousal caregivers

The propensity of spousal caregiving (a term used to include both married and civil partners), and its intensity (as compared to caregiving by daughters and sons) was broadly in keeping with national trends which record that unpaid care for adults aged 65 or above is most commonly provided by a spouse (ONS, 2013). It was notable that male spouses within the sample were often providing greater levels of informal care than female spouses (Table 5.9). While this defies historical patterns of gender alignment within spousal caregiving (Bamford *et al* 2008; McGee 2008), recent statistics show *slightly more* male spouses providing unpaid care than female spouses within the 65 and above age bracket (ONS 2013). However my figures exceeded what might have been expected as a share of the caregiving population for service users within this age bracket with almost one fifth of the sample receiving support from a male spouse versus 11% receiving care from a female spouse (Table 5.9). This figure was largely driven by the domination of male caregivers within the husband and wife teams. As evidenced in recent national statistics, these over 65 male spouses were most likely to provide highly intensive support, often exceeding 50 hours per week (often comprising day and night care) (Table 5.10). On average, male spouses were providing 10 hours more unpaid care than female spouses (Table 5.4). A further salient feature was the extent of poor health amongst male care-giving spouses, which far exceeded general trends, including those observed among unpaid carers within this age bracket known to local authorities (ONS 2013; Pickard *et al* 2016). This phenomenon appeared to be related to a particular suitability of DP for circumstances where male co-habiting spouses were highly implicated in the care of their wives, notably, despite circumstances of marital co-morbidity (see chapter 6), although given the relatively small sample caution needs to be exercised when suggesting that this could reflect a wider trend.

There were other notable differences in the context in which male and female spouses provided unpaid care. Far fewer male spouses were supported by a secondary unpaid carer (SUC) than female spouses (Table 5.7), while female spouses were far more frequently acting as an appointee for indirect payments and related to this were far more frequently caring for a spouse with a cognitive impairment. Only one male spouse was still employed whereas one third of female spouses were, reflecting a tendency for female spouses to be younger than their husbands/ partners (Table 5.7). Wives and female partners were also slightly less frequently providing support with ADLs than male spouses (Table 5.8).

There were also significant differences in the generosity of care packages provided to people with female and male spouses. Mirroring the gender imbalance between care allocations for those dependent upon daughters and sons; service users receiving support from their wife or partner tended to receive greater funded support than those reliant on their husbands (Table 5.9). Unlike the situation with those dependent on sons, male spouses appeared to compensate for this disparity by increasing their supply of unpaid care, smoothing the differences once funded and unpaid care where accounted for (Table 5.5).

Carers' assessments were an obligation for local authorities at the time of the research, for all carers receiving "substantial regular care" (Pickard *et al* 2015). Rates of caregiver assessment were anticipated to reflect the intensity of hours of unpaid care being provided, as well as the caregiving context which although not relevant to the qualification of substantial regular care, should be considered in relation to the risk of unwanted outcomes. From this perspective, most male spouses should have received a carers' assessment, being more isolated than other unpaid carers and providing greater hours of unpaid care. Although more male spouses had received a carers' assessment (39%) than any other category of unpaid caregiver, including wives (22%) (Table 5.8), this figure was still low, considering that two-thirds of male spouses within "husband and wife teams" provided between 50-99 hours of unpaid care per week (Table 5.10). These were very early days in the implementation of carers' assessments and carers' packages. It was only in 2004 that the Carers (Equal Opportunities) Act had placed a statutory duty on local authorities to "inform people with regular and substantial care needs of their right to a separate assessment of their own needs" (Brooks *et al* 2016), while the number of carers receiving a specific carers service as a percentage of clients receiving community-based services was introduced as a performance indicator for local councils in 2004-2005. According to Pickard *et al* (2016), by 2009/10 among unpaid carers known to councils, the vast majority received an assessment (83%) – most of whom were providing care for 20 hours a week or more (79%).

Table 5.10: Intensity of unpaid care by sample sub-group

		Sample whole		Sample by sub group							
				Lone users		Self managers		Managed DPs		Husband & wife teams	
		n	%	*n*	%	*n*	%	*n*	%	*n*	%
Intensity of care	No regular hours	11	**13**	11	**100**	0	**0**	0	**0**	0	**0**
	< 10 hours a week	18	**22**	0	**0**	15	**71**	3	**8**	0	**0**
	10-19 hours a week	13	**16**	0	**0**	4	**19**	7	**19**	2	**14**
	20-34 hours a week	12	**15**	0	**0**	2	**10**	9	**25**	1	**7**
	35-49 hours a week	5	**6**	0	**0**	0	**0**	3	**8**	2	**14**
	50-99 hours a week	19	**23**	0	**0**	0	**0**	20	**28**	9	**64**
	100 plus hours a week	4	**5**	0	**0**	0	**0**	4	**11**	0	**0**
	Total	82	**100**	11	**100**	21	**100**	46	**100**	14	**100**

Purchasing additional care privately was, for those that could afford to do so, one possible means of reducing the intensity of unpaid care required. Table 5.7 shows that the purchase of private care closely corresponded to the incidence of having received a carers' assessment, suggesting a possible link between the two. Certainly both Attendance Allowance (received by the service user) and Carers' Allowance were being used to pay "privately" for additional hours of care, particularly to ease the burden of household tasks. This also suggests that where unpaid carers were unlikely to be eligible for the means-tested Carers' Allowance, fewer carer assessments were performed. Although slightly more private care was purchased by people supported by male spouses, as a share of the total care received service users reliant on their wives received the greatest amount of self-funded care (Table 5.6).

Other unpaid carers

Some service users relied on others as their primary source of unpaid care. This included: a sister; a brother; a granddaughter and two neighbours/ local friends. None of these unpaid carers was relied upon to manage DPs. Equally, none provided support with ADLs and levels of input were much lower, averaging 5 hours per week. These findings were consistent with wider research (Bamford *et al* 1998). Interestingly, the incidence of paying the unpaid carer to provide care through DPs was higher among those with other unpaid carers (Table 5.7).

Secondary unpaid carers

Aside from the main or primary unpaid carers ('primary caregivers') 30% of service users also received input from secondary unpaid carers ('secondary caregivers'). In order of frequency these included sons-in-law (n = 7), daughters (n = 5), sons (n = 4), daughters-in-law and granddaughters (n = 4). Secondary caregivers were more frequently employed as paid caregivers through DPs (see section below). Also there were notable differences in the consumption of private care: only 14% (n = 29) of service users with a secondary caregiver purchased private care versus 34% of those that did not (n = 41), with private care largely appearing to be a last resort for families that had exhausted their combined limits of funded and unpaid care.

5.3.3. Unpaid care and the caregiving context

The context in which unpaid care occurred appeared to have a very significant bearing on its nature and intensity. Qualitative data analysis revealed four distinct categories which distinguished service users in the sample according to the caregiving context. This allowed us to explore the data obtained for the current chapter in relation to caregiving context.

I start by describing the four categories of service user.

The four service user categories

Type 1: Lone service users

Lone service users were categorised as having no access to regular unpaid care of any intensity. There were only eleven service users in this category.

Type II: Self-managers

Self-managers, as the term suggests, were wholly responsible for managing their DP. These service users had access to some unpaid care. Almost one quarter of the sample were self-managers (Table 5.4).

Type III: Husband & Wife teams

Husband and wife teams were identified as couples which operated DPs as a team (where the DP was usually provided to the wife), in a context where both were limited by chronic illness, but neither showed signs of cognitive impairment. Fourteen of the eighty-one service users in the sample fitted into the category.

Type IV: Indirect payment receivers

One group of service users was categorized by the inability to manage their DP, a function which was assumed by an unpaid carer(s) (albeit acting in response to verbal or non-verbal preferences). This assumption of responsibility to manage the DP took place under the auspice of enduring power of attorney, a practice which was prevalent at the time of the study (Laybourne *et al* 2014) and has since been recognized by the term "indirect payment", where a recognized "suitable person" may be granted permission to act as a proxy where a person lacks capacity to manage a DPs and consent for them (Jepson *et al* 2015). This comprised the largest sub-group of service users within the sample, consisting of 44% of the sample. Inability to manage the DP was due to cognitive impairment, extreme frailty or a combination of both.

Service user categories and unpaid care patterns

As would be anticipated, indirect payment receivers had some of the highest levels of unpaid care, averaging 48 hours per week (Table 5.4) but there was considerable variation in the intensity of unpaid care received by this group (Table 5.6). This was almost equivalent to levels of unpaid care received by sample members with suspected or diagnosed cognitive impairment who comprised 83% of this group (Table 5.10). Symptoms varied widely - a factor which accounted for the wide variations in unpaid support. Many receiving indirect payments lived with their caregiver, but not all: one third lived alone (Table 5.10). They were also more often receiving input from a secondary caregiver (50%) (Table 5.11).

Surprisingly this group was exceeded by "husband and wife teams" in weekly hours of unpaid care received (Table 5.4). Among this group, levels of "co-morbidity" (where both husband and wife had chronic health issues; cf. Booker & Pudney 2013), were high, primarily affecting their functional status as none of these service users suffered from a cognitive impairment. Levels of disability impacted significantly on the couple´s ability to self-care and many of these service users had 24-hour care needs. As a result, the more physically able member of the team tended to provide very significant quantities of unpaid care to the more disabled other half amounting to around 57 hours per week (Table 5.4), a figure higher than the average for co-habiting service users. Service users from the husband and wife category were most likely to receive support with ADLs by the person providing unpaid care (Table 5.12). Very often this included personal care despite the fact that this group was mainly composed of husbands caring for their wives. The hours of unpaid support for this group were also heavily skewed towards higher intensity care: as Table 5.6 shows, 64% of husband and wife teams were receiving in excess of 50 hours of unpaid care per week, versus only 39% of those receiving indirect payments.

Service users who managed their DPs alone (the “self-managers”) tended to receive much less unpaid support, regardless of the care recipients´ dependency level (Table 5.4). At an average of only eight hours per week, this group did not receive “substantial care”, commonly interpreted in practice to be equal to 20 or more hours per week (Pickard, King, Knapp 2015). This pattern is likely to have been influenced by the fact that few lived with the person who provided unpaid care (Table 5.10), a factor widely known to limit the provision of regular unpaid care (Thompson *et al* 2014; Mentazakis *et al* 2009). This equally affected the type of support provided, with only 9% of self-managers receiving any support with ADLs (Table 5.12).

In terms of allocated social care, indirect payment receivers and husband and wife teams received very similar quantities of funded care (Table 5.9) which combined with average levels of unpaid care, made for similar levels of combined funded and unpaid input for both groups (Table 5.5). However, when self-funded care was accounted for (Table 5.13) it became apparent that husband and wife teams made significantly greater use of supplementary “private” care, albeit typically paid for by state benefits: either the service users’ Attendance Allowance and/ or the unpaid carers’ Care Allowance. This difference appeared to be due to the very physical nature of care needs for this group, combined with a high incidence of chronic illness among the unpaid carers involved. Nevertheless this did not result in a notable substitution from unpaid to private care. Indeed it seems that self-funded care was used to compensate for comparably lesser quantities of allocated care received by husband and wife teams, particularly among those of moderately high dependency for whom allocated care represented only 17% of total care input. Wider research suggests that families only resort to additional self-funded care when a service uses’ publicly funded care allocation and their capacity to provide informal care is exhausted (Stabile *et al* 2006). Notably only one fifth of husband & wife teams had the support from a secondary caregiver (Table 5.11). In this respect the differences between indirect payment receivers and husband and wife teams were associated with the previously described gender imbalance in access to secondary caregivers. The incidence of having had a carers’ assessment was also equal between husband and wife teams and indirect payment receivers (Table 5.11), leading to the conclusion that the intensity of unpaid care was a more important factor in determining access to carers assessment that the relationship of the primary caregiver to the service user.

Table 5.11: Caregiving circumstances by sample sub-group

Caregiving circumstances	"Husband & wife team"	[3]Indirect payment receivers[2]	"Self-managers"[5]	"Lone" DP user[+4]
n	14	36	21	11
	%	%	%	%
Shared care with other unpaid carer	21	50	43	-
Had carers' assessment	29	28	9	-
Used private care	36	22	25	18
Care recipient with cognitive impairment	0	83	9	18
Employed	7	55	68	-
Employed by DP (main carer)	28	5	20	-
Care recipient lives alone	0	33	80	100

Table 5.12: Contribution of main unpaid carer to IADL and ADL needs by sample sub-group

Contribution to IADL and ADL needs	"Husband & wife team"	[3]Indirect payment receivers[2]	"Self-managers"[5]	"Lone" DP user[+4]
n	14	36	21	11
	%	%	%	%
ADL	86	64	9	-
IADL	100	100	86	-

Table 5.13: Allocated social care, unpaid care and self-funded care as a proportion of total weekly care input

Dependency level	ALL					Moderate dependency					Moderate high dependency					High dependency					Highest dependency				
Care receipt characteristics	n	%	Allocated social care	Unpaid care	Self-funded care	n	%	Allocated social care	Unpaid care	Self-funded care	n	%	Allocated social care	Unpaid care	Privately funded care	n	%	Allocated social care	Unpaid care	Self-funded care	n	%	Allocated social care	Unpaid care	Self-funded care
Lives alone	39	*47*	72	22	5	8	*10*	82	18	0	8	*10*	64	26	11	15	*18*	73	23	4	8	*10*	67	23	5
Cohabiting	42	*51*	49	45	7	2	*2*	68	32	0	5	*6*	32	47	21	17	*21*	53	45	3	18	*22*	48	46	7
UC: Male	37	*45*	55	41	4	4	*5*	64	35	0	4	*5*	34	66	0	19	*23*	59	38	3	10	*12*	52	40	9
UC: Female	33	*40*	54	37	0	3	*4*	78	22	0	7	*8*	52	21	26	9	*11*	55	41	3	14	*17*	50	45	3
Care by male spouse	18	*22*	50	47	3	0	-	-	-	-	2	*2*	26	74	0	12	*15*	56	40	4	4	*5*	44	53	2
Care by female spouse	9	*11*	44	44	12	0	-	-	-	-	-	-	-	-	-	2	*2*	50	50	0	6	*8*	49	50	2
Care by son	18	*22*	59	37	4	4	*5*	65	35	0	2	*2*	43	57	0	6	*8*	63	37	0	6	*8*	56	31	13
Care by daughter	20	*24*	57	39	4	2	*2*	68	30	-	4	*5*	68	31	2	6	*8*	54	41	5	8	*10*	52	42	5
Service user cognitive impairment[1]	34	*41*	52	44	4	4	*5*	67	33	0	2	*2*	30	70	0	11	*13*	55	45	0	17	*21*	49	43	8
"Husband & wife team"[2]	14	*17*	49	40	11	0	-	-	-	-	3	*4*	17	50	33	8	*10*	63	32	6	3	*4*	43	54	3
Indirect payment receivers[3]	36	*44*	52	44	4	5	*5*	59	41	0	2	*2*	30	70	0	12	*15*	52	48	<1	17	*21*	53	39	8
"Self-managers"[4]	20	*24*	65	30	6	2	*2*	100	0	0	6	*8*	66	21	14	8	*10*	62	34	7	4	*5*	50	23	26
"Lone" DP user[5]	11	*13*	92	0	8	3	*4*	100	0	0	2	*2*	100	0	0	4	*5*	93	0	7	2	*2*	74	0	27
ALL	39	*47*				8	*10*				8	*10*				15	*18*				8	*10*			

[1] Suspected or diagnosed cognitive impairment.
[2] "Husband & wife teams" are units where the DP was jointly managed by a team of cohabiting spouses.
[3] "Indirect payment receivers" refers to cases where the DP was managed by an unpaid carer(s).
[4] "Self –managers" are categorized as DP recipients that took full control of managing their DP but received some unpaid care.
[5] "Lone DP users" were those without any unpaid care. All users in this category lived alone.

Self-managers employed self-funded care as frequently as lone DP users (Table 5.13). This was unsurprising given the limited extent of unpaid support received by self-managers, particularly the lack of support for ADL tasks (Table 5.7). This was despite the fact that 42% of self-managers received some input from a secondary caregiver (Table 5.11). Self-funded care was almost always paid for by Attendance Allowance and thus ultimately also state-funded. Separate analyses of factors associated with increased benefits (outcome gain) from DPs (see chapter 4) show that service users in receipt of self-funded care reaped greater benefits from DPs.

5.3.4. The transformation of informal carers to paid care givers.

In sharp contrast to cases in the USA where the majority of service users employ family members (Benjamin *et al* 2008), only 18% of service users in the sample hired someone who had previously provided informal support. Primary caregivers were paid to provide care far less frequently (14%) than secondary caregivers (27%). Where service users received regular unpaid carer from someone who was a more distant member of the family or non-related (such as a neighbour), it was even more likely that the unpaid carer was paid through DPs than if they were a close relation (Table 5.7), especially if they were occupying the position of primary caregiver. Among close relatives, slightly more daughters than sons were employed under DP and slightly more husbands than wives (Table 5.7). Among those acting as secondary caregivers, daughters (40%, n=5) were employed more frequently than sons (25%, n=4) while daughters-in-law (n = 4) and sons-in-law (n = 7) were employed as frequently as sons. Added to this there were a further two out of four granddaughters acting as secondary caregivers who were simultaneously employed through DP.

Since the outset of direct payments to older people it has been stipulated that hiring of spouses should only be permitted in exceptional circumstances (Department of Health 2009). Moreover the hiring of first degree relatives (spouses or children) is perceived by social workers to potentially increase the incidence of conflicts of interest and/ or abuse (Stevens *et al* 2016; Manthorpe *et al* 2009). It has been suggested that adult caregiving children may receive payment but not consistently provide the level of care required, and that the care recipient may have little power over the care arrangement although no studies have found this to be the case. At the same time there are concerns that paying first-degree relatives may only add to the burden they carry (Larkin & Mitchell 2016).

There was evidence that *extreme* caution had been taken in decisions to allow the hiring of a primary caregiver in the case where the service user was cognitively impaired as only 5% were in situations where their primary caregiver was paid (n=34) – specifically two daughters. However significantly more secondary caregivers were being employed by primary caregivers managing indirect payments (33%, n=18). There were said to be benefits from receiving care from someone who was accepted by the service user – particularly when caregiving tasks included dealing with problematic behaviour. These packages were managed by the primary caregiver, who acted as proxy and was therefore instrumental in employing the secondary caregiver – a situation in which everything was effectively arranged *within the family unit* - a situation viewed by many "as creating risks of dependency and closed systems" (Manthorpe *et al* 2010). Questions have been raised as to whether local authority resources are sufficient to provide sufficient review to cases such as these (Manthorpe & Samsi 2013) where "the status of a paid family carer may be indeterminate" (Manthorpe *et al* 2009: 1473). There was no obvious evidence from this study to suggest that these circumstances were not in the best interest of the service users concerned, but it must be noted that it was outside the capacity of the research to spend sufficient time with the families to permit a full analysis of the dynamics – much as may be the experience of assessing social workers. Ismail *et al* (2017) have recently undertaken analysis of abuse data in relation to uptake of DPs and managed personal budgets. There was some evidence that financial abuse was more prevalent among some PB holders including those in receipt of DPs and managed personal budgets (although data limitations meant that they could not differentiate between the two). There were also greater referral rates for suspected financial abuse in more deprived areas. The authors suggest that increased poverty within the family unit could "potentially lead to a situation where the DP comes to be perceived as core family income rather than specific to the needs of care users" (*Ibid*: 21).

A further consideration is the preference of families from black and minority ethnic backgrounds to employ relatives under DP-type models, a phenomenon well documented in the USA (Benjamin *et al* 2008). While broadly the data appears to suggest that payment to relatives was tightly restricted, rates of employing unpaid carers were notably higher for black members of the sample: two out of three of the black families where paid by DP versus only 25% among white families (n=25), and two out of five black secondary caregivers were paid versus 15% of white secondary caregivers (n=20). On the other hand, none of the seven Asian families in the sample employed a relative. Obviously, these subsamples are very small, and so any conclusions need to be very tentative. In US research on racial preferences for consumer-directed care highlights the need to look beyond global racial/ ethnic variables to life situational or attitudinal factors to understand within-group differences (Sciegaj *et al* 2004), while Larkin & Mitchell (2016: 10) remind us that "wider issues of class, race and gender can also interact with professionals' assumptions". One more obvious consideration is whether unpaid carers that become paid carers under DPs are predisposed (and deemed to be more suitable) to take on this role as a result of previous employment history in the care industry. A high proportion (45%) of carers who acted simultaneously as unpaid carers held a professional care qualification suggesting that this was a factor.

Reports by service users (and proxies) on the quality of care received by unpaid carers now paid through DPs were overwhelming positive. Accounts repeatedly emphasised the benefits of hiring a *trusted* care worker who offered continuity and was able to act intuitively to meet individual needs – similar reports are to be found from US sources (San Antonio *et al* 2009). In a much larger study in the US which considered the impact of the choice of provider comparing specifically between family and non-family providers, recipients with family providers reported more positive outcomes than those with non-family workers on five outcomes related to safety and service satisfaction, controlling for service model and recipient characteristics (Hagglund *et al* 2004). A further US study in 2011 found that outcomes in a consumer-directed programme were comparable among those using relatives as paid carers as those using non-relatives (Newcomer *et al* 2011). One interesting feature of this study was that increased turnover was associated with adverse health outcomes. Unsurprisingly, the retention of paid carers was particularly high.

Service users who paid unpaid carers to be their personal assistant frequently reported that additional hours were being provided in excess of the hours for which they were contracted. Although this was also reported among service users who had hired personal assistants that were *not* related to them, the situation of being related and receiving employment from a relative clearly led to a particular willingness to help (wherever feasible) and flexibility over working hours. This was a bonus for service users but researchers have criticized these sorts of arrangements as a potential blurring of ‘life’ and ‘work’, leading to infringements upon the empowerment and social rights of paid care givers (Ungerson 2003; Manthorpe *et al* 2009). Little research exists on this area but some have suggested that personal assistants derive greater satisfaction with their work by participation in decision-making and opportunities for increased flexibility (Leece 2006; Benjamin & Matthias 2004), while others have underlined risks of ‘informiality’ of employment conditions and heightened isolation (Christensen & Manthorpe 2016; Cairncross & Crick 2014; Land & Himmelweit 2010). Local authority practice is said to have moved on considerably in response to the growing workforce of personal assistants as requested by central government (Department of Health 2011). Monitored by Skills for Care, it reports that “year-on-year, local authorities are making and maintaining a core offer of support to individual employers and PAs” – albeit with significant gaps remaining (Skills for Care 2015: 3). The fact remains that no research appears to have focused exclusively on the position of unpaid carers operating simultaneously as paid caregivers.

Returning to the principle question: what was the impact of the transformation of informal carers to paid care givers on receipt of unpaid care, we can conclude that restrictions (both in policy *and* practice), on hiring first-degree relatives clearly influence the extent to which DPs can affect the balance of formal and unpaid care. Moreover the significant reductions in DP allocations in response to the availability of unpaid care limited any possible crowding out of unpaid care as illustrated clearly in Tables 5.6 and 5.13. A further issue is the hiring of secondary caregivers. Previous unpaid support from these caregivers was, by most accounts, marginal due to restraints on time and resources whilst working or studying elsewhere. The opportunity to transfer the locality of paid employment to the locality of unpaid care made it possible for these secondary caregivers to provide more intensive unpaid support than would have otherwise been the case, hence the effect was not substitution of unpaid to paid care but the promotion of unpaid care combined with the use of an alternative labour source from the ever-constrained supply of community care. Table 5.6 shows clearly that the availability of a second unpaid carer was significantly associated with more weekly hours of unpaid care and a larger share of total care input derived by unpaid care.

However, comparing the percentage of total care input composed of unpaid care between those where a secondary caregiver was paid (n=8) and where they were not (n=21), there was minor difference between the two (42% versus 52% for those where the secondary caregiver was *not* paid by DP). Clearly the sample size is too small to draw conclusions: and even if this was a significant difference, it is far from clear that it is related to a substitution effect. Since the accounts tend to suggest that without the payment mechanism regular unpaid care from a secondary caregiver would not have been available, these differences could easily be explained by wider contextual factors affecting their supply of unpaid care such as competing roles and responsibilities.

All this shows that payment of unpaid carers is a complex issue with multiple potential risks, benefits and trade-offs for the various individuals involved and yet it is a situation almost certainly likely to increase given the continued push for DPs to older people.

5.3.5. Responses to direct payments: the growth in managerial care

A less recognised aspect of unpaid care is managerial care which includes care-related discussions with other family members or the care recipient about the arrangements for formal services and financial matters, doing relevant paperwork, and seeking information (Rosenthal, Matthews & Keefe 2007), roles increasingly being referred to as ‘care-coproduction’ (Weinberg *et al* 2007). The inevitable prominence of managerial care in DPs was identified in research on Individual Budgets (the forerunner to Personal Budgets) (Glendinning *et al* 2008; Glendinning *et al* 2009). Unlike care with ADLs, managerial care by informal caregivers tends to be less dominated by women (Rosenthal, Martin-Matthews & Keefe 2007) and this was reflected in the sample: 22% of unpaid carers were sons and a further 22% male spouses.

Managerial care by informal carers was an important factor in the success of DP packages both where care was purchased from a home care agency and from personal assistants (which informal caregivers had a major role in recruiting). Unpaid carers supported (and often led) the decision-making process and service users benefited from their knowledge, information-gathering skills, ability to deal with professionals and their resources (such as the internet) (Arksey & Glendinning 2007) – although unpaid carers also frequently referred to outside support from Direct Payments Support Schemes as critical (see chapter 4). This was not always without initial costs and setbacks. Where service users encountered problems trying to purchase care from home care agencies this was a due to a lack of information about local agencies, the nature of the support they provided , their geographical coverage and their cost. Other teething problems occurred when the characteristics of service providers did not fit with the needs of users leading to a breakdown in the care relationship but as a result the importance of information gathering to find an agency that offered a service that appeared to match the service users' needs was learnt among other skills that were acquired in the process of managing care through DPs (Arksey & Baxter 2012). Once care was set up family involvement was influential in relaying specific messages about preferences, needs, aspects of safety and where needed concerns regarding the quality of a particular care worker – both ensuring quality and occupying a safeguarding function (Coles 2015). The result of this was that managerial care by unpaid carers was significantly associated with greater success in commissioning care as illustrated in chapter 4.

Their also appeared to be benefits for unpaid carers. The ability to purchase directly from service providers allowed informal caregivers to ensure that *their* role in supporting the outcomes of care was recognised by care providers. Families who had previous experience of local authority commissioned care felt that reported previously their role had been overlooked, there had been little or no opportunity to liaise with staff and neglected their needs and concerns leading to increased stress. Improved coordination between informal caregivers and formal providers as a result of using DPs could lead to decreased caregiver stress, greater willingness to provide informal care, findings consistent studies (Weinberg *et al* 2007, Glendinning *et al* 2009). Such benefits did in the words of the informal carers, "*outweigh the burden of managing a direct payment*" regardless of the fact that many reported spending a number of hours a week on managerial care, aside from other support ADL's and IADL's that they were providing. In a more exceptional case where working daughter managed the care for her mother via DP through a team of personal assistants (PAs) arrangements were highly coordinated: the PAs kept a daily diary to communicate changes in the service users' needs. Additionally they kept a duty diary where they negotiated their working schedule together as a team in advance to ensure that all times were covered.

The involvement of families in managing care is by and large a basic reality of long-term-care (particularly if self-funders are also considered) (cf. chapter 7). It is also something which “services” often frustrate by inflexibility and poor communication systems. Yet it has been considered unacceptable that the quality of care secured through DPs often hinges on the capacity of families to manage care. Social workers were initially reluctant to recognise families as competent administrators of service user budgets and were not willing to permit them to purchase care on the behalf of a relative (Glendinning *et al* 2008; 2009). Many referred to the risks that carer involvement may compromise service user independence and choice, a discourse which has become increasingly focused on pathways to protect those whose care packages are managed by a “suitable person” (Jepson *et al* 2015), with practice developments continuing to lag behind demand for indirect payments.

Above all, there are increasing concerns over the weight of responsibility being shifted onto unpaid carers as a result of much wider uptake of DPs among older people. To this end the impact of managerial care versus practical care is receiving greater attention. Individual budgets were found to be associated with improved outcomes for carers (Moran *et al* 2011; Jones *et al* 2014) but a recent study found slightly greater burden among unpaid carers supporting older people receiving DPs, as compared to those receiving managed budgets (council-commissioned services), with repeated complaints from families about lack of support and information (Orellana 2013; NEF 2012). Wider research on the impact of managerial care on unpaid carers, suggests that it can lead to job costs (such as conflict between family and work and reduced hours of work) and personal costs over and above the negative impacts associated with providing hands-on informal care (Rosenthal, Martin-Matthews & Keefe 2007). A gender bias in negative consequences is also reported, with greater impact among women (Rosenthal & Martin-Mathews 1999). However all negative consequences observed were specifically linked to *one aspect* of managerial care, referred to as “*orchestrating care*” a five-item concept including the item, looking into places that provide long-term care, seeking information about services, discussing care arrangements with the older relative, discussing care arrangements with other family members and arranging for a relative to receive services. This is important because many of these items are specific to the *initial* demands of setting up care and potentially open to mediation from the type of personalized guidance that can be available from information and support services (see chapters 3 and 7 for a more detailed discussion of the role of Direct Payments Support Services).

Rosenthal *et al's* (1999) findings also highlight the potential for adverse consequences due not to the emotional demand of negotiating acceptability with the person being cared for and other family members involved. Livingston *et al* (2010) provide a thorough analysis of problematic areas of decision-making for family members in dementia care which is also very relevant to any family situation with a mentally frail older person. In DPs this may be compounded because navigating the social care system can very challenging, as identified in various studies (Arksey & Baxter 2012; Baxter & Glendinning 2010) - yet in the long-term these stressors may be offset by more responsive services.

To date the only study (Woolham *et al* 2018) that has compared carer burden among UCs supporting older DP users, with that of UCs of older people receiving council-commissioned services. This found only small differences in carer burden which were not statistically significant[23]. Above all negative experiences reported in this study cited situations where there appeared to have been no contact with a Direct Payments Support Services; or where conflicting information has been given by different sources. These really underline the worst in practice, echoing reports on 'the barriers of implementing direct payments' documented throughout the past decade (see Carr 2013; Hasler & Stewart 2004). The accounts of UCs presented in chapters 6 and 7 offer a very different (more positive) picture of the experience of managing DPs.

5.4. Conclusion

This study has searched for evidence that DPs to people over the age of 65 alter the balance between unpaid and formal care. Much of the wider evidence suggests that informal care tends to complement or supplement formal care provided within the community rather than substitute it. This seems to be particularly true in circumstances

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[23] This was a cross-sectional study of self-selected carers responding to a postal questionnaire in which the response rate was far lower for carers of DP users (153 carers of DP users versus 1347 carers of people receiving managed care budgets).

where services to older people are heavily targeted at the frailest older people (Sundström, Malberg & Johanasson, 2006; Litwin & Attias-Donfut 2009). My results are very much in line with this conclusion suggesting that the limitations on allocated care in response to unpaid care prevented any crowding out of unpaid care.

The balance between supporting needs through allocated social care and titrating state-funded care in response to the availability of unpaid care (thus relying on unpaid carers to meet some needs) is delicate and controversial. White-Means & Rubin (2004) have suggested that if publicly funded services are more generous in providing support for Instrumental Activities of Daily Living (IADLs), state support can result in a decrease in informal care for support with IADL tasks, while withdrawing support for assistance with Activities of Daily Living (ADLs) does not always result in an increase in informal caregiving to plug the care gap. There is particular preoccupation with limiting support with Activities of Daily Living (ADLs) on the grounds that providing personal care might require skills that unpaid carers may not have, or may be inappropriate – the person being cared for may be uncomfortable being washed or toileted by a child or spouse – equally performing such tasks may cause undue stress to unpaid carers (Bonsang 2009). We have seen that in the context of DPs a high proportion of unpaid carers assisted with ADLs. It is not clear whether or not this had increased as a result of receiving DPs, but what is clear is that the contribution of unpaid carers to ADLs was related to the generosity of allocated care but also varied according to the relationship of the unpaid carer to the person being cared for. Sons were not usually supporting ADLs and provided fewer hours of unpaid care. Surprisingly, there was also a substantial difference in the generosity of care packages allocated to DP users cared for by a son or daughter. The net result was that service users supported by sons received significantly lower levels of input. Both findings raise some serious issues about local policies and practice in allocating care in response to *reports* of how much unpaid care is being provided given the likely gender bias in how parents' needs are perceived and therefore reported. They also offer a reminder of the variations in the circumstances of primary caregivers linked to variations in wider family networks, which arguable should be taken into consideration when allocating care. The results show quite clearly that when differences in access to a secondary caregiver were accounted for, the unpaid support provided by sons and daughters was much more comparable.

The data also shows that wives were much more frequently operating indirect payments for a cognitively impaired husband than vice versa. One possible reason for this may be that wives were deemed more suitable for the role – they also were more likely to be supported by a secondary caregiver. Despite this, there was a considerable presence of male unpaid carers, above what would typically be expected. We cannot be sure that this was due to a particular preference among caregiving sons and husbands for a DPs mechanism, but chapters 6 and 7 on *husband and wife teams* and *working carers* provide some qualitative support for this notion.

This chapter offers unusual detail on the extent to which unpaid carers contribute to the care of DP users over the age of 65. While employment of first-degree relatives was infrequent – especially if the person had a cognitive impairment - paying a secondary caregiver to be a personal assistant was much more frequent. The findings put into context some of the concerns from social work about the hiring of unpaid carers under DPs. Where secondary caregivers were employed, families reported that this was a means of simultaneously securing formal care and additional unpaid care – certainly families were very satisfied with the flexibility that this offered and the added support that it gave to primary unpaid carers. However there was a small quantitative discrepancy in the amount of unpaid care between those who had a secondary caregiver who was not paid, and those that had a secondary caregiver who was paid, suggesting a potential shift from unpaid care to paid care where a secondary caregiver was employed. More research would be required to establish whether or not this was really this case and if so, how it should be evaluated against the potential benefits, such as creating more dependable, frequent and/ or flexible input from a .

Finally I discuss the role of managerial care as a significant function of unpaid care being provided to older DP users. As is demonstrated in chapter 3 this was also a significant function of outcome gain for service users. There are concerns that the demands of managing DPs increases burden on unpaid cares, but the only evidence of this mirrors early findings of poor practice in providing DP, particularly in access to support services. As such research needs to be exploring what is going wrong in supporting unpaid carers to manage DP and why.

5.5. References

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6. Husband and wife teams: a profile of older direct payment service users

Background

- Long-term care policy makers wish to optimize the balance between reliance on unpaid care and provision of formal care. They must weigh-up concerns regarding the productivity and effectiveness of social care versus the willingness and capacity of families to provide unpaid care.

- In chapter 4, we saw that older people for whom unpaid care represents a greater extent of their overall care input benefited more from DPs. The question is if this occurs at the expense of the unpaid carers' wellbeing? Previous studies suggest that direct payments can assist unpaid carers in gaining more control over their time and daily lives and improve their quality of life, but such studies represent a small section of unpaid carers helping individuals with direct payments (mostly daughters).

- As shown in chapter 5 there was considerable diversity among unpaid carers supporting older people receiving direct payments, but also a possible increased prevalence of male primary carers. A noteworthy group in the sample was husbands caring for their wives. These unpaid carers did not manage the direct payments but they did provide high levels of unpaid care and contribute to the benefit their wives derived from the service (chapter 4).

- Little is known about spousal caregiving. What is known suggests that it is the most common source of unpaid care for people aged over 65, that it is more duty-driven than other types of unpaid care and that its prevalence is relatively unaffected by morbidity and gender factors. Older male spouses are statistically the most intensive unpaid caregivers but they are largely absent from research on caregiving and accounts of direct payments use.

- The husband and wife team sub-group in the sample shared particularly interesting characteristics. The husbands provided very high levels of unpaid care (chapter 5) and mostly did not have support from a secondary unpaid carer. Moreover there was a wide gap between their care allocations and the sample average, despite the wives' high dependency levels. Exploratory qualitative analysis showed that there was significant co-morbidity with both wives and (caregiving) husbands suffering chronic health issues.

- Husband and wife teams (n = 14) composed two groups, half were very old, while the other half were not. Otherwise their circumstances were very similar but the wives in the very old group had twice as frequently been admitted unexpectedly to hospital in the preceding twelve months, underlining the precariousness of their situations. This chapter focuses on the half that was very old.

Aims & Objectives

The analysis presented sought to:

- Quantify the role that these husbands played in supporting older women receiving direct payments;

- Assess the impact of direct payments on the dynamics of unpaid care among the couples and on their wellbeing.

- Explore that factors that were instrumental in the success that they had with direct payments.

Key findings

- Both husband and wife played their own role in managing their lives. Team working appeared to be a coping mechanism which helped to recognise and preserve the wives' capacities in the face of their physical dependence on their husbands. While the husbands were substantially required for Instrumental Activities of Daily Living and Activities of Daily Living tasks, the wives coordinated and gave moral support.

- Using direct payments (as opposed to other services) enabled the couples to manage precariousness of their situations; optimize their resources and maintain control. Such ‘resources’ were multifaceted, ranging from their own physical and mental well-being; environmental assets such as home adaptations and social support networks, some of which were semi-formalized through direct payments.

- The couples had surprisingly limited social support networks at the outset of using direct payments; many had children who lived far away. Still they found unexpected sources of support, mostly through neighbours not previously well known. For example home-working neighbours were a point of emergency contact; others had led to care worker contacts.

- The value of domestic support for husbands was evident as it helped to reduce the physical burden of caring and allow the wives to be in control of their homes.

- Having tight control over care schedules allowed break periods from outsiders; time for social participation and room to set goals. This was compared to being otherwise at “the beck and call” of home care agencies.

- Being able to choose the care worker and manage their schedule allowed the couples to find support that respected their lifestyle and routine, and provided the attention to detail and time that they required. This helped the wives to feel (and be) less disabled, and the husbands to feel that their role in care was respected.

- There were many intervening factors in the couples’ ability to manage, although on the face of things they appeared vulnerable. Their forward planning with respect to home adaptations and mobility equipment was essential. External support from direct payment support schemes was considered important. Daily through to long-term decisions and their ability to continually adapt to their circumstances was supported by the couples’ ability to get on. Direct payments maximized this strength by allowing the couples to organise care around their needs and preferences, for instance allowing husbands to take an active role in personal care.

6.1. Introduction

Receiving funds in lieu of care services as *direct payments* (DPs) is an increasingly popular option among older people receiving state-funded social care, particularly for those with family and friends involved in their care (Laybourne *et al* 2016; Moran *et al* 2013) , although it continues to have lower take-up than policy makers would like (Routledge *et al* 2015). Their appeal stems from offering unpaid carers a major role in organizing care, and with it the possibility of combining formal care and unpaid care to make best use of the available resources (Le Bihan & Martin 2012). In so doing DPs, at least in principle, can support the optimal balance between formal and informal care where the policy goal is to ensure that state-provided social care does not crowd out informal care, while simultaneously meeting the preferences of unpaid carers and the people they support (Lundsgaard 2005).

For researchers concerned with the impact of caregiving and the increasing shift from formal to unpaid care, DPs tend to be viewed with some scepticism. Services to older people are heavily targeted at the frailest older people (Sundström et al 2006) and such targeting has increasedas a result of austerity measures in the UK, as in many other countries (Audit Commission 2013; Alakeson 2016; Fernandez *et al* 2013; Ng *et al* 2015). For those that do receive care, limited allocations mean that access to both formal and informal support is often a prerequisite to living in the community (Brose van Groenou & De Boer 2016, Dunér & Nordström 2007). Despite this, adjustments are made when allocating care in England, to account for the availability of unpaid care (Brooks, Mitchell & Glendinning 2016). This mechanism reduces funding in response to the level of unpaid care. Amidst a backdrop of substantial reliance on unpaid care, countered only by marginal supports for unpaid carers[24] (including the option of a direct payment to meet the assessed needs of the carer), DPs seems to traverse a precarious tightrope where promotion of the productivity and effectiveness of unpaid care lies on one side and exploitation of the willingness and capability of families and individuals to provide care lies on the other.

Research has barely scratched the surface in understanding the dynamics of unpaid care for older people where care is organized with funds received in the form of DPs. Studies have focused on: the process of appointing someone to act as a proxy if a person lacks capacity to manage a DP - a role which is invariably taken up by the primary unpaid carer (Laybourne *et al* 2016; Jepson *et al* 2015); the impact of DPs on unpaid carers (Glendinning *et al* 2009; Woolham *et al* 2018), and the tensions and dilemmas between the overlapping needs of unpaid carers and care recipients at the time of assessment (Mitchell, Brooks & Glendinning 2014). The latter is a matter of controversy due to the competing requirements to a) allocate support to meet the "needs" of carers (which in practice means offering limited support to help maintain them in their caregiving role), while, b) simultaneously reducing the allocation of services to any individual in response to the level of unpaid care available. However, generally positive effects have been reported on carers, although an Australian study of consumer-directed care (CDC) concluded that carers may experience an increased sense of isolation and lack of support as a result of CDC (Ottman, Laragy & Haddon 2009).

Of major relevance is the question of who provides care, to what extent and with what (if any) wider support (Bauer & Susa-Poza 2015; Bamford *et al* 1998). While the prevailing image is of the middle -aged daughter caring for an ageing parent, among the over 65s unpaid care is most commonly provided by a co-resident spouse (ONS 2013). Arguably spousal care is more obligatory and duty-driven than care by extra resident

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[24] Support for unpaid carers is divided into three types: (1) social services, (2) financial compensations and (3) advisory services (Courtin *et al* 2014):
(1) Services for the person being care for, and/ or for the person which may be taken in kind in the form of DPs.
(2) Includes a means tested benefit called the Carers Allowance for people caring for someone for 35 hours or more per week, National Insurance credits (for those in receipt of a carers allowance); pension credits and paid leave (for working unpaid carers).
(3) Advisory services available at a local level or national level from third sector organisations aimed at providing information about rights, benefits and services and assistance when planning support.

family members (Schmidt *et al* 2016). Certainly, there is increasing evidence that it is more intensive and may be unaffected by a caregivers' morbidity status and gender (Pickard, King & Knapp 2015; Schmidt *et al* 2016). Moreover, recent data suggests that male spouses are most likely to provide the most highly intensive support of all the caregivers supporting older people known to local councils (Pickard, King & Knapp 2015). Other studies have concluded that close-kin relationships are associated with more negative caregiving consequences, particularly for spouses (Bauer & Sousa-Poza 2015; Lyonette & Yardley 2003), while at-risk carers are categorized as, "caregivers who provide intensive care and who co-reside with the cared-for person" (Courtin *et al* 2014: 10). Yet, very little is known about the circumstances of male spouses providing unpaid care regardless of the type of social care being received (Milligan & Moreby 2016; Davidson, Arber & Ginn 2010; Calasanti & Bowen 2006; Ribeiro & Paúl 2008; Ribeiro *et al* 2007; Milne & Hatzidimitriadou 2003). With respect to DPs, samples – where they relate to the over 65s - have mainly featured daughters (and sons) acting as unpaid carers. The current paper arises from a study of direct payments to older people in England which identified a significant sub-group of couples where both husband and wife had chronic illnesses, but the main caregiver was the husband as their wives were the more disabled of the couples. On the face of things these caregiving husbands appeared to be a particularly vulnerable group considering on the one hand, that receipt of DPs may increase the isolation for unpaid carers (Moran *et al* 2011) and / or the intensity of unpaid care of care they provide (Woolham *et al* 2018) – and on the other – that male carers are generally reluctant to seek help (Courtin *et al* 2014). The analysis presented sought to quantify the role that these husbands played in supporting older women receiving DP and assess the impact of DPs on the dynamics of unpaid care among the couples.

6.2. Methods

6.2.1. Recruitment

Participants were recruited from ten English local authorities, as part of a wider study on DPs to older people (n=81) which took place between 2005 and 2007 for which

ethical approval was granted from the corresponding University as per the regulations at the time. Participants self-selected after receiving a letter and information booklet about the study and a freepost envelope to return if they wanted to participate sent to them by the local authority to ensure anonymity. All older people in receipt of a DP in each council were initially contacted by their local authority and roughly eight service users were interviewed per site. This was often around half the total number of older people receiving DPs per authority (Davey *et al* 2007). Participants offered a wide range of experiences, geographical setting and socio-economic characteristics. . Almost one quarter of the sample were male spouses (versus only 11% receiving care from a female spouse), exceeding what might have been expected as a share of the caregiving population for service users within this age bracket. Among those receiving support from their husband, roughly half were managed budgets, where the spouse acted as the "suitable person" to manage the DP, while the other half (n=14) were termed "*husband & wife teams*" on the basis of initial quantitative and qualitative analysis.. In these cases the wives managed the organisational and administrative side of DPs but had very substantial care needs much of which was met by their caregiving husbands.
Although 21% of older DP users recruited to the study were from a black or minority ethnic background (BME), all husband and wife teams were White British.

6.2.2. Data Collection and Analysis

Semi-structured interviews with the *husband and wife teams* were conducted in the participants' homes. This provided insights into the "we" perspective of their shared experience (Eiskowits & Koren, 2010) and, "may elicit a more complete account of couples' joint experiences and allow the observation of the dynamics and power relationships between partners" (Barnett *et al* 2013: 2). Dyadic interviews have been used in numerous studies to draw rich data on older couple´s experiences of caregiving (Koren 2011; Masters *et al* 2013; Racher *et al* 2000; Torgé 2014).

A framework was used to ensure that specific detail on service users' caregiving arrangements was collected, some of which has been used for quantitative purposes - such as to calculate hours of unpaid care, and Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) indices (Collin et al 1988, Lawton &

Brody 1969). Despite this interviews were conducted in a manner which allowed participants ample “space” to describe in detail how they managed their daily lives and the role that DPs played (Charmaz 2013). This was facilitated by one of two interviewers involved in the study[25] - both experienced professionals with a health and social care background. They were predominantly two-way conversations between the couples, where they “constructed shared perspectives of reality” (Racher *et al* 2000: 370), negotiating dialogue, “with each partner assuming the role of intermediary or facilitator to mediate communication for the other” (*Ibid*: 377). Interviews were typically between one and half and two hours in length.

Data analysis was driven by grounded theory methodology which involved moving back and forth between data and analysis from the start (Charmaz 2013). Recurring themes from fieldwork notes were identified early, while the interviews were being undertaken to assure their inclusion in subsequent interviews. Field notes were analysed and from this around one third of the interviews were transcribed, split randomly and evenly between participants with and without unpaid care. The initial transcripts were read and all recordings were listened to in full, from which unexpected sub-groups and themes emerged which were cross-referenced, and fueled by findings from descriptive data. At this stage the sub-group of husband and wife teams was identified and further interviews were chosen for transcription. In total, half of interviews linked to this sub-group were transcribed verbatim (see sample characteristics). A literature review was conducted once the first clear picture of themes emerged. Interviews were coded iteratively: a process from which a larger number of “open” codes were gradually reduced into more conceptually inclusive by constant comparison of codes across the data (Charmaz 2013), with the aid of ATLAS.ti computer software (version 4.2).

6.2.3. Sample characteristics

The paper uses qualitative data from *half* of the fourteen participants identified as husband and wife teams. The fourteen husband and wife teams were split equally between two age groups: that is seven of them were people aged 65-70 years of age who had long standing limiting illness that had started *prior* to reaching retirement age,

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[25] Approximately two-thirds of the interviews were conducted by the author.

while the remaining seven were people who had developed disabilities *after* retirement, and were generally much older, with a mean age of 83. Those **excluded** from the qualitative analysis were service users within the 65-70 year age bracket.

This distinction was based not only on overall age and age at which they had started using social care, but also because of other factors. Most specifically, the spouses of the seven participants included in the qualitative analysis were significantly affected by health issues, while the spouses of the excluded seven were either less, or unaffected, by ill health. Unpaid carers in the included group also provided more intensive care: averaged at 60 hours care per week, versus 54 hours per week for the younger group.

In all other respects the two groups – that selected for qualitative analysis and those that were not - were very similar. Almost all the caregiving spouses helped with ADLs, and all helped with IADLs. The average number of hours of state-funded support received per week was 14 hours, equal for both groups. However a notable difference between the older husband and wife teams and the younger ones was the rate of unexpected hospitalization in the year preceding the interview. Of those presented in the paper, six out of the seven had been hospitalized unexpectedly; this was twice the rate of the younger husband and wife teams.

6.3. Results

Husband and wife teams shared important traits, most notably, that all the husbands were also affected by chronic physical illness and that they provided very substantial levels of unpaid care. As the term suggests, the couples operated DPs as a team: a mechanism which enhanced their ability to manage, despite the dual demands of unpaid care and morbidity. DPs were critical to sustaining these couples' daily lives and increasing their health and social capital. The analysis revealed seven categories: (a) the contribution of husbands to ADLs IADLs; (b) managing precariousness; (c) maintain gender identities; (d) managing resources; (e) marital partnership; (f) social participation; (g) maintaining control; (h) wider support networks. Direct quotes from participants are used to illustrate themes within each category. All names have been changed to ensure anonymity.

6.3.1. The contribution of husbands to help with ADLs and IADLs

The majority of male spouses were supporting most IADL and significant ADL needs (Table 6.1). Whilst forced to relinquish the practical role, the cared-for wives often retained the planning role in shopping and cooking, and this was described by some couples as a joint enterprise epitomizing the husband and wife team. The couples tended to speak in an upbeat manner about the management of IADLs, particularly cooking and shopping. Their abilities to adapt in a positive way seemed critical to other aspects of their overall coping. The wives recognized the immensity of their husbands' responsibilities - simultaneously running the home and providing care - and were very aware of their own limitations, meaning that tasks were organized to limit the strain on their husbands, for example, using online shopping. Team work and supervision was essential because their husbands' skills were newly acquired in response to their wives' physical limitations - but a sense of humour seemed to be of equal importance to maintaining a positive dynamic. Wives frequently praised their husbands for their abilities, while the husbands tended to downplay their IADL skills which appeared to make for a more enriching exchange designed to bolster each other´s well-being.

"[The other day] we had a breast of chicken so I cut that up, and put some peas in the microwave, then Derek took them out because he said, "You mustn't take them out" - because I drop things, you know. And so I had some onions that I had cooked inside the chicken that I had roasted. I'd put the onions in there. He takes them out of the oven – he does everything like that – because I'm likely to drop them. We work between us."

(W5)

There was a sharp contrast between the upbeat manners in which the couples talked about the management of IADLs, against the detail of personal care being undertaken by husbands (Table 6.1). Couples who in planning and preparing meals appeared to maintain meaningful roles were unable to find this balance with respect to ADLs involving very personal tasks.

“So to toilet my wife… It means going in from here to the bedroom, getting the sling underneath, lifting her up, put it on the bed. Take off her pad and nicks… Then up and onto the commode and take her into the toilet and then back. And then do the necessary and put her back on the bed with the sling and hoist. Get the new pad and knickers on. Get her up again and back onto the chair. That involves forty minutes.” (H4)

Husbands were clearly self-conscious when recounting such intimate care, apologizing to their wives for revealing the detail of routines and for the indignity that they caused them, or using humor to counteract the tension.

“But I’ve got – you’d laugh – I’ve got a system of ropes and things and I haul the poor girl into bed really.” (H1)

Equally noticeable was the contrast between the detailed and often light-hearted discussions of how the couples found ways to limit the strain of IADL tasks on the husbands, versus the relative silence of cared-for wives when discussing ADL tasks, linked to the resignation of husbands when describing highly demanding personal care routines.

“It´s just the way it is.” (H1)

Within this context it became apparent that the ability to work as a team in the daily routine of managing the home was fundamental to their coping abilities. This crucial dynamic appeared to have various functions. On the one hand, it allowed the care recipients to demonstrate their capacities and skills. On the other hand, it provided moral and practical support to husbands who were previously strangers to many of the domestic tasks. Lastly, it fermented a relationship of meaningful exchange centered on getting-by on a day-by-day basis. Each side of the equation demonstrated their own skills in maintaining this equilibrium. Wives showed a deep appreciation of their husbands’ role, while husbands consciously, understated their domestic skills and underlined the necessity of their wives support (Table 6.1).

“For eleven years he’s been one in a million… I couldn’t cope. I would have had to have gone in a home... He helps with everything for me. He’s my lock, stock and barrel… How he manages sometimes, I haven’t a clue.” (W7)

Table 6.1: Caregiving husbands’ contribution to IADL and ADL tasks.

	On housekeeping (IADLs)	**On personal care (ADLs)**
H&W1	Interviewer: *“So who does all the meals in the day and that stuff, do you manage that between you?”* Husband: *“I do all that. **She has to put up with my cooking, God love her.”*** Husband: *“Tesco’s on my internet and I order all the groceries.”*	Husband: *“Getting her into and out of bed is um – and again twice every night, when we both get up to go to the toilet. But I’ve got – you’d laugh – **I’ve got a system of ropes and things and I haul the poor*** **girl into bed really**… *About eighteen months ago, we had a midnight crisis and I said ‘look it’s crunch time’. At that time her weight was three stone heavier than it is now. We’ve lost three stone in a year.”* Wife: *“I have.”* Husband: *“She has, sorry. Not we”* Interviewer: *“You’ve done well. You’ve done well then to do that.* “ Husband: *“I couldn’t – she couldn’t stand up from the bed.* “ Wife: *“No, no.”* Husband: *“And so it’s all a lot better now.”*
H&W2	Wife: *“My husband does the cooking…because standing at the cooker – if I stand for any length of time I get giddy, and even with my elbow crutch it isn’t very… **He is a very good cook.”*** Wife*: “We like to visit garden centres. We’ve got two or three that we like, that we go to, and my husband pushes me in the chair and we go round, and they do nice meals at some of these places, and we’ll have a meal out once, perhaps twice a week – depending on the finances – and then he doesn’t have to cook. Otherwise, if he’s cooking every day it’s not much for him really.”*	*Wife: “It’s alright as long as I’m sitting down, but to stand up, to hold onto something for my balance, and trying to get your knickers on with one hand, you know – [laughs].”* *Wife: And then having a shower and washing my hair and things like that… it’s not only that, it’s coping with the breathing as well.”*
H&W3	Wife: *“Not a lot. I mean, he’ll open jars and things like that, and he’ll take the washing out of the washing machine and put it in the dryer but his back is so bad it’s not something that I encourage him to do.”* Wife: *“I don’t cook – in fact, I’m told I’m not to cook because I can’t stand for very long… we don’t have Meals on Wheels but we have either various private firms… (or) dinners that really you just put in the oven and take it out again. Mr Tesco does (the shopping) that, and I’ve got a son who comes down on occasions and he will bring things or **there’s always somebody**.”*	Wife: *“My shoulders are affected and I can’t get things over my head. And you have to put your arms backwards to get into a button-through, and so my husband dresses me.”*

H&W4	Interviewer: [To husband] "*Do you do all the cooking and the domestic work?"* Wife: "*Yes."* Husband: *"I had never cooked. Never boiled an egg before."* Wife: *[laugh] "***But you're managing."** Husband: *"In fact, I was forty-six before I ever made a cup of tea"* Husband: *"We have a dishwasher, but I don't use it. I wash up so that [my wife] can dry the dishes sitting at the table. It gives her something to do."*	Husband: "*So to toilet my wife, which is an independent thing - she won't go normally when the nurse is here. It means going in from here to the bedroom, getting the sling underneath, lifting her up, put it on the bed. Take off her pad and nicks which she wears, she's not incontinent, except to wee. (To wife)* **I have to put a basic view – you don't mind?"** Wife: "*Yeah. No, no, it's fine. No it's fine. Yeah."* Husband: "*Good. Then up and onto the commode and take her into the toilet and then back. And then do the necessary and put her back on the bed with the sling and hoist. Get the new pad and knickers on. Get her up again and back onto the chair. That involves forty minutes nearly."*
H&W5	Wife: *"Ron does all the food preparation and I will supervise the cooking and if there's any straining to be done or anything, he has to do it, but I'll sort of supervise it sort of thing because he's…. Well,* ***he's getting better but he says he's no good.*** *[Both laugh.]"*	Wife: "*When [my husband´s] away. When he's gone away, I don't ever take the commode out of the bedroom because I can't. I can't undo the things – they're very stiff – so I take the potty out and walk as carefully as I can with it, and empty it, and then come back and put some disinfectant in it and pop it in there and that's where it stays all the time he's away, because otherwise he does it for me."*
H&W6	Interviewer: *"Do you do the cooking? "* *Wife: "He* **can** *do."* *Husband: "I can do, yes."* *Wife: "I supervise, you see."* *Interviewer: "And you do bits of shopping together?"* *Wife: "Yes."* *Husband: "Yes."* *Interviewer: "But you wouldn't be able to shop on your own?"* *Wife: "No".* *Husband: "Oh, no."*	*"Wife: "You see, as good as he is, some things are really personal, aren't they? … You know…. And we're old fashioned….You know, I've never sort of related to him doing really personal things at all."* Husband: *"Well, I have to wash her back, but that's as far as it goes."*
H&W7	Interviewer: *And do you do all the cooking and the shopping and washing the clothes and changing the beds and all those things?* Husband: *Yeah, the lot yeah.* Wife: ***He's my lock, stock and barrel… How he manages sometimes, I haven't a clue.*** Husband: *"If I do the shopping I always – I'm gone about an hour and then so, I make sure she's in bed. She doesn't get up time I'm out. She's there all the time and when I come back, then she can move a bit."*	Husband: "*Babs usually gets up about 9ish – I go in about nine and – bathroom facilities – she's about an hour, an hour and-a-quarter sometimes, then she pops back to bed for an hour."* Wife: *"I am better in struggling to do it myself and I ring a bell, I've got a bell in every room … I ring a bell should I need his assistance. And he comes and he knows exactly how I have to be – how my body has to be treated."*

6.3.2. Managing precariousness

Given the immensity of the caregiving role being undertaken by the husbands (Table 6.1), it would be easier to assume that they were in relatively good health. This was far from the truth. All of the caregiving husbands had been hospitalized in emergency circumstances during the previous year and had chronic health problems.

"He did the beans one day – and his hip came out, and he laid on the concrete there for half an hour, and it wasn't until my neighbour went out… I was sitting here knitting you see and I couldn't hear him and I couldn't see him… He's had – it's come out three times." (W7)

I mean, he's diabetic and that gets out of control on occasions. Also his eyes aren't good which of course, is a diabetic thing. (W3)

"We have had a scare because now he's got prostate cancer, and we had to go to the hospital two or three times a week and yes, he's got another hospital appointment next week" (W6)

"My husband has got very high blood pressure… he can't bend down because of the pressure on his nose… his nose just goes 'pop'. Also, he has got to be careful now with lifting because this hemorrhage of bladder – they said he might not ever have it again or it could happen often, lifting or if something is causing pressure… it's a weakness now" (W2)

The combination of fluctuating chronic illness and caring (for wives whose condition also fluctuated) formed realities in which daily life was dominated by managing precariousness. Given that the couples were highly dependent upon each other and relatively isolated from other support, their options were limited and DP input was crucial. The focus of concern was on coping in the event that their spouse was hospitalized, an event that many had already experienced. The arrangements procured with DP funds offered many of the couples' contingencies for such an emergency. Precise arrangements varied according to their general use of DP. One couple who contracted care via an agency had settled upon an agency that guaranteed flexibility.

"My husband has got various problems and he has to go into hospital occasionally as well… So then he can be rushed off and I need someone to stay with me… So you know, it's nice to be able to think well, I can have someone and I can pay them... They're very good the agency – and because we've not got any family around now, because my husband's family has all died off." (W2)

Others were secure in the knowledge that their PA could step up care, either alone or in conjunction with other support from family and friends.

Managing precariousness required much more than contingencies for emergencies. All the couples focused heavily on managing their daily lives to maintain their carers´ wellbeing, out of fear of what might happen if their husband was unable to continue caring. While care workers were employed for aspects of personal care, many of the couples concluded that the most effective means of lessening the burden on their husbands was by employing care workers to provide domestic support. Domestic tasks were routine (unlike many other aspects of care performed by the husbands on a 24-hour basis), and predictably strenuous tasks, that many of the husbands could not manage repeatedly due their health status. This was seen as a means of giving their husbands the strength to do the rest.

"My husband… he does so much anyway…. this is why we needed someone to help with the housework and ironing and things like that." (W2)

Managing precariousness was a joint narrative between the couples which recognised the physical burden of caring. There was less discussion of the psychological burden partly, it seemed, because of the strong motivations for caregiving, adequate caregiving arrangements, and strong marital relationships which fostered a sense of reciprocity. Mr Hunt, one of the more isolated husbands alluded to his wellbeing.

"I think I'm managing at the moment, but there's some days when I feel I can't…I get bad days and good… I have good days when I´m talking to someone… I get a lot of bad now. I think it's the hot weather and the age." (H4)

6.3.3. Maintaining gender identities

Focusing part of the DP on domestic support in the home was a key part of managing precariousness as it reduced the physical burden of caregiving on the husbands. It also appeared to preserve gender identities. There were tasks which wives described as not their husbands' "*forte*". Domestic support offered peace of mind to the wives, and allowed them to ensure that their homes were maintained in a manner which *they* felt comfortable with, thus maintaining their control over the home. All the couples purchased *some* domestic support but to a varying extent depending on what they perceived to be necessary, whereas for others the bulk was undertaken by the husband and paid support only enlisted for very specific tasks.

I: [H6] *"You're doing some of the food preparation stuff are you?"*
H6: "*Yes, oh yes.* "
I: *"And do you do any of the housework, sort of cleaning and all that stuff, or does [the care worker] do it?"*
H6: *"Er… well….* "
W6: *"He will* ***if he's got to****."*
H6: *"I do the washing up, do all the repairs to any electrical stuff.* "

"*He's very good – he'll put the vacuum cleaner around. He's not a lot of good at dusting – I don't think men are. And there again, with the ironing, I can't do the ironing. He can't iron. He can put the washing in the machine, he'll peg it on the line or he'll put it in the dryer."* (W2)

The fact that wives considered that household tasks remained their responsibility was clear. A common theme was the manner in which the wives sought ways to manage what they could alone, regardless of their physical limitations. This was limited but had important symbolic value. Wives' tasks included stripping the beds, loading the washing machine, drying-up, cutting up vegetables, and ironing.

“One of my jobs is my ironing, and [the care worker] hasn’t time to do that. I can do it, but I can only do it for so long and I have to leave it. At the moment you see, there’s a basketful there waiting, and every day I say to Sid, “I’ll do a bit of ironing…” (W6)

Accepting that much was beyond their limitations, their role in coordinating domestic tasks was paramount.

..” Yes, well, between us we will usually strip the beds and [the care worker] comes, and she will pop them in the washing machine and she makes the beds up clean.” (W5)

Some managed to part fund this from DPs, particularly if their care workers were willing to multi-task. Among those that purchased it privately, it was usually paid for out of their Attendance Allowance[26]. The fact that they could combine both funding sources to increase the hours of support was a particular flexibility of DPs.

6.3.4. Managing resources

To manage precariousness the couples needed to manage their resources. There was compelling evidence to suggest that the couples’ ability to cope was influenced by their ability to manage their resources well. This ranged from the day-t- day, to long-term issues:

“That’s another thing, I keep a very good store cupboard and I keep the freezer full up so if by any chance I am here on my own, I’ve always got something that I can put in the oven you know, straightaway, or in the microwave.” (W5)

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[26] Attendance Allowance is a UK state benefit for people aged 65 or over who have a physical disability (including sensory disability, for example blindness), a mental disability (including learning difficulties), or both, for which the disability is severe enough that the person requires help or supervision to self-care. It is paid at different rates according to the extent of disability and is currently £55.65 a week (low rate) or £83.10 a week (high rate).

With regard to the longer term, it was very evident that the couples had proactively managed their resources to adapt to their circumstances and maintain their independence and quality of life. One couple had given up their home in return for a disabled bungalow supplied through a housing association. Others had adapted their homes with outside ramps, level-access showers and grab rails. Much of the home adaptations or equipment being used was self-funded. Often it was purchased proactively (i.e. at the first sign of trouble and potentially prior to the point at which they may have been eligible for funding).

"Essentially we use this as a bungalow… We've got – we've had friends to come and stay and got the beds all ready, but ***we*** *never use them. And I rarely use the bathroom upstairs. We always use – we both use the shower. So that's one great direct asset, we treat it as a bungalow."*
(W1, early modification of home to allow downstairs to be used as a bungalow with a level-access shower)

H1: *(The wheelchair) "It's our own…"*
W1: *"A push one"*
H1: *"You see at that time, I did have some money, and I never thought of asking people for things. I just thought – you know – I was used to doing things for myself."*

The couples shared the attitude that they had to make their own efforts to meet equipment needs by whichever means necessary.

"I went to price them and …. Whoa! And then the MRS people came. They were very good, they loaned me one, didn't they Sid? But it was a little bit run down and the wheels had conked out, you know…Well, as I say, it was most uncomfortable to ride in but at least it got me out. And I said to her you know, I would return it. Well, then I was reading the paper and I saw there was an auction coming up, so I thought… And there was a wheelchair there! Funnily enough, there were only two people bidding for it. And it is one that I can work myself as well. It's got an inside wheel, so I can use it in the house if need be… I got it for five pounds. So I thought, well, this is great." (W6)

W6: *"We saved up until I could have a bed."*

I: *"They don't come cheap either, do they?"*
W6: *"No, they don't… And some of it is so essential isn't it? It makes it so much easier."*

Later they tended to have received more external support. Generally there seemed to be a snowball effect occurring from the point at which any couple first came into contact with social services, and with it the realisation that there were alternatives to self-funding. Noticeably, the couples that were in housing association accommodation (bungalows) were particularly fortunate (Table 6.2).

I: *"So there's a ramp at the front door and back door is there?"*
W5: *"Yes, a huge one out the back, because it was high, you see."*
I: *"So you didn't have to pay for that one?"*
W5: *"No, thank goodness because I don't know what we…. We wouldn't have afforded it".*
(W5, lives in housing association bungalow)

The need to manage resources or seek means to acquire equipment was ongoing, but the couples were able to recognise their needs.

"I've got an automatic bed which I bought myself, but I haven't got anything – I really need something over the top really, to hold on, to pull myself up with, because I still can't get out of bed properly. Derek has to very often help me." (W5)

Finally, managing resources did not stop at things that were objectively essential to maintaining independence. The couples also spoke of their need to maintain aesthetic features.

"There's a very little (garden) out there. … We made absolutely sure when Derek got poorly, that gravel went down there and that's paved out there, part of it …" (W5)

For one couple who had spent money on a pond on the promise of a grant from Relief to Care, which was never paid, spending resources on aesthetic features had led to a trade-off with funds for mobility.

W2: "The Relief to Care said to us that Frank would be eligible for a one-off payment – something to help him to relax… We decided alright, we would do this fish pond...He drew the money out of the savings... thinking well, alright, he would have that to go back, and then the turned round and told him they said… that it had got to be something that help him within the house or something."
H2:"Well, actually, the money was for in a year's time for the Motorbility car
– have to put a deposit on you see, so now I've spent the car money on the fish pond! So we'll just have to play it by ear now and see how it comes out."

6.3.5. Marital Partnership

Characteristics of the couples' marital partnerships were revealed in the dynamic of support being performed by the caregiving husbands. There were numerous ways in which their depictions of daily life revealed the strength of marital partnership and their appreciation for each other. Aside from the dynamics of care and daily life and their open appreciation of each other, they frequently conferred with each other in conversation:

I: *"A perching stool?*
W6: "*Yes. One for outside and one for inside. As I say, they have been very good. We thought, anyway, didn't we? "*
H6: *"Yes, yes, they have. Excellent."*

One husband and wife team had what appeared to be a less functional relationship and their dynamics of daily life were striking in contrast to the other couples. This wife was not only unable to count on his assistance with many tasks that he would have been physically able to perform, but she was also fearful of his reaction to her receiving more outside care

"You see, he's a difficult man really generally, and I don't like [the housework] to be left to my daughter because she's got a busy life with a family and job and what have you." (W3)

Table 6.2: Circumstances of husband and wife teams.

	Age (wife)	**Home**	**Mobility**	**Social Network**	**Private/ other care**	**Other sources of unpaid care**
H&W1	79	House used "as a bungalow". Upstairs only used by visitors. Manual wheelchair (SF), walk-in shower (SC), grab rails (SF), raised toilet and grab rails (SC), two commodes (SC)	Battery for wheelchair (SF) which goes in their car (SF).	Wide network of friends that they visit often staying overnight. Son (not local).	Crossroads "sitter" two hours per week . Often go out shopping while husband writes. Weekly private cleaner.	None
H&W2	92	Bungalow, now housing association – previously council housing. Level-access shower, ramps front and back doors, grab rails (HA).	Mobility car (GF). Motorized wheelchair with oxygen cylinders.	Relatives visit occasionally (cannot visit if they have a cold). Friends that drop in and have also advised about care.	Member of disability group. Regular contact with relief to Care.	None
H&W3	77	Flat	No car. Travels occasionally in a taxi.	Three children with whom they have little contact.	None	None
H&W4	84	Bungalow. Ramp into garage (SF).	Unable to get into the car. Only uses an ambulance for weekly trip to day centre.	Limited contact within neighbourhood and to ex PA. Regular contact with Extra Care – first PA was a volunteer – now the PAs´s daughter.	Crossroads "sitter" 1/7. Day centre 1/7 (husband uses the time to shop and visit his sister).	Neighbour pops in at least once a week and provides respite for will stay while husband goes out.
H&W5	76	Disabled bungalow acquired through a housing association. (Gave up previous home as unable to manage garden.) Commode (OL), disabled shower, electric bed (SF), ramp and grab rails - front and back of bungalow (HA).	Walker with seat to reach car (SF). Electric buggy which goes in most cars (SF).	Daughter (employed as PA), other PA (not related) considered a good friend, son, cleaner.	Private cleaner - Daphne (told they could not use DP for cleaning). Picks up dosett box refill and subs for PAs.	Private cleaner also provides unpaid care, such as taking Mary out in the car. Daughter (PA) provides around 6 hours extra unpaid care per week. Son takes them to lunch on Sundays.
H&W6	76	House with downstairs bathroom. Grab rails throughout house (SS).	Electric buggy (SF).	Member of the Sunshine club and goes on bus trips with them while husband does other things.	None	Neighbour visits once a twice a week and will help out.
H&W7	92	Bungalow. Level access shower (SC), Electric bed and pressure relieving mattress (OL), chair raisers (OL), grab rails (SC),	Manual wheelchair (SS) used to sit in the garden. Unable to leave house.	Occasional visits from family (none nearby). Neighbour has key for emergencies and comes once per week (paid).	Crossroads 1/7 for two hours.	None

SF – Self-funded; OL – On Loan; SC – Provided/ funded by social services; GF – Government funded; HA - Housing Association

“*I am going to have to stay in bed in the morning until the district nurse comes to put the elastic stockings on because I’ve got no strength in my wrists at all, and he wouldn’t be able to do that either, so then I would have to stay in bed and that would totally wreck the system altogether, because if he is working and I’ve got people coming in to help me…*” (W3)

Later in the interview she explained that her husband had a history of anxiety and depression. Despite her increasing functional limitations, her struggle was centred on compensating for his anxieties rather than addressing her own wellbeing.

A further feature of the other husband and wife teams (who in contrast had mutually supportive relationships) was the wives role in financial matters. All had a significant bearing on the household finances but for some their role overtook their husbands’ and featured as a further way in which they were needed at home…

I: *“Who does the management of the money and the bills and all that stuff?* “
W6: *“I do all that.”*
I: *“You do all that, do you?* “
H6: *“Yes”*.
W6: *“I do all that – I know where it is then!* “
H6: *“She’s the financial wizard here. Her brains and my brawn actually*.”
(H & W6)

“He was sixty-three when he went on retirement, and we went to the Inland Revenue place, and we sat there, the pair of us, and this lady eventually came up, she sat down and she looked at Derek. She said “Now, what…” and he said “It’s no good talking to me. You talk to her. I don’t want to know. You talk to her.” And she looked, and sighed. I don’t suppose she had ever had anybody come in and say “I don’t want to know about it, give it to my wife.” [Both laugh]. Well, she looked so shocked.” (W7)

6.3.6. Social Participation

The couples were also notable in their level of social activity given their circumstances. The couple, whose husband had to “haul” his wife into bed every night had a fulfilling social life visiting friends on day trips or for a few days at a time (although the number of friends with whom they could stay overnight was dwindling due to practicalities such as lack of a downstairs bedroom or bathroom). They also got out and about regularly in the car for shopping. Social participation was strongly linked to resource management as access to a car that could take a wheelchair was absolutely crucial (Table 6.2).

W6: “When I go out, then I’ve either got to have the wheelchair or my little scooter.”
I: “You’ve got one of these motorised…”
W6: “Yes.”
I: *“Is that yours, or have you borrowed it from somewhere?* “
W6: *“No, no, we bought it.”*
H6: “*We bought it.”*
W6: “*We saved up and saved up, because I couldn’t get out you see.”*

W5: *“When I walk out, I walk from here to the car. I can just about manage that, and I have a wheelie thing with a seat on it, you know - a walker. You can push it along and it’s got a seat. You can put a seat down… And then I’ve got an electric buggy which we put in the car.”*
I: *“Is that yours?* “
W5: *“Yes.”*
I: *“You bought it yourselves?*”
W5: “*Yes, I* ***had*** *to.* “ (W5)

6.3.7. Maintaining control

A further feature mediating the feasibility of the lives of the husband and wife teams was maintenance of control. Where control was synonymous with independence it could be promoted in many ways, as previously described which decreased dependency on formal care. Yet the care needs of these couples were such that all were also dependent upon outside help. This represented a potential threat to maintenance of control. Many had experiences of formal help which was discordant with their own efforts to maintain independence, maximise privacy and optimise their quality of their lives. As with the other themes, this was a shared phenomenon, affecting both the cared-for wives and their caregiving spouses. Taking control over securing formal care, made possible through receipt of DPs, was pivotal to couples' maintenance of control. The transition to a state of feeling in control often took some time.

"For a month we had someone different every day, which was very difficult for me and it was very difficult for my husband, because they were late coming; sometimes they didn't come; they would come if they had got a cold, and they've all been warned they must never do that. So I tried and tried to explain to them but they didn't want to know, so I decided to change my agency, which I could do because of direct payments."

(W2 – early experience purchasing care with DP through agencies)

"When she first came. When Julie first came. You see I was struggling and I was in a state, but she, you know, she did do it…. It took oh, three months at least… just to feel comfortable."

(W6 - experience with PA after having previously unsatisfactory experiences with agencies).

For Ms Brown (W2) her perseverance in seeking a better experience paid off, resulting in a much more satisfactory experience and increased wellbeing.

"She knows sort of what we like done, and now we're used to her, because we've had her for quite a while now – a year – she just does it. It's very nice, and then she'll say, oh is there anything else you want doing or do you want anything done different today? Or something like that, so yes, she's very good."

(W2, current experience with an agency)

Other wives reflected on how their lives would alter if they had to return to their council arranged services.

"Well, I would then be sort of at their beck and call. I would have to stay here and wait until whatever time they would want to come to give me a shower and help me get up – I wouldn't have any choice…. At the moment they come – my husband wakes me up about 8 o'clock time because it takes me that long to do all my medicines and such – with a cup of tea – and then my carer comes between quarter to nine and 9 o'clock. That is ideal for me – that is when I asked for them. I mean, she would come earlier or later – whatever we wanted – but that to me is fine, and then after that, that gives us the rest of the day" (W2)

"On the ordinary system… I couldn't go anywhere, no. They would come and do my shopping." (W5)

The timings of care (and their reliability) were extremely important to the couples, echoed in numerous statements reflecting the importance of being able to go about life according to their routine. This was echoed by the caregiving husbands at least as frequently as by their wives, if not *more* so, who themselves were required to organise the day around a schedule in order to keep on abreast of domestic and caregiving responsibilities, and schedule in some break periods. It also meant that they could organise outside input around the high and low periods of the day. As a result they could focus on higher objectives, such as rehabilitation. This was about much more than peace of mind.

"Then having had a little bit of breakfast, she's able to walk enough on her own. We've got as far as nine steps… So we'll do it every day and each week we increase another step. (H1)

Other interviewees highlighted the relational aspects of care that created a sense of control.

"When you disabled, every small thing is important to you. I'm not finding fault with anything or anybody. But sometimes you need things to be explained to you"

(W7)

"I can't put my hand on it. It's just the fact that I just feel happier… I feel so much happier" (W4)

Mr Hunt´s experience, on the other hand, was much more specific. The breaking point from council-arranged services came when it was ruled that he was unable to substitute for a second care worker:

"It might sound silly to you … but the first morning that they sent two people, they came into the bedroom and I went and stood by the window so I was out of their way while they worked. And they put the sling under Jean and when they lifted her it catched her hip and she went 'ooh' you know. And I stepped forward to comfort her. And they said, 'stand back Mr Hunt, we're doing this' and it got me immediately. And the next morning they came and they gave the same attitude…that was what got me down… Up ´til then the lady who came and myself had always done it. They then had the idea that I couldn't do it. And I have been doing it and I still do." (H4)

For those receiving personal care, maintaining control was also wrapped up in how care was given. What was also common, however, was the overlap that this had on physical wellbeing.

"She will shower me and wash my hair… so will Sandra … and I mean, as they laughingly say, if they think you can do this in an hour with you, you know… they're very much mistaken. And then I have to have a rest before I get dressed because usually I'm worn out, sort of thing just having a shower." (W5)

For one lady who was multiply restricted in her daily life (by her disability; by the anxieties of her husband - which limited company and formal help, and by a lack of transport options for getting out and about), maintaining a sense of control was about pursing a goal which provided her a sense of accomplishment. In this instance, she used a fraction of her DP to pay a university student to assist her in writing up her family tree, including making trips to libraries to search microfiches, writing-up dictated notes and helping to compile the paper work. The significance of this little extra could only be fully appreciated in consideration of her wider circumstances. As a result, what may have seemed a luxury provided her with a key resource (a sense of control) which she employed as psychological buffer to her circumstances.

"…that bit for the quality of life is marvellous – it really is, it makes a big, big difference." (W3)

6.3.8. Wider Support Networks

It is often assumed that older people choosing to manage their care have access to wider support networks. Only one fifth of caregiving husbands benefitted from support from a second unpaid carer (Table 6.2). Many of the couples did not have children living close by. Yet, their accounts describe the role of wider support networks, which often developed in an unexpected manner when neighbours stepped in to help.

"I mean, Monica didn't know me from Adam. As I say, she lives over the garden wall sort of thing, but I mean, as soon as she knew I was ill she was round, and now she calls round every Monday night without fail - just to check to see how I am."
(W6)

"..When I had my hernia Mr. Singh, said 'we know you're on your own, would you like me to stop in the hospital every day or two?' People say they don´t do this now – but to me they were wonderful."
(H4)

For another couple, the trend to working from home meant that they had someone to call on in an emergency:

… "He is running an accountancy firm there so they're there all the time. And he's got at least one young man – and so if Anita falls over, I can give them a buzz or go – and they come over like a shot. So we're really lucky, cos you know this place is deserted in the day – the husbands and wives are away."
(W1)

While neighburhood support was most often described as occasional, for some it was regular and had taken on some of the characteristics of kin-support in terms of the intensity of support and in having a role in brokering access to care (cf. Nocon & Pearson 2000).

"While I was ill Mary was coming in and cooking me a dinner at night and making sure that I'd got everything, you know. And so she said "Why don't you apply?" I said, "I can't do that…" So she said "But you can, and you know that you're struggling, why don't you apply?" So of course, that was the start of it. She got me the forms and helped me fill them in and that was it."
(W6)

This neighbour worked full-time and could not continue providing so much unpaid care long-term, hence her support reduced to weekly visits when a PA was employed under DP. However a further local contact also came forward to help on an unpaid basis and this eventually developed into a paid relationship, through DP. This employment had since terminated and the couple received regular visits from their ex PA.

"Her father lives over there, and she lives round the corner, and she came to see her father, and she came round to see me and she said, "Oh, let me come in and help you." So I said, "I'm sorry Julie, but I just can't afford you." So she said, "Well, no, just let me come in. I don't like to see you like this." (W6)

Regular visits from ex PAs and unpaid care being undertaken by current PAs was a pattern repeated throughout the sample (Table 6.2). Likewise some current PAs also morphed into sources of unpaid support.

A significant factor in DP-related improvements in care and quality of life for some participants stemmed from the fact that the DP had enabled them to set up caregiving arrangements employing trusted family members with whom they shared meaningful social relationships. This occurred where DP was employed for respite care. All of the family and friends involved were not providing regular unpaid care due to either work commitments and/ or geographical distance. Financial reimbursing was key to providing the conditions which enabled this exchange as it compensated for travel costs and offered a basis on which to request a formal commitment.

"Linda from Scotland came and our niece came from Bexhill last time and spent the week for us." (H7)

"You haven't mentioned that you had Monica and Keith and another lady down from Staffordshire when I had the prostate operation. That was about five days wasn't it?" (H1)

In other examples, neighbours whose capacity (or willingness) to provide unpaid care was otherwise limited to emergency support were being paid through DP to provide a regular service. In another example, respite had been organised while one husband was in hospital for planned surgery, through a combination of care in which the service users's son travelled to and from his work every day for a week to undertake (paid) night duty, with voluntary care from neighbours to fill the day time.

Other sources of wider support came from formal voluntary services for carers such as Crossroads and Extra Hands.

Finally some participants found wider support through organisations providing DPs support.

"I have a direct contact with Independent Living… They're ever so good. I mean, David Jones, who comes here occasionally, he's like a bosom friend, he's – we're together, you know." (H4)

"As I say, their staff is wonderful. They give you time to think… When the staff come to visit…they talk to me, they explain things to me, they make it so simple and so easy… And I feel very proud to think that I have come to know them." (H7)

6.4. Discussion

Domestic support and the maintenance of wellbeing for the frailest unpaid carers

A notable feature of the use of DPs by the husband and wife teams was domestic support within the home, employed to reduce the physical strain on caregiving husbands. This phenomenon feeds into the debate on the formal-informal substitution potential of DPs. There is little doubt that a caregiving husband providing such levels of unpaid care and struggling to keep up with domestic tasks previously undertaken by his wife, would be considered eligible for state-funded social care (cf. Fernandez & Snell 2012). Yet there is an inconsistency between this “on the job” reality and local resource allocation guidelines which prioritise personal care tasks. Added to this, task restriction among contracted homecare agencies limits the range of tasks that care workers are permitted to perform. This bias has much to do with concerns of replacing unpaid or self-funded care with formal care and its impact on allocative efficiency.

Caregiving tasks are regarded as either technical or non-technical, with personal care considered technical versus non-technical domestic tasks. Unpaid carers are categorized as capable of replacing formal care for *non-technical* tasks, while personal care tasks are considered more likely to remain unfulfilled as a result of a reduction in formal care (White-Means & Rubin, 2004). Hence resource allocation favours support for personal care and in so doing makes implicit judgments about what tasks an unpaid carer *should* and *should not* do (regardless of a couple’s choices). In this context, DPs offered a more flexible approach to the structural and normative context – by permitting service users to make up the rules – so long as the service users’ needs were met.

The preference of husband and wife teams for domestic assistance was justified in various ways by participants. They prioritized limiting outside care to timings which *promoted* rather than *infringed* on their daily routines. They also concluded that the need for domestic assistance was more predictable than the need for personal care, and constituted a chunk of strenuous activity that if performed by a care worker would tangibly reduce the physical burden on caregiving husbands *and* provide the cared-for wives with a sense of mastery in directing these tasks.

Some also felt that their husbands were more adept at meeting their personal care needs than care workers - a view shared by the husbands who were equally keen to help their wives maintain control and dignity. This served to reduce some of the loss that can result from the process of receiving social care (cf. de São José *et al* 2016). This dynamic fostered a sense of control and mastery, which they recognized as promoting their wellbeing - and has a proven role in reducing the negative effects of caregiving and disability (Muratore & Earl 2014). There were also strong parallels with the attributes 'control over the caring' and 'fulfillment' in the Carer Experience Scale developed by Al Janabi *et al* (2008), which focuses on the process of providing care, as a more direct assessment of carers´ welfare than health outcomes. These are important findings because the contribution of male spouses to personal care needs is not always readily accepted by health and social care professionals due to gendered norms about the acceptability of personal care provision by cross-sex unpaid carers (Arber 1995).

Partnership and the management of resources

A variety of authors focus on the dynamic of *resources* in long-term care (Epsing Anderson 1999). In adaptation to old age, resources are often conceived in terms of material (e.g. income), health (e.g. ability to care for oneself) and caring (e.g. access to social support) each of which contributes positively or negatively to outcomes (Arber & Gin 1991 in Schmidt *et al* 2016). In the couples studied, we see multiple threats to these resources. Both members of the couples had declining health status, with one person experiencing severely limited functional status. Most had fairly limited social support from other sources (Table 6.2). Neither of these scenarios was unusual, comorbidity among couples is a recognised phenomenon (Bauer & Sousa-Poza 2015), and social support from non-spouses is increasingly limited by factors such as the increased participation in the labour force among daughters and the demands of caring for young families with motherhood occurring later (Grundy & Henretta 2006).

In material terms the couples' strove hard to make best use of their resources. With respect to allocations of care – the couples' resources were limited by norms that result in reduced allocations for services users able to receive spousal support. Husband and wife teams received on average 14 hours state-funded care per week. This was 12 hours per week *below* other service users in the wider study (including those with and without unpaid care). Husband and wife teams had multiple factors stacked against their ability to manage and yet coped on surprisingly limited care allocations. Their narratives provide insights into how and why this was the case.

A major factor in their ability to cope was the strength of marital partnership. This was evidenced in various ways: In the preference among some for the husbands to perform the bulk of personal care tasks and in the sharing of key responsibilities (meal planning, domestic tasks, finances). It was also evident in the open appreciation of each other’s inputs which increased the sense of control felt by wives compensating for their experience of physical dependence. These accounts echo those of younger couples coping with multiple sclerosis (Boland et al 2011).The couples’ proactive long-term approach to resource management also epitomized relationships where couples are able to “*get along*”, with joint decisions a core barometer of carer wellbeing (Al-Janabi *et al* 2008). Of further note was their ability to find ways of pursuing leisure or quality of life goals as a couple and apart, adapting to their reducing mobility (Lloyd *et al* 2014), and their mutual interest in each other’s well-being and admiration for each other (Boland *et al* 2012).

The key characteristic of a strong marital partnership thus led to other protections from the negative consequences of disability and ill health. Better quality relationships with the person receiving care are associated with less caregiver stress (Lyonette & Yardley 2003) and more positive emotions related to caregiving (Daley *et al* 2017). This study also shows how the quality of the marital partnership impacted upon adjustment to new challenges and decision-making. In particular, strong marital partnerships smoothed the way to better resource management in response to reduced functional status, resulting in households which were optimally organized to promote independence, among other things. The contrast in the case of the husband and wife team whose relationship appeared to be dysfunctional was particularly evident. The wife was unable to engage her husband in planning for the future, even for relatively simple issues, and received significantly lower support from her husband.

Resource management was also critical in the opportunities for social participation available to the couples, as it affected how resources were sought and deployed to enable the couples to get out and about.

Direct payments funded care: supporting resource optimization

Lloyd *et al* (2014) in reference to work by Woolhead *et al* (2004) state how it is in contact with health and welfare services where dignity, identity and independence are most threatened among older people in the ´fourth age´. The couples´ in the sample vividly describe how their care organized through DPs enhanced their autonomy, dignity and identity. These experiences may be quantified under the term, “control over daily living”, a variable included in outcomes assessment across adult social care - and generally poorly met by council commissioned services (HSCIC 2016). Our data suggests that the realities tied up within this overarching concept have a complex interaction with 1) the sustainability of care packages and, 2) the psychological and physical health of those involved.

Health capital offers a social model for understanding the components of health with opportunities for augmentation or depletion. According to work by Bergland & Slettbø (2015) this is “fundamentally about how people interact with each other and can support each other”. Trust (including being able to depend on people), tolerance and safety are key factors. DPs *increased* health capital by means of care that was dependable, flexible and agreeable. This increased their sense of dignity in daily interactions but it *also* enabled a timetable which enhanced opportunities for leisure and rest (even if leisure consisted merely in having the time and energy to sit at the end of the garden).

For some recipients, DPs also served to strengthen and/or widen their network of supportive contacts by enabling them to develop formalized arrangements with contacts who otherwise would not have been available. It was notable that these arrangements often involved both: a) people who for reasons such as work commitments or geographical distance were not available; and b) crossing “normative boundaries” to secure care from friends and family who were not tied to providing unpaid care through close-kin connections (Nocon & Pearson 2000: 364). Some had stepped in voluntarily to help in the event of need but the service users recognized the difference between initial offers of help and continued input. By formalizing these offers of help through payment the husbands and wives benefitted from support that was characteristic of the interpersonal relationship of friends and kin (Sánchez Rodriguez *et al* 2014; Bauer & Sousa-Pouza 2015) but avoided negative effects (to themselves) that could stem from concerns that they were exploiting good will, or compromises associated with having to accept whatever they were offered without being able to request what they really needed (Nocon & Pearson 2000). A further bonus of DPs for some was that relationships that had started on a formal basis with PAs and agency carers had evolved to bridge the overlap between formal and informal care.

The avoidance of negative consequences cut across every aspect of daily life for the husbands and wives as caregivers and care-receivers. For the cared-for wives, a substantial sense of control was associated with having the ability to direct how the home environment was maintained, consistent with findings from Larkin (2015). They relaxed in the knowledge that they had ensured that things were properly taken care of and that a tangible proportion of the demands placed on their husbands were alleviated. This was clearly significant to their wellbeing: Wittenberg & Prosser (2013: 490) found that "the burden imposed by caregiving can also cycle back to the ill person in terms of guilt about needing assistance, and worry about the demands placed on the caregiver". Despite this, public funding focuses on breaks and respite for unpaid carers, rather than the alleviation of daily domestic tasks despite the obvious fact that being older, spousal caregivers find the physical effort more onerous (Bauer & Sousa-Pouza 2015), not least given their own morbidity.

Finally DP-purchased care offered the caregiving spouses *protection* against the disempowering aspects of reliance on outside care that caused increased stress for caregivers, such as the sensation of 'intrusion' or their 'care contract' being challenged (Larkin & Milne 2014: 27). Such a situation (often experienced by the participants prior to taking up DPs), could directly threaten the utility of a caregiving relationship characterized by strong feelings of reciprocity and with it critical psychological protection against caregiving burden (Oudjik *et al* 2011).

6.5. Conclusion

The suitability of DPs for older people is still treated with scepticism. Amidst the literature on unpaid care, writers have concluded that, "*some groups are less-likely to benefit from self-directed care than others, for example older people.*" (Larkin & Milne

2014: 28). Doubts also stems from concerns about the capacity and willingness of unpaid carers to be bound up in DP-related responsibilities and concerns that their needs may be overlooked and overwhelmed as a result. Yet at the same time there is recognition that when a service user is dependent upon a relative to care for them, the issue of carer/ service user empowerment is a shared one (Larkin & Milne 2014). It was not anticipated that in the course of evaluating DPs to older people we would find couples where husbands, themselves affected by chronic physical illness, cared for their disabled wives. Not least because their characteristics would heighten social workers concerns "for people's safety and wellbeing" and "adding to preexisting care tasks" which shape recommendations for services, and restrict access to DPs (Stevens *et al* 2016: 11). Nevertheless this profile of service users is increasing with gender differences in care provision reduced among people with multimorbidity (Schmidt et al 2016; Pickard, King & Knapp 2015). The study offers a timely perspective on role that husbands can play in supporting older women receiving DP and on the impact of DPs on the dynamics of unpaid care. It is limited by the size of the sample albeit understandably so as an initial exploration of this phenomenon derived from a natural sample. The accounts from joint interviews were able to capture a shared narrative of caregiving arrangements and the role played by DPs with detailed insights into the circumstances of the couples. Future work may seek to include interviews with husbands and wives separately in addition to a joint interview to explore the "energy and emotions that [the husbands] put into their efforts to support [their wives] in their shared goal of maintaining independence" (Vellone *et al* 2014: 132), and vice versa. This would require great sensitivity. It is known that caregiving-receiving couples focus on the present as a positive coping strategy (Boland *et al* 2012). In this study spouses focused on the facets of their daily living could operate as a team in part as a coping strategy - designed to protect against the emotional labour associated with the irreconcilability of some aspects of their dependency.

Their circumstances of the husbands and wives in this study offer examples of "positive risk taking", much talked about yet poorly understood. Two issues stand out which have particular relevance for practice: resources and relationships. Directing care interplayed with other facets of resources. Employing DPs represented an additional phase in adaptation to the difficulties associated with their increasing dependence. There were obvious parallels with the concept of resilience as “a confluence of individual, social, physical and environmental factors” (Otmman & Maragoudaki 2015).

The participants’ accounts suggest that their capacity to benefit from DP depended in part upon decisions taken years prior, particularly related to housing and equipment. It is not difficult to distinguish how greater external support to achieve “resilience-shaping housing” could assist other older people, particularly since many participants acted on the advice of others. An overlapping factor was the strength of the personal bond between husbands and wife which played a crucial role in their long-term efforts to maintain independence and in the way they managed their resources but control over managing care offered by DP was crucial to preserving spousal roles and needs, versus local authority managed care which could jeopardize them. There is increasing development in emotion-focused coping and interventions (trying to reduce the negative emotional responses associated with stress) to caregivers (Revenson *et al* 2016; Livingston et al 2014). Far less attention is paid to relational-focused coping mechanisms, or the cognitive and behavioural effort to maintain and sustain intimate relationships during stressful events (Coyne & Smith 1991). This study suggests that social care should take into account couples’ relationships and prioritise preservation of these mechanisms. As shown here, such a perspective would provide a very different outlook on the risks versus benefits of directing care in such circumstances.

The accounts also question the assumption that older people choosing DP have wider social supports readily available prior to choosing to take-up DP (Moran *et al* 2011). Many of our participants did not have these, but an increase in wider social support was evident as a by-product of organizing care with DP.

Finally the study raises questions about how to best support older male spousal caregivers. There remains much debate about how best to support unpaid carers´ needs in general and particularly in relation to the allocation of DPs to unpaid carers in response to their needs (Brooks *et al* 2017; Mitchell & Glendinning *et al* 2016). As a practical issue, this study shows that domestic support was critical for husbands, but there were variations in how this was paid for and whether or not the DP could be spent on it.

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7. Working and managing care: exploring the experiences of working carers managing direct payments on behalf of an older person

Background

- Most of the older people receiving direct payments in the study had received some unpaid care. Many of the unpaid carers were found to be employed. A few did not provide regular care, and a handful of primary caregivers were employed as personal assistants paid for via direct payments (chapter 5) but the majority were employed in other occupations.

- Concerns that direct payments shift responsibility of securing and monitoring state-funded care from local authorities to families are particularly raised in relation to working carers. Managing care is viewed as a potential source of added burden and stress but no research to date has examined the experience of working carers supporting older people using direct payments.

- When it comes to working and caring, other studies have shown that the value of any service depends upon the fit with the needs of the service user and their carer. Unreliability, poor quality and inflexibility of services can make unpaid care incompatible with paid work.

- A striking sub-group of working carers, managing direct payments on behalf of their mother or father emerged through the descriptive analyses undertaken for chapter 5 and early qualitative analysis of the interview data. These carers were not paid by direct payments and were very involved in managing their father’s or mother’s care despite working. These cases were selected for further qualitative analysis,

Aims and objectives

This chapter aims:

- To explore the circumstances, motivations and experiences of working carers heavily involved in managing DPs for their father or mother.

- To examine how “managerial care” as a key aspect of unpaid care compares when direct payments are used versus when being in receipt of council-commissioned services.

- To discuss the findings in relation to recent policy and practice advances including the advent of support planning and service brokerage to increase choice and control for people receiving council-managed personal budgets.

Key findings

- The working carers were employed in a wide range of occupations. Their wider families were geographically spread out, affected by factors such as divorce (which reduced the presence of secondary caregivers), and involved multiple generations, such as a son who lived with his father and had his children to stay every other week. None had prior knowledge of direct payments but became aware when tipped to breaking point and desperate for a solution.

- Most of the service users involved had some degree of cognitive impairment – some very severe. Prior to receiving direct payments there had been serious difficulties arising from lack of supervision; general shortfalls in the quantity and quality of care.

- The working carers described their role in trying to manage their mother’s or father’s care before direct payments as one of crisis management. They spoke of difficulties in controlling key aspects of care and in getting a response from home care agencies commissioned by social services. This resulted in time wasted, frustration, anxiety and negative impact on their wellbeing and work, while the failings in care precipitated a downward spiral for their parents.

- Taking on direct payments led to a shift in responsibilities. External support with financial and administrative matters was available from direct payments support schemes and was considered a prerequisite to taking on the role. Working carers were enabled to orchestrate care rather than crisis-manage and most had support for recruitment.

- There were various ways in which direct payments offered them added value. They were mostly able to obtain reliable care, recruit the "right" person, control care schedules and had the flexibility to pay extra to cover all necessary hours to ensure compatibility with their work schedules, including irregular schedules. Some also used the opportunity to dovetail direct payments to funded and self-funded care, employing the same personal assistant(s) or care agencies.

- Working carers' leverage over care providers varied. Those recruiting care for full-time packages, regular hours, or with some private funding to boost the package appeared to have greater leverage. They also had access to a wider pool of providers (not just those contracted by the local authority), and receiving recruitment support from a DPSS were aiding factors.

- The findings challenge the notion that council-managed care reduces the burden on unpaid carers, while direct payments increase it, and emphasise the need for administrative and recruitment support with direct payments.

- The benefits of combining publicly funded care with self-funded (paid through Attendance Allowance and pensions) and unpaid care was very evident, particularly where families wished to avoid residential/ nursing home care.

7.1. Introduction

Direct payments have been available to service users over the age of 65 since 2000, but the place for them is still debated. While the Community Care (Direct Payments) Act 1996 (which made legal direct payments for disabled people of working age) was celebrated as a turning point for disabled groups, the later inclusion of older people received very little wider attention having been prompted by a small number of direct payment users that had turned 65 and wished to continue using them (Glasby & Littlechild 2002). Specifically it was not actively promoted by government, nor by the main older people's charities and social workers for older people had virtually no awareness of their existence (*Ibid*). However the mood quickly shifted amidst recommendations that direct payments could help to alleviate: rising demand for services; increased disparity between the expectations for services and their provision; difficulties controlling the quality aspects of services by either contractual or regulatory approaches (even with the most comparatively sophisticated of approaches); decreased willingness and capacity among families to provide informal care support; and dwindling supply of care workers (Lundsgaard 2005).

The low take-up of direct payments by older people was the driving force behind the introduction of a statutory duty to offer direct payments to all eligible clients from 2003 onwards, and although the marginal benefits of DPs for older people have been called into question (Moran *et al* 2013; Netten *et al* 2012), the emphasis on promoting DPs to older people has been unwavering (Department of Health 2008a, b; 2010a; Carr 2013; Newbronner *et al* 2011; Routledge *et al* 2015).

Unpaid care underpins a large proportion of state-funded social care, especially for service users aged 65 and older, and as such the acceptability of DPs to unpaid carers (UCs) is critical to implementation. Notably, DPs have never attracted publicity as a *breakthrough* for (unpaid) carers – indeed much of the debate around the suitability of direct payments to older people has focused on potential negative consequences for UCs. The main concerns are: that DPs may lead to increased burden on UCs and greater isolation, due to the private and independent nature in which care arranged through DPs is managed. Or, that DPs will lead to increased "inequality of experiences of social care services as more informed and able families may take better advantage of its flexibilities" (Miller & Larkin 2013: 4), or even greater levels of abuse (Manthorpe *et al* 2009; Mitchell *et al* 2015; Moran *et al* 2011; Manthorpe & Samsi 2013; Stevens *et al* 2016; Woolham *et al* 2018; Ismail *et al* 2017). Yet there is scarce evidence to support these concerns. Moran *et al* (2012: 464) found that, direct payments "increased opportunities for the carer(s) to reduce their own direct care-giving responsibilities; and the flexibility to arrange support that met the needs of the service user, the carer and the wider family". Carers UK (2008: 2) reported on a survey of families using direct payments to manage care arrangements with one quote stating, "*direct payments is the best thing since sliced bread*."

There are strong ideological elements to the ambivalent reception to direct payments. For some DPs suggest a return to "familialism" (Larkin & Mitchell 2016) – characterised by policies which provide incentives for private households to secure the welfare of their members (Leitner 2010). This is in contrast to "de-familialism" where family carers are unburdened by means of state or market provision of care services (Leitner 2010: 359) – albeit only partially. Although familialism is more generally associated by a lack of state-funded support, DPs – as funded support, are seen a shift towards familialism as unpaid carers are typically instrumental in the co-production of service users outcomes while carers' interests and well-being are prioritised but only in so far as is necessary to sustain their care-giving capacity (Pickard 2001). This is compounded by a tendency to assume that if a service user is unable to manage a DP that their unpaid carer will (Mitchell *et al* 2014) - indeed the 2014 Care Act created an incentive to doing so by allowing family members to be paid for managing a DP. But there are also other "issues" underpinning these concerns such as fears of a 'de-professionalisation' of social work.

Yet DPs are not the only option available: arguably we are reaching a middle ground in England, of "optional familialism", where caregiving families have several options for services, as well as "supportive care policies" (Leitner 2010: 359) with the potential to strengthen the "caring family" but also (partly) unburden them from caring responsibilities.

In terms of services, since 2005 allocations of care to service users within the community have been referred to as 'personal budgets' (Department of Health 2005).

PBs – in contrast to previous care plans – require local authorities to detail the ‘cost’ to the local authority of meeting a service users´ support needs for all service users[27], not just those requesting a cash budget in the form of a direct payment. One of the main objectives of personal budgets has been to provide alternatives to the dichotomy of care organized entirely by the service user – or the service users’ family - as in DPs, versus services commissioned by the local authority. A service user may opt to ‘deploy’ his/ her PB in a number of ways to secure services: 1) as a direct payment, 2) as an Individual Service Fund (ISF) - where there service user´ chooses an independent provider (typically a home care provider) to manage the funds and offer a personalized service, 3) as a council-managed service, increasingly known as a managed budget (MB).[28] Or they may receive any combination of the three. Regardless of how a service user (or their family) chooses to deploy their PB, they should have assistance to develop a ‘support plan’. This is a legal document which specifies the needs of an individual, which needs meet the eligibility criteria for local authority support and how their needs will be met and the monetary value of the personal budget. One of the core principles of a support plan is “the wellbeing principle” (Care Act 2014) – among other things that local authorities must ensure “a balance [is achieved] between the individual’s wellbeing and that of any friends or relatives who are involved in caring for the individual” (TLAP 2015: 9), although research has thrown into question the weight of this priority in practice (Brooks *et al* 2016).

In terms of supportive care policies, since 2005 the Carers (Equal Opportunities) Act has placed a statutory duty on local authorities to, “inform people with regular and substantial care needs of their right to a separate assessment of their own needs” (Brooks *et al* 2016) – a right that had existed since 1995 but not been implemented satisfactorily. To further bolster compliance, a performance indicator for local councils was added to monitor the number of carers receiving a specific carers’ service as a percentage of clients receiving community based services. As a result, by 2009/10 the vast majority of unpaid carers known to councils received an assessment– most of whom were providing care for 20 hours a week or more (Pickard *et al* 2016). More recently in 2014, the Care Act (c23. 2014) was passed with the aim of strengthening all

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[27] Personal budget statements also specify the amount that the service user must pay towards that cost themselves (on the basis of their financial assessment).

[28] Options 2 and 3 are interchangeably referred to as managed budgets although government has tried to encourage differentiation between the two terms (House of Commons 2016).

previous measures aimed to reduce carer burden. This places a duty on local authorities to undertake a carers’ assessment to unpaid carers, irrespective of the hours of support being provided and obliges local authorities to provide support to meet assessed needs – a move aimed at ensuring access to early intervention rather than rationing care to those at the end of their tether (Pickard *et al* 2016), the impact of which has yet to be seen. Services to unpaid carers are also available *in kind*, through cash payments as DPs to carers (Mitchell & Glendining 2016). Aside from these measures, unpaid carers have access to some (means tested) financial support and pension credits – or, if employed - a degree of paid leave and the right to flexible working [29] (Courtin *et al* 2013; Starr & Szebehely 2017). There has also been growth in support from third sector organisations for unpaid carers (Sutcliffe *et al* 2016), as local authorities have been both encouraged to ensure a consortium of local voluntary organisations are available for independent assistance with “support planning and brokerage” (TLAP 2015; Orellana 2010), and required to more actively provide information and advice to service users and carers (Arksey & Baxter 2012).

These developments, while still a long way from being fully achieved in practice[30], do offer hope for the future – but the value of any services depends upon their fit with the both the needs of cared-for persons, and unpaid carers needs (and situation). For unpaid carers that work this fit is even more crucial – unreliability, poor quality and inflexibility of services can make unpaid caring incompatible with paid work arrangements (Brimblecombe *et al* 2018). While statistically unpaid carers are likely to relinquish paid employment to some degree (King & Pickard 2013), at the individual-level financial imperatives and other considerations are often such that reducing paid work is not an option (Arksey & Glendinning 2008). If the services available to people being cared for in the community are not compatible with carers´ work arrangements, ultimately the only solution may be entrance into residential or nursing care. For some families who wish to avoid this scenario, increased control over services through DPs might offer a solution. Yet there is substantial reluctance from social work practitioners to promote this model because of fears of placing unpaid carers in a situation that

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[29] Dependent upon employment contract and may be refused by employers on business reasons (see Courtin *et al* 2014).

[30] Its critiques have suggested that the Care Act will make little difference to the lives and well-being of older people and their carers in the face of cuts to public spending and increased demand for care with “family care far less of a ‘voluntary option’, with negative consequences for both parties”. (Starr & Szebehely 2017: 118)

induces additional stress from the responsibility that comes with organizing care and has the potential to increase the hours they spend caregiving. There is very limited evidence to substantiate these concerns (Table 7.1), but it has created pervading arguments (Brooks *et al* 2017; Larkin & Mitchell 2016; Mitchell *et al* 2015; Moran *et al* 2011; Glendinning *et al* 2015). Woolham *et al* (2016: 17) argue that, "'practice wisdom´, professional judgement or ´street-level bureaucracy' amongst front-line practitioners (Ellis 2007), may have benign or even positive consequences for older service users and carers if based on a realistic assessment of [their] capacity to cope with the additional responsibilities and workload involved with DPs". Yet carers of older people are an extremely diverse group and there is an absence of targeted studies on particular groups of carers (Glendinning *et al* 2009) – and of unpaid carers operating in different contexts. Recent work suggests that the significance of caregiving context is paramount to the function and organisation of unpaid and paid care in the context of DPs (cf. chapters 5 & 6). Of particular interest is the situation of working carers who have opted to manage DPs as a means of improving care (and with it quality of life) for the person they care for *and* coordinating care with their employment, a context which has been overlooked in research.

The suggestion that organizing care through DPs could induce additional stress among UCs stems from work by Rosenthal *et al* (2007, 1999) who sought to quantify families' efforts to organise care as distinct from direct care (i.e. supporting relatives with Instrumental Activities of Daily Living and, or, Activities of Daily Living). They introduced the term 'managerial care' and their study was the first (and only) to show that managerial care impacted adversely on unpaid carers. The study relied on a sample of unpaid carers who provided managerial care but not direct care which they found in a sample of unpaid carers that were employed full-time. Managerial care was found to include three distinct concepts: orchestral care, financial and bureaucratic management and financial assistance (Table 7.2). It was found that *orchestrating* care was associated with work-family conflict and job costs (for both men and women) and with higher stress for women (but not for men) (Rosenthal *et al* 1999). Higher stress was also associated with money management for female unpaid carers (but not for men) although to a lesser extent than orchestrating care.

The inevitable prominence of managerial care for unpaid carers supporting DPs was quickly identified in relation to self-directed care (Glendinning *et al* 2008; Glendinning *et al* 2009). Given Rosenthal et al's (2007, 1999) findings it would be logical to assume that managing DPs may have particularly adverse effects on working carers. Yet research with working carers suggests that inadequate service quality is a key issue which compounds the irreconciliation of unpaid care and employment (Brimblecombe *et al* 2018; Pickering & Thompson 2017) and it is in this area that studies of DPs converge in support of their benefits (Hatton & Waters 2014; Moran *et al* 2011; Moran *et al* 2013; Netten *et al* 2012; Newbronner *et al* 2011; Orellana 2010; Rodrigues & Glendinning 2014). Moreover attempts to distinguish between the level of stress experienced by unpaid carers supporting older people using DPs, versus council-commissioned services[31] have not established a significant difference between the two (Woolham *et al* 2018). Much needs to be learnt about how the task of managing care is experienced. As a small step towards this, this chapter draws on interviews with working carers supporting older people to use DPs interviewed as part of a wider study on direct payments to older people. The analysis explores their circumstances, motivations and experiences of managing DPs. The findings are discussed in relation to ongoing developments within the field.

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[31] Specifically, managed budgets.

Table 7.1: Research on the impact on unpaid carers of supporting direct payments for an older adult.

Study author(s)	**Aims and objectives**	**Sample and methods relevant to the management of DPs by unpaid carers supporting older people**	**Relevant findings**
Woolham *et al* (2016)	To examine the impact of personal budgets – whether as DPs or MBs, on unpaid carers of older PB users.	As part of a study based mainly on a postal survey of unpaid carers supporting community-based social care recipients aged 75 or over receiving either a DP or a managed budget (MB), 31 carers were interviewed in brief telephone interviews (twenty minutes). They number of unpaid carers interviewed supporting DP users, was not specified, but 18% of the survey sample supported DP users. Respondents excluded unpaid carers managing a DP on behalf of the service user (indirect payments).72% of the sample was female – predominantly daughters (67%). 96% of the sample were White.	Only a minority of carers from either group acknowledged feelings of stress arising from their role. Mean care giver burden scores were slightly higher for those supporting DP users but ***not*** statistically different.
Glendinning *et al* (2015)	To explore the experiences of assessment, resource allocation, support planning and managing personal budgets among unpaid carers.	Interviews with 14 service users- unpaid carer dyads of which four were carers of older people. Three were wives caring for husbands with dementia and one was a husband caring for his wife with dementia. The ethnicity of the interviewees was not specified.	Carers played an important role in assessment and support planning and wanted to be involved. Carers found it difficult to identify support needs of their own because of their interdependence with the service user. **The paper did not comment on whether or not there were differences in service users' experiences according to the service user group being cared for.**
Larkin (2015)	To explore carers' perceptions of the carer–service user relationship before and after the advent of the personal budget.	Data were gathered through semi-structured face to face interviews with 23 carers in long-term dyadic relationships with an adult in receipt of social care who had changed to a personal budget. Nine of the interviews were with people caring for an older person. The paper does not specify how many of the people interviewed supported someone receiving a DP but much of the results do relates to DP use. The ethnicity of the interviewees was not specified.	Around half of the cares were anxious about the recruitment and training of personal assistants; were frequently unsupported - but that anxieties eased with time related to their confidence in their ability to find replacement care. Just under half used other services to support them with managing the personal budget, such as carers groups, third sector organisations and broker services (such as DPSS). **The paper did not comment on whether or not there were differences in service users' experiences according to the service user group being cared for.**
Hatton *et al* (2014)	To explore whether personal budgets were associated with better outcomes for carers.	Surveyed 1,328 carers of service users of all ages using personal budgets from 19 council areas and 20 NHS organisations via postal survey. 93% of respondents who were White; 69% were women. The report does not describe what percentage of these carers supported people receiving a PB in the form of a DP. It is also does not specify the percentage of unpaid carers supporting older people.	The majority of unpaid carers reported positive outcomes including improvements in: their ability continue caring (78.6%); quality of life for the person being cared for (79.6%); and quality of life for the carer (71.3%). But, older carers were less likely to report a positive impact of the person's budget on the person's quality of life and on the (perceived) opportunities for carers to engage in paid work or volunteering (presumably among those who were not working). **The relevance of the findings is limited due to the lack of differentiation between reports from unpaid carers according to the type of service used, and a lack of detail on UC characteristics.**
Rodrigues & Glendinning (2015)	To describe how choice and competition within community-based social care for	Reported on interviews with 18 older people (without dementia) who were receiving personal budgets recruited via home care agencies – some of whom received DPs. An unspecified number of the interviews were dyadic interviews with unpaid carers.	**No findings specific to the experience of people supported by unpaid carers, or on the experience of unpaid carers were reported.**

	older people was being operationalized within six local care markets.		
Moran *et al* (2012);	To explore the extent to which Individual Budgets included and support carers.	Carers of service users who had consented to take part in the main IBSEN study (Glendinning *et al* 2008) were identified and invited to take part in this study to talk about their own experiences of IBs; 129 structured interviews were conducted and analysed, sixty with carers of service users in receipt of an IB and sixty-nine with carers of service users in receipt of conventional social care services (the control group). Sixteen of these were with carers of older people. Eight percent of the sample overall were from BME groups.	Unpaid carers of people using IBs were more likely to have been involved in assessment process (for the people they car for) and in the support planning process but some carers felt that their needs were unaccounted for during the process. The key benefits of IBs were reported by carers to be greater choice, control and use of time; improved quality of life for the service user; and enhanced family relationships. Support with financial management was frequently sought from DPSS. Carers of older people in receipt of IBs were significantly more likely, compared with carers of the other user groups to report having no outstanding needs for social participation and involvement
Jones *et al* (2012)	To describe the impact and outcomes of IBs on carers.	This paper draws on the full report of the study (Glendinning *et al* 2009 - see below and above).	Results suggested that positive impact on the carers' quality of life, social care outcomes and psychological wellbeing could in part be due to the carers' involvement in assessment and support planning, and the impact of receiving a budget on the carer-related activities. Carers in this study who were looking after an IB user appeared to spend more time on care-related tasks than carers supporting someone in the comparison group who continued to receive standard social care services.
Glendinning *et al* (2009)	To study the impact and outcomes of individual budgets on carers.	Sample details as per Moran et al (2012). Standardized outcome measures were used to measure the following: psychological well-being; perceived health; perceived quality of life; social care outcomes; satisfaction and quality of services and carers' perceptions of their caregiving role. Alongside this the study collated descriptive about carers interviewed (demographic characteristics; household composition, previous service package, employment status and relationship to service user), and the service users they cared for (service user group, FACS level, basic demographic information, activities of daily living, presence of carer). Sixteen of the interviews were with people acting as unpaid carers to older people receiving IBs.	IBs were associated with positive impacts on carers' quality of life, social care outcomes and psychological well-being. In relation to all these outcome measures, carers of IB users scored higher than carers of people using standard social care services; the difference between the two groups of carers was statistically significant in relation to carers' quality of life. the slightly lower costs of IBs compared with standard social care support. However results suggested that lower package costs may be offset by greater inputs of unpaid carers' time – although the results were not significantly significant.

Table 7.2: The care management construct

Concept	Items included
Orchestrating care	Looking into places to provide long-term care Seeking information about services Discussing care arrangements with the older relative Discussing care arrangements with other family members Arranging for a relative to receive services
Financial and bureaucratic management	Managing money Completing forms and documents
Financial assistance	Financial assistance Putting money aside to help an older relative

Adapted from Rosenthal & Matthews (1999)

7.2. Methods

7.2.1. The study

In 2005, in parallel to the increased priority being given to delivering to mainstreaming DPs as a core option for providing state-funded care to older people in the community, the Department of Health commissioned a substantial evaluation of DPs to older people through which 81 older people and/ or their family members were interviewed (late 2005-2006) front ten local authority areas for which ethical approval was granted from the corresponding University as per the regulations at the time. This work provided further evidence to the benefits of DPs for older people which fed into the ongoing policy drive (Davey *et al* 2007). The data also provided rich detail on the circumstances in which unpaid carers were supporting older people using DPs that was not fully analysed at the time of the study due to resource limitations which have been analysed for the current chapter.

Three quarters of the sample receiving support from an unpaid care to manage their direct payment to varying degrees. Nearly half of the sample (44%, n = 36) had their direct payment fully controlled by an unpaid carer owing to their inability to do so themselves (due to advanced frailty, limited speech and/ or cognitive impairment). The others who were able to control their DP but still relied on their unpaid carers support, also mostly opted for their unpaid carers to be involved in the interview. As a result, around 51 unpaid carers of older people were interviewed which lasted roughly two hours.

The interviews were semi-structured but were conducted in a manner which allowed participants ample "space" to describe in detail how they managed their daily lives and the role that DPs played (Charmaz 2013). They sought service users' caregiving arrangements using a daily diary approach (Van De Berg & Spauwen 2006). Interviewees provided details of how the DPs care package was used throughout the week, and what additional inputs were included as hours of unpaid care; self-funded care or formal care that was commissioned directly by the local authority and did not form part of the DPs care package. They sought information on their means of securing care and managing DPs including any support obtained, such as through a Direct Payment Support Scheme (DPSS) and how the experiences had altered over time. Interviewees were asked about their experiences of DP funded care and earlier non-DP experiences (where applicable), on their motivations for taking up DPs and how they learnt of DPs. Unpaid carers involvement in and experience of managerial care was central to the interviews. Surprisingly, this early study still offers the largest and most diverse sample of interview data from unpaid carers supporting older people receiving DPs (Table 7.1).

7.2.2. Sample characteristics

Thirty-two participants from the main study had working carers but many of these were excluded from the current analysis due to the following criteria: Unpaid carers who were not present during the interview (n=5); unpaid carers who worked as a result of being paid to provide care (n=2); unpaid carers who worked but had employed a close family member to provide care (n = 3); unpaid carers who had only a minimal role in supporting direct payments (n =3); unpaid carers that were working but semi-retired (n = 2). Fifteen interviews remained of which *seven* were purposively selected after preliminary analysis as they were deemed to be most representative of the range of circumstances faced by todays working carers.

Reflecting wider research on UCs (Skills for Care 2012), the caregiving families in the sample selected were geographically ‘spread out’, affected by marital dynamics such as divorce and involved multiple-generations (Table 7.3). The majority worked full-time

They were evenly spread between sons and daughters supporting either a mother or father. Further characteristics of the sample are described in Table 7.4 and 7.5 including details of care received, service user needs and their home environment.

7.2.3. Data Analysis

The analysis of the selected interviews of working carers followed a lengthy process drawing on grounded theory methodology which was crucial to the identification of working carers as a distinct subgroup. All recordings of interviews identified as working carers were listened to in full. Notes on recurring themes were taken and qualitative impressions were cross referenced against data from descriptive data (cf. chapter 6) to examine the representativeness of each case to the subgroup. After excluding a number of cases, (cf. sample characteristics) seven interviews were selected and transcribed verbatim. Each transcribed interview were coded iteratively: a process from which a larger number of “open” codes were gradually reduced into more conceptually inclusive by constant comparison of codes across the data (Charmaz 2013) with the aid of ATLAS.ti computer software (version 4.2). A literature review was conducted simultaneously as the first clear picture of themes emerged.

7.3. Results

7.3.1. Desperate for a solution

All of the narratives started with descriptions of why and how the families had ended up receiving DPs. All but one of the families had fallen upon DPs as a last resort. For two sons, this was as a result of long running difficulties related to the inadequacy of previous care packages managed by social services and provided by local home care agencies which had contributed to deterioration of their parents’ condition.

Table 7.3: Unpaid carer details

Reference	Relationship to service user	Caring for	UC dynamics	Employment details
UC1	(NR) Son	Mother, aged 74	Son, lives with partner and daughter 10 mins drive away. Has two sisters who live too far away to help regularly. Shares care with his father who is the main carer to his wife.	Runs own business (a cleaning company)
UC2	(NR) Daughter	Mother, aged 85	Middle daughter (older sister and younger brother). Married with children in their early twenties. Only regular UC as siblings too far away to help.	Works full-time as a school teacher.
UC3	(R) Son	Mother, aged 74	Only son. Lives with mother.	Self-employed journalist. Travels frequently with little prior warning.
UC4	(NR) Daughter	Mother, aged 71	Only daughter in a family of four. Shares care with her father who is the main carer for his wife. One son lives next door with daughter-in-law who provides all meals to her parents-in-law.	Works full-time at a University
UC5	(R) Daughter	Mother, aged 88	Only daughter. Married with daughter (at University). Husband provides some UC.	Works part-time as a nurse – reduced hours to fit in with caregiving demands.
UC6	(R) Son	Father, aged 84	Only son – divorced. Has two teenage daughters who visit for weekends. Only provider of regular UC.	Works as rent collector
UC7	(NR) Son	Mother, aged 91	Middle son (older and younger brother). Only regular UC as siblings too far away to help regularly. Married. Wife provides some input. Mother member of catholic church. Receives regular visits from church members and neighbours who cover (for free) at weekends.	Runs own business (stationary).

NR = Non resident; R = Resident

Table 7.4: Care allocated and received

Reference	Formal care received	Care allocated	Private care	Unpaid care*	PA or agency
UC1	6 hours per week	6 hours per week as DPs	-	41 hours per week 35 hours per week (husband); 6 hours per week working son	PA
UC2	31 hours per week *4.5 hours care per day - distributed across four visits*	32 hours per week as DPs	.	5 hours per week - Working daughter	Agency
UC3	35.5 hours per week (variable) *2.5 hours per day Mon-Fri distributed in three visits* *1.5 hours per day per weekend distributed in two visits* *20 hours per week night care*	17.5 hours per week as DPs	-	14 hours per week - Working son	Both PA and agency
UC4	54 hours per week *8 hours per day (08:00-12:00 and 14:00 to 18:00) six days a week, and six hours on Sundays.*	46 hours per week as DPs	.	63 hours per week Husband – 56 hours per week; working daughter – 7 hours per week	PA
UC5	70 hours per week *Night care 10 hrs x5 per week,* *1hr home care AM x 7 per week* *Day centre 5 hrs x3 per week.*	45 hours per week 25 hours per week as DPs 15 hours per week day centre care 7 hours per week council-commissioned home care	25 hours per week (Paid by daughter)	86 hours per week Working daughter – 78 hours per week; unpaid sitters (friends and neighbours) – 8 hours per week	Both PA and agency 3 nights covered by PA, 2 by agency

UC6	47.5 hours per week *08:30 to 18:00 Monday to Friday*	40 hours per week as DPs	7.5 hours per week (Paid with Attendance Allowance/ occupational pension)	50 hours per week- Working son	Both PA and agency PA does ¾ of the hours and an agency the rest
UC7	136 hours per week *Live-in carer Mon-Fri*	40 hours per week as DPs	36.75 hours per week (Paid with widows pension)	12 hours per week Working son – 6 hours per week Unpaid sitters (friends and church members) sit in at the weekends – 6 hours per week	Agency

*Unpaid care was estimated using a daily diary approach for an average week (cf. Van de Berg & Spauwen 2006). Unpaid care was attributed to time spent directly caring for the person (providing personal care, cooking and shopping – where the service users was unable to perform the task (or unable to perform the task unaided). Estimations for supervision time were difficult because of the need to discount 'joint activity' (cf. McDaid 2001). For night supervision, if the service user tended to interrupt the unpaid carer at various times throughout the night and for an extended period, the whole period was counted. If the service user only woke once or twice following a fairly regular pattern and only need minimal intervention, only the period required to wake, attend and return to sleep was estimated. Finally, if the service user required someone in the house at night for general safety reasons - but received this because the unpaid carer was normally co-resident, no overnight unpaid time was counted. During the day general supervision was *not* counted if the person could be left at home alone for short periods and if the unpaid carer could participate in a leisure activity while at home – such as watching the television or reading (as in UC1). However, if the unpaid carer was likely to be frequently interrupted and required to intervene on an almost constant basis while at home, any period at home without alternative care was considered unpaid are on the grounds that the unpaid carer was both ensuring the safety and wellbeing of the service users and could not realistically enjoy any leisure time. This was the scenario of the case of two service users with advanced dementia (UC5 & 6). An estimation of time spent exclusively on the administration or management of DPs – or general coordination of care was also included in the calculation.

Table 7.5: Service user characteristics: dependency status and home environment

Reference	Dependency status	Home environment
SU1	Disabled from a stroke (two years ago). Now able to walk small distances with supervision. Needs constant supervision due to memory loss and confusion. Needs assistance with personal care. Unable to cook or maintain the home but undertakes small tasks as part of rehabilitation goals.	Lives in a bungalow. Raised toilet seat. Grab rails.
SU2	Unable to dress and wash. Needs help toileting. Eats pureed meals and nutritional drinks. Needs help to take medication. Unable to cook. Unable to do household tasks. Walks short distances with frame with assistance for safety.	Lives in downstairs of the house. No downstairs bathroom so only has strip washes (which she prefers). Electric bed, raised chair, pressure relieving seat pad, grab rails, emergency call bell.
SU3	Needs help to get washed and dressed. Unable to cook. Unable to do household tasks. Rarely leaves home. Unable to answer the front door. Able to transfer and walk few paces with supervision.	Downstairs level-access shower. Bath seat. Wheelchair. Adjustable bed. Grab rails. Zimmer frame. Adapted kitchen. Reclining armchair.
SU4	Disabled following stroke. Bed/ chair bound. Needs help with all personal care. Needs to be fed. Fully incontinent. Very limited speech in Urdu. Often anxious and confused.	Lives in downstairs living room, converted to a bedroom. Electric bed, pressure relieving mattress, hoist, commode, reclining chair.
SU5	Advanced dementia. Mobile within the home but unsteady. Needs prompting and supervision for personal care tasks. Unable to make meals or drinks. Very anxious. Unable to be left alone. Incontinent of faeces.	Lives in downstairs of the house. No downstairs bathroom so only has strip washes. Awaiting DFG to install downstairs bathroom.
SU6	Advanced dementia. Needs prompting to wash and dress. Erratic behaviour – sometimes aggressive or inappropriate. Unable to be left alone.	Lives in downstairs of house. Living room converted to bedroom. Downstairs bathroom. Son and grand-daughter live upstairs.
SU7	Bed bound/ chair-bound. Age related cognitive impairment. Needs help to get washed and dressed. Needs help with feeding.	Lives in downstairs living room, converted to a bedroom. Electric bed, pressure relieving mattress, commode, reclining chair.

“During that year the level was stepped up a little bit, they gained an extra quarter of an hour or so here and there and someone came in the middle of the day as well – just for half an hour, But they never really quite did what they were supposed to do… “ (UC7)

“Over time mothers’ physical health deteriorated…I think she was becoming very immobile and the pads were a bit of a problem in that they weren´t being changed and she was getting sores and at that point she became very run down and she went into hospital...” (UC7)

“One of the things that triggered, ´no this isn’t working´ - I came in one day and meals and wheels had come and gone and they’d (Meals on Wheels) left her meal without knife and fork. She was trying to eat whatever there was with her little finger.” (UC7)

A further two families had started their journey in hospital – both of whom had mothers who had suffered severe strokes. Both families were disappointed with the lack of rehabilitation.

“She was in hospital for three months and my Dad used to stay with her all day. We had debates with the consultants because we felt they’d written her off really…They weren´t putting her in a chair, and they would say. “Well we haven´t got a chair”… And they didn´t really bother with rehab.”(UC4)

On top of it, there were severe delays in accessing social services – one month passed before they were referred to social services – two before they were first assessed. After three months their mother remained in hospital due to a lack of home care capacity –at which point the family discharged her without any support because of the affect hospitalization was having on her and the family.

“We were all really exhausted by then, running to the hospital, running back again. In the morning I’d have to bring my dad…we didn’t leave her alone really, because, well, the hospital was short-staffed… In the evening… I’d have to go from work… to the hospital. Because we noticed that even on the wards people weren’t necessarily getting fed… we just wanted to be there to make sure she was alright.” (UC4)

The other mother was sent home with her husband post social care assessment without any support. It took her son nearly a year of going between SS, occupational therapy and different GPs, before the families need for support was recognized.

All but one of the families eventually was offered DPs by a social worker without previous knowledge of DPs. What unified these families was that they had questioned the care that was received and taken the view that – even if they did not know what it was that ***´there must be an alternative´***, signaling (eventually) to care managers they came into contact their potential commitment to take on DPs.

In all cases, there were two overlapping priorities for UCs. The first was to find a way to get the best possible outcomes for their relative. The second was to deal with the personal crisis that the situation had imposed that affected all areas of their life.

"It was getting to the stage where I was going home, not knowing if he was going to be there or not…I had to keep reporting him as a missing person… And then I took to locking him in during the day. At that time he had someone going in in the morning to check he was okay and then someone who used to go in at lunchtime… But because I started locking him in social services refused to send anybody because they said it was a health and safety risk. Then I came home one night and had smashed his way out with a hammer through the front window. Then he had to go into a home because I thought I just can´t cope with him anymore." (UC6)

His father was actually admitted to residential care – although it was not what he or his really wanted. It was only some weeks after he had been admitted that a social worker suggested direct payments.

In contrast to this history, one daughter – also caring a parent with dementia (her mother) - had overseen a move to residential care, at her mother's request, but found the care was not acceptable.

"All I got from the psychiatrist was that the system was stretched. So that was their excuse for sedating her. And beyond that they left her to sit alone – unattended to go and walk to find somebody because her anxiety levels were so high." (UC5)

Her daughter reported that while in the residential home, her mother oscillated between wandering – or being heavily sedated due to the insufficiency of supervision. As a result she had numerous falls. Eventually she brought her home for a break – at which point the home refused to have her back. It was this crisis point that prompted a social worker to offer DPs, realizing that the daughter's job was at stake.

In contrast between the idea that council managed services reduce the burden of managing care for unpaid carers, every son and daughter interviewed had been managing their parent's care long before they started using DPs. As their efforts had often by futile and their expertise often overlooked this fueled their levels of stress. Common themes was the lack of leverage over care commissioned through SS; time wasted in attempts to communicate with agencies and its impact on their lives (including their employment); rising anxiety and frustration and poor outcomes for their parents.

"Beforehand, I would ring the agency and I would leave a message and they wouldn't get back to me and you know, it was always a hassle." (UC2)

"When I spoke to [the social worker] she said ***there wasn´t much they could do****. They just sort of said, 'Well that's down to you to make sure they´re doing what they're supposed to be doing'. But that aspect was terribly difficult to control. I couldn't be there to check what they were doing. And they were not employed to me – they were answerable to an agency. You could talk to the agency and they'd put up a brick wall. They'd say, ´oh they´re our best girls´, you know and ´dah, dah, dah´."* (UC7)

"No one ever asked me what his needs were. To give you an example, I´ve always given him his tablets – even when I didn´t live there. I used to call in every night and sort him out, and give him his tablets. At some stage the health visitor just started visiting and didn´t check with me – and started giving him his tablets in the morning. For about a week he was on double dosages!" (UC6)

Such situations were compounded by the fact that the UCs were working and unable to be present. All of the carers referred to the amount of time (and energy) taken up with telephone calls, more often than not in work time.

“That [was] the worst thing… especially as a busy teacher – when you leave messages for people and they don’t bother to get back to you. And then you’ve got to find the time to phone them again.” (UC2)

7.3.2. Switching to direct payments: shifts in responsibilities

Receiving DPs entailed new roles, responsibilities and new means for control. The interviews explored the experience of starting DPs, recruiting care and developing a system to manage the administrative burden.

Starting DPs

All of the interviewees had received satisfactory support to set-up DPs, without undue delays once a DP was agreed to. Much of the potential stress associated with ‘additional roles and responsibilities’ was alleviated by representatives from direct payments support schemes or payroll agencies.

“The [social worker] said, I´m no expert but… and she gave me a contact name [at the support organisation]…. So I went to see him and he was a very impressive character – terribly supportive and right this is what we´ll do. You do this, you do that, we´ll…´And so he facilitated – he arranged for it to happen.” (UC4)

“For the payroll I employ a [payroll agency]. They’re very good. They came round initially and gave answers to all the questions I was not getting answers from the DPSS.”(UC6)

“And then there were a couple of instances early on where the money never went into the bank account and there wasn´t money there to pay people. I went into a blind panic

that I would not be able to pay the carers but [the payroll agency] said, "don't worry – we know it's coming". (UC6)

Recruitment

Five out of seven of the families used agencies to secure care. Only two of the families exclusively used agency care. In both cases this was a conscious choice prior to actually receiving payments due to the confidence they had in the agency they used. Two secured care exclusively from a PA. Again this was a choice taken prior to receiving payments. This decision was driven by language considerations and the perceived benefit of employing a PA for slightly more hours than allocated, and though having met the right person for the job in the lead up whilst waiting to be awarded DPs. Then there were three families who aimed to employ a PA(s) to provide care but ended up unable to cover the entire package (Table 7.3). The remainder, either relied on a council-commissioned service (UC5), or sought extra care themselves through an agency (UC3, UC6).

There were advantages to a mixed-package as it offered a fall back mechanism, albeit at greater cost. Generally though, these families would have preferred to avoid this dependence as they felt that employing a PA had greater advantages – if the right person could be found.

"The ideal solution would be to get rid of [the agency] and have somebody that my Mum gets on with that will give her the level of care according to what she needs." (UC3)

"I've had a lot of problems with the problems they send in for personal care but I haven´t had any problems with the people that I've chosen. The girl that I have, she's got a nice way with her. She's very in tune." (UC5)

One son in particular had persevered to find a solution. Early in the process he employed a PA who not long after taking to job explained that she had a problem with childcare. The son agreed that she could bring her toddler along (because his father liked children), but quickly realised that the situation was unworkable.

"A couple of time I went home and the little girl was screaming her head off, and I thought, 'Is this really right for my Dad?'" (UC6)

It took some time to find the right person but the eventual outcome was described as "*fantastic*". Recruitment support from his local DPSS was of variable quality. They purported to offer a service of PA lists but its value was limited:

"It can be a bit hit and miss... Firstly I had to chase and chase for the CVs. And then the CVs that I got weren't really… because I said what I'd really prefer was someone middle-aged who had experience and lived locally and all I got were CVs for teenagers." (UC6)

There were also complaints that although the DPSS's supplied lists of local agencies, they refused to give recommendations. This left UCs with the formidable task of searching for criteria to target particular agencies with very limited information. Whilst the experience of employing PAs had (eventually) resulted in high levels of satisfaction, the experience of care supplied from home care agencies was more mixed (see below).

Administrative responsibilities

Unpaid carers added to their catalogue of responsibilities the administrative roles associated with DPs, either alone or in tandem with another caregiver. All had to provide financial returns but those employing a PA had to provide official employer-employee records. All relied on initial budgeting support from a DPSS plus ongoing use of a payroll agency (either available from the DPSS or from a payroll agency). Some benefited from the availability of holding accounts. Their comments suggestions that these services protected them from increased burden:

"The support organisation worked it out. They worked out how much we can pay her, how many hours we can have. They work it out taking out all those costs [bank holiday, holidays etc.] – what is the maximum amount of hours you can have with a reasonable salary." (UC4)

“As I say, I don´t have enough time to do what I’m doing, let alone having to do tax affairs [but]… it is quite straightforward. We have help from a payroll agency – they do the pay slips. They tell us, ‘that’s what you owe us and that’s the pay slip – that’s what you have to pay them“(UC1)

“You know, I´ve got enough on my plate without all that. So I´ve opted not to. Just let them take over completely.” (UC5)

In terms of keeping records for the financial return, interviewees talked of their system for doing so:

“My Dad is really good. He keeps excellent records. He’s got a little book and he writes it in…We´ve got our own system going now, it’s just me and him and we just do it between us.” (UC4)

“The payroll agency do the payroll slips which I pass on with [the PAs] check that my father signs. We’ve got the other paperwork that kept for the calculation reports…So they’re all done and I write down the cheques number and that amount for that month, so it corresponds with the cheques book. So it’s all tied up for monitoring. And then I keep the bank statements to check that what comes out is correct.” (UC1)

Some appeared to manage their records like clockwork but others sought reassurance and needed assistance to deal with minor issues that they did not properly understand.

“I’ve been in contact with them reasonably frequently. They’ve been very supportive….If I didn’t have that sort of relationship – where I can pick up the phone – it would be more of a worry.” (UC2)

Sticking points tended to be related to timings for keeping track of payments for service user contributions and surplus funds. There was a tendency to be risk-averse, by slightly over-paying or running a surplus over fear of not receiving funds at any given time and not being able to pay carers. But this was grounds for penalization and thanks to early intervention from DPSS representatives had not led them to serious problems. Even among those that became very independent, it was not unusual to have sought reassurance early on. Support also encouraged unpaid carers to use available funds as needed within the realm of meeting assessed needs promoting the flexibility for unpaid carers.

“I don´t use the agency very often [for emergencies], but if I have had to, there’s been enough money in the account to cover that. And the chap that deals with the direct payments [from the DPSS] said that if we run short we’ll just go back to the social worker…” (UC5)

7.3.3. Brokering agency care

Two of the families exclusively used agency care: one had simply switched to DPs on the advice of the agency to avoid losing continuity when the local authority decided to no longer commission services from the agency. The other knew provided accountancy support to the agency chosen. Both were circumstances where the clients appeared to be treated with a special loyalty. Beyond being known clients, these packages of care were easy to organize from the providers’ perspective: both were for regular and substantial hours. Both service users and unpaid carer benefited from regular carers, increased communication and working things to the service users’ needs, such as; shifting the first visit of the day to an earlier time to promote continence and spacing visit out evenly across the day. Unpaid carers also mentioned that they assisted them in giving them ideas for how to improve care. In one case this prompted the service user to seek a review and led to an increase in the DP allowance and therefore in the care provided by the home care agency.

“I’ve actually been quite forward in saying to social services – well, you know – in collaboration with the agency - because the carers are quite open with me if something isn’t really working…I´ve found that has been really good because they’ve given me ideas of her needs that I really need to sort out.” (UC2)

In contrast there were three cases where the circumstances of the care sought from agencies were considerably more challenging. These included two service users with severe dementia whose problems included anxiety, repetitive behaviours, occasional aggression, inappropriate behaviour and incontinence (such as defecating in the living room). One sought regular hours and was relatively satisfied with care received.

"It's more expensive but it's easier because they find the person…If I´m unhappy with the person I can just say to the agency I don´t want them – send someone else." (UC6)
The other sought care only in emergencies and was less satisfied with the attitudes of the care workers sent.

The final situation was a case which required regular daycare and sporadic overnight care, sometimes requested last minute, due to the nature of the son's job (Table 7.3). This was the only instance where council commissioned care had not been received prior to DPs (and DPs had been the only option offered), a situation which reflected general difficulties in brokering unpredictable demand. This unpaid carer had had many negative experiences, not just with one but with various agencies employed. He detailed a catalogue of complaints: mischarging, poor attitudes, poor quality of care from care workers, not fulfilling the allocated time; lack of continuity, breaches of safety including losing the front-door keys; leaving the front-door open when leaving. Above all his greatest frustration was related to a lack of means of quality control and redress:

"The previous agency… wouldn´t turn up – or they'd turn up horribly late, basically meaning I have to do the thing anyway. And I was like saying, not charging isn't a sanction for this" (UC3)

"[The agency] had this carer who had done nights for my Mum before, and she knew exactly what was entailed. She knew the difference between what she needs going to bed - at night - and waking up but they insisted on putting somebody in with no experience and said it was no different…" (UC3)

As he saw it, in the absence of some sort of control mechanism taken by the local authority he was in a situation of very little power.

7.3.4. Benefits of DPs

Combining resources to maximize care

For some of the people interviewed, the social work reviews which lead to being offered DPs occurred in conjunction with an increase in the level of care allocated relative to the prior circumstances. This was the result of a final recognition of what was required, the inadequacy of previous arrangements and acceptance of their preference to avoid residential/ nursing home care. Nevertheless this invariably fell short to some extent of the support that unpaid carers felt was necessary.

DPs enhanced the value of these allocations in two ways. Firstly they were able to tailor it to preferences and in the case of those employing PAs – they were able to employ someone for more hours (Table 7.4). Secondly it permitted dovetailing care funded through DPs with care funded privately (predominantly paid for from the state benefit Attendance Allowance), often using the same provider. This allowed unpaid carers to cover *everything* that was needed.

UC7 recognized a spend time at the weekends with his family rather than being entirely occupied with unpaid care. His mother needed constant supervision and the DP only covered a live-in carer during the working week. Using funds from his mother's small widow's pension, he funded the "weekend people" that attended in combination with visits from friends and family which he coordinated.

UC6 needed to leave home for work at 08:30 every morning after getting his father up, changing his bed, showering and dressing him and handing him over to the carer. He was not able to get back home until 18:00. This left an 8 hour surplus from the care that could be purchased with the DP allocation. This excess was paid for from his father's Attendance Allowance. UC5 - a single mother with a daughter away at University wanted to care for her mother at home but couldn't cope with her own job on a recipe of broken nights. Five nights care per fortnight were allocated – the daughter added to this budget to fund support every night (partly using her mother's Attendance Allowance which she administered and partly her own income). She also organized a rota of friends and neighbours who supervised during the day, as her work schedule did not always coincide with the three days of day care that were also allocated. This package was an alternative to state-funded residential care.

Maximizing quality of life for service users

All of the unpaid carers (with the exception of UC3 who had unsatisfactory experiences) felt that the package of care organized through DPs maximized their parents' quality of life.

"I know if he goes into a home, he's going to be plonked into a chair." (UC6)

"It's much better. It really, really works. My mothers, um, quality of life has been much, much better." (UC7)

Among the notable differences were descriptions of how their parents' conditions had improved as a result:

"Now that she has a carer full-time she's got her using the commode – which has restored a bit of normality back to her life."(UC7)

"She's practicing hand-writing with her and looking at pictures – she gets Mum to pick out certain pictures. All sorts of things – cooking as well." (UC1)

Control over timings was also crucial.

"It's the timings as well. Because my parents go to a social club on Wednesdays and Thursdays and I really wanted to keep that…" (UC1)

Support for carers: coordinating care with employment

Reliability of care, control over schedules, the flexibility to pay extra to cover all necessary hours and being able to recruit the right person (albeit for some to a limited extent), were the key ingredients to supporting carers to reconcile work with unpaid care. Even amongst those who had had some difficulties in the process of securing care, DPs was still considered to be a superior option.

"Without the direct payments there's no way I would be able to cope. He would either be in residential care or I'd have to give up work and look after home full-time, and my brain would explode to be honest with you." (UC6)

"It does give the flexibility… because the money is on a month to month basis as I don't use it all the time - it depends when the work comes. One or two weeks I could be at home and not go anywhere and in the next one I could be away for two weeks" (UC3)

7.3.5. Non DP related sources of stress

There were aspects of caring for their relatives that were stressful and demanding regardless. Interviewees spoke of the intrusion of sharing one's home with care workers.

"There is no space, there's no sanctuary anymore. That's what you've lost. I can get up in the morning and come through to make myself a cup of tea. I just want to be quiet for five minutes – and a carer comes though." (UC5)

For another UC that was not resident an ongoing source of stress was dealing with crucial paperwork sent (inappropriately) to her mother's address.

"It's just crazy. Mum had a letter the other week from the incontinence pad people, saying that now they have to be ordered by the client. But they had put no address, no phone number, you know – please contact us! So I took it home – looked them up on the internet… I mean my Mum she wouldn´t have a clue, faced with that letter. She would just put it to one side…and that would be the end of it, no more pads!" (UC2)

Coordinating care was not just limited to DPs but also involved being constantly on top of their parents' long-term conditions, coordinating appointments, visits from friends and family, relaying information and so on and so forth.

“I get lots of phone calls- you see my time, it´s very hard to estimate, because an awful of it is phone calls”. (UC7)

Finally, as could only be expected the unpaid carers talked off the emotional strain from witnessing their loved ones deteriorate:

“The person you used to know, he has gone. He´s not there. Every now and then you get a slight glimmer of it come out, but basically he doesn´t know if he is alive or dead. He´ll ask me, ´Am I dead?´” (UC6)

“It’s aged my father as well, ten years. You know, it’s difficult. It’s aged me as well.” (UC1)

7.4. Discussion

The data presented provides a snapshot of the circumstances in which seven working carers managed direct payments. These narratives are not expected to be wholly representative but their experiences may be considered generalizable (Miles & Huberman 1992). The interviews were conducted a decade ago, and changes in policy and practice that would affect current unpaid carers in similar situations are expected to have occurred. Complaints about the irreconcilability of relying on services directed by social services as working carers trying to keep track of their parents’ care from one end of telephone- and of the inadequacy of council-commissioned services resonate strongly with the findings from more recent studies (Brimblecome *et al* 2017; Ryan 2012) suggesting that the kind of experiences which drove these unpaid carers to contemplate DPs are still very prevalent. Hence this discussion focuses on the factors relevant to working carers (and unpaid carers of older people, in general) on receipt of DPs. Three issues are discussed at length: access; (the development) of support and brokerage services, and the debate surrounding the burden of ‘managerial care’.

7.4.1. Access issues

Most of the working carers in the sample experienced difficulties with social and/or health services. One hopes that some of these hurdles have been overcome during a decade of policy development. One of the issues was a poor fit between resource allocation and service delivery in conjunction with the capacity of working unpaid carers. This was most acute for service users with dementia who required almost constant supervision for safety reasons. The Department of Health has sought to improve this scenario. In 2014 the category "memory and cognition" was created as a primary support reason for activity data collection (HSCIC 2016a) but few older people receiving social care in the community for memory and cognition are receiving DPs (Alzheimers Society 2016). As in the research presented here the pressure to control expenditure continues – particularly if a service can be "obtained" through the voluntary sector – thus limiting choice. In a study by Rabiee *et al* (2016) home care agency managers reported that allocations of care via PBs did not permit provision of sitting services.

There were also issues with access to DPs from hospital. One family suffered delayed discharge attributed to a lack of available home care but in reality due to a lack of appreciation of DPs as a possible alternative among hospital social workers. As the data shows this is not just a cost to the NHS but has a cost to families involved with prolonged hospitalization placing a great deal of stress on family members. Figures were published in June 2017 which showed that delayed discharges were at a record high, with "the highest proportion of delays attributed to social care since monthly data was first collected in August 2010" (Government Statistical Service 2017). Care managers continue to be uneasy about presenting service users (and their families) with choices about how care is delivered while they are awaiting hospital discharge, particularly when the responsibility to provide unpaid care is new – suggesting that families should settle into new routines at home first (i.e. with local authority commissioned care) (Rabiee *et al* 2016).

A further barrier to access to DPs for individuals such as these working care/ parent dyads lies in the processes developed for circumstances where DPs are managed by a relative on behalf of the person being cared for. The sample of working carers carried out this role under through the power of attorney as in other studies (Coles 2015; Jepson *et al* 2016; Laybourne *et al* 2016; Glendinning *et al* 2008), but since the introduction of the Mental Capacity Act, social workers must now determine if there is an appropriate (and willing) ‘suitable person’ to manage DPs (DH 2009). This process is designed to discourage someone from inappropriately taking over the controls but appears to have resulted in greater delays for families awaiting the availability of so called ‘best interest assessors’ (Baker 2017). On the face of things it seems that working carers today would continue to face difficulties accessing DPs in the circumstances that the sample found themselves in.

7.4.2. Support planning and brokerage

Since the study was undertaken “support planning and brokerage” have become part of the cycle of providing a PB. These functions have been taken up by DPSS as an extension of what they were already offering to DP users, as well as by other organisations within the voluntary sector as a result of the concordat Putting People First which required that support planning and brokerage to be available both for those in receipt of statutory funding and for those who don’t qualify for financial support (Brookes *et al* 2015; Rabiee *et al* 2016; Jenkins & Hay 2010; Orellana 2010). Support planning is supplied to all service users, while brokerage focuses is mainly associated with support in securing services from a home care agency (while support with hiring a PA is still termed recruitment support (cf. chapter 4). As this was common among the sample, these developments are relevant.

An obvious question is what is termed support planning and brokerage may have improved the efforts of unpaid carers to manage care through DPs, versus the individuals sampled. To start with, it is hard to specify exactly what kind of support is provided under the terms support planning and brokerage due to differentiated terms.

Recent studies suggest that *support planning* is in effect the new care planning with its focus primarily on determining a support plan with the client, outlining their hopes/fears and aspirations, and/ or drawing up a budget as part of support plan. However there are many wider definitions, with suggestions that support planning also include, “informing older people about available service options and their costs; helping to identify potential options and choosing between these" (Rabiee *et al* 2016: 454) – a definition which combines planning with brokerage. However official guidance on "support planning and brokerage" tends to use the terms support planning and support brokerage interchangeably, to refer to what is essentially support planning with no discussion of the extent to which support brokers may be involved in supporting service users to secure services (DH 2010b).

In contrast representatives from user-led DPSSs have described brokerage as potentially supporting clients to researching available service provision; negotiating costs; drawing up contracts; general negotiation with service providers, such as negotiating the terms of the contract and /or assisting other voluntary sector organisations to provide support (Davey 2010).

These differences in definitions suggest that the experience of support planning and brokerage vary substantially –overlapping functions may also be termed care-coordination (Sutcliffe *et al* 2016). On balance though, it seems that support planning is now "overwhelmingly carried out by, or with help from council staff" (Rabiee *et al* 2016: 456), despite initial aims that support planning should be undertaken by various sources. This is explained by the fact that social work practice seems unable to disentangle the development of a support plan from the allocation of resources, and as such find it difficult to accept a support plan developed by an independent party (Glendinning *et al* 2008). In one pilot in the South West, social work staff boycotted a project designed to develop independent support planning and brokerage from a local voluntary sector organisation because of concerns about unqualified volunteers taking over staff roles (Kendall *et al* 2010). As a result the voluntary sector appears to have focused its efforts on self-funders (Orellana 2010).

Where local authorities *have* encouraged independent support planning and brokerage, some people report confusion from multiple visits during the start-up period suggesting that recent developments may be counter-productive. In particular they struggled to understand the role of independent support planners in conjunction with the remit of social service practitioners (Orellana 2010, Rabiee *et al* 2016). Most of these accounts refer primarily to devising support plans, an area which the interviewees managed satisfactorily with guidance from DPSSs – and all reported high levels of satisfaction with this.

To focus on an area where the sample had some difficulties and its overlap with these new functions, we need to consider the act of recruiting care from care agencies. Of the concerns raised, was the desire for *specific* or personal recommendations when choosing a home care agency, in common with other studies (Trigg *et al* 2017; Baxter & Glendinning 2013). DPSSs (which were their main source of support) were either reticent in the information they imparted (for fears of potential legal ramifications of making specific recommendations) or limited (in their knowledge of local providers). This situation continues as local authorities explicitly prohibit DPSSs from, "introducing implicit monopolies by influencing customer choice" (Bolton 2012). Instead, some local authorities have opted to provide online data on provider options (Wilberforce *et al* 2012) - the utility of which has yet to be established. Multiple sources continue to cite inadequate information for service users and their families as key obstacle in the use of PBs/ DPs (Orellana 2013; NEF 2012).

The second concern was for means of leverage when commissioning care. At the time of the research the only families directly commissioning home care agency were DP users and self-funders. With the introduction of personal budgets, recipients of managed budgets are now expected to be able to select their provider and specify conditions to some extent. To facilitate this, in-house brokers have recently been introduced, acting as "intermediaries between support planners and home care providers" – available to DP recipients and people opting for managed budgets (Baxter *et al* 2013: 402).

It is through this function that the most significant improvements would be expected – that could facilitate the use of DPs for greater numbers of working carers. Yet it is far from clear that this function meets its objectives. One study reported that support brokers working in-house had limited knowledge of local home care agencies, while the aspirations of support plans were unmet due to restricted capacity of providers to respond to individual preferences (Rabiee *et al* 2016). Another found that "brokers knew very little about individual older people and their needs; their information came entirely from paper and email records rather than personal contacts" (Rodrigues & Glendinning 2015).

Five out of the seven working carers included in this study used home care agencies to secure some (or all) of the care purchased and only one had had serious difficulties. In brief, agencies responses were not consistently better simply because the client controlled the purse strings. The findings offer a glimpse at the complex mix of incentives related to client characteristics, care package characteristics, payment rates and provider context - such as the position of an agency within any particular market - that are likely to influence the experiences of individual purchasers. Arguably these extend beyond observations that can be picked up at a quantitative level (cf. chapter 4) – but it can presumed that the significance of these dynamics will have multiplied with the growth in take-up of DP.

This analysis provides insights into the impact and existence of certain dynamics. 1) That providers are in a position where they can influence unpaid carers (as in the case of UC2) particularly where unpaid carers are less present and rely on their feedback as in the case of working carers. 2) That providing DPs for ‘inconvenient packages’, such as one requiring irregular hours (Baxter *et al* 2010) (as in the case of UC3), shifts the inconvenience to the individual. Hence the legitimate concerns over the increase in the use of DPs where capacity among existing providers is exhausted (National Audit Office 2016). 3) That intensive and consistent packages consisting in large blocks of time (rather than multiple short visits) are appealing to providers. From the outset of DPs, care mangers in many areas could offer DPs as a means of accommodating clients with more complex needs to pay an hourly rate for care above the limit for council-commissioned providers (much as self-funders do), or to use ‘the DP allocation’ to purchase more hours by contracting a PA at a lower hourly cost (Davey 2006). As shown, this flexibility could be enhanced by the addition of private funding (with funds from Attendance Allowance). Thus at the outset individual purchasers may be advantaged or disadvantaged - and as would be anticipated this can be associated with variations in experiences.

The unpaid carer who was the most disadvantaged at the outset (UC3) appealed for greater support from the local authority. For example with protection mechanisms for over-charging and means of redress for care that was of poor quality. It is said that the appetite among local authorities for focusing on managing the market for self-directed care and self-funders has increased (Department of Heath 2013; Jenkins & Hay 2010) - but very little research has focused on specific details of these efforts or on their impact. In a single study concerning six local authorities, only one had managed to negotiate for DP users the same rate for home care services that they charged the authority (Rodrigues & Glendinning 2015). Meanwhile a representative of the United Kingdom Homecare Association Ltd (UKHCA) warns against requiring providers to committing to a maximum charge to self-directed users, capped at the going price for high-volume contracts (increasingly a prerequisite to being accepted as an accredited provider) - if the price for a place on the list is a commercially unsustainable charge rate (Angel 2010). Clearly the tensions are great with local authorities battling increasing demand for services with substantially reduced budgets.

There are also many possible extra complications to market management such as local monopolies due to geographical restraints in cost-efficiency (Baxter et al 2011), thereby reducing any need for providers *"to be constantly proving themselves and proving their worth"* (Baxter *et al* 2013: 402). Some authorities are taking more radical steps to drive up quality. This includes stipulating that DP users are visited by the same carers on each occasion (Rodrigues & Glendinning 2012); introducing a daily log of difficulties encountered by brokers/ service users with a system for immediate follow-up (Bolton, 2012); purchasing care as activities tied to outcomes (Bolton 2012); requiring providers to provide salaries to staff to improve retention (Bolton 2012) and encouraging payment of retainers for irregular hours (Baxter *et al* 2011). It is important to recognise that these are exceptions to current norms. More research is needed to understand the conditions necessary to success. Bolton (2012) notes that the around 50% of service users in Wiltshire are self-funders – significantly higher than the average (UKCA 2016). Self-funders often subsidise the costs of local authority funded clients, meaning that home care providers with higher proportions of self-funders may be under less financial constraints (and therefore better able to respond). Also related to the different relationship they have with self-funded clients they are likely to be more open to such proposals.

Essentially the situation of any individual commissioning care with a restricted budget calibrated to prices paid by local authority commissioner, within any market (i.e. a service users or unpaid carer receiving DPs) is one subject to the challenges faced by local authority commissioners or ‘brokers’, yet with the potential to resolve the challenges via a more flexible approach or a set of tools which local authority commissioners are not permitted. For example, commissioning from a non-accredited provider, paying extra for care or simply investing more time and energy in negotiating with providers or in trial and error.

Much has been made of the necessity for information on available services to support DP users, but very little attention has been placed on developing systems to ensure that DP users have some leverage over quality or the price of services. Despite reports of an appetite for this, there is likely to be considerable opposition– from providers who oppose the imposition of further constraints and shifting of risk - and from local authorities who oppose the idea (and cost) of acting as middle man.

7.4.3. Managerial burden

As demonstrated in the work by Rosenthal *et al* (1999) on working carers, the UCs in the sample, while more limited in their time spent providing direct care but were substantially involved in providing ‘managerial care’ prior to taking on the role of managing DPs and specifically in orchestrating care which Rosenthal *et al* (1999) found to be associated with work-family conflict and job costs for men and women and with higher stress for women. Other studies on the role of unpaid carers in supporting DPs fail to recognise previous roles in managing care (Table 7.1). The results show that working carers were obliged to provide managerial care prior to using DPs as a means of trying to keep things in order while they were absent (even if they were not resident). This was demoralizing as services were often inadequate and their inability to improve matters was very limited. For the older adults they cared for, there were obvious - and sometimes serious consequences. It was also threatening their employment (Brimblecombe *et al* 2018), and they were suffering risks to their psychological well-being linked to their frustration in being unable to control care (Al Janabi *et al* 2008). The extent of unpaid carers managerial input in the context of council-commissioned services and the fact that it was considered an unavoidable burden, call into question the notion that care organized by local authorities reduces family burden. This is at least partly due to what Bode (2007) describes as the disorganised governance of homecare for older people in England, where the responsibility for outputs has been devolved to independent providers subject to the risk of bankruptcy and fluctuations in local care market. A situation which reduces local authorities leverage in controlling quality to *expost* controlling, (i.e. dealing with complaints). From this perspective, the accounts presented, of working carers who felt obliged to try and coordinate control the quality of care delivered through services commissioned due to its inadequacies may be regarded as a natural consequence of the system.

In response to these circumstances, unpaid carers searched for an alternative and in being offered the alternative (DPs) took on an alternative but not necessarily lesser managerial role. Wider research has mixed reports of the impact on unpaid carers of the *administrative* burden of DPs but these reports have one thing in common. Negative reports have been from unpaid carers that had not had support from a DPSS (or similar)[32] …. or from one whose services were inadequate … while all reports that can be found from people who have received support with administrative responsibilities have been positive (Arksey & Baxter 2012;Woolham *et al* 2018; Larkin 2015; Glendinning *et al* 2009). All but one of the unpaid carers in the sample had received substantial support from a DPSS or payroll agency and these inputs had served to prevent the administrative burden being onerous. This has parallels to the financial and bureaucratic management component of managerial care from Rosenthal *et al* (1999) and suggests that external support may help to alleviate this, something that could be of benefit to other unpaid carers (such as those supporting self-funders) . Most importantly, increased control over care, the ability to improve the quality of support received by their parents and the ability to organize care to fit in with their work demands all served to reduce the stresses of managing care – even if they spent more time ‘orchestrating’ care. Research needs to question the assumption that greater time spent managing care is a likely indicator of negative outcomes of DPs for unpaid carers, as has been suggested elsewhere (Woolham *et al* 2018; Glendinning *et al* 2009).

Finally in relation to working carers managing DPs, the most significant mediator of outcomes was recruitment. The working carers interviewed were more inclined (or

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[32] In a study by Arksey & Baxter (2012) one UC, a disabled mother of three initially refused direct payments in favour of council-commissioned care but subsequently opted for direct payments when she discovered she could have administrative support.

obliged) to recruit from a home care agency than other service users in the wider study (cf. chapter 5) and were thus more influenced by dynamics which predestined them as advantaged or disadvantaged when recruiting. This status appeared to be relatively unaltered by access to information on providers. Arguably local authorities should be taking much greater responsibility in assessing the relative accessibility of local care markets to service users and unpaid carers attempting to purchase care through DPs.

7.5. Conclusion

The involvement of families in managing care is by and large a basic reality of long-term-care (particularly if self-funders are also considered). Unpaid carers that are employed are at the acute end of this being especially dependent on services doing what they are supposed to do in their absence. Where means of control and flexibility are poor, DPs can offer a solution. The literature on DPs and unpaid carers is awash with concerns about the burden for unpaid carers but has not accounted for how experiences might vary according to the support received (in administrative matters and recruitment); the accessibility of local care markets and intervening factors. Instead research is essentially concerned with individual ***capacities*** be they those of the person receiving services, or of the person managing care.[33] Consequentially circumstances that might limit the capacity to take on 'additional' responsibilities and are added to the list of circumstances unlikely to be suitable – at least until all other options are exhausted. A key example of this is the scenario of working carers. The research presented shows that management of DPs was akin to *alternative* rather than additional responsibilities.

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[33] As just one example, Jepson et al (2015: 7) concluded that "the benefits of DP may be accruing chiefly to those who have 'suitably' skilled enablers, potentially excluding vast numbers whose families do not have necessary skills to manage a budget".

7.6. References

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8. Conclusion

This PhD has set out to understand how direct payments work in practice for older people and what factors contribute to the benefits gained from DP.

First, a general view on policy and practice developments is obtained by tracing the evolution of DP support in the past decade (chapter 3).

This is followed with a series of analyses drawing on data from interviews with 81 older people receiving DPs conducted as part of the evaluation of the Direct Payment Development Fund (Davey *et al* 2007), which took place immediately prior to the implementation of Personal Budgets (PBs). The work presents new findings of old data which offers a level of detail unmatched by previous studies and discusses the insights that these provide, both as an example of how DPs to older people can work in practice – and as a tool for trying to understand how DPs may be currently working in practice. The exploration of profiles of support across a decade of direct payments development also offers a new outlook on this.

The analysis of the interview data takes on lots of perspectives, drawing on a conceptual model which conceives that a broad range of service user characteristics and circumstances may combine with external factors influencing care market conditions, leading to differences in the intermediate output (i.e. the types, quantities and qualities of care received). This is demonstrated by a combination of quantitative and qualitative analyses. Each of the five empirical chapters culminates in conclusions which are ultimately interrelated. The objective of this final chapter is therefore to highlight some of the key cross-cutting themes, and discus how the insights from the work may be taken forward to inform future research.

8.1. Limitations and strengths of this work

Before getting on with the detail of what has been learned and what may follow from this work it is helpful to revisit some of the limitations and strengths of this research. The chapters consist of analyses of two data sources: a national survey of Direct Payments Support Schemes and follow ups to the original responders in 2011, 2014 and 2016 (chapter 3); and face-to-face interviews of 81 older people receiving direct payments between 2005 and 2007 which were transcribed, and coded for quantitative (chapters 4 and 5), and qualitative analysis (chapters 6 and 7).

Survey of direct payments support schemes and its follow-up

Coverage of English Authorities in the original survey was good (2/3) but not complete, hence the follow-up equally excludes the organisations and their local authorities that did not participate. In its favour, the original respondents were mainly direct payments support schemes which, along with the corresponding local authorities were more advanced in the implementation of direct payments. This suggests that the analysis of direct payments support profiles was sufficiently comprehensive, but when it comes to seeing how provision has evolved it would have been interesting to include the non-responding areas for descriptive and comparative purposes– although for the analyses of the relationship between individual DPSS factor scores in 2006 and subsequent status this data would have been redundant.

The chapter employs a complex three-stage methodology (exploratory factor analysis, multivariate regression and marginal effects models), each of which needs to be interpreted in a manner that is appropriate to the data and the objectives of the research. All efforts were taken to ensure this.

No other work to date has systematically examined the state of direct payments support schemes or charted local authority commissioning of direct payments support. The work demonstrates just how radically direct payments support has changed over time: inevitably this calls into question the current applicability of the support profiles. While it is useful to have focused on profiles of support at an historical point in time for the purpose of exploring subsequent local authority commissioning behaviour, to fully understand the current supply of services would require reprofiling.

***Quantitative** analysis of interviews with direct payments users and proxy respondents*

In chapter 4, the interview data was employed to identify associations between outcomes gained by direct payments and factors such as service users' characteristics and the types and quantities of care purchased.

The data provides an historical cross-section of a relatively small sample. The sample itself self-selected but is arguably more diverse than the samples of older people receiving direct payments in previously published studies that come to use direct payments either through contact with disability groups, or at the direct request of family members. Two-thirds of the sample used for the analyses presented here had only found out about DPs through social or health service sources.

The results of the model are not considered predictive but explanatory. Their explanatory capacity is greatly aided by the mixed-methods approach as each one of the covariates in the model relating to the individual characteristics of service users and patterns of direct payment service provision (cf. Figure 2.2) was explored in much greater detail in the subsequent chapters (5, 6 and 7).

A further strength of the data relates to the manner in which it was collected. Most quantitative data included in analyses in the previous studies of direct payments use data that was obtained through questionnaires. The fact that the data used for this thesis was obtained face-to-face has many advantages. The number of missing values in the dataset for the indicators used was negligible - a factor which offers considerable protection against modelling risks such as overfitting.

The interviewer's observation also reduces the risk of inaccuracies and over-or under-estimation of crucial measures, particularly the measure of outcome gain, and the hours of unpaid care. It also helped to ensure the validity of combining proxy with non-proxy responses which was a necessity due to the highly dependent individuals sampled and the high proportion for which an unpaid carer managed their direct payment.

Finally, the face-to-face means of obtaining data permitted collection of data which offers an unprecedented level of detail. This leads to the gain versus limitation of the dataset given its historical basis. Its detail and its timing allowed me to explore the relevance of changing structural factors (affecting who receives direct payments, what external support they have available, what are the subsequent recruitment patterns, and so on) versus individual characteristics, such as the balance between DP-funded care, self-funded and unpaid care.

Among other things, this underlines the importance of direct payments support with recruitment and employment management. The vast changes in direct payments support and the high turnover of direct payments support schemes means that this ‘input’ is no longer available for many service users, in the sense that it was when the research was conducted. Does this mean that results offer a “historical lesson” rather than “direct application” value? Herein lies the value of the overlapping strands of work in the thesis. The results of chapter 3 show clearly that a sizeable proportion of local authorities have continued to pursue (and update) the model of direct payments support developed a decade ago.

The same critique may be applied to aspects of service provision included in the model, particularly the generosity of care packages and/ or the extent of unpaid care. This is discussed at length in chapter 4 (section 4.7.3) as the issue is complex and subject to local and individual variation. What matters is that the care packages received by the sample were aligned with current resource allocation principles and also applicable to today’s context with services being skewed towards the most dependent. The results offer novel insights, showing that particular attention needs to be paid to the *discrepancy* between total care input (which could include unpaid care and/or self-funded care) and direct payments-funded support.

This leads on to the use of the interview data in chapter 5 to determine how unpaid care varied among the older people receiving direct payments. The detailed elaboration of variations in unpaid care showing the ratio of purchased (funded) care to total care relative to both unpaid and/ or self-funded care (Table 5.13) is the first of its kind. It offers a clear comparative basis for future studies on direct payments to older people (ideally with larger samples) to assist in moving beyond the focus on care allocations in monetary terms. It also helps to identify the types of service users for which such discrepancies were highest. These turned out to be mainly individuals with cognitive impairment, people supported by a male spouse and co-habiting service user-unpaid carer dyads.

***Qualitative** analysis of interviews with direct payments users and proxy respondents*

The two qualitative chapters offer rare insights into two sub-groups of the overall sample: husband and wife teams and working carers managing direct payments on behalf of their mother or father. The focus in each is on a small number of interviews that most characterise each group. The goal is not to present the results as ‘representative’ of all individuals that might fit within these groups but to present findings that have transferability and relevance to others in similar circumstances.

Chapter 6 offers the first research perspective on the role that husbands can play in supporting older women receiving direct payments and on the impact of direct payments on the dynamics of unpaid care. Equally chapter 7 provides the only exploration of the the circumstances, motivations and experiences of working carers heavily involved in managing DPs for their father or mother, and of their experience of ‘managerial’ care.

As discussed throughout the thesis, the context in which DPs are supplied has changed dramatically in the past decade. Service users and their carers’ are less likely to have the kind of support that was previously available to help recruit care workers and they are also now subject to a vastly more precarious state of home care services and greater costs brought about by factors such as the introduction of the national minimum wage for sleep-ins (dependent upon certain factors). The findings must therefore be treated with caution but what the high level of detail offered allows future researchers to examine the impact of such changes.

Both chapters aim to offer a more nuanced understanding of the impact that direct payments can have on unpaid carers through their narratives. Since the research was undertaken, significant advances have been made to develop tools for measuring unpaid carer wellbeing which - if they had been available at the time of the research - would have been incorporated into its design.

Finally it is worth reflecting that many positive benefits from receiving direct payments were revealed through the qualitative analyses among service user ‘types’ which quantitatively may have been associated with lower outcome ***gains*** from direct payments due to the large discrepancies between total care input and DP-funded care. I think this offers an important reminder that ‘acquiring less outcome gain from direct payments’ is not equal to being *unsuitable* for direct payments. Everything comes down to the context and the priorities of direct payment service users and their families.

8.2. The changing face of DPS and it potential impact on the experience of service users

DP management requires completion of core administrative tasks and other skills related to securing and supervising care either by the service users or by an agreed “suitable person”. Since DPs were first introduced, external direct payments support (DPS) has been an integral part of the model, provided by entities referred to collectively as Direct Payments Support Schemes (DPSS) – yet it was not until cerca 2006 that a major policy drive to promote DPs had expanded the sector significantly. Its impact was to ensure that most local authorities held a contract with a DPSS – most of which were the first and only scheme operating within each local authority area (Davey *et al* 2008). Little did these original providers know at the time just how far successive governments were likely to embrace the ideology of “self-directed care” – nor that it would form the basis for a radical overhaul of social care delivery under the umbrella term “personalisation” that would force the mainstreaming of direct payments alongside alternatives - aimed at embracing some of the features of direct payments on a more limited basis but with the advantage of *shifting less risk to the individual* - a phrase employed under the assumption that greater local authority control ensures greater protection of clients, particularly more “vulnerable groups” such as older people.

The past decade has seen massive turnover in DPSS services – in some cases with changes in the provider of services occurring on an almost yearly basis. Considering the consensus that DPS was an integral part of the model supporting better outcomes, this level of turnover appeared to have some relevance. After all, the majority of providers commissioned by to provide social care are awarded a minimum of three year contracts – and more often than not, five year ones (Fernández, D’Amico & Forder 2012)

Yet the field of DPSS has by and large been overlooked by research. To start with, there has been no investigation of patterns in the range of services available, or attempts to link the characteristics of organisations with particular profiles of support. Yet there *were* widespread perceptions that differences in DPSS were affecting their evolution.

These have been anecdotal and based on fears that DPSSs run by Centres for Independent living (CILs) and other user-led organisations (ULOs) were increasingly being decommissioned, amidst a growth of for-profit agencies offering lower-priced services with less direct contact with service users. These concerns were symptomatic of a decreasing prominence of CILs in setting the agenda for the implementation of personalisation across social care and – specifically steering delivery of direct payments. This could hardly have been predicted previously given their historical legacies in driving forward independent living. The nature of this debate failed to consider underlying factors that may have affected the evolution of "*original*" providers such as their size, structure and sustainability thereby creating polarized arguments from stakeholders on either sides. Much of this has been due to an absence of data.

Equally there has there been insufficient focus on understanding how the services provided by DPSS may influence the benefits derived from DPs and moderate the risk associated with them, particularly given the wide variation in what was available (Davey *et al* 2008). Nevertheless a number of qualitative studies suggested that there was a particular need for DPS to support older people to access DPs (Newbronner *et al* 2011), which led this to become a focal point of this thesis.

For the author of this work, what is particularly surprising is the failure to recognise the local authority agendas shaping DPS. This appears to be in direct contrast to the situation in the USA where many states mandated that recipients of Medicaid funded self-directed care programs access financial management services (akin to DPSSs), due to concerns about both lack of compliance with fiscal responsibilities and risk of abuse (Scherzer, Wong & Newcomer 2007). As such, a key element of "counseling" in the Arkansas cash and counseling demonstration was ensuring that recipients understood and *adhered* to these responsibilities. In the UK, research has repeatedly demonstrated how access to DPs is blocked by care managers' lack of confidence in handling them, combined with their concerns about managing risk and professional responsibility (Ellis 2007; Mitchell & Glendinning 2007). Not discounting the plethora of discourse surrounding risk management in the use of DPs prioritizing protocols for abuse detection and prevention (Carr 2010a, Department of Health 2010; Manthorpe *et al* 2009).

A further area in which DPSS have developed (chapter 3), is in assisting service users in the management of personal assistants (PAs). Studies that have explored the nature of direct employment of PAs, both in the UK and elsewhere, have revealed the immensely complex nature of these support relationships (Ahlström & Wadensten 2010; Cairnocross & Crick 2014; Christensen 2010; Leece, 2010; Glendinning *et al* 2000). Direct employers and their PAs' lives are often intertwined with each other in a way that those of homecare workers and other their service users are not (Ahlström & Wadensten 2010; Leece, 2010). PAs complete a far wider range of work than homecare workers and frequently express a personal closeness to the person in their care; indeed, this can be such that it can be viewed as crossing the boundary of a 'purely professional' relationship.' Moreover, they also report high levels of reciprocity and freedoms within the "workplace", typical of other within home care work, which can lead to difficulty in differentiating between 'work' tasks and what could be considered 'social interaction' (Ahlström & Wadensten 2010; Christensen & Manthorpe 2016; Leece 2010). On the other hand, service users tend to report the need for more information on the short and longer-term implications of choosing the 'right' personal assistant (Arksey & Baxter 2011) and being fully informed about employment law and there has been some research highlighting the vulnerabilities of PAs (Cairncross & Crick 2014). The repercussions of the 'wrong'- fit, combined with misunderstanding of responsibilities, can result in cases that fall heavily on the shoulders of DPSS, local authorities and, where involved, the providers of employers´ liability insurance. Here in lies the question of whether it is really within the capacity of DPSS to mediate the relationship between service users and PAs and to what extent these types of high-intensity services are prioritised by local authorities.

In the USA "fiscal intermediaries" can process enrollment, review fiscal records for accuracy, write checks to (agency) providers, and maintain payroll for PAs (Cook *et al* 2008). Despite being developed with a view to also safeguarding the position of personal assistants research suggests that fiscal intermediaries are likely to have had limited effectiveness in improving worker training, safety, wages, benefits and retention (Scherzer, Wong & Newcomer 2007). This would suggest that the scope that DPSS have in employment management, beyond the structures for supporting administrative and fiscal responsibilities may be crucial in protecting the cared-for and the care-provider (PA). This has been underlined by the work of Skills for Care whose remit includes supporting adult social care organisations and individual employers in England support the PA workforce. In a recent report they stated that;

"*…strong links between local authorities and their ULOs can have huge value and it is important that both parties develop relationships built on trust, openness, shared expectations and clear communication. This can ensure clarity of understanding between roles for both parties and avoid duplication of effort in local support arrangements* "(Skills for Care 2015) - Whilst also underlining that much of the current support for PAs is organized in-house.

When it comes to assessing the direct benefits of DPS to service users, the evidence base is also very limited. There has been enough research supporting it to provide an impetus for commissioning DPS - but insufficient detail for shaping the nature of that support.

The thesis tackles this lack of evidence in two ways. Chapter 4 provides for the first time a statistically significant link between receiving *recruitment support* (which was viewed as **critical** - telling us something about the *quality* of the support) - and obtaining greater benefit from DPs among the "older people" interviewed. In reality much of this support was directed to families and unpaid carers that were managing DPs on behalf of their relative. Other than this, the work demonstrates how beyond the influence of individual characteristics, the types of care purchased influenced direct payments outcome gain (DPOG). Individuals, who purchased care that was flexible, in that it deviated marginally from standard home care, achieved greater gains. This is relevant to the discussion because purchasing this type of care was most prevalent among service users who used a PA and the majority of those who recruited a PA had done so with some form of support from a DPSS. In addition, half of those who did not recruit a PA also used recruitment support where the DPSS acted as brokers for individuals purchasing care from home care agencies. This support was ongoing / as required and generally free at the point of use (something that is no longer the case for many DP users today – cf. chapter 3).

The fact that recruitment support (viewed as critical) was the aspect of DPS that was associated with greater outcome gain (and administrative support did *not*), does not contradict previous research findings that have mainly highlighted access to payroll support as a key factor in individual decisions to take on the management of a DP or not (cf. Arksey & Baxter 2012; Glendinning *et al* 2008; Clark *et al* 2004). Indeed, in chapter 7 we see that for working, carers much of the potential stress associated with ‘additional roles and responsibilities’ was alleviated by using payroll services, either available through DPSS or other payroll services offered by accountancy services . This service was a necessary prerequisite to certain choices being a realistic option – first in the decision to take up DPs and secondly in the decision to employ a PA. It was a predominantly a time saver – or enabled people to avoid making simple mistakes but in itself it did not directly affect outcomes experiences so long as the service was conducted efficiently. This contrasts with the case examples of working carers in chapter 7 who found that recruitment support did not fulfil their needs who had struggled to find appropriate care.

Chapter 6 on husband and wife teams describes the wider factors which influenced the benefits these couples derived from direct payments, rather than focusing on the dynamics and minutiae of arranging care which features heavily in the accounts of working carers in chapter 7. It therefore does not dwell on the role that DPS that played. This is not to say that it did not also serve an important role in these cases. Excerpts from their interviews highlight this:

[The DPSS team, they’re]… the greatest people I have ever met…. When the staff come to visit, they visit just like you do, they talk to me, they explain things to me, they make it so simple and so easy…. And if that’s anything that could be done, they will do it for you.” (H7)

“I mean, [the DPSS representative], who comes here occasionally, he’s like a bosom friend. If there’s a problem, I would go to him. … Because I can’t always contact [the social worker] -you get a telephone playing a tune and then someone says, she’s not there. “(H6)

It was also apparent that the ongoing contact with DPSSs helped to keep some people in check in terms of the way they managed PAs. Speaking about a PA who was taking maternity leave one service user recounted:

“I had to assure [the DPSS representative], that we’d parted on amicable terms and I didn’t sack her. She was here yesterday, she brought her kid. So I also had to assure him that I have told her that when she wishes, and when she’s able to, she can come

back. Now this would hurt me a little bit with the girl I've got now, but nevertheless I've got to keep that option open." (W6)

So what insights can be drawn between these findings and the survey of DPSS? Chapter 3 describes how a decade ago, during a period that coincided with significant expansion in the commissioning of DPSS by local authorities, support services were patterned by five distinct profiles: fiscal moderators; employment managers; recruitment advisors; recruitment agents and enablers. Essentially each of these profiles was rather more or less concerned with the three objectives of DPS described above: fiscal and administrative tasks, recruitment support and supporting the relationship between service users and PAs. This in itself shows that unequal priority was being given to each, and that the availability of particular types of support varied widely. Specifically fiscal moderators were far more prominent than the other profiles.

The survey follow-up revealed that the model of DPS that gained prominence during the first half of the past decade focused on safeguarding statutory and fiscal responsibilities and meeting *basic* demands for personal assistance management (e.g. compiling contracts and job descriptions, support with interviews and providing employment law advice). These were the fiscal moderators. These were arguably better placed to safeguard basic PA rights and benefits but on the face of things did not offer support in the dynamics of employing – or 'being' employed.

Fiscal moderators gained prominence as a result of substantial decommissioning of services which did not fit this profile (65% of the original DPSS had lost their contract by 2011), coupled with the tendency for decommissioned organisations to be replaced by organisations offering a profile of services akin to the fiscal moderators (more often not from branches of large national voluntary organisations). This process was facilitated by the short-term contracts granted to DPSS (Davey *et al* 2008). This phenomenon suggested that local authorities were responding more and more to policy priorities centred on safeguarding statutory and fiscal responsibilities, and the provision of basic services supporting relational aspects of PA management, including employment law advice - but this left some organisations that had established profiles focused on intensive employment management to flounder.

Much of what occurred between 2006 and 2011 might be understood to have arisen primarily because of weak relationships with commissioning local authorities and lack of financial sustainability. For example, the first lost contracts were among organisations established solely through DPDF funding, in what appear to have been weak partnerships with local authorities who for one reason or another, were not willing to support them. The other clear loser was the enablers who also operated on a very minimal income base although they were not newcomers. Both had minimal managerial capacity, directing most of their resources to direct contact with users. The former provided intensive (face to face) support for recruiting and managing a PA – while the latter were ULOs that offered services that may have caused a conflict of interest with their funding local authority. The 2012 TLAP report *Best Practice in Direct Payments Support – a guide for commissioners*, placed much of the onus for this on DPSS citing reports (from commissioners) of, an "unhealthy dynamic" between user-led organisations and local authorities leading to low referral rates and eventual under utilisation of services rendering them "unsustainable" (Bennet & Stockton 2012) – but DPSSs function also depends heavily on the efficiency of local authority processes (Williams *et al* 2014); procedures in place for sharing information about clients and their willingness to engage with DPSS. The same report advocated for a "mixed market of direct payments support" instead of "single service solutions", alongside other recommendations for practice; such as maximising the use of volunteers, encouraging self-management through peer-support, and using Skype as a (cost saving) alternative to home visit – all with a view to obtaining "a reduction in formal support hours per direct payment user" (Bennett & Stockton 2012).

The results of the analyses conducted for chapter 3 suggest that this 2012 report was a critical "game changer". Certainly it directly preceded a major shift in commissioning patterns impacting on organisations, which previously appeared to have a competitive advantage in tendering. Above all, the period marked a turning point in interpretations of DPS, with LAs that had developed a more mainstream approach dividing into those that were more market-driven (and seeking immediate cost-savings), those that sought in-house solutions and those that stuck to their original path and their longstanding relationships with providers (many of whom are user-led).

The period between 2012 and 2016 was also marked by substantial disruption for service users, with 44% of total turnover recorded in 2014 represented by repeated decommissions. The potential disruption for service users was already evident among one of the husband and wife teams who remarked:

…"but now they've changed. It's [another DPSS] now. Not [the one we had before]… I don't know what's going to happen. As far as I know, I opted to go with [the new DPSS] and I did have a talk to them, and they said they would send me everything through the post and I've had nothing." (W5)

The follow-up work also found that there has been a shift in the approach towards providing recruitment and/ or employment management support. DPSS are now less often commissioned to provide ongoing employment support. In contrast, conventional homecare agencies are being encouraged to target service users with intensive employment support needs and/or third party management of funds, effectively taking on roles previously occupied by employment managers. Services that are increasingly prioritised for direct funding from local authorities now tend to be low-intensity services. These include online PA matching or lists of local accredited providers by specialty/geographical area, given prominence in various sources of "best practice" advice (DH 2009). The motivation behind such measures is fairly clear. In 2010 it was reported that, "*the difference in cost units between face-to-face contact, telephone contact and web-based contact was 40: 15: 1*" (Carr 2010b: 23). Many local authorities have also introduced pre-paid card schemes that shift the focus from face-to-face supporting to electronic monitoring, and is claimed to create a disincentive to hire a PA.

But the most seismic shift has been in the development of spot purchasing - whereby service users (who have to first ask themselves if they consider themselves as *requiring support)* have now to pay for it directly from personal budgets choosing from a list of recommended DPS providers without the local authority having any commissioned DPSS. Thus raises a multitude of questions. Will individuals reduce their use of DPS when confronted directly with its cost? Will DPSS remain viable if their only source of funding is individual commissions from DP users? Will these new forms of DPS support (such as those provided by conventional home care agencies or social services personnel) lead to similar patterns in the types of support being purchased by DP users?

Figures already suggest that the percentage of DP users employing PAs has dropped which could be affecting outcomes given that PA use is associated with receiving more flexible care which in turn led to greater outcome gain from DP (chapter 4).

The analysis presented in chapter 3 is unique in its ability to quantify the wide differences in the evolution of DPS across the decade despite its limitations such as its scope (it was limited to following organisations which responded in 2006 which covered two-thirds of English authorities). A key strength is that it not only offers detail on emerging trends but also provides insights into the characteristics of the DPSS that survived the decade. The findings of chapter 3 in combination with the results of other chapters, challenges the invisibility of DPS among research on DP/ PB and establishes the need for greater consideration of DPS.

It also raises questions about the hitherto absence of awareness of the dynamic between DPSS commissioning, the characteristics of the support schemes and wider LA characteristics. This might include factors such as the share of DPs among users of adult social care (and the speed of growth in DP take-up); local authority commissioning procedures across the period; changes in funding for adult social care; local authority size, and more. However the most pressing, relates to the quality of DPS. There is no precedence for the new models of DPS compared to the previous model as shown in chapters 4 and 7. Notably this ‘old’ model is still the preferred mode for many local authorities.   A pressing question is how new modes such as individual purchasing of DPS compare in terms of the user experience to the that of individuals served by “remainers”. Remainers are an interesting group as they represent local authorities which have consciously maintained continuity with DPSSs over a decade and worked with them to respond to the challenges of the personalisation agenda. An obvious way to combine the two objectives would be to focus on sets of local authorities that fall into either group (remainers and spot purchasers).

8.3. Allocations of care and the balance between funded care, unpaid care and out-of pocket care

One of the key areas of concern regarding direct payments to older people relates to the perception that it will increase the demands on unpaid carers. This theme has been discussed from various perspectives in chapter 4, 6 and 7. However it is in chapter 5 that an exceptional level of detail is applied to evaluating how patterns of funded, unpaid care and out-of pocket care varied, according to caregiver circumstances. Miligan & Moreby (2016: 5) stated that in research on unpaid care, “even when gender *is* considered; it is often simplified to a male/ female comparison, so failing to identify potential variations within groups”. As described in the methodology,, chapter 5 on the role of unpaid care in the provision of direct payments to older people, was critical to the direction of the thesis, in that the analyses led to the identification of sub-groups of carer-service user combinations associated with particular traits in terms of; the intensity of unpaid care provided; the dynamic between formal care, unpaid care and care funded out of-pocket (self-funded care); the tasks involved (IADLs vs. ADLs); and their wider circumstances (support networks; employment status). This revealed a greater participation by male unpaid carers than expected. This culminates in chapters 6 and 7 which focused on two of these groups: working carers and husband and wife teams.

From these overlapping sections of the thesis it appears that accounting for these differences in caregiver circumstances, was key to understanding what DPs were used for and *why*.

The starting point for this was revelations in variations in the balance of care according to caregiver circumstances and service user characteristics (primarily their dependency level). This was a novel approach as most studies report only data on the value of allocated care (and sometimes the level of dependency) and do not take into account how this translates as a share of the total input *relative to the portion fulfilled by unpaid care*. Such as approach is arguably key to interpreting equity in the distribution of publicly-funded social care to older people, an argument developed by Wimo *et al* (2002) in an unusual study evaluating time spent on informal and formal care giving for persons with dementia in Sweden. In this instance the analysis has been possible due to the availability of unusually detailed data.

The comparisons of total weekly care input, the product of the allocated care package and unpaid care and self-funded care revealed some unanticipated findings.

Service users supported by daughters received simultaneously the most generous allocations of DP-funded care and the greatest intensity of unpaid care. The former was expected as it has been reported in other research but the latter was surprising. Essentially it appeared that individuals cared for by daughters had an unfair advantage when it came to the way in which care was being allocated. The most obvious explanation for this is that daughters' perceptions of the needs of those they cared for were different from sons – possibly because of differences in the emotional burden they experience from caring (Brimblecombe 2016). This appears to have led to greater allocations of care in response to their reports of unpaid care.

In the same chapter, we see that male spouses from the sample were often providing greater levels of informal care than female spouses and were least likely to have support from a secondary unpaid carer. There were also significant differences in the generosity of care packages provided to people with female and male spouses. Mirroring the gender imbalance between care allocations for those dependent upon daughters and sons; service users receiving support from their wife or partner, tended to receive greater funded support than those reliant on their husbands. Unlike sons, husbands appeared to compensate for this disparity by increasing their supply of unpaid care, smoothing the differences once funded and unpaid care were accounted for. They were also most likely to be supporting ADL tasks of all the types of unpaid carer (wife, daughter, son or husband). Husband carers also tended to have their own health issues. (This situation is discussed in greater detail in chapter 6.)

These noticeable gender discrepancies in allocations of DP support are of concern. The age of the data is such that they cannot be considered representative for todays' climate *but* given the diversity of the sample (cf. chapter 4) they can be considered representative of the way care was allocated depending upon the service user-carer sub-type at the time of the research. This raises important questions for whether the new resource allocation systems (RAS) described briefly in chapter 2 have the potential to compound these hidden disparities or provide a fairer system. There is very little published to date which explores the new RAS. A study by Mitchell & Glendinning (2016) identifies how points' based systems were used in their sample to identify allocated care to carers to meet their needs based predominantly on reported hours spent caring. What is really lacking is any work that *simultaneously* compares different RAS in the way that they respond to the provision of unpaid care when determining the allocation of resources according to need, with the allocation of support to carers (also via a carers RAS) according to their reported need. Series & Clements (2013) have suggested that questionnaires being used for points based systems are extremely sensitive to gaming – but this was in relation to RAS for the individuals being cared-for and not carers. Nevertheless it seems possible – or even inevitable - that the same may apply. Certainly the results of chapter 5 highlight the risk inherent in systems which allocate support to carers based on their reports of the intensity of care they provide. Notably they disadvantage those that under-report their care-giving activities (and/ or the impact it has on them). According to the thesis, it would seem that this disproportionately affects male caregivers.

The research presented cannot in itself, provide further insights into how this may be jeopardizing carers –for example the husband and wife teams presented appeared to cope on very limited allocations of care certainly in terms of their levels of satisfaction albeit partly due to their use of self-funded care. However six out of the seven had been hospitalized in the year previous to the interviews owing to their own long-term health problems – probably coupled with the demands of caregiving.

The phenomena described his is not a DP specific problem but affects social care for older people generally. However there is one important insight from the exploration of factors affecting direct payments outcome gain that is relevant. This is that large discrepancies between total care input and DP-funded support reduced outcome gains (for the cared-for person), irrespective of the value of allocated care. Taking *this* into consideration, along with the understanding of the role that unpaid carers play in supporting DP outcomes it is clear that this needs to be a priority for future research (without overlooking the need to also evaluate the burden placed on unpaid carers).

8.4. Supporting DPs and the burden on unpaid carers

Much of the debate around the suitability of direct payments to older people has focused on potential negative consequences for unpaid carers. The main concerns are: that DPs may lead to increased burden on unpaid carers and greater isolation, due to the private and independent nature in which care arranged through DPs is managed. Yet there is scarce evidence to support these concerns. Chapter 7 takes a very through look at the task of managing DPs focusing on a group of carers that were overstretched and overburdened. Their main motivation for doing so was a lack of control over the quality of local authority commissioned care. The working carers found multiple benefits from DPs, not least the ability to coordinate care with their employment, ensuring the quality of services and with it their peace of mind.

Recent research highlights the impact that inadequate service quality can have in compounds the irreconciliation of unpaid care and employment (Brimblecombe *et al* 2018), but this has not previously been paired with a realization of the potential benefits of DPs for working carers. The chapter focuses heavily on the way working carers managed care. This does not include objective outcome measures for carers (a priority for future research) but it does qualitatively explore how the task of managing care is experienced. Unlike the majority of the sample of older people, working carers were drawn to using care agencies to recruit care - both out of choice and out of necessity. Inevitably their accounts touched upon the role of external support agencies especially DPSS - but they also gave indications of the relationship with care agencies and their responsiveness - which was key to their experiences and their satisfaction with the care being provided to their mother or father.

Payroll support was described as a basic prerequisite to employing a PA due to their lack of time to deal with the administrative burden but satisfaction with the services received was very high. On the other hand recruiting was a struggle for some and not all were satisfied with the recruitment support they received. The knock-on effect from this was that home care agencies were employed in some cases as a necessity rather than a choice. Exploration of the dynamics with home care providers demonstrated how their situation as individual commissioners (with a restricted budget calibrated to prices paid by local authority commissioner) was subject to the challenges faced by local authority commissioners or ‘brokers’, but differed in that there was some potential to resolve the challenges via a more flexible approach or a set of tools which local authority commissioners are not permitted. For example, commissioning from a non-accredited provider, paying extra for care or simply investing more time and energy in negotiating with providers or in trial and error.

Many of the individuals being cared for by working carers suffered from cognitive impairment and in these cases much of the required care was for supervision and surveillance. These cases were seemingly penalized by the community care assessment process and these were further examples where there was a large disparity between the total funded care and the total care input (chapter 5). However there was a propensity to dovetail care funded through DPs with care funded privately. This was predominantly paid for from the state benefit Attendance Allowance and partly by their parents’ occupational pensions. This possibility was – *and still is* – unique to direct payments and was in some cases key to the value of DPs. Also in the case of those employing PAs – they were able to employ someone for more hours (Table 7.4).

Reliability of care, control over schedules, the flexibility to pay extra to cover all necessary hours and being able to recruit the right person (albeit for some to a limited extent) - were the key ingredients to supporting carers to reconcile work with unpaid care. Even amongst those who had had some difficulties in the process of securing care, DPs was still considered to be a superior option.

Sadly there are numerous threats to these situations being replicated today. Recruitment support has become more arms-length and potentially less accessible to working carers that struggle to manage care via the end of a telephone during their working day. Secondly there is the ongoing struggle in relation to suitable allocations of care to cover night care, since the legal framework for reimbursing night care has shifted (House of Commons Library 2018). On the other hand, today's working carers may be better supported by available brokerage services – although the evidence for this suggests that their leverage is not necessarily any greater than that of unpaid carers working alone. Discounting these contextual factors (which can change over time), the chapter offers new insights, which challenge the widely held perception that managing DPs increases the burden of providing managerial care. It does this by revealing the substantial and often futile previous ongoing attempts to control the care that their parents receive when it was commissioned by local authorities. Because these carers were employed they were at the acute end of this being especially dependent on services doing what they are supposed to do in their absence whilst at the same time being unable to have much (or *any*) face-to-face contact with care workers and providers.

The chapters' main conclusion is that the involvement of families in managing care is by and large a basic reality of long-term-care that should not be underestimated and that management of DPs was akin to *alternative* rather than additional responsibilities. It suggests that this reality derives from a context in which long-term care operates through "disorganised governance", where the responsibility for outputs has been devolved to independent providers subject to the risk of bankruptcy and fluctuations in local care market (Bode 2007). This situation reduces local authorities leverage in controlling quality to *expost* controlling, (i.e. dealing with complaints). Nothing could underline this more than the results of a recent PSSRU survey of local authority arrangements for commissioning services for older people (Fernández, D'Amico & Forder 2012), which indicated that only 52% of local authorities follow-up between 81 and 100% of contracts with independent home care providers at least every 6 months.

8.5. Getting the most out of DPs: a lesson in the complex interplay of external and internal resources

DP based or not, the benefit of care can depend upon a complex interplay of external and internal resources as introduced in chapter 2 – but in the case of DPs, the freedom to engineer arrangements to meet priorities and preferences enables individuals to shape their care packages to fit in with whatever resources they have to play with. This argument derives from the qualitative analyses of interviews with husband and wife teams, presented in chapter 6.

The circumstances of husband and wife teams were representative of the trend for reduced gender division in the provision of unpaid care among people with multi-morbidity (Schmidt *et al* 2016; Pickard, King & Knapp 2015). The majority of male spouses were supporting most IADL and significant ADL needs, and on the face of things these caregiving husbands appeared to be a particularly vulnerable group. Yet they employed various "resources" to increase their ability to cope – and benefit mutually from DPs.

The participants' accounts suggest that their capacity to benefit from DP depended in part upon decisions taken years prior, particularly related to housing and equipment. An overlapping factor was the strength of the personal bond between husbands and wife which played a crucial role in their long-term efforts to maintain independence and in the way they managed their resources. The control over managing care offered - made possible by DPs - was crucial to preserving spousal roles and needs, versus local authority managed care which could jeopardize them. This was because local authority managed care was either at odds with their daily routine, or just unreliable, or experienced as intrusive – findings that echo with other research on home care (Ryan 2012). The chapter enables us to perceive how this could directly threaten the utility of a caregiving relationship characterized by strong feelings of reciprocity and with it critical psychological protection against caregiving burden (Oudjik *et al* 2011). DP-purchased care offered the caregiving spouses protection against the disempowering aspects of reliance on outside care that caused increased stress for caregivers. The chapter shows how having control over care allowed the couples to focus on the facets of their daily living they could operate as a team. This was an essential coping strategy - designed to protect against the emotional labour associated with the irreconcilability of some aspects of their dependency. Therefore DPs became part of the *solution* rather than part of the problem (as had been their previous experience with local authority commissioned care). This was a theme that was also very prevalent in the accounts from working carers (chapter 7).

This offered further examples (or many throughout the thesis) of the pivotal role of service quality echoing Malley & Netten (2009) assertion that, "even though a service might have the potential to meet needs in certain domains of outputs, poor processes or quality in general, might mean that those needs are not fully met in practice."

In the case of the husband and wife teams, needs were being met, despite the fact that their allocations of care were small (relative to their level of dependency and the hours of unpaid care being undertaken by the husbands). The caveats to this were that many also relied on small – but critical quantities of self-funded care – mainly funded through Attendance Allowance and mainly for domestic support. Again the value of being able to add to the DP package corresponded with the experience of working carers (chapter 7). These findings explain how in chapter 4 purchased care that was self-funded was associated with greater gains from direct payments. The extent of self-funded care should not be overplayed. It was predominantly very marginal to other care inputs (funded and unpaid). These findings have relevance for the debate on the future of adult social care that will take place as part of the forthcoming green paper. DPs remain the only mechanism by which service users and families can choose to add to their funded package, but in the past this has provoked heated debates about the risk of a two-tiered service. It is therefore relevant that the thesis reveals that this small but pivotal element was often funded by benefits. It also feeds into the debate about the impact of Attendance Allowance (Corden *et al* 2010).

Chapter 7 offers a number of considerations for future practice. Firstly, it suggests that greater external support to achieve "resilience-shaping housing" could assist older people to be better prepared for change in their dependency status. It was apparent that many of the participants had proactively adapted their homes on the advice of others (which not everyone will have). Obviously this needs to take place before most people come into contact with social services and this could be a role for external agencies – but they may need financial backing from local authorities. Work by Malley *et al* (2012) has also highlighted that social care outcomes are influenced by adaptations in the home.

Secondly, it feeds into the debate about how best to support unpaid carers´ needs in general and particularly in relation to the allocation of DPs to unpaid carers in response to their needs. Chapter 7 shows domestic support was critical for husbands, but there were variations in how this was paid for and whether or not the DP could be spent on it echoing other reports (Arksey & Baxter 2012).

The accounts also question the assumption that older people choosing DP have wider social supports readily available prior to choosing to take-up DP (Moran *et al* 2011). Many of the participants did not have these, but an increase in wider social support was evident as a by-product of organizing care with DP.

Finally, the circumstances of the husbands and wives in this study offer examples of "positive risk-taking", much talked about yet poorly understood. This findings indicate suggests that social care should take into account couples' relationships and prioritise preservation of these mechanisms – there is also an argument for considering extra support to individuals in less functional relationships. As shown in chapters 6 (and 7), such a perspective would provide a very different outlook on the risks versus benefits of directing care in such circumstances.

Employing DPs represented an additional phase in adaptation to the difficulties associated with their increasing dependence. There were obvious parallels with the concept of resilience as "a confluence of individual, social, physical and environmental factors" (Otmman & Maragoudaki 2015) and the results pay credence to the necessity to apply a wide conceptual framework when evaluating the outcomes of DPs (chapter 2).

Unfortunately the work was limited to evaluating the outcomes of the individuals being cared-for. Any future work would need to combine qualitative data with data from standardized measures of caregiver outcome (caregiver burden, care related quality of life) to offer a fuller picture. Still this is the first time that research has accounted for the experiences of caregiving husbands in the realm of DPs. Ultimately a key message is that research has barely scratched the surface in understanding the dynamics of unpaid care for older people where care is organized with funds received in the form of DPs.

8.6. References

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9. Appendix I – Outcome measures used in the analyses for chapter four.

Table 9: Independent variable measures

Indicator	**How measured**	**Min/ Max (n)**	**Mean (SD)**
Indicator	**How measured**	**Min/ Max (n)**	**Mean (SD)**
Dependency level	Service users were categorised on the basis of itemized ADL and IADL scores (cf. Table III). Moderate dependency was used as the base category. No dependency (1), low dependency (2), moderate dependency (3), moderate-high dependency (4), high dependency (4), highest dependency (5).	3/6 (81)	5 (0.998)
Lives Alone	yes (1), no (0)	-	-
Significance of DPSS employment support (critical)	yes (1), no (0)	-	-
Adapted IADL: medication use	Is responsible for taking medication in correct dosages at correct time (1), takes responsibility if medication is prepared in advance in separate dosage (2), is not capable of dispensing own medication (3).	1/3 (81)	2 (0.894)
Adapted IADL: handling finances	Manages finances independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income (1), manages day-to-day purchases but needs help with banking major purchases (2), incapable of handling money (3).	1/3 (81)	2 (0.880)
Adapted IADL: use of transport	Travels independently on public transportation or drives own care (1), arranges own travel via taxi, but does not otherwise use public transport (2), travels on public transportation when accompanied by another (3), travel limited to taxi or automobile with assistance of another (4), does not travel at all (5).	1/5 (81)	4 (1.181)
Adapted IADL: ability to do shopping	Takes care of shopping needs independently (1), shops independently for small purchases (2), needs to be accompanied on any shopping trip (3), completely unable to shop (4).	1/4 (81)	3 (0.787)
Adapted IADL: food preparation	Plans prepares and serves adequate meals independently (1), prepares adequate meals is supplied with ingredients, heats serves and prepares meals but dies not maintain adequate diet (3), needs to have meals prepared and served (4)	1/4 (81)	3 (0.923)
ADL score	*Bowels* - incontinent (0), occasional incontinence (1), continent (2) *Bladder* – incontinent or catheterised/ unable to manage (0), occasional accident (max 1x 24 hrs) (1) *Grooming* – needs help (0), independent (1) *Toilet Use* – dependent (0), needs help but can do something (1), independent (On and off. Dressing and wiping) (2) *Transfer* – unable (0), major help (1), minor help (2), independent (3) *Mobility* – immobile (0), wheelchair independent (1), walks with help of one person	0/17 (81)	9 (4.982)

	(verbal or physical) (2), independent (but may use any aid, e.g. stick) (3) *Dressing* – dependent (0), needs help, but can do half unaided (1), independent (2) *Stairs* – unable (0), needs help (verbal, physical, carrying aid) (1), independent (2) *Bathing* – dependent (0), independent (1) Maximum score = 17		
Presence of unpaid carer	yes (1), no (0)	-	-
Chose and received DPSSs (general and employment support) *	yes (1), no (0)	-	-
Use of an agency	yes (1), no (0)	-	-
Length of time using direct payments	In months	2/156 (77)	26 (27.045)
Difference between package size and total care input	Package size measured as hours of SS funded care per week (DP plus any other services) Total care input calculated as hours of SS funded care per week + hours of unpaid care per week + hours of self-funded care per week. Difference between package size and total care input = total care input (hrs/wk) – package size (hrs/wk)	0/126 (81)	27 (33.223)
Percentage of **total care input** composed of self-funded care	(Self-funded care (hrs/wk)/Total care input (hrs/wk))*100	0/53 (80)	5 (11.369)
Percentage of **total care input** composed of unpaid care	(Unpaid care (hrs/wk)/Total care input (hrs/wk))*100	0/87 (80)	34 (31.132)
Percent of care package spent on home[1] care	(Home care (hrs/wk)/Package size (hrs/wk))*100	0/100 (79)	19 (30.008)
Percent of care package spent on combined home care/ personal care[2]	(Combined home care/ personal care (hrs/wk)/Package size (hrs/wk))*100	0/100 (79)	29 (38.207)
Percent of care package spent on combined home care/ social and leisure care[3]	(Combined home care/ social and leisure care (hrs/wk)/Package size (hrs/wk))*100	0/100 (79)	2 (12.977)
Percent of care package spent on therapeutic management[4]	(Therapuetic management care (hrs/wk)/Package size (hrs/wk))*100	0/100 (79)	4 (16.539)

*Includes any of the following: general advice and support; assistance with recruitment; lists of personal assistants; lists of local agencies; assistance compiling job descriptions; assistance with interviews; assistance compiling contracts; assistance with training; financial advice (budgeting); bank of emergency staff; any other back-up service. [1] Home Care (provision of meals, laundry, housework, shopping); [2] Combined home care/ personal care. For example, the carer comes in the morning and supervises self-care, while also doing some cleaning. [3]Combined home care/ social and leisure care. For example, the service user is escorted shopping with the carer. *The service user considers the activity to fulfil a social and or leisure function as well as a home care function*. [4]Therapuetic management. For example, occupational therapy.

Table 9.2 Dependent variable measure for direct payments outcome gain

Indicator	**How measured**		**Min/ Max (n)**	**Mean (SD)**
Direct payments outcome gain	Weighted index value for level of met need with service– weighted index value for level of met need without service, per outcome domain:		10/113 (79)	66 (23.705)
	Level of met need	*Level of need without service*		
Food & Nutrition	No problem (13) All needs met (13) Low unmet needs (10) High unmet needs (0)	No problem (13) All needs met (13) Low unmet needs (10) High unmet needs (0)		
Personal care	No problem (32) All needs met (32) Low unmet needs (15) High unmet needs (0)	No problem (32) All needs met (32) Low unmet needs (15) High unmet needs (0)		
Safety	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)		
Social participation	No problem (28) All needs met (28) Low unmet needs (17) High unmet needs (0)	No problem (28) All needs met (28) Low unmet needs (17) High unmet needs (0)		
Control over daily living	All needs met (18) Low unmet needs (16) High unmet needs (0)	All needs met (18) Low unmet needs (16) High unmet needs (0)		
Control over home environment	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)		
Leisure pursuits	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)	No problem (9) All needs met (9) Low unmet needs (4) High unmet needs (0)		

Note on Table 9.2. The outcome measure used was an adapted version of OPUS with four levels for each domain: no problem, all needs met, low unmet needs and high unmet needs. This measure has been taken over by ASCOT. ASCOT includes all seven outcomes domain included in the DP adapted OPUS, plus one extra: dignity. ASCOT also has a four level scoring mechanism but the definitions of each scoring level differ. Specifically "no problem" which referred to no preexisting needs, has been replaced by "ideal state" (a) – a state in which, "the individual´s wishes and preferences in this aspect are fully met". While "**all** needs met" has been replaced by "no needs" (b) – defined as a state in which, "the individual has no or the type of temporary trivial needs that would be expected in this area of life of someone with no impairments". This is a crucial difference because it offers a scenario in which needs are met adequately (b) - which can be compared to scenario a, where there are either no preexisting needs or needs a met as much as the individual could ever wish for (a). ASCOT has become to tool adopted for the Adult Social Care Outcome Framework (ASCOF) which data on adult social care users is collected nationally. For national reporting responses a, and b are combined to form, "the measure on those individuals achieving the best outcomes, identifying no or limited need" (DH 2017: 11) in this area.

Source: DH (2017) The Adult Social Care Outcomes Framework 2016/17. Handbook of Definitions. Department of Health, London.

10. Appendix 2– Outcome scores comparison for chapter four.

In results, paragraph 1, the levels of met needs of the DP sample of older adults as recorded using a DP-adapted version of the Older People’s Utility Scale (OPUS) conducted between 2005/2007 are compared against results from the Adult Social Care Outcomes Framework which among things, supplies data on the level of met needs among adult social care users in England as measured by the Adult Social Care Outcomes Tool (ASCOT). Data have been collected nationally year on year since 2010/11.

A number of things need to be considered when comparing these figures:

National figures express the average level of met needs across *all user groups* of adult social care users within the community. This is an unfair comparison. It is known that responses from learning disabled clients record higher levels of met need, while results for older people and “people of Asian or Asian British ethnicity” show considerably lower levels of met need for (HSCIC 2013: 16).

Data from the Adult Social Care Outcomes Framework are supplied by postal survey and do not include proxies. They therefore also **exclude the most dependent, frailest and cognitively impaired service users** – in contrast to the study sample.

Prior to 2014/15 figures were drawn from samples of adults in receipt of LA-funded services following a full assessment of need, but since this time samples consists of ‘service users in receipt of long-term support services funded or *managed* by the LA following a full assessment of needs’ (HSCIC 2015: 18). The major distinction between the two is that the latter includes ‘full-cost clients’ who were not previously included. (The slight upward trend in results post 2014/15 needs to be viewed with this in mind.)

Further to these features, there are differences in the measures (ASCOF versus DP adapted OPUS) which limit the extent of comparison.

As described in chapter 4, the DP outcomes data were collected using a DP-adapted version of OPUS. OPUS has four scoring levels for each domain: no problem, all needs met, low unmet needs and high unmet needs. ASCOT similarly has a four level scoring mechanism but the definitions of each scoring level differed. Specifically “no problem” which referred to no preexisting needs, has now been replaced by “ideal state” (a) – a state in which, “the individual´s wishes and preferences in this aspect are fully met” (Netten *et al* 2011: 4). While “**all** needs met” has been replaced by “no needs” (b) – defined as a state in which, “the individual has no or the type of temporary trivial needs that would be expected in this area of life of someone with no impairments” (Netten *et al* 2011:4). This is a crucial difference because it offers a scenario in which needs are met adequately but not necessarily entirely.

Where ASCOT is used for research purposes, “ideal state” and “no needs” are scored differently, with the former receiving a higher score. However when ASCOT is used across local authorities in England as part of the Adult Social Care Outcome Framework published results combine the two responses to form “the measure on those individuals achieving the best outcomes, identifying no or limited need” (DH 2017: 11) in each area.

In contrast Public Health England, which includes results solely for the domain of “social participation” as one of its key indicators, only counts the response for “ideal state”. As a result there is a significant difference in reported results with reported outcomes for adult social care appearing to be significantly better.

Equally the results of the DP sample presented refer solely to the percentage of service users who declared that ***all*** their needs were met and exclude anyone who felt that "some" needs were unmet.

For all of the above reasons it is notable if the outcomes recorded for DP users in the study outperformed national average outcome scores at *any* time since data were first recorded.

Below I provide a summary of published ASCOF results for each of the domains included in the study since data were first recorded (Table I). Data specific to over 65s (who self-reported) are available only for the domain 'control over daily living' for the past two years. These data show that results for over 65s were two percentage points less than the average for all user groups. We have therefore adjusted the national results accordingly to give a truer picture of nationally recorded outcomes for over 65s.

This figure (Table 10.1) shows that despite the factors discussed, **the results for the sample of DP users were well above the nationally recorded average for the domains of *control over daily living* and *safety* – not just in 2010/11, but across the entire time period**. The result for the sample of DP users for leisure/ occupation was also above the recorded average for 2010-2011.

Table I0.1: Comparison of levels of met needs between DP service users sample and adult social care users.

	Percentage of service users reporting some or complete unmet needs						
		ASCOF results					
	DP Users (2005-2007)	2010-2011	2011-2012	2012-2013	2013-2014	2014-2015	2015-2016
Food and nutrition	93	93	93	93	93	92	92
Personal care	92	93	93	92	93	92	93
Safety	76	61	62	63	64	67	67
Social participation	*70*	75	75	75	76	76	76
Control over daily living	83	73	73	75	74	**75***	**74***
Home environment	85	93	93	93	93	93	94
Leisure/ occcupation	65	61	63	64	65	66	67

*****Actual figures. All other figures are adjusted for over 65´s with a 2% reduction of the published national average.

Sources:
HSCIC (2014) Personal Social Services Adult Social Care Survey 2013-14, Final Release. Health & Social Care Information Centre, London [Contains data for 2010-11, 2011-12, 2012-13 and 2013-14]
NHS Digital (2016) Personal Social Services Adult Social Care Survey
England 2015-16. NHS Digital. [Contains data for 2014-15 and 2015-16]

For the remaining domains the impact of the sample being highly dependent and unable to score that needs were met "adequately" can be seen in so far as the results for the sample of DP users do not exceed the average for personal care and food and nutrition. Results for social participation and the home environment were slightly lower than the national average which is expected given the differences between the two measures and the sample characteristics.

10.1. References

Department of Health (2017) The Adult Social Care Outcomes Framework 2016/17.
HSCIC (2015) Personal Social Services Adult Social Care Survey 2014-15. Health & Social Care Information Centre, London

Netten, A., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Towers, A-M., Trukeschitz, B., Welch, E., Windle, K. (2011) *ASCOT Adult Social Care Outcomes Toolkit. Main guidance v2.1.* Personal Social Services Research Unit, University of Kent.