

Social care for older people: the role and function of direct payments



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Highlights for practitioners and policy-makers

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Executive Summary

Direct payments (DPs) are cash-payments that eligible individuals can receive to purchase care services by themselves. This instrument is central to current social care policy in England, but 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 previous and newly collected 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.

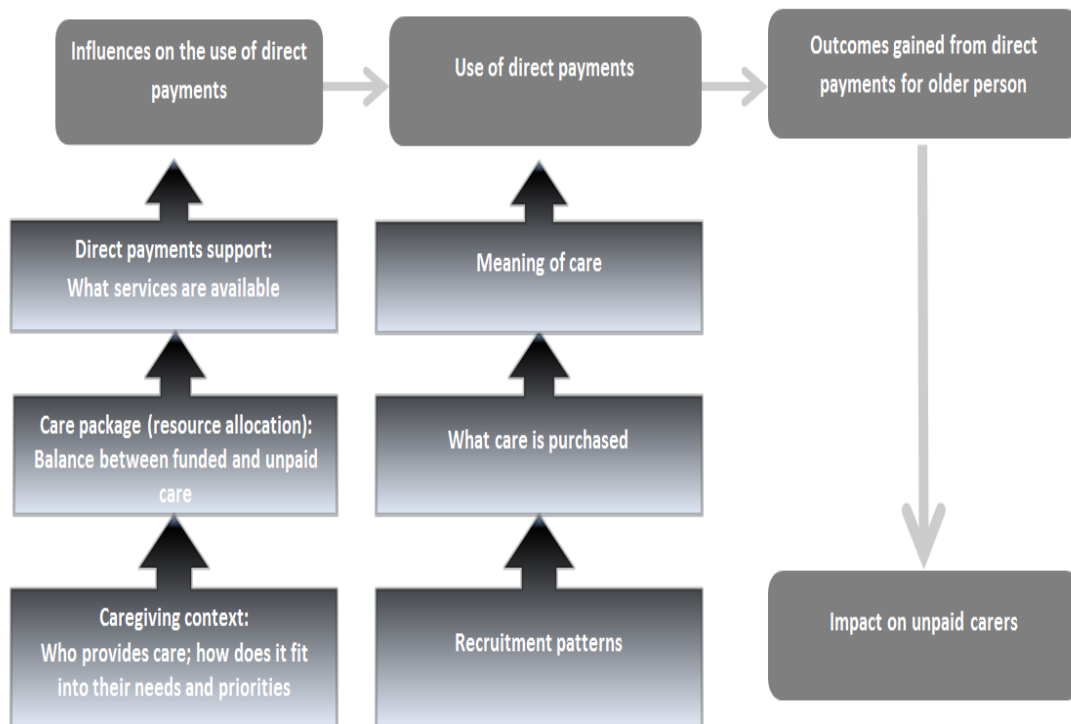
The main aim of the research is to understand and identify what factors influence the use of DPs by older people and how particular combinations of these may shape the experience of DPs, the benefit derived from them, and their impact on unpaid carers.

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Research Design

The main aim of the research was 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 the impact of DPs on unpaid carers. The thesis comprised five empirical chapters, describing overlapping streams of quantitative and qualitative work. They are organized (as below) around two key inputs controlling outcomes of DPs to older people: factors influencing the uptake of DPs and the nature of DPs use. This ‘mixed-methods’ approach provides a better overall picture.



Unusually for social policy, the work derives primarily from data that is primarily historic. Four out of the five chapters result from 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 participants' homes. The data obtained in these face-to-face interviews offers unprecedented level of detail on the use of direct payments among older people. The sample was predominantly composed of very dependent service users, mirroring current targeting of services on individuals with highest unmet needs.

A framework ensured that specific detail on service users' caregiving arrangements was collected. It was anticipated that unpaid carers would occupy important roles and with this in mind, detailed unpaid carer characteristics were noted. Aspects of the physical environment (equipment and accessibility) were also recorded.

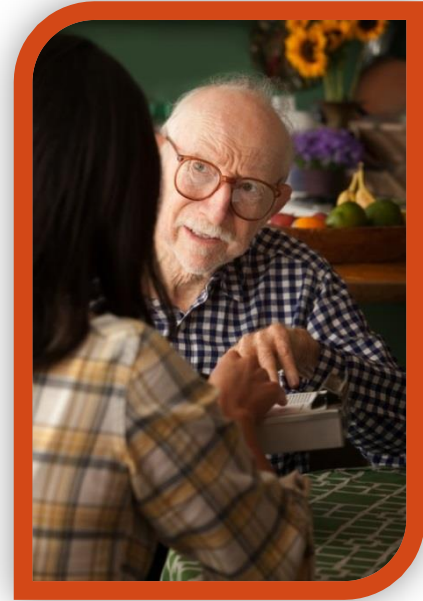
The interviews also sought information on participants' means of securing care and managing DPs, including any support obtained, such as through a Direct Payment Support Scheme (DPSS) and how their experiences had altered over time. This early study still offers the largest and most diverse sample of interview data from unpaid carers supporting older people receiving DPs. A notable feature of the data is that it was collected prior to the advent of PBs. The introduction of personal budgets has set off a cascade of changes to the context in which social care services are delivered, particularly DPs. One of the impacts has been to radically change the provision of direct payments support. Given the centrality of this support, the thesis starts with a separate study charting the evolution of the 'market' for direct payments support over the past decade. This relies on follow-up at three points of time of organisations that responded to a survey on Direct Payments Support Schemes across England conducted in 2006.

There are also concerns about the way that direct payments have been promoted since personal budgets were introduced. Fierce efforts to control costs and recruitment and retention difficulties have combined to make it increasingly difficult 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. As a result there are now huge variations in the provision of direct payments to older people. In contrast to this situation, the data I collected and analysed is from a period when the context in which direct payments 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 permits meaningful reflection on how the changing context of direct payments may have altered experiences in recent years.

Direct payments support across a decade of direct payments development

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, an integral part of the model has been external direct payments support (DPS), provided by entities referred to collectively as Direct Payments Support Schemes (DPSS). In 2006 a major policy drive to promote DPs ensured that most local authorities held a contract with a DPSS. Its impact was to expand the sector significantly. In 2007 organisations operating as ‘Direct Payments Support Schemes’ (DPSS) were very heterogeneous in size and capabilities, dominated by voluntary organizations and ideological centered around User-Led Organisations and Centres for Independent Living.



The provision of direct payments support has undergone substantial change in the last decade fueled by increasing demand as successive governments embraced the ideology of “self-directed care” and increased pressure on local authorities to provide direct payments. By 2010, significant turnover in DPSS was being reported and with it widespread perceptions that differences in DPSS were affecting their evolution. The work set out to systematically examine the state of direct payments support schemes and document the changes in related local authority commissioning. A picture emerged of radical change in direct payments support over time.

Aims

- 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 some 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.

Key findings

- DPSS turnover in the period 2006-2016 was colossal and likely caused significant disruption to DP users.
- Five profiles of DPS existed in 2006 – each focused on a specific set of priorities.

Initial profiles of direct payments support



- The most prominent profile in 2006 was ‘fiscal moderators’, focused on safeguarding adherence to statutory and fiscal responsibilities, recruitment support and employment law advice. It was characteristic of 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. This wave of turnover favoured three kinds of provider: emerging for-profit organisation and/or community interest companies, in-house schemes and branches of national voluntary organisations (BNVOs), and resulted in far fewer contracts with the local voluntary sector.
- 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

Direct payments support schemes by provider type: 2006-2016

Year	<i>n</i>	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%

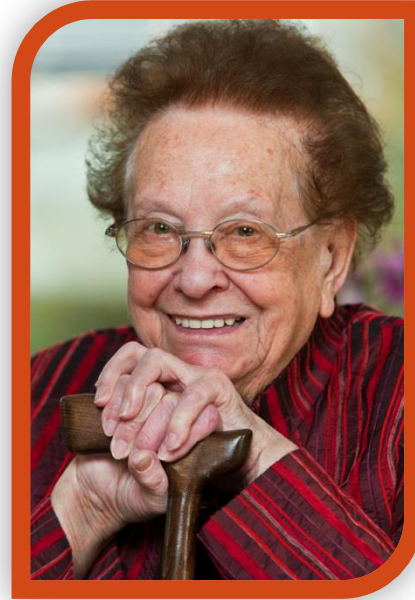
¹ 69% ULOs (of which 29% were Centres for Independent Living – ‘CILs’); 31% other local charities. ² 80% ULOs (of which 47% were CILs); 20% other local charities. ³ 82% ULOs (of which 52% were CILs); 17% other local charities. ⁴ 79% ULOs (of which 50% were CILs); 21% other local charities.

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 users 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?

Outcomes from direct payments among older people

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. The debate is muddled by a staged deployment in which direct payments have been bundled with other policy instruments, amidst increasing budgetary constraints. As a result, little unequivocal



evidence is available about the effectiveness of direct payments as an instrument for older people care.

Aims

- 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.

Key findings

- Direct payment contribution to outcomes was high and positive. Participants reported higher levels of safety and control over daily living than the general population of

community care recipients aged 65 at *any* time since national outcomes data were first recorded. The contribution was also positive, even if more limited, with respect to the home environment and social participation. The intensity of care packages was consistent with practices at the time, and comparable to current direct payments allocations.

- Recorded outcomes were especially notable given the differences between what comprises national outcomes data and the results presented. National outcomes data conflates two response states: one where needs are met *adequately* but not necessarily entirely and one where all needs are met, 'the ideal state' to provide its figures on levels of met need. In contrast the study of older people receiving direct payments refers exclusively to all needs met.
- A further feature of the results was the inclusion of proxy responses, i.e. responses given by representatives of service users who were unable to respond themselves. This was made possible by the fact that outcomes were recorded on a face to face basis, through discussion with representatives and direct observation. The inclusion of proxy responses ensured that the sample reflected the high levels of dependency representative of older people receiving state-funded social care (in contrast to national outcomes data and survey findings which exclude proxy responses).
- Service users who received substantial support from unpaid carers achieved significantly greater gains from direct payments. 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 increasing the benefit derived from direct payments. The extra work that this implies for carers needs to be balanced against the benefits they may derive from the arrangement.
- 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. This raises concern about reported decrease in the employment of personal assistants, possibly linked to changes in the provision of direct payments support.

- The freedom to combine care packages with self-funded care enhanced the impact of direct payments. This was predominantly funded by the social security benefit Attendance Allowance.
- Large discrepancies between total care input and direct payment-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.

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

The analysis of outcomes of direct payments for older people sheds light on the importance of unpaid care. This part of the work followed on from these findings to look at whether 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

- Determine how unpaid care varied among older people receiving direct payments.
- Identify who those unpaid carers 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

Key findings

- Helping to manage a direct payment did not reduce the amount of hands-on care performed by unpaid carers. Furthermore, when 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 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.

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

Unpaid care can increase the benefit of direct payments but is that at the expense of the unpaid carers' wellbeing? The work shows that the diversity of unpaid carers supporting older people receiving direct payments is much greater than has been represented in previous studies.



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 contributed to the benefit their wives derived from the service.

This section of the work focused on a narrow sub-group of the sample of female direct payments users with supported by their husbands. These couples were of advanced age and frailty with both wives and (caregiving) husbands suffering chronic health issues. The husbands provided very high levels of unpaid care and mostly did not have support from a secondary unpaid carer and the amount of care allocated to them was below average, despite the wives' high dependency levels.

Aims

- 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.

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 before 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 and long-term decisions, continual adaptation to their circumstances were enabled 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.

Working carers managing direct payments on behalf of an older person

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. 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 previous research had examined the experience of working carers supporting older people using direct payments.

A sub-group of working carers that was very involved in managing their father's or mother's care while working was selected for further qualitative analysis.

Aims

- 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 using direct payments 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.

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 and 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.

Lessons from the work

Direct payments support

- There has there been insufficient focus on understanding how services provided by DPSS may influence the benefits derived from direct payments and moderate the risk associated with them. What is particularly surprising is the failure to recognise the local authority agendas shaping direct payments support.
- When it comes to assessing the direct benefits of DPS to service users, the evidence base is also very limited. The thesis tackles this lack of evidence in two ways. Firstly it demonstrates a quantifiable link between receiving *recruitment support* and obtaining greater benefit from DPs. It also demonstrates that flexible care that deviated marginally from standard home care was associated with greater gain from direct payments, particularly among service users who used a personal assistant.
- The accounts of husband and wife teams and working carers provide further insights into the role of direct payments support. For working, carers much of the potential stress associated with 'additional roles and responsibilities' was alleviated by using payroll services. They were predominantly a time saver helping people to avoid simple mistakes. It also showed that if recruitment support was lacking people struggled.
- For husband and wife teams, direct payments support taught them how to use their direct payment flexibly and provided moral support. Ongoing contact with DPSSs also



helped to keep some people in check in terms of the way they managed personal assistants.

Direct payments and unpaid care

- A key concern is that direct payments could overburden unpaid carers with extra demands. There was huge diversity in their extent of input; some were at the acute end, while others provided only minimal input. These important differences were revealed by exploring how the 'balance of care' (ratio between funded and unpaid social care), varied depending on caregiver characteristics, i.e. their gender, their relationship to the older person, whether or not they lived with them, as well as service user characteristics (how dependent they were). This is a novel approach, arguably key to discussing equity in the distribution of publicly-funded social care to older people both in general and specifically the complex, but not uncommon situation where direct payments are managed by an unpaid carer.
- When outcomes are measured as 'levels of met need' the more a person's needs are met by an unpaid carer the less 'gain' can be derived from any service provided. This does not necessarily mean that the service is not beneficial. A service can provide benefits which extend beyond levels of met needs and can be of mutual benefit to the service user and their carer. Better understanding of the impact of direct payments could be gained by considering outcomes for services users and carers, not just as separate measures but in tandem.
- To understand better the wider benefits of direct payments for service users and carers, we looked in detail at two groups of typically overstretched and overburdened carers: 'husband and wife teams' and 'working carers'. These

overlapping sections show how accounting for differences in caregiver circumstances was central to understanding what direct payments were used for and *why* and the difference they made.

Resource maximisation

- Direct payments based or not, the benefit of care depends upon a complex interplay of external and internal resources but in the case of direct payments, the freedom to engineer arrangements to meet priorities and preferences enabled individuals to shape their care package to fit in with whatever resources they had to play with.
- Services are one of many resource sources that very dependent people require to secure an acceptable quality of life. Any given service might have the potential to meet needs but there are many reasons why it will not do so in practice - too often services actually detract from quality of life even if they fulfil the most basic needs. The qualitative work with husband and wife teams and working carers, showed very clearly how - at the acute end of the spectrum of need - direct payments could make a huge difference to quality of life for service users *and* carers, and in turn to the sustainability of care.
- For working carers, added value was gained by being able to recruit the right person and achieve reliability of care, control over schedules and effective communication with care workers. This saved them time and energy which maximised not only their input with their parents but also its *quality*, at the same time as improving their sense of wellbeing. This contrasted sharply with their previous experiences with care that appeared to undermine all of these things. Therefore direct payments became part of the *solution* rather than part of the problem (as had been their previous experience with local authority commissioned care). The responsibility for managing

their parents care was not a greater burden, but an alternative one that was acceptable when adequate support was available for tasks such as recruitment and admin.

- The 'husband and wife teams' lived such precarious lives that every possible resource should contribute to support their wellbeing, rather than work against it. Many had previously found that services threatened their dignity, independence and wellbeing because timings were either at odds with their daily routine, or just unreliable, or experienced as intrusive. In contrast, direct payments allowed them to find care workers with whom they could establish trust, thereby enhancing their health capital. Its impact was also apparent in very practical ways; having control over care allowed them to focus on the facets of their daily living they could operate as a team maximising the independence of the 'cared-for' wives while also helping to reduce some of the physical strain on the caregiving husbands. Working as a team was an essential coping strategy, which gave some protection against the irreconcilability of some aspects of their dependency. Quantitatively marginal control over timings and tasks also helped to preserve spousal roles which bolstered their feelings of mutual reciprocity, a further psychological resource which appeared to reduce caregiving burden and contribute to the sustainability of care.
- Given their high levels of physical disability, the husband and wife teams relied heavily on home adaptations and mobility aids. A further characteristic of the couples was their level of forward planning in this respect, helped by the good relationships the couples had which permitted constructive decision-making and a commitment to saving for some items. 'Resilience-shaped housing' is clearly a huge priority but it should also be recognised that sometimes counselling is required to take proactive decisions. This needs to take place before most people come into contact with social services and could be a role for external agencies – but they may need financial backing from local authorities.

- A number of the husband and wife teams and working carers employed extra resources in the form of small but critical quantities of self-funded care, mainly funded through Attendance Allowance. For husband and wife teams this was mainly for domestic support (from the same personal assistant, or agency care worker), while for working carers it was used to provide better coverage of times when they were unable to provide direct care. Direct payments 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. The small but pivotal role of self-funded care and its link to the provision of Attendance Allowance is relevant to the debate on the future financing of adult social care.