



Think Local Act Personal Partnership

**Follow-on study: older people who
pay for care**

Final report

January 2012

Think Local Act Personal Partnership

Follow-on study: older people who pay for care

Final Report

Headline Findings

Following on from the Putting People First Consortium publication *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market*, a project was commissioned to explore in more detail the local factors which may affect self-funded care and third party top-ups. For this project data was obtained from four local authorities, care providers, and people who pay for their own home care.

There is wide variation in the rate of self-funders in care homes from a low of 15% in Hartlepool to a high of 57% in Hampshire. Levels of deprivation appear to be the key factor – affecting the ability of service users to pay for a care home place, and the likelihood of whether they will be eligible for local authority funding. This indicates that implementation of the Dilnot report on the funding of long-term care would have a differential impact across local authorities.

There is also a wide variation in the proportion of people in care homes with third party top-ups: from 1% in Hartlepool to 21% in Bradford. This is influenced to some extent by local authority policy and practice.

The proportion of placements partly funded by third party top-ups (18% of all local authority placements) appears lower than previously estimated by other researchers, although higher than the local authorities' own estimates.

The value of third party top-ups varies widely – but is not always linked to higher quality. According to providers in the four authorities, families pay TPTUs to provide older people with greater choice of care home and extra facilities, such as en suite and larger rooms.

From a limited number of responses, about 30% of home care clients are self-funders, and a further 6% pay for additional services on top of local authority funded services. There appears to be a link to FACS criteria – with more people paying for home care, where FACS eligibility criteria are high. Other assessment factors are also likely to play a part.

Purchasers of home care, self-funders and top-ups, pay for similar services: cleaning, personal care, shopping, support to get out and about, and sitting services. Self-funders frequently mention personal care, cleaning and shopping, gardening, transport and handyperson services. This confirms the importance of domestic support to maintaining independent living. As well as wide variation in the kind of care and support that people pay for in their own homes: there is also a broad range in terms of volume and provider.

People who pay for home care are likely to use an agency for personal care; for other help such as cleaning, shopping and gardening, they are more likely to have an arrangement with an individual. Non-personal care is frequently sourced through friends and neighbours. Trusted sources of information and advice such as AgeUK and local faith organisations also have a useful role.

Overall self-funded home care is often sourced through informal networks and paid for in cash. This makes it a difficult market in which to ensure consistency in standards and safeguarding.

Self-funded, informal and state-funded home care are not mutually exclusive, but may complement each other.

The less intensive forms of self-funded home care and support are difficult to regulate because of their tendency to be informally arranged. However, access to reliable and trusted sources of information and advice will enable people to make better informed choices about the home care that they pay for.

Direct payments are mainly used for domiciliary care and day opportunities – providing service users with the possibility of purchasing more personalised and specialised services. Take-up of direct payments by older people remains relatively low.

The key implications of the report are that: the implementation of Dilnot or other policies relating to self-funders will have a differential impact depending on existing rates of self-funding in different parts of the country; there is an ongoing need for access to trusted sources of information and advice for self-funders and their families to enable them to make informed choices about their care; and there are unique challenges to ensuring consistency in standards and safeguarding for self-funders of home care in particular which need to be addressed.

Introduction

This report was commissioned for the Think Local, Act Personal Partnership as a follow-on study to the Putting People First Consortium's publication *People who pay for care: quantitative and qualitative analysis of self-funders in the social care market* (2010) which provided an estimate of the number and distribution of self-funders in England using national survey data, and discussed the emerging tasks for local authorities with respect to self-funders.

The earlier report concluded that the size of self-funded care market is now a significant part of the total care market. Self-funding in care homes was estimated at £4.9 billion, with additional top up funding for more than an estimated 168,000 local authority sponsored places. Self-funding of home care was estimated at £652 million.

The follow-on study aims to complement the earlier work undertaken for *People who pay for care* by producing a more in-depth analysis of four case study areas and the local factors which may influence self-funded and unregulated care. The project explored the extent to which there are local variations in the rate of self-funding across the country related to factors such as affluence, levels of owner occupation, and level of FACS criteria in operation. A second element of the project was the collection of data on self-funded and unregulated care in the home to identify what type of assistance, if any, may be needed to enable the smooth running of this section of the social care market.

1.1 The approach

The previous study identified a number of factors which affect the availability of reliable data on self-funding:

- Providers are an obvious source of data, however, many are unable or unwilling to provide information on the numbers of people who self fund.
- In the home care market, there is no requirement for registration by providers of non-personal care (eg, cleaning, shopping) which would provide a route to capturing data on the number of self-funders.
- Many people might receive quite high levels of care from (usually) non registered providers, often described as offering 'help around the house', where neither the purchaser nor the provider views the service as 'care'.
- Some people are in receipt of council funded services, but top this up through informal care or buying additional hours from registered providers. Consequently, there can be some element of double counting.
- With the use of direct payments, some people will organise and pay for their care themselves, but be funded by their council. Providers may not always be able to identify which care is self-funded and which is funded by the state.

To overcome these obstacles, the follow-on project adopted a three-pronged approach to obtaining data to tackle some of these obstacles: from local authorities, provider organisations, and self-funders themselves. Four local authorities: a London Borough, a southern county, a northern metropolitan borough and a northern unitary representing a cross-section of types of authority, affluence, and rates of owner occupation, agreed to be case studies for

the study (see Table 1). Bradford and Hartlepool are characterised by low house prices and high levels of deprivation, while Hampshire and the Royal Borough of Kensington and Chelsea (RBKC) are affluent areas. However, there are also contrasts within all four areas, for example, affluent areas in Ilkley and Wharfedale in Bradford, and deprived parts of North Kensington in London. Average house prices in Kensington and Chelsea are more than ten times the average in Hartlepool. However, rates of owner occupation among the very old are very low in RBKC with high rates of private renting. This may be compounded by some owner occupiers moving out of London around retirement. Of the four case studies, Hampshire and Hartlepool have higher FACS eligibility criteria in operation, than Bradford and Hampshire.

Table 1: Characteristics of case studies (2010-2011)

	Bradford	Hampshire CC	Hartlepool	RBKC
Type of authority	Northern Met.	Southern Shire	Northern Unitary	London Borough
FACS eligibility threshold	Moderate, substantial & critical	Substantial & critical	Substantial & critical	Moderate, substantial & critical
Index of Multiple Deprivation ranking where: 1/326 and 1/149= most deprived	26/326	139/149	24/326	103/326
Rate of owner occupation among 85+ population	61%	68%	49%	29%
Average house price in March 2011	£102,849	£209,178	£87,687	£889,668

Sources: POPPI, ONS & Land Registry

Each of the local authority case studies provided information on direct payments and third party top-ups, while care home and home care providers responded to a postal survey (supported by the ECCA and NCF) on the number of people paying for care, either as full self-funders or through third party top-ups, and the reasons they are paying for care. A sample of providers was followed up with telephone calls to boost the response. The postal survey of 212 care home providers across the four case study areas achieved an overall 27% response rate which is reasonable for this kind of survey. Care home respondents reflected a good cross-section in terms of size and type of home.

The survey of 101 home care providers yielded a low overall response rate of 9%. This is disappointing but not untypical in our experience. It may reflect uncertainty about who is a self-funder and who pays for care with a direct payment which some home care organisations have expressed. The data on home care should be treated with caution but provides some information in an area which has proven difficult to research.

Focus groups with self-funders in each area were scheduled, but due to difficulties in recruiting participants, individual interviews were arranged instead with help from local third sector organisations and conducted in August and September. A total of 20 interviews were carried out across the four authority

areas with self-funders. These provided information about the profile of people paying for care in their homes, the kind of care purchased and how they sourced it.

2 Care homes

2.1 Care home self-funders

In *People who pay for care*, using data from the Care Quality Commission and regional vacancy rates collected by Laing and Buisson, we estimated that around 170,000 care home places are self-funded, representing 44.9% of the 378,053 registered care home places in England. The proportion of self-funded places in residential care homes was estimated to be 39.6%, and 47.6% in nursing homes (see Table 2).

Table 2: Estimated number of people who pay for their own care home place in England based on data from CQC and Laing and Buisson

	Total numbers of places available at 30.9.09 A	Vacancy levels B	Local authority funded placements C	NHS funded placements D	Number of self-funders by each local authority A-B-C-D=E
Residential care home	187,330	18,809	93,247	1,118	74,156
Nursing care home ¹	179,393	17,830	75,521	673	85,359
Total	378,053	37,749	168,768	1,788	169,748

Note: The sum for column A does not agree between the total number and the numbers of people in residential and nursing care. This is because there are some undefined places in the CQC data - it is therefore correct. For this reason the totals in column E also do not agree, and this is once more correct.

In the postal survey, care home providers were asked for information about the number of residents they had who were fully self-funded, and the number partially funded through third party top-ups (TPTUs). Table 3 indicates that across the four authorities, the proportion of self-funded care home residents was 37%: ranging from 15% in Hartlepool to 57% in Hampshire. As might be expected, the study confirmed that the rate of self-funding appears to correspond with the relative affluence of the area.

Table 3: Self-funding and third-party top-ups at 31.3.2011

	Wholly LA funded A	Third-party top-up B	Wholly self-funded C	Total places covered by survey response A+B+C=D
Bradford	48%	21%	31%	512

¹ Nursing home: this category includes any home with one or more beds designated for nursing. Not all beds in all homes will be nursing beds – some will be for personal care.

Hampshire CC	33%	10%	57%	445
Hartlepool	84%	1%	15%	268
RBKC	63%	3%	34%	220
Total %	52%	11%	37%	1,445 100%

Excludes PCT Continuing health care funded placements
 Figures subject to rounding may not add to 100%

A factor which may influence local rates of self-funding is the number of people moving into available care home spaces from outside the area. However this was not tested in this particular study as the information was not available within the project timescales. It would be interesting to explore this in future work.

2.2 Third party top-ups

Care homes may receive top-up payments from family or friends for local authority funded residents. There is very limited evidence available about the total number or proportion of care home residents who are partly funded through top-up fees.

In 2007, Forder² estimated that out of 199,000 people aged 65 and over in England receiving local authority funding for a care home place, 70,000 made top up payments themselves, equivalent to 35%. This is based on OFT's estimate in 2005 that 35% of council supported people also receive private third-party payments³. The results of surveys undertaken for Laing & Buisson⁴ in 2009 indicate that rates of top-up funding are at least 28% of council-funded care home places. Thus previous studies indicate a likely figure of about 30% of all council-funded care home placements are topped up by third party payments.

The survey responses reveal considerable variation across the four areas in terms of the proportion of *homes* receiving payment through third party top-ups: nine out of fourteen (64%) care homes in Hampshire reported receiving payment from TPTUs, compared with eleven out of 25 (44%) in Bradford, two out of five (40%) in Kensington and Chelsea, and one out of 14 (7%) in Hartlepool. A survey by Bradford Council found that one-third (35%) of care homes in the area would only accept local authority funded people if a TPTU was available.

The data from the survey of providers indicate that the proportion of care home funded places where a TPTU is paid is lower than previously estimated; although higher than the level reported by the four case study authorities themselves. A recent study for OFT also noted that levels of TPTUs were probably higher than local authorities were aware of⁵.

² Forder J (2007) *Self-funded social care for older people: an analysis of eligibility, variations and future projections*, PSSRU Discussion Paper 2505, PSSRU and CSCI.

³ Office of Fair Trading (2005) *Care Homes for Older People in the UK: A market study*. London: Office of Fair Trading.

⁴ Laing & Buisson (2009) *Care of Elderly People: UK Market Survey 2009*, London.

⁵ Office of Fair Trading (2011) *Evaluating the impact of the 2005 OFT study into care homes for older people*, London: OFT.

According to the survey responses, 18% of all local authority funded placements are supplemented by a TPTU, or 11% of the total number of occupied places. It was not clear that affluence or deprivation was associated with TPTUs. As such payments must come from family members or friends who do not necessarily live in the area, it may be that other factors influence the level of TPTUs. For example, in RBKC, the low level of TPTUs was explained as a result of the council's policy and practice on placements (see below). According to the recent OFT report (2011), the majority of local authority respondents (around two-thirds) indicated that they attempt to limit the existence or level (or both) of third party contribution charges (or 'top-up fees') levied by care homes for older people.

The cost of TPTUs ranged from the lowest of £15 per month in one Bradford care home, to around £600 per month in two care homes with nursing – one in Bradford, and one in Kensington and Chelsea. There did not appear to be a strong relationship between the payment of TPTU and the type of care home. Given the wide variation in the level of top-up fees within areas and similar types of care home, it is not possible to use the results to estimate the likely total value of TPTUs.

2.2.1 Bradford

Data from Bradford council indicate that there were 260 people aged 65+ who received TPTUs (equivalent to 14% of the local authority funded residents). However, staff thought that there might be further arrangements between care homes and family members for TPTUs which are not formalised on the contract. As a percentage of *all* local authority funded placements, the survey indicated that 31% of placements (108/353) may receive a TPTU, indicating a significant level of additional payments by families and friends.

Work carried out for a review of in-house residential homes highlighted the difficulty of finding standard-rate placements in two areas of the authority. The review concluded there is some association between inspection quality of homes, and the payment of a top-up. However, standard rate homes showed general good quality, and a few were judged excellent; while some "poor" homes charged top-ups. Factors such as land and labour costs, along with local demand and relative affluence were considered possible influences over the charging of top-ups.

2.2.2 Hampshire

Hampshire has been collecting data routinely on TPTUs for a relatively short time (since January 2011). According to their data, over the six months from January to June 2011, there have been a total of 41 third party top-ups, over the same period there were 990 admissions of older people to a care home. Thus the council data indicate that 4% of new admissions in a six month period were TPTUs, while provider data indicate that the figure is 23% of *all* local authority placements (ie not just recent admissions).

In addition, the council reported that the number of deferred payments associated with older people clients between 1st June 2010 and 31st May 2011 was 102 (excluding respite placements). In 2009/10, Adult Services had 5,664 older people in residential or nursing care.

2.2.3 Hartlepool

Hartlepool reported that there were only four people that they support who also have third party top up payments, only one of whom is in the local authority area (out of 674 people placed in residential care – of whom 601 aged 60 or above): the other three are residents of homes in Stockton, the neighbouring borough. As far as they can ascertain, the TPTUs are all for: "*extra facilities, such as en suite or direct access to gardens via patio doors*". The provider data also indicate a low number of TPTUs equivalent to 1% of *all* local authority placements.

2.2.4 RB Kensington and Chelsea

Data provided by the RBKC indicated that there are currently only 3 people who pay a third party top-up out of 248 older people in care home placements (1.2%). Provider data also indicate a low level of TPTUs (4% of local authority placements) slightly higher than the local authority figure for TPTUs.

The local authority's view was that the reason for a TPTU was always because an older person had a preference for a home above the borough's fee limit for older people residential and nursing fees. The very low level of TPTUs was due to the application of a TPTU policy which means that when the Residential Care Coordinator searches for a placement, they generally only look for homes that are within the fee limits. Care managers tell the older person's family/friends from the outset that if they have a preference for a particular home that falls outside of the fee limits they must top up the placement. Most family and friends are not in a position to do so or want to commit to this. There may be exceptional circumstances due to a change in need or the absence of a third party where the policy may be waived.

2.2.5 Reasons for TPTUs

Providers were asked for their views on the main reasons why people paid for TPTUs. The main reasons cited for paying TPTUs concerned: being able to have a choice of care home; to get: "*the quality of care they feel they need and can get*"; and extra facilities such as en suite, a larger room or more modern facilities. Some respondents commented that local authority funding was inadequate to cover their costs. In one case the home had decided to focus on end of life care as a strategy to secure its viability. Clearly, a necessary precondition for the possibility of a TPTU, is that family or friends have access to the financial resources to pay it. A couple of respondents observed that not all families had the funds available to pay a TPTU. One provider replied that: "*Top ups are always negotiable and are assessed with families prior to admission*".

3 Home care

3.1 Home care self-funders

Forder (2007) estimated that 751,000 older people receiving community based care (13.2% of all older people in England). This total broke down into: 145,000 (19%) paid for their own care, and 154,000 (21%) topped up local authority provided care, with the remaining 60% being fully and only funded by their local authority. According to Forder, the additional amount of care purchased is

usually modest at around 4 hours a week, although some older people buy a lot more.

In *People who pay for care*, using data from the English Longitudinal Survey of Ageing (ELSA) and the most recent population projects, it was estimated that 168,701 or 1.97% of *all* older people pay for home care in England, with a total of 271,536 (or 3.2%) paying for support with home care and the instrumental activities of daily living, such as housework and shopping. However, there were no ELSA data available on the extent to which older people receiving local authority funded home care, topped up this service with self-funded care or support.

Evidence from the postal survey indicates that 30% of the home care providers' clients across the four local authorities were full self-funders. The low numbers limit the value of analysis at the individual authority level, however the rate ranges from 14% in Kensington and Chelsea, and 22% in Bradford, to 36% in Hartlepool and 64% in Hampshire. Although these figures should be treated with caution, there is some correspondence with the FACS eligibility criteria in operation across the four areas. Other aspects of the assessment process may also be significant.

Providers were asked about the services provided to full self-funders. Personal care and cleaning services were most frequently mentioned, followed by meal preparation, showering, sitting and escorting to the shops and doctors.

The interviews indicated the wide variety of arrangements existing for self-funders: both in terms of the amount of care purchased – from one or two hours a week to two people with full 24 hour care seven days a week. Interviewees mostly lived alone but about one-third lived with someone else: partner, other family member or friend.

Eight of the twenty people interviewed paid for varying amounts of personal care. Nearly all of those interviewed paid for help with cleaning (17) and nearly half (9) paid for a gardener – in some cases two gardeners. Interviewees also mentioned paying for help with shopping, handy people, taxis and other transport services – particularly for health appointments. Chiropodists, hairdressers, and laundry services were also mentioned.

In a couple of instances, people appeared to be topping up a council funded service. However, a number of respondents mentioned that they had received council funded care, but following assessment had been assessed as over the income threshold and been obliged to pay. In a quarter of cases, the interviewees had assumed that they were not eligible for local authority funded care. A couple of interviewees mentioned financial worries – for example, one interviewee who was spending around £1,000 a week on care and support. Two people used Attendance Allowance to help pay for support.

Most self-funded personal care was provide by an agency – in some cases based on information or advice receive from adult social care; in one case the interviewee had a friend who ran an agency; and in a second the interviewee obtained suggested agencies from the Phillippines embassy. The other main sources of care and support were friends and neighbours' recommendations,

AgeUK and local church. Only one person mentioned their GP as a source of information.

Most of these arrangements (for non-personal care) were informal – apparently cash in hand. This makes the self-funders market for home care a difficult one in which to ensure consistency in standards and safeguarding.

For some interviewees self-funded care was not a replacement for informal care but supplemented it. It is clear that informal care, state-funded care and self-funded care are not mutually exclusive but may often co-exist to enable people to continue to live independently.

3.2 Topped up home care

The postal survey of home care providers across the four authorities indicated that 6% of clients receiving a service from these providers paid a top-up or for additional services over and above the home care funded by the local authority. This is considerably lower than Forder's estimate but only covers providers registered with the CQC. Evidence from Hampshire in an earlier study by IPC indicates that 11% of people receiving personal care (formal and informal) pay an individual to provide it.

Providers of home care were asked for details of what people spent their money on, when topping up local authority funded home care. Cleaning, personal care, shopping, support to get out and about, and sitting services were all mentioned. There is a close overlap here with the services paid for by full self-funders – reflecting to some degree the services available from these providers.

When asked about the reasons for people topping up the available local authority care, providers mentioned this might be due to the limited funding package from the local authority. Additional funding was needed for older service users to pay for activities such as cleaning, escorting and night sitting; or for extra care outside allotted times.

3.3 Direct payments

The current project sought data from the local authority case studies on the extent of direct payments and the types of things that older people spent their direct payment on, along with a request for information from home care providers on the amount of self-funding and the kind of services paid for.

Table 4 – Direct payments and services received 2010-2011

	Bradford	Hampshire	Hartlepool	RBKC
Numbers receiving DP aged 65+ in 2010/2011	241	549	116	228 (excluding carers)

Source: Local authority case studies

Table 4 indicates that take-up of direct payments by older service users was relatively limited across the four authorities. Applying data provided to the ADASS personal budgets survey, it appears that between 5% and 12% of those receiving services aged 65 and over received a direct payment in each local authority case study. Nationally, a third of personal budgets are delivered via a

direct payment, almost half of all personal budget funding is allocated in these payments, suggesting that the people offered larger funds are choosing direct payments as their preferred delivery method⁶. In the case studies, most people used their direct payments to purchase domiciliary care, day opportunities, equipment or cleaning. These findings correspond with a recent study by Claudia Wood of 770 care users across 10 local authorities. Wood found that those with direct payments were far more likely to use personal assistants, home carers and home helps, than other groups⁷. The evaluation of the individual budget pilot programme⁸ found that many of those who took their individual budget in cash chose to employ personal assistants. A survey of 1,114 personal budget holders across 10 local authority demonstrator sites found that older adults were less likely to use direct payments, less likely to know how their personal budget was managed, and more likely to have a personal budget managed by the council⁹.

Apart from the individual budget pilot evaluation, there is very little information about how older people are spending direct payments in cash. The availability of data on how people used their direct payments was variable across the four local authorities. One local authority commented that direct payments are given on the basis of need, and do not therefore relate to a specific service. While brokerage services may have some information available, not every client uses a broker.

The case study examples provided by the authorities (see Appendix 1) demonstrate the potential value of direct payments in enabling people to obtain tailored or specialist care suited to their particular needs.

3.3.1 Hampshire

Of the 549 clients in Hampshire who received a direct payment during 2010-11, 83.6% purchased domiciliary care, and the remaining 16.4% would have been used to purchase equipment and day opportunities.

3.3.2 RB Kensington and Chelsea

Take-up of direct payments was highest in RBKC. A survey of 47 older people who received a service from the main brokerage provider at RBKC during 2010-2011 indicated the main use of direct payments were for:

- Buying care from an agency 47%
- Employment of own support worker 47%
- Use of cleaning agency 4%
- Other (eg daytime activities) 2%

However, the authority commented that the proportion of *all* older direct payment holders choosing to employ their own support worker was likely to be much lower (25% maximum) with the majority buying care from an agency, because the people using a brokerage service are likely to be doing it because

⁶ ADASS (2011) *Personal Budgets Survey – Summary Results 29.6.11*.

⁷ Wood, C (2010) *Personal Best*, London: Demos

⁸ Glendinning C, et al. (2008) *Evaluation of the individual budgets pilot programme: summary report*, York: Social Policy Research Unit, University of York.

⁹ Hatton C & Waters J (2011) *The National Personal Budget Survey*, In Control/Lancaster University on behalf of Think Local, Act Personal Partnership.

they have chosen to employ their own support worker. The majority of people surveyed opted to manage money themselves and/ or with help from family. Only 15% took up an ongoing service to manage the money on their own behalf.

4 Conclusion

This report presents the findings from local authorities, the care providers' survey, and the qualitative data from the interviews with self-funders.

The results of the project lead to the following conclusions and key findings:

- There is considerable variation in the rate of self-funding in care homes across authorities, from a low of 15% to a high of 57%. Levels of deprivation appear to be the key factor – affecting the ability of service users to pay for a care home place, and the likelihood of whether they will be eligible for local authority funding. This indicates that implementation of the Dilnot report on the funding of long-term care would have a differential impact across local authorities.
- Third party top-up payments to care homes appear to be higher than local authorities are aware of, although previous studies may have over-estimated the proportion. Just under one in five (18%) of all local authority funded placements are likely to be partly funded by a third party top-up. Local authority policy and practice appears to be a key factor in determining the extent of TPTUs. According to providers, families pay TPTUs to provide older people with greater choice of care home, better facilities such as en suite rooms, and a better quality service.
- From responses by a limited number of home care providers, it appears that 30% of clients are full self-funders (with a range from 14% to 64%), and a further 6% pay for additional services on top of services paid for by the local authority. The overall proportions are likely to be higher as the survey only covered CQC registered providers. The figure for fully self-funded home care is higher than previous estimates, while that for topped-up home care is lower. Levels of self-funded home care appear to correspond with FACS eligibility criteria in operation, rather than the relative affluence of the area. Other assessment factors are also likely to play a part.
- Purchasers of home care, self-funders and top-ups, pay for similar services: cleaning, personal care, shopping, support to get out and about, and sitting services. Self-funders frequently mention personal care, cleaning and shopping, gardening, transport and handyperson services. This confirms the importance of domestic support to maintaining independent living.
- While agencies provide the more intensive end of self-funded home care, self-funded support is frequently informal and unregulated – and sourced through neighbours and friends. This means that it is difficult to ensure consistent standards and safeguarding in this part of the market.
- The less intensive forms of self-funded home care and support are difficult to regulate because of their tendency to be informally arranged. However, access to reliable and trusted sources of information and advice will enable people to make better informed choices about the home care that they pay for.

- Self-funded, informal and state-funded home care are not mutually exclusive but may complement each other.
- Direct payments are mainly used for domiciliary care and day opportunities – providing service users with the possibility of purchasing more personalised and specialised services. Take-up of direct payments by older people remains relatively low.

The key implications of the report are that: the implementation of Dilnot or other policies relating to self-funders will have a differential impact depending on existing rates of self-funding in different parts of the country; there is an ongoing need for access to trusted sources of information and advice for self-funders and their families to enable them to make informed choices about their care; and there are unique challenges to ensuring consistency in standards and safeguarding for self-funders of home care in particular which need to be addressed.

Appendix 1 – Case Studies

To illustrate how service users were using their personal budgets, including direct payments, the local authorities provided a number of case studies.

Miss X

Miss X is 101 years old and lives alone in a one bedroom flat. She is using her personal budget to employ private carers to assist with personal and practical care. She chose to employ carers as she wanted Polish speaking carers only. She recruited her carers from her local Polish Society through her close friend who is the manager of the organisation. Miss X has a friend who manages her finances and is also acting as an agent for the administration of her Personal Budget. By employing Polish speaking staff that live locally to her, Miss X is having her needs met in the way that she has chosen that would not have been possible through using an agency.

Mr Y

Mr Y is using a cleaning company to meet his needs. He has practical care needs only, and chose a cleaning company because he could purchase more hours for his Personal Budget than if he opted for a domiciliary care provider. He was supported to choose a reputable cleaning company that vet their staff and provide written references. Mr Y manages his Personal Budget himself using the council's Visa Card. The cleaning company invoice him on a four weekly basis and he then transfers the funds to the cleaning company over the phone.

Mrs Z

Mrs Z became a full funder when the new contributions policy came into effect. She chose to continue using a domiciliary care provider to meet her personal and practical needs. Mrs Z chose the homecare agency because she likes her carers and they have been supporting her for a number of years. Mrs Z suffers from dementia so the continuity of staff is very important to her as is staff that know what to do when they are on shift. Mrs Z's daughter manages all her finances as she does not have the capacity to manage it herself.

Mrs A

Mrs A is 70 years old and has dementia. She is very active but now unaware of risks and dangers, and is at risk of wandering so needs support when at home and outside. She wants to remain as independent as possible, thus requires a lot of support and prompting in all activities of daily living. A direct payment has been in place in 2008. Mrs A purchases 16 hours per week of domiciliary care with her direct payment, which provides support and respite for her and her family. As a result, the family are very happy, and require very little Care Manager input apart from regular reviews.

Mr B

Mr B is 71 years old and lives at home with his partner. He had a stroke in 2004 and has right sided weakness and expressive and receptive dysphasia. He receives a mixture of direct payment and commissioned services. The direct payment is for a private carer to assist bath twice a week, and for accessing the community and giving respite to the partner. The commissioned services are for care each morning to help with getting up.

Mrs C

Mrs C is 81 years old and suffered a stroke in 2006. She has some vascular dementia as a result, and is partially sighted. She is able to make decisions. She lives with her son who manages her direct payment to purchase day and domiciliary care. Mrs C attends a day centre weekly and has carers to bath/shower twice a week. There is little Care Manager input required now th direct payment is in place, only annual reviews required.

Mr D

97 years old Mr D wishes to remain in his own home. He uses a direct payment to purchase 14 hours on domiciliary care: the family manage the payments and package on his behalf.