“Personal budgets will revolutionise social care delivery, but only if local authorities are fully prepared…”

PERSONAL BEST

Claudia Wood

DEMOS

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Claudia Wood
October 2010

Executive summary

The social care system is undergoing significant reform, at the heart of which is a drive towards greater personalisation for those who use care services. The previous government articulated this vision in the strategy document *Putting People First*, which clearly linked personalisation to the greater use of personal budgets. By providing cash in lieu of services for those eligible for state funded care,[1] personal budgets enable people to plan and purchase their own care and support services instead of having this decided by their local authority. *Putting People First* set a target that by April 2011, 30 per cent of council funded care users across the country will be using a personal budget. As around 13 per cent of people currently have one, this represents a major shift in a very short space of time. The new Coalition government, supportive of personal budgets and showing interest in expanding them to health care, has left this target in place.

Both local authorities and service providers need to respond to this development. For the former, it means a radical role change: from directly shaping the local market as its single largest purchaser, to ensuring a healthy and affordable market through the provision of support and information to providers (not just of care) and consumers. As our findings demonstrate, this will be no mean feat. For the latter, personal budgets will require greater responsiveness to individual consumer demands rather than the fulfilment of local authority contracts – this may mean, variously: diversifying and offering a more flexible range of services, working with mainstream services as partners and maintaining stability of service. Again, not an easy task.

The research presented here provides some insight into how commissioners and providers will need to go about these new responsibilities. It summarises the findings from a survey of

770 care users across ten local authorities,[2] which focused on what people wanted to change about their lives and the care and support they might like to use. As it includes personal budget and direct payment users, council funded care users (yet to be offered a personal budget) and self funders, it paints a unique and detailed picture of the future of care and support provision.

As this is an ongoing project, Demos will be collecting more data over the coming months so that by early 2011 we will have a sample of over 2,000 care users. This is a unique dataset, the first and largest of its kind to explore the preferences of those care users who have yet to receive personal budgets and to provide intelligence about the forthcoming changes that may occur in the wake of the wider roll out of personal budgets. Given the pace of change set for the next seven months as local authorities race to meet the 30 per cent personal budget target, the findings here provide an invaluable insight into imminent market changes for providers and commissioners.

This executive summary sets out the key findings of the survey.

Demographic overview

Data from 770 care users were analysed for this report; 59 per cent of them were women, and 71 per cent described themselves as 'White British'. The rest of the sample was made up of 13 per cent Indian, 4 per cent Black Caribbean, 3 per cent White Irish, 2.5 per cent Pakistani, and smaller numbers of many other ethnic groups.

Broken down into needs groups, the most commonly represented primary needs were physical impairment (43 per cent, 334 people), old age (23 per cent, 181 people), learning disability (14 per cent, 111 people), and mental health need (13 per cent, 103 people). Less common need groups were those with visual and hearing impairments (14 and 6 people respectively said this was their primary reason for needing care, though 53 and 21 people said this was a secondary reason), followed by deaf blind (3 people).

The sample was made up of 449 people who had their care

wholly funded by their respective local authorities, another 49 people particularly funded by the council (for the purposes of the following analysis we include them in the council funded group), 138 self funders (including 36 people who said their family paid for their support), 93 people using a direct payment or personal budget (for the purposes of our analysis we treat this as one group) and 41 who did not know how their care was funded and/or said they received NHS care.

We analyse each of the survey questions by need group, funding group and ethnic group as appropriate, but exclude analyses in cases where sample sizes are too small to draw relevant conclusions.

People's lives

The most common concerns for respondents, and the percentage with this view, were:

- keeping healthy and well (77 per cent)
- having a good quality of life (64.5 per cent)
- having personal dignity and respect (50 per cent)
- choice and control (48 per cent)
- economic wellbeing (25 per cent)
- freedom from discrimination (19 per cent)

The average life satisfaction score across all care users was 2.64, a slightly positive result (a score of 1 represents very satisfied, 3 neither satisfied nor dissatisfied, and 5 very dissatisfied). Self funders are the most satisfied overall, with an average score of 2.45. Those with direct payments or personal budgets score 2.53, with council funded care users the least satisfied at 2.64. The largest between-group differences can be seen in ethnic groups, where scores range from 2.04 for the 'White Other' group, to 2.74 among Pakistani care users. Scores were particularly low for economic wellbeing among Pakistani and Black Caribbean groups.

The current picture – what services do people use now?

Across the entire sample, the most frequently used care and support services are:

- day centres (36 per cent of the sample say they use these)
- informal family support (34 per cent)
- transport (31 per cent)
- personal assistants (PAs) or home carers (30 per cent)
- home help (for example cook, cleaner, gardener) (26 per cent)

However, this masks large differences between funding groups (council funded, self funder, direct payment user). For example, self funders and direct payment or personal budget users are around twice as likely to use leisure services as council funded care users. Those with direct payments are also far more likely to use PAs, home carers and home helps, than other groups. It is most interesting to note that although self funders and council funded care users rely on their families to a similar extent, those with direct payments or personal budgets do so to a lesser degree.

The differences between funding groups were, surprisingly, larger than those between need groups (learning disability, older person, and so on), suggesting that the way one's care is funded has a larger impact on the services one uses than one's needs (or indeed preferences) do.

More than half (55 per cent) of self funders say they spend less than £5,000 per annum on care and support services, although 36 per cent did not know how much they spent; 64 per cent felt they received value for money, though those who did not think this were disproportionately from minority ethnic groups.

What people would like to change about their lives

The five areas care users most commonly wanted to change were their physical health (41 per cent), their opportunities for holidays (37 per cent), what they do on weekdays (32 per cent), the control over their lives (29 per cent) and their financial

situation (29 per cent). This priority list is similar to that highlighted in the first report *At Your Service*, where physical health, holidays, money, weekday activities and control over life were the top five priorities for care users, in that order.

With this latest data, we are able to establish that the differences between funding groups were again more significant than those between need groups. There are fewer differences between the responses of different ethnic groups, with physical health, holidays and weekday activities important for all groups, with the exception of Black Caribbean care users, who distinguish themselves from other groups by identifying their financial situation as their main concern.

Again, this suggests that the areas of their lives care users wish to change are more likely to be influenced by how their care is funded than by their care needs. Overall, direct payment and personal budget users wanted to change the fewest things about their lives and council funded care users the most.

Would people change their care and support?

Nearly half (42 per cent) of self funders would like to change their care and support if they could. This is an important message when considering personal budgets – simply having control over one's finances may not be sufficient to exercise choice and control. If we combine these data with our life satisfaction scores, we can see that those who did want to change their care and support were less satisfied than those who did not – average scores were 2.74 for the 'changers' and 2.09 for the 'non changers' (where a lower score denotes greater life satisfaction). The largest difference between the scores of the two groups is in economic wellbeing – whereby those wanting to change their care and support were significantly less satisfied with their financial situation than those who did not want to change their care. This suggests that financial constraints may be a reason why self funders are unable to change their care and support.

We also asked council funded care users whether they would change anything about their current support package if

they had a personal budget. It should be pointed out that two-thirds (65 per cent) of care users had no knowledge of personal budgets at the start of the survey. Overall, 45 per cent of council funded care users in our dataset said they would not change anything about their care and support if they had a personal budget. Those with mental health needs and older people were less likely to want to change their care than those with physical impairments and learning disabilities.

What help would people need to make changes in their lives?

Once we had established what changes people wanted to make to their lives, we asked what help they would need to action those changes. The most common changes for all care users, and the percentage asking for them, were:

- more information regarding what I can do (54 per cent)
- more face to face advice (52 per cent)
- someone to speak to in an emergency (46 per cent)

Having more information and face to face advice were the top concerns for White British, Indian, Pakistani and Black African groups, but the top priority for White Irish and Black Caribbean groups was having someone to help in an emergency. They also both placed having more face to face advice ahead of having more information. Black African groups put help with planning their care as their third most important issue, much higher than all other groups, whereas Indian care users' third priority was having more choice and control over their care.

What services do people want with a personal budget?

The most popular responses to this question were holidays (selected by 44 per cent), leisure activities (42 per cent), PAs or home carers and home helps (both 38 per cent), transport (36

per cent) and day centres (36 per cent). The least popular options to spend personal budgets on were residential care (6 per cent), a car (8 per cent), and paying friends for care and support (14 per cent).

If we consider these data according to need and ethnic group, we can see that older people express an interest in the most 'traditional' care services, while those with learning disabilities have far more interest in non traditional and universal services. These groups have the greatest interest in education and training. A fairly large proportion of those with mental health needs say they would use a personal budget to pay their family to provide support. There are more noticeable differences between ethnic groups – in particular, the preference for paid family support among white Irish and Black Carribean care users, the interest in education and training among Indian and Black Carribean groups, and the use of personal budgets to pay friends for support among Pakistani care users – this group was twice as likely to select this option as the sample as a whole.

The scale and nature of change

Comparing what council funded care users do now with what they say they will do if they had a personal budget, we are able to establish that:

- leisure service use would increase significantly – 18 per cent of council funded care users say they use leisure services now, compared with 73 per cent who say they would use leisure services if they had a personal budget
- holidays and education and training would also increase significantly, from 9 per cent to 44 per cent and 12 per cent to 22 per cent respectively
- using family for support would fall, from 39 per cent to 26 per cent, and day centre use would also fall, from 46 per cent to 37 per cent
- residential care use would only fall slightly, from 8 per cent to 6 per cent

However, these headline figures hide some very different trends in specific need and ethnic groups. For example, although day centre use decreased overall, it actually increases very slightly among older people. Similarly, home help increases substantially among older groups, but remains the same or falls slightly in other groups. Reliance on family decreases among all groups except White Irish, where it increases from 29 per cent to 42 per cent in the form of paid family support.

To establish whether the hypothetical preferences among potential personal budget users hold weight once personal budgets are actually used, we asked existing direct payment or personal budget users what types of support they spent their money on before and after receiving this form of funding. These comparative data confirm the general trends seen above:

- Use of PAs and carers has increased substantially among those now with direct payments and personal budgets – 45 per cent of this group used them before having this form of funding, now 76 per cent do
- Leisure service use has similarly increased – from 9 per cent to 26 per cent
- None of this group used their care funding for holidays before having a direct payment or personal budget – now 21 per cent do
- The reliance on friends and family has decreased substantially – from 32 per cent to 3 per cent for friends and from 50 per cent to 21 per cent for family
- 2 per cent use residential care before a direct payment or personal budget, now none do

What is important when choosing a service?

In answer to this question care users prioritised staff knowing you personally and continuity of service (47 per cent), being locally based (46 per cent) and professional training of staff (42 per cent). Self funders are less concerned about the professional training of staff and national accreditation, and value the recommendations of others. Interestingly, breaking these data down by need group uncovers relatively few differences – all

need groups have the same four priorities – professional training of staff, being locally based, staff knowing you personally and continuity of service. However, there are more significant differences in the priorities of ethnic groups, relating to cultural sensitivity, staff sharing your interests, and professional training of staff.

Using personal budgets

We asked care users with personal budgets and direct payments how they had found the process of receiving and using this form of funding. Around half of the group said it had been easy to find out about personal budgets, get control over the money, plan the support, and get the support. However, only 32 per cent said it had been easy to carry out their self assessment. The fact that half of this group said they had *not* found it easy to find out about personal budgets may help explain why 65 per cent of the council funded group said they knew nothing about them.

When asked what help they might need with a personal budget, more than half (57 per cent) of council funded care users said they would need information on what to spend their personal budget on; one-quarter (25 per cent) said they would need no help. Those with sensory impairments were most likely to say they needed no help – 33 per cent said this, followed by those with physical impairments (30 per cent). At 15 per cent, those with learning disabilities were least likely to say they needed no help.

Implications for commissioners

- *Managing change for care users*: 55 per cent of council funded care users would change their support if and when they are given a personal budget. Local authorities must help their existing clients to make changes, and this will range from a significant reordering of care packages including a change of service and provider, to smaller changes that require negotiation with existing providers.

- *Maintaining stability*: commissioners will have to ensure that services are maintained and remain consistent (continuity was the joint most popular choice when we asked people what they looked for in a service, selected by 47 per cent of care users) throughout this period of transition and upheaval.
- *Improving public awareness*: the lack of awareness of personal budgets is a concern. Two-thirds (65 per cent) of council funded care users said they knew nothing about personal budgets at all. This lack of knowledge could hamper take up of personal budgets, or could see people not using their personal budgets effectively.
- *Market affordability*: self funders may be constrained in their choices by a lack of resources. Local authorities will need to consider whether all services in their local area – not just traditional care services – are affordable for their self funders. In the light of imminent budgetary cuts to social care, this may also become an issue for those with personal budgets.
- *Supporting the shift to mainstream and universal services*: there will inevitably be a reduction in clients for some providers, but ensuring they respond positively to this challenge (changing their service, diversifying, working with others, and so on) could be an important role for the local authority in ensuring the care market remains healthy and responsive to demand. Local authorities are best placed to take a strategic overview of the local market, not just of care services but of all services. In the light of the findings in this report, local authorities will have to consider whether there are adequate leisure and cultural services available for personal budget holders to make use of, as well as suitable transport.
- *Commissioning for diversity*: how people's care is funded dictates both the types of activities they engage in and the services they use. However, personal budgets have the potential to change this, by giving people's preferences and needs greater sway. In taking an overview of the services and facilities available in their local area, local authorities must consider the full scale and breadth of preferences expressed by different groups of users.

Implications for providers

- *Market shifts*: a shift towards leisure and holidays; a demand for a greater range of activities during weekdays; an increased demand for home helps, PAs and help going out (including transport) will clearly have variable impacts on the care and support market. There may be opportunities to diversify and meet new and emerging needs as a means of offsetting potential declines in client numbers.
- *Market stability*: although 55 per cent of care users say they would not change their care with a personal budget, 37 per cent said they would change it 'a little'. Providers will have to maintain the stability and consistency of traditional services while making small-scale service changes, diversifying their offer to offset potential declines in business, and make significant organisational and staff changes to ensure personal budgets can be dealt with administratively and operationally. Maintaining stability for existing clients while driving change is a dual role, which is likely to be the greatest challenge for providers in the wake of personal budget roll out.
- *New markets*: given the potential limitations of existing mainstream services to meet the specific needs of those with physical, sensory impairments or learning disabilities, it may be that providers might consider developing new services to meet emerging demands for example in the area of leisure, holidays, transport and home helps, as well as personal budget support, where care users may require help spending their budget and managing their care plan, employing a PA, and so on.
- *Marketing*: the key to entering new markets will be how providers market themselves. It requires a greater understanding of the needs and demands of the potential clients for different services across a diverse population; the development of a trusted brand and reputation for quality, flexibility and reliability; and initiatives that provide information and increase awareness of the options available. Raising brand awareness and providing service information by providers is vital given the low awareness of personal budgets.

General points

In summary, our findings represent a significant challenge for providers and commissioners. Potential issues of affordability, lack of consumer information and hands on guidance, and providers (care related and those in mainstream services) unprepared for significant shifts in demand could all combine to create a highly 'imperfect market', where care users cannot secure the services they want and need and where some providers may be driven from the market unnecessarily.

With more time and resources, the data Demos now hold could generate extremely interesting and in-depth investigations regarding, for example, the users of one type of service, one minority ethnic group, gender differences, and so on. The analysis in this report has already uncovered some interesting and unexpected findings:

1. When it comes to the current level of satisfaction with life and priorities for change, and current services used and activities engaged in, there is a greater difference between funding groups than between need groups. This suggests that the way in which people's care is funded is more of an influence on people's lives and the services they use than the reason they need that care – for example because of a physical impairment or learning disability.
2. However, comparing the services that different need groups use now with what they select if given free choice (with a personal budget), it is clear the interests and preferences of different need groups is far more diverse that their current service use suggests. We can only conclude that the way in which care is funded stifles this difference and, with the roll out of personal budgets, the full diversity of preferences will be reflected in purchasing decisions.
3. The idea that self funders are in some way 'free' to choose their own care is too simplistic. Just 45 per cent of self funders say they wouldn't change their care and support if they could, the same percentage as council funded care users. The fact that a larger proportion of self funders want to change their financial situation than other groups, and that those wanting to change their care are particularly unhappy with their financial situation,

suggests that a lack of money must play its part in constraining self funders' choice.

4 Personal budgets seem to be a question of how not what. The activities that people want to be able to undertake changes less than the types of services they want to use. With some specific exceptions, care users often want to do more of what they are already doing – socialising, meeting new people, going out and engaging in specific activities like art and music. But how these outcomes are met looks set to change from traditional care and support services to more universal and mainstream services.

1 Background to the project

Personal budgets – their development

The social care system is undergoing substantial reform. The vision behind this transformation is of personalisation, choice and control, which began with the Community Care (Direct Payments) Act 1996. This enabled some disabled people of working age to have a cash payment in lieu of social care services to spend themselves – known as a direct payment. The right to direct payments was extended to all care users by 2003, and this was followed by a series of strategies further promoting choice and control, most notably the adult social care green paper, Independence, Well-being and Choice,[3] in 2005 and the 2006 white paper, Our Health, Our Care, Our Say.[4] However, it was in 2007, with the launch of Putting People First,[5] that personalisation was fully articulated as a founding concept of social care reform.

Putting People First stated that its mission was 'to make sure anyone who needs care and support can exercise choice and control to live their lives as they want'.[6] At its heart is the use of direct payments and personal budgets to achieve this. Five 'milestones', targets which all local authorities had to meet within a set time frame, were issued. Milestone 2 was entitled 'self directed support and personal budgets', and stated that:

- *By April 2010: Every council will have introduced personal budgets, which are being used by existing or new service users/carers.*
- *By October 2010: All new service users/carers are offered a personal budget. All service users whose care plans are subject to review are offered a personal budget.*
- *By April 2011: At least 30 per cent of eligible service users/carers will have a personal budget.*

Those people who are eligible for social care funding (according to an assessment of need and income – for three-quarters of councils this means having needs assessed as substantial or critical[7] and having £22,500 in savings or less) are currently assessed by a care manager and allocated a service that has been selected and purchased by the local authority. But soon they will instead be offered a personal budget — often a cash budget (a direct payment), but possibly also a budget help by a third party — to use to buy services themselves.

To receive a personal budget, care users carry out a self assessment of their needs to determine the amount offered, and then design their own care plan detailing what they will spend their budget on. Once agreed by the local authority, this money is released to the care user who becomes the commissioner of his or her own services. People are able to spend their personal budget on whatever they see fit, providing the local authority is satisfied that it will help keep that person safe and well. This will see the role of local authorities as current service commissioners and the role of care providers change dramatically. The ability of local authorities to influence the price and quality of what is on offer locally is being lost as they will soon no longer be the single largest purchaser of care services. For providers, there is a shift from fulfilling local authority (often block) contracts for groups of clients, to having to attract and keep individual clients and being open to consumer-led market forces.

Personal budgets and the coalition

Personal budgets were supported by the Liberal Democrat and Conservative parties when in opposition, and the new Coalition government took a supportive stance on the use of personal budgets in social care, with the Labour government's milestone still in place. Personal budgets certainly resonate with the Coalition's drive towards personal and community responsibility and devolution of power to the front line and service users. Indeed, all signs seem to indicate that the Coalition is taking a more radical line on personal budgets than the Labour government had by providing £4 million additional funding to

pilot personal health budgets. The Care Minister Paul Burstow stated:

A similar scheme has been a huge success in social care, letting people choose services that fit in with their life, rather than fitting their life around the service. Today's investment into personal budgets for healthcare will ensure that patients using the NHS will be able to benefit in the same way.[8]

However, he went on to suggest that personal health budgets and personal (social care) budgets might become integrated to enable people to purchase health and social care as part of their support package more seamlessly:

If personal budgets can achieve one thing, let's hope they can rid us of the unseemly stories of managers squabbling over whether a bath is a 'social care bath' or a 'health bath'. The person needing help doesn't care who pays. They don't distinguish between the organisation providing the services. Nor should they. Personal budgets can help us end this stand-off.[9]

Such a move would certainly be in keeping with other radical reforms currently being ushered in by the new government to blur the boundaries between health and social care, including GP commissioning and hospitals arranging community care for recently discharged patients.

However, the current economic climate and impending budgetary cuts may require a more considered approach to the adoption of personal budgets. Personal budgets are simply a form of funding – they do not change the amount provided. As social care is subject, like most other departmental budgets, to a 25 per cent cut, and as council tax rates are frozen, local authorities are under more pressure than ever before to cut costs in what has been acknowledged as an already critically underfunded service. It is to be hoped that the new Commission for Care Funding will resolve the funding problem when it reports at the end of the year, but until 2015 social care budgets will need to function under what will be an extremely tight settlement brought in by the imminent Comprehensive Spending Review.[10]

There is a risk in this context that personal budgets will be seen as a cost cutting measure – anecdotal evidence suggests that some care users with personal budgets are receiving less in monetary value than they once received in services, justified perhaps by early evidence that individuals with personal budgets spend less on care than local authority commissioners had.[11] However, reducing the amount people have to spend on their care could have serious consequences – some may find themselves priced out of the local market of care and support services. Arguably, as they have less influence over price and quality than say the local authority would have had as a single large purchaser, they may find they can only purchase less care or lower quality care than they actually need. If this becomes a common phenomenon in an area, local providers may see their client bases shrink and a downward pressure on prices, which could endanger the financial viability of smaller and voluntary sector providers.

We should also bear in mind that tightening eligibility is also used by local authorities to bring down costs, with more and more authorities each year providing services just to those with the highest assessed needs. As a result there has been an increase in 'self funders' – people who pay for their own care and support. As eligibility for state funded social care is based on both need and income, self funders have always made up a large proportion of the populations of wealthier local authorities, where many people have higher income or savings than the £22,500 benchmark. However, as criteria relating to need become tighter, so self funders are becoming more numerous across the country and many of these will have relatively low incomes to spend on their care and support. For providers, this represents a 'double whammy' of change – their client bases will increasingly be made up of self funders and personal budget holders.

The latest figures from the NHS Information Centre show that 13 per cent of disabled adults, older people and carers who were eligible for state funded care were receiving personal budgets in 2009/10, up from 6.7 per cent in 2008/9.[12] If local authorities are to meet their 30 per cent target of social care users using personal budgets, however, the pace of change will need to increase substantially over the next seven months. Yet as

personal budgets are a comparatively new development, and relatively few people have them, there is limited information on how these are being spent now, how they might be spent in the future, and what the implications of these spending patterns will be, particularly for providers of services.

Our first report on this subject, *At Your Service*,[13] outlined the findings of the most important existing sources of intelligence relating to personal budgets, which includes the phase 1, phase 2 and now phase 3 reports from InControl[14] and the Ibsen pilot study.[15] However, such evaluations tend to be based on relatively small sample sizes, and usually evaluate what current personal budget holders have spent their funding on. The drawback to this approach is that the data captured are from the 'vanguard' of personal budget users – those who have been the first enthusiastic cohort to sign up to personal budgets, often as a result of being unhappy with their care and support. These care users tend to be younger, more eloquent and have a clear idea about how they want their care to change. This tells us little about the preferences and purchasing decisions of older people, for example, who have tended to be the group least enthusiastic about personal budgets and slowest to receive them. It is also a backwards looking approach, learning lessons from previous cohorts of personal budget users, rather than considering what the next wave of personal budget users – likely to include older people, those with greater needs, a wider range of minority ethnic groups, and so on –will use their personal budgets for. These studies also do not capture the spending preferences of self funders, which, as a growing segment of the market, also need to be considered alongside their state-funded counterparts if providers are to be able to respond to new market forces.

As a result of the limitations of existing available data, many local authorities and care providers are facing a sea change in how care will be planned and purchased, without a clear idea of how they will need to prepare.

The national dataset

With this in mind, Demos began the process of collecting market

intelligence relating to personal budgets in early 2009, starting with four local authorities and with the support of the providers Barchester and Castlebeck. The objective was to collect a larger sample of data than had been attempted in the past, to include a wider range of care users (particularly older people) and self funders, and perhaps most importantly to capture the views of those yet to receive personal budgets. This would give as a unique, future facing insight into what average care users know about personal budgets and how they might use them if and when they received one.

Following the publication of *At Your Service*, including data from 269 care users across four local authorities, nine further local authorities contacted us and asked to be involved in the project. All were eager to undertake an analysis of their care populations to find out how personal budgets might be affecting their role as commissioners and the providers in their local area. Some focused on specific black and minority ethnic (BME) groups; others included self funders to see how these care users were faring in the local market. Overall, their contributions make up a uniquely varied dataset.

This report combines the data from six of these nine new local authorities with the data from the first four local authorities, to form what is now the largest sample of care user intelligence in existence, with data from 770 care users. A further report, with the next three providers currently collecting personal budget data and any others that may subsequently join them, is set to be published in early 2011. By then, we hope to have a sample of over 2,000 people.

It is interesting to note that in many areas the results of our first analysis, reported in *At Your Service*, are similar to this second analysis using a larger sample. This suggests that our original sample was not particularly unrepresentative, and expanding our dataset is improving, refining and substantiating some of our earlier findings.

Methodology

Data were generated via a multiple choice survey, including an

easy read version, which was distributed to care users in ten local authorities. Cheshire East County Council, Hull City Council, Nottinghamshire County Council and Lancashire County Council collected their data in 2009 and this was originally analysed using SPSS 15.0. The London boroughs of Barking and Dagenham, Havering, Hillingdon, Ealing and Harrow, and Birmingham City Council collected their data between December 2009 and July 2010, and the results of their completed surveys were broken down into Excel format before being analysed using SPSS 17.0.

The original questionnaire and easy read was designed by a steering group convened for this project. However, following the first survey, the questionnaire was adjusted slightly and new questions were added, for example on specific activities people engaged in and whether self funders felt they received value for money. We now have a slightly smaller sample (501) for some of the questions analysed here as a result.

We analyse the data according to three main variables:

- *funding group* (whether someone is a self funder, council funded care user or personal budget or direct payment user)
- *need group* (older person, learning disability, physical impairment, mental health need or sensory impairment)
- *ethnic group* (White British, Black Caribbean, Indian, Chinese and so on)

We chose not to analyse the data by gender because of time and resource constraints.

In many cases, the results do not sum to 770 or 501. There are three reasons for this:

- Not all care users answered every question in the survey; sometimes we can therefore only consider a smaller dataset of care users who completed each question.
- Many questions are multiple choice, so the numbers of responses are far greater than 770.
- People were asked to state their primary and secondary need for using social care. Where this is the case, analysis by needs group

will double-count these individuals in order for their view to be expressed under both need categories.

Although our sample is large – 770 – and certainly the largest in existence, some sub-set groups were too small to draw any constructive conclusions. For example, we only have one Bangladeshi care user (an older person) and three Chinese (two with physical impairments and one with a mental health need). There is little value in analysing the preferences of such BME groups and suggesting they hold any weight nationally. We have analysed BME and need groups where there are sufficient data – so for example, when looking at the entire dataset we may include those with sensory impairments, but when analysing the responses of self funders we might exclude this group as only a very small number of self funders have sensory impairments.

Definition of terms

- *Personal budgets are an allocation of funding given to care users after an assessment; this budget should be sufficient to meet their assessed needs. Users can either take their personal budget as a direct payment, or – while still choosing how their care needs are met and by whom – leave councils with the responsibility to commission the services. Or they can have some combination of the two.*
- *Direct payments are given to individuals to choose, organise and pay for the social care services they need, rather than using the services offered by their local authority. They are cash payments in lieu of community care services.*
- *Personal assistants (PAs) are people employed by a care user to provide care and support. Self directed support allows individuals to use their personal budget to employ a PA directly and dictate what support that person provides. A PA could be a friend or relative, a qualified nurse providing intensive support services, or just someone to accompany a care user shopping or on outings.*

- *Home help – this is distinct from home care and includes handyman services, cleaning, cooking and gardening. They might be delivered by mainstream commercial providers or third sector/statutory providers specifically for those with care needs.*
- Self assessment *takes the form of a questionnaire to help identify a person's social care needs. The assessment looks at personal care needs, aspects of daily living, keeping safe, social inclusion, and so on. A person can complete the questionnaire on their own or with help, and it is used to give an indication of how much money a person requires to meet their needs.*
- Fair Access to Care Services (FACS) *is the national eligibility criteria set by the government for social care services. The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence and wellbeing or other consequences if needs are not addressed. These bands are critical, substantial, moderate and low. Currently, three-quarters of local authorities only provide care to those whose needs are substantial or above.*

2 Demographic overview

Data from 770 care users were analysed for this report; 59 per cent were women, and 71 per cent described themselves as White British. The rest of the sample was made up 13 per cent Indian, 4 per cent Black Caribbean, 3 per cent White Irish, 2.5 per cent Pakistani, and smaller numbers of many other ethnic groups (figure 1).

Figure 1 **Breakdown of non-white British groups (as percentage of total sample)**

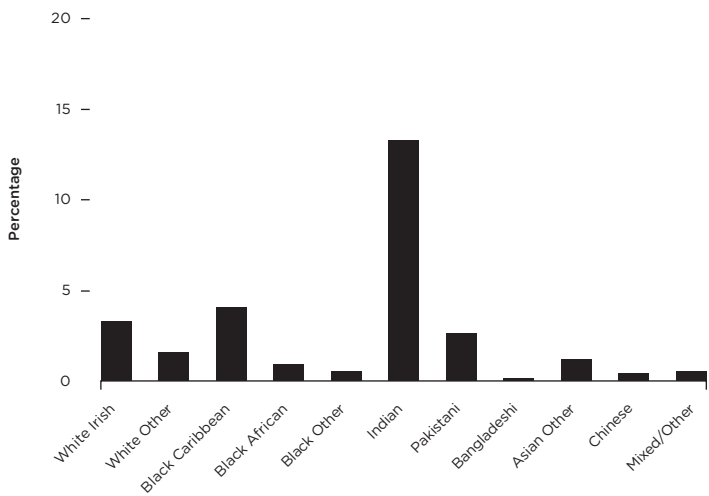
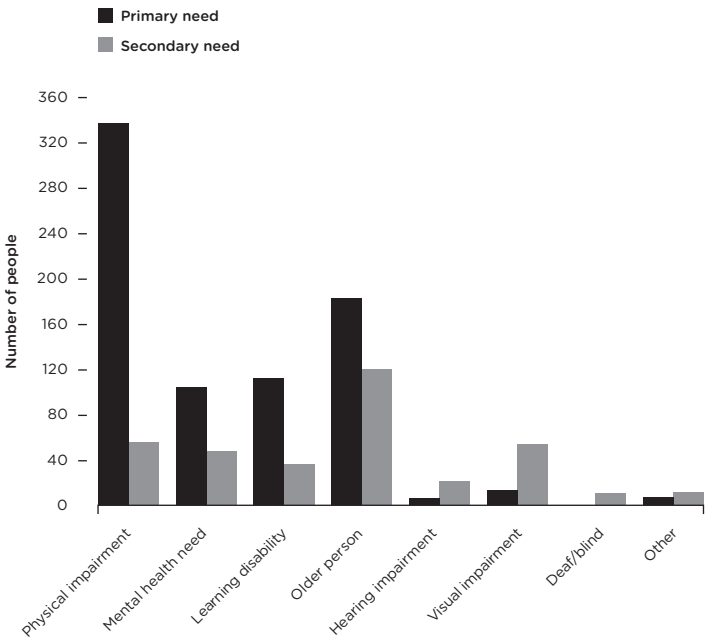


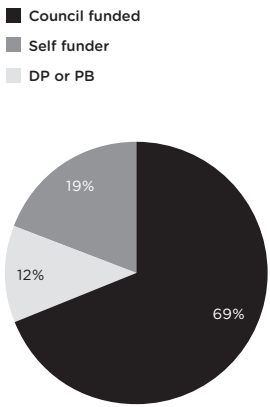
Figure 2 **Why do you need care and support?**



We asked people what they considered to be their first and second priority care needs. Figure 2 shows that the most common primary reasons for needing care were having a physical impairment (43 per cent or 334 people), old age (23 per cent or 181 people), having a learning disability (14 per cent or 111 people) and having a mental health need (13 per cent or 103 people). Less common reasons were having visual or hearing impairments (a primary reason for 14 and 6 people and a secondary reason for 53 and 21 people, respectively), followed by being deaf blind (3 people).

The sample was made up of 449 people wholly funded by their respective local authorities, another 49 people particularly

Figure 3 **How is your care and support paid for?**



funded by the council (for the purposes of the following analysis we include them in the council funded group), 138 self funders (including 36 people who said their family paid for their support), 86 people using a direct payment or personal budget, and 38 who did not know how their care was funded (figure 3). Figures 4 to 6 show breakdowns of need group by funding source, of ethnic groups by primary care need and of ethnic group by funding source.

Since *At Your Service* was published we now have a much larger proportion of minority ethnic groups and of those with learning disabilities and mental health needs, providing interesting insights into these hitherto under-represented groups.

When asked about their needs assessment and FACS criteria, 225 people did not respond. Of the 545 who did, a large proportion did not know their FACS band (54 per cent, 296 people). Just 4 per cent said they were in the 'low' FACS band, 12 per cent said they were moderate, 22 per cent substantial and 7.5 per cent critical.

Figure 4 **Breakdown of need group by funding source**

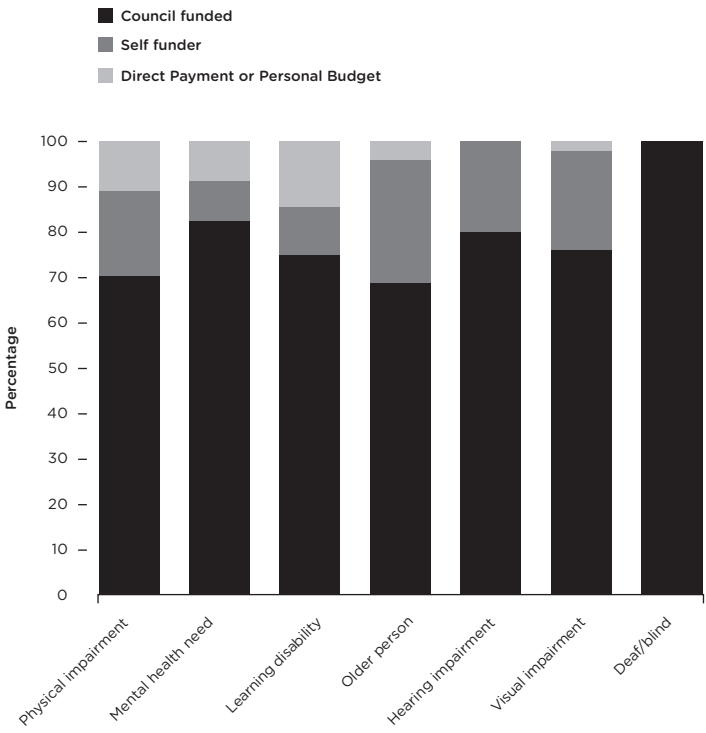


Figure 5 **Ethnic group broken down by primary care need**

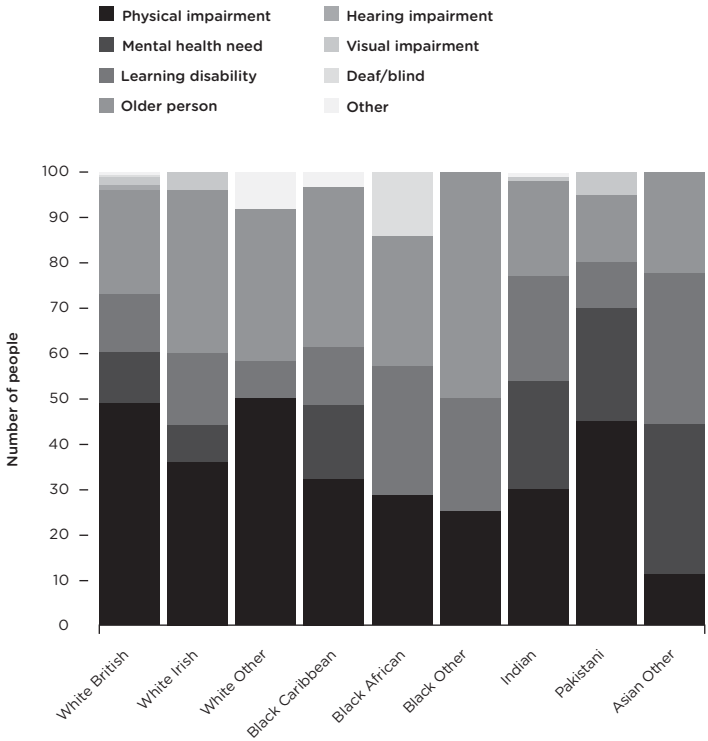
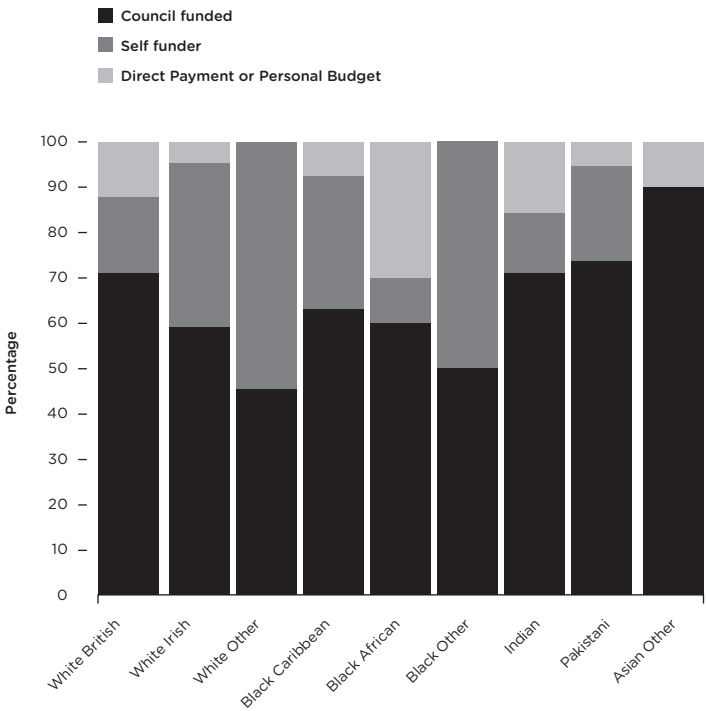


Figure 6 **Ethnic group broken down by funding source**



3 People's lives

What do people want from their lives?

Before asking people about the social care services they used, we asked them more general questions about how important it was to achieve a number of life goals and how happy people were in their lives (tables 1 and 2).

The most common life goals people felt it important to achieve were:

- keeping healthy and well (77 per cent)
- having a good quality of life (65 per cent)
- having personal dignity and respect (50 per cent)
- having choice and control (48 per cent)
- enjoying economic wellbeing (25 per cent)
- being free from discrimination (19 per cent)

The top four priorities are the same across all need groups, with the exception that those with learning disabilities have their fourth and third preferences the other way round. There were more interesting difference in lower-order priorities, for example:

- Although just 21 per cent of older people felt economic wellbeing was important, this rose to 43 per cent among deaf blind care users and 42 per cent among those with hearing impairments
- Just 6 per cent of older people felt that it was important that people treated you fairly, compared with 24 per cent of those with learning disabilities

We asked care users to add their own suggestions to this list; other important areas of life identified were:

Table 1 **What people think are the most important life goals to achieve, by funding group**

Most important goals to achieve	Funding group		
	Council funded	Self funder	Direct payment or personal budget user
Keeping healthy and well	77%	80%	71%
Good quality of life	65%	64%	69%
Dignity and respect	54%	38%	55%
Choice and control	49%	46%	55%
Economic wellbeing	25%	25%	30%

Table 2 **What people think are the most important life goals to achieve, by ethnic group**

Most important goals to achieve	Ethnic group				
	White British	White Irish	Black Caribbean	Indian	Pakistani
Keeping healthy and well	74%	72%	87%	84%	80%
Good quality of life	65%	56%	58%	65%	65%
Dignity and respect	50%	40%	58%	47%	60%
Choice and control	48%	36%	58%	52%	40%
Economic wellbeing	26%	24%	29%	27%	30%

- family
- religion/faith
- keeping mentally stimulated
- independence
- feeling happy and a sense of achievement

Satisfaction with life

We asked people to rate how satisfied they were regarding seven elements of wellbeing, based on the outcomes for adults specified in the white paper *Our Health, Our Care, Our Say*:[16]

1 improved health
2 improved quality of life
3 making a positive contribution
4 exercise of choice and control
5 personal dignity
6 freedom from discrimination and harassment
7 economic wellbeing

A score of 1 represents very satisfied, 3 neither satisfied nor dissatisfied, and 5 very dissatisfied. The average score nationally, among all care users and all seven aspects of life, is 2.64, a slight positive result. The area where people are least satisfied is in making a contribution to their community (2.9) followed by their financial situation (2.8). They are most satisfied with their degree of dignity and respect (2.4). See table 3.

Overall, those with mental health needs and deaf or blind groups are slightly less satisfied than others, while those with hearing impairments are slightly more satisfied. However, the differences between needs groups are relatively small.

There are slightly larger differences between groups if we consider how they pay for their care. Self funders are the most satisfied overall, with an average score of 2.45. Those with direct payments or personal budgets score 2.53, with council funded care users the least satisfied at 2.64. Interestingly, their rates of economic satisfaction were similar – 2.8 for council funded care

Table 3 Average satisfaction with seven elements of wellbeing, by need group

Element of wellbeing	Need group							
	Physical impairment	Mental health need	Learning disability	Older person	Hearing impairment	Visual impairment	Deaf/ blind	Total satisfaction score
Health	2.8	2.6	2.5	2.7	2.4	2.7	2.9	2.65
Quality of life	2.7	2.7	2.4	2.6	2.5	2.5	2.9	2.61
Making a contribution	2.9	3.1	2.7	2.9	2.9	2.8	3	2.9
Choice and control	2.6	2.8	2.4	2.5	2.5	2.6	3.1	2.64
Personal dignity	2.2	2.5	2.4	2.3	2.2	2.2	3	2.4
Freedom from discrimination	2.4	2.7	2.6	2.3	2.5	2.3	2.5	2.47
Economic wellbeing	2.7	3.1	3	2.6	3	2.6	2.6	2.8
Total satisfaction score	2.61	2.79	2.57	2.56	2.57	2.53	2.86	

users, 2.69 for self funders, and 2.73 for direct payment or personal budget users.

The largest between-group differences can be seen in ethnic groups, where scores range from 2.04 for the White Other group (these include European and American care users living in the

UK), to 2.74 among Pakistani care users. Lowest scores can be seen in the economic wellbeing and contribution to community among Pakistani groups (3.15 and 3.35 respectively) and economic wellbeing among Black Caribbean groups (3.1)

4 The current picture

In the next stage of our survey, we asked people what specific types of support they were using at the moment, covering traditional support (care home, day activities, and so on) and wider leisure services, and whether they were being supported by friends, family or personal assistants (table 4).

Services

Across the entire sample, the most frequently used care and support services are:

- day centres (36 per cent)
- informal family support (34 per cent)
- transport (31 per cent)
- PAs or home carers (30 per cent)
- home help (eg cook, cleaner, gardener) (26 per cent)

There were clear differences in the types of services used by those who were funded by the council, those using personal budgets or direct payments, and those who were self funding. It is interesting to note, for example, that self funders and direct payment or personal budget users are around twice as likely to use leisure services than council funded care users (just 17 per cent of this group say they use leisure services). Those with direct payments or personal budgets are also far more likely to use PAs, home carers and home helps than other groups. Perhaps as a result, none of this group reported being in residential care, compared with 8 per cent of council funded and 10 per cent of self funded care users. Also, 23 per cent of this group reported using day centres, lower than other groups.

Table 4 **Types of support people use, by funding group**

Council funded	Self funder	Direct payment or personal budget user
Day centre (46%)	Transport (41%)	PAs or home carers (70%)
Transport (34%)	Leisure services (31%)	Home help (44%)
PAs or home carers (34%)	Day centres (30%)	Leisure (39%)
Home help (29%)	Home helps (24%)	Transport (30%)

Personal budget and direct payment users spent their personal budget on various activities:

Personal care, escorting within the community (to the doctors, nurses, hairdressers appt., shopping, meals out). Also spend money on Christmas, Easter and Birthday presents. Clothing and cosmetics.

Direct payment user with learning disability and sensory impairment, age 52

I spend four hours every day with my carer. I go to the gym, cinema, leisure activities, etc. I plan my days with him. Every week I do different things as I want and he helps me with my doctor's appointment too. I change my activities every week. It all depends on what I want to do according to the weather. I always have some new ideas.

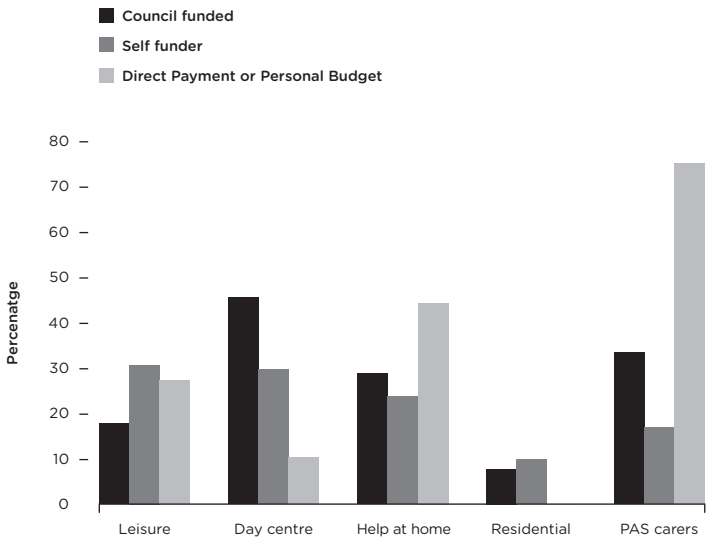
Direct payment user with learning disability, age 35

Piano lessons and support in leisure activities and being escorted and trips and shopping excursions.

Direct payment user with learning disability, age 30

My direct budget is a great help to me to function in everyday life. I use it to provide personal care, shopping, housework, gardening etc, jobs

Figure 7 **Service use broken down by funding group**

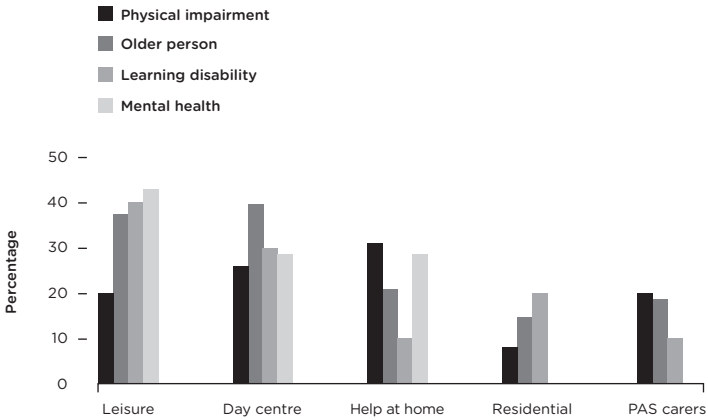


that I am unable to do for myself, but make me feel better when they are done.

Direct payment user with physical impairment, age 55

Figure 7 shows types of services used by funding group. There are differences between groups and between different need groups within funding groups. For example, if we consider self funders in isolation (figure 8), we can see that their average service use hides variations between different need groups – only 20 per cent of self funders with physical impairments report to use leisure services, compared with 43 per cent of those with mental health needs. Some 20 per cent of self funders with learning disabilities use residential care, compared with none of those with mental health needs and 8 per cent of those with

Figure 8 **Service use broken down by need group — self funders only**

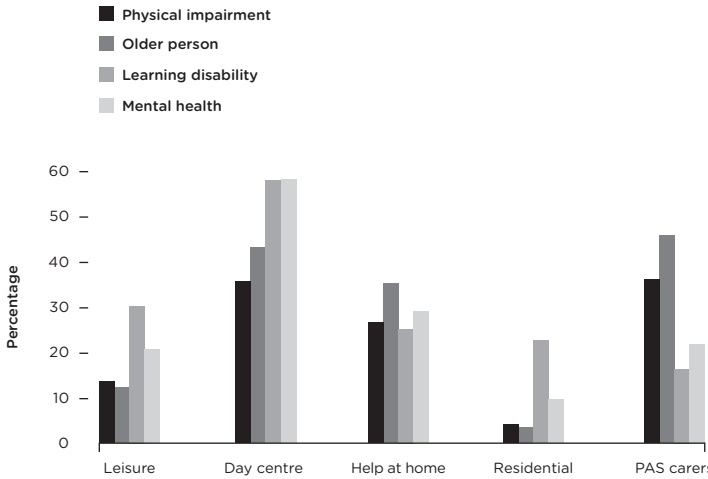


physical impairments. Just 2 per cent of self funding older people say they use education and training services, compared with 14 per cent of those with learning disabilities.

Different need groups among council funded care users (figure 9) show similar differences – 60 per cent of those with mental health needs use day centres compared with 38 per cent of those with physical impairments. Just 4 per cent of this group use residential care, compared with 23 per cent of those with learning disabilities; and 32 per cent of those with learning disabilities use education services, compared with less than 2 per cent of council funded older people.

Those using direct payments and personal budgets also differ in their service use by need (figure 10). More than one-quarter (27 per cent) of older people with direct payments or personal budgets were using their funding on leisure services compared with 72 per cent of those with learning disabilities. None of the older people in this group, but 44 per cent of those with learning disabilities were engaging in education and training.

Figure 9 **Service use broken down by need group — council funded care users only**



The largest differences between need groups are in the self funding group, suggesting these care users have the most diverse range of service use. The smallest differences can be seen in the council funded group, who were more likely to use similar services in spite of their different care needs.

However, if we consider the entire sample according to need group (and ignore funding source), it is clear that differences in service use between funding groups is more pronounced than between need groups, as all need groups have very similar profiles (see table 5). This suggests that the source of care funding may have more of an impact on service use that actual care need.

When it comes to family support, which we would class as informal care and an unfunded service, a similarly large proportion of all need groups reported relying on their families, between 40 per cent of those with learning disabilities and 45 per cent of those with mental health needs. Differences between ethnic

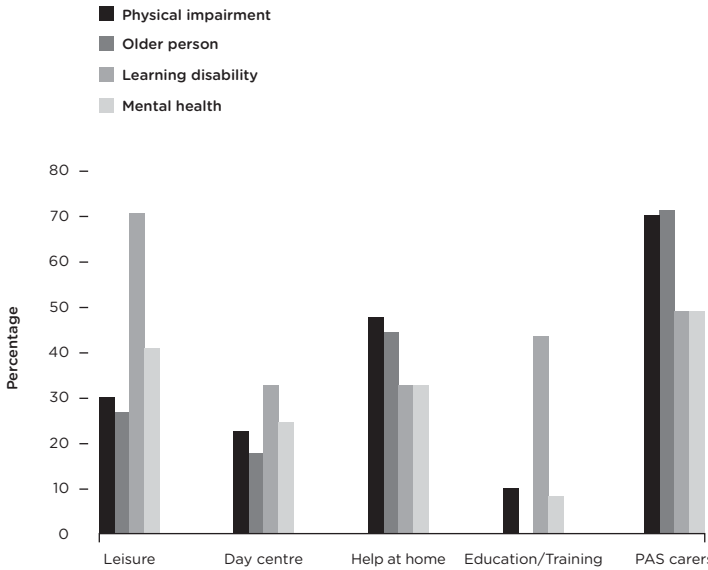
Table 5 **Service use, by need group**

Learning disability	Mental health	Physical impairment	Older person
Day centre (55%)	Day centre (55%)	PAs or home carers (47%)	PAs or home carers (46%)
Transport (41%)	Transport (42%)	Day centre (42%)	Day centre (39%)
Leisure (38%)	Help at home (29%)	Home help (40%)	Home help (37%)
Education and training (32%)	Leisure (27%)	Transport (37%)	Transport (36%)
Home help (27%)	PAs or home carers (22%)	Leisure (20%)	Leisure (20%)

Table 6 **Service use, by ethnic group**

White British	White Irish	Indian	Pakistani	Black Caribbean
PAs or home carers (41%)	Day centre (43%)	Day centre (59%)	Day centre (50%)	Transport (54%)
Home help (34%)	PAs or home carers (34%)	Transport (36%)	Home help (36%)	Day centre (49%)
Day centre (31%)	Leisure (22%)	Leisure (28%)	PAs or home carers, transport and education (21%)	Home help (42%)
Leisure (30%)	Home help (17%)	PAs or home carers (22%)		PAs or home carers (24%)

Figure 10 **Service use broken down by need group — Personal Budget and Direct Payment users only**



groups is slightly larger – 48 per cent of Black Caribbean care users say they rely on their family, compared with 28 per cent of Indian care users at the other end of the scale (table 6). However, it is most interesting to note that although self funders and council funded care users rely on their families to a similar extent (41 per cent and 38 per cent respectively), only 21 per cent of those with direct payments or personal budgets rely on their families.

I like going out – I rely on the day centre.
Indian self funder, age 91

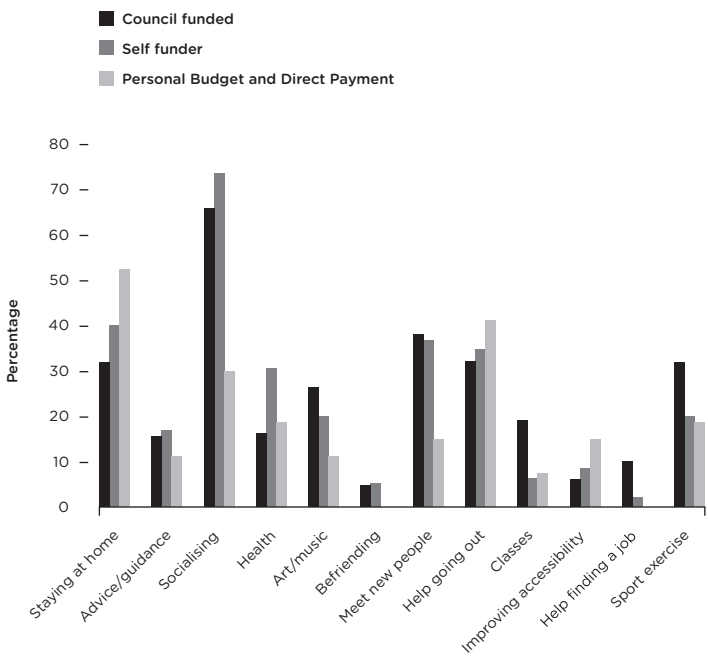
I rely on my son and daughter. I rely on my daughter to take me out; I am very reliant on my family.
Irish self funder, age 96

Specific activities

We asked people what specific activities they were taking part in now, which were supported by council funding, their own resources or a personal budget or direct payment. The most commonly reported activities across the whole sample were:

- socialising (56 per cent)
- activities which allow them to stay at home (41 per cent)
- help with going out (35 per cent)
- meeting new people (30 per cent)
- sport and exercise activities (23 per cent)

Figure 11 **Activities broken down by funding group**



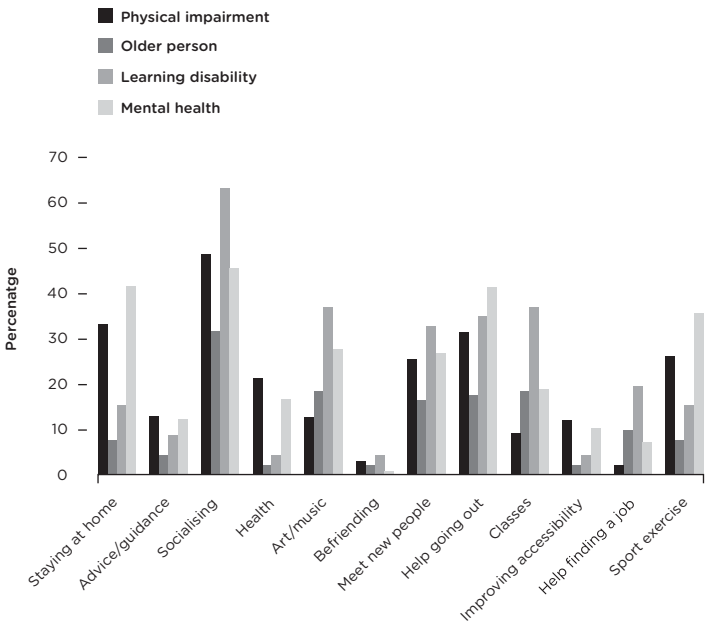
When considering these data according to funding group (figure 11), it is interesting to note that those using direct payments or personal budgets are far less likely to say they 'socialise' in a general sense or meet new people, but far more likely to say they stay at home and have help going out. This might be linked to the fact that care users in this group are far less likely to use day centres than other groups, and use mainstream leisure services and transport far more. Meeting people in a general sense may be linked to attending a day centre. Other interesting differences include the fact that those with direct payments or personal budgets are more likely to engage in accessibility improvement, such as the installation of ramps. Self funders report engaging in health related activities a lot more than other groups, although more council funded care users report engaging in sports activities.

Broken down by need group, older care users engage in the fewest activities and those with learning disabilities engage in the most. Those in the learning disability group are the most likely to engage in classes, job hunting and art and music – less traditional care related activities (table 7 and figure 12).

Table 7 **Most common activities carried out, by need group**

Learning disability	Mental health	Physical impairment	Older person
Socialising (61%)	Socialising (44%)	Socialising (47%)	Socialising (31%)
Classes (36%)	Help going out and staying at home (40%)	Staying at home (32%)	Art and music and classes (18%)
Help going out (34%)	Sports and exercise (34%)	Help going out (30%)	Help going out (17%)
Meeting new people (32%)	Art and music (27%)	Sports and exercise (26%)	Meeting new people (17%)

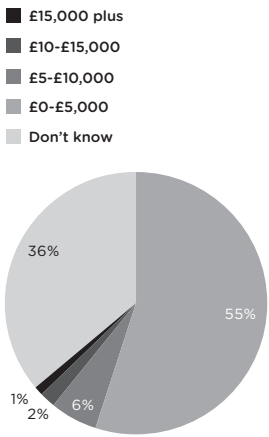
Figure 12 **Activities broken down by need group**



There were some interesting differences when these data were broken down by ethnic group:

- Indian care users were most likely, and Pakistani care users second most likely, to engage in sports and exercise as well as arts and music.
- Black Caribbean care users are most likely to seek advice and guidance, for example through Citizen's Advice, the local council or third sector care-specific advisory services.
- Irish care users are most likely to socialise, and Pakistani care users the least. Pakistani care users are also least likely to engage in meeting new people (half as likely as Black Caribbean care users) and most likely to stay at home.

Figure 13 **How much do you spend on your care and support?**



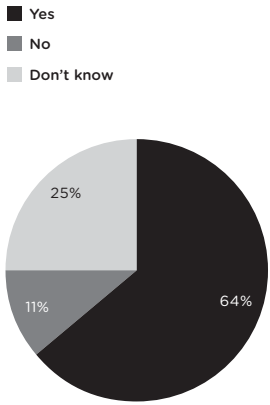
- White British and Irish are least likely to seek advice and attend classes.

Costs and value for money

Self funders in our sample were asked additional questions about how much they spent on the care and support services and activities they currently used and engaged in. Of the 101 self funders who answered this question, just over half (55 per cent) said they spend under £5,000 per year on their care and support. The next largest group (36 per cent) did not know how much they spent on their care. See figure 13.

We then asked self funders whether they thought they got value for money for what they spent. As figure 14 shows, the majority felt they did get value for money. Interestingly, of those who felt they did not receive value for money (11 care users in total), 6 were non White British (around 54 per cent). This is interesting given that 42 per cent of self funders are non White British, suggesting that other ethnic groups are more likely to

Figure 14 **Do you think you get value for money for what you spend?**

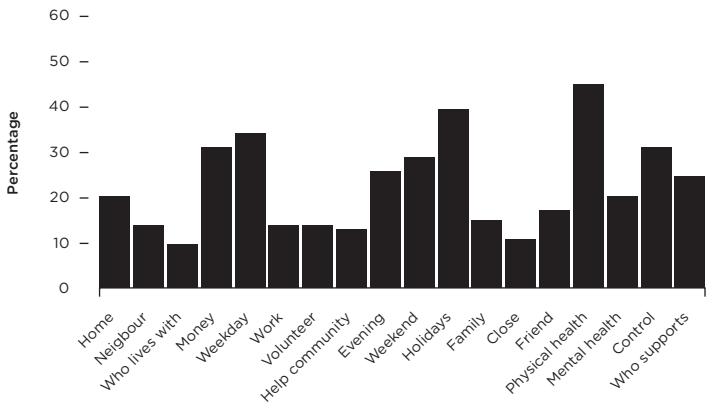


think they do not get value for money. However, as these sample sizes are so small, we cannot be certain of the relevance of these data. Similarly, the group of 11 was made up of four older people, three with physical impairments, two with mental health needs, and one with a learning disability, so we cannot determine whether or not getting value for money is linked to care need. Nearly three-quarters of care users who did not know if they got value for money were non White British – 18 out of 25 (72 per cent). This suggests that non white British groups are disproportionately represented in the 'don't know' group, while 19 of the group of 25 were older people, or an older person with a physical impairment. Again, these sample sizes are too small to draw definite conclusions.

My son manages the money – I think I could get better value.
Irish self funder, age 96

I no longer need care but still have to pay as carers are on site 24-7.
Self funder with physical impairment, age 67

Figure 15 **People's priorities for change, as a percentage of total sample**



Making changes

Once we had established a current snapshot of people's lives, how happy people are with different aspects of their life, and the services they use and activities they engage in, we went on to ask whether there was anything they might like to change.

The five areas people most commonly wanted to change about their lives were:

- their physical health (41 per cent)
- their opportunities for holidays (37 per cent)
- what they do on weekdays (32 per cent)
- the control they have over their lives (29 per cent)
- their financial situation (29 per cent)

The least commonly selected responses were changing close relationships (9 per cent) and changing who people lived with (9 per cent), followed by contributing to the community (11 per cent), work (12 per cent) and volunteering (12 per cent) (figure 15).

These findings are interesting when combined with other data in this report. A picture seems to be emerging which suggests that although people are not particularly happy with how they currently contribute to their communities, this is not a priority for change. This may be explained by the fact that 'making a positive contribution' was not a popular response when we asked people about what was important to achieve in life. Instead, health and wellbeing were priorities, and the fact that many people reported wanting to improve their physical health is understandable in this context. It is also interesting to note that although improving one's financial situation is a priority, finding paid work is not.

Table 8 shows that there are only a few differences in these top priorities when comparing different need groups; all care users would like to increase their holidays and change their weekday activities. Some details of interest are that those with hearing impairments are most concerned about their financial situation, and 32 per cent of those with mental health needs said changing their mental health was a priority – but surprisingly five other issues are more important, including the control they have over their life. Overall, those with learning disabilities seem to want to change the greatest number of things, and older people the fewest.

Differences between what care users most want to change about their lives by funding group (table 9) are more significant than those between need groups. For example, although changing weekday activities is a common response across all need groups and 40 per cent of council funded care users say the same, just 26 per cent of self funders and 19 per cent of those with direct payments say this. Again, this suggests that areas in need of change are more likely to be influenced by how one's care is funded, rather than by one's care needs.

Overall, direct payment and personal budget users wanted to change the fewest things about their lives and council funded care users the most. These are some other interesting differences between the groups:

Table 8 **What care users most want to change about their lives, by need group**[17]

Learning disability	Mental health	Physical impairment	Older person	Hearing impaired	Visually impaired
Opportunities for holidays (43%)	Opportunities for holidays (42%)	My physical health (65%)	My physical health (43%)	My financial situation (42%)	My physical health (45%)
What I do on weekdays (38%)	What I do on weekdays (37%)	Opportunities for holidays (39%)	Opportunities for holidays (32%)	My physical health (39%)	What I do on weekdays (43%)
My financial situation (36%)	What I do on weekends (35%)	What I do on weekdays (34%)	What I do on weekdays (28%)	Opportunities for holidays (33%)	My financial situation (39%)
What I do in the evenings (35%)	The control over my life and what I do in the evenings (34%)	The control over my life (30%)	What I do on weekends (24%)	The control over my life (26%)	Opportunities for holidays (36%)

- Self funders and those with direct payments or personal budgets are 10 percentage points less likely than council funded care users to want to change the control they have over their lives.
- Self funders are most likely to want opportunities for holidays; 48 per cent said this compared with just 26 per cent of direct payment or personal budget users.
- Those with direct payments or personal budgets are significantly less likely to want to change their weekend, evening and weekday activities compared with the other two groups.
- Those with direct payments or personal budgets are less likely to want to change their financial situation than the other two groups; 27 per cent of those with direct payments or personal budgets say this compared with 38 per cent of self funders and 32 per cent of council funded care users.

Table 9 **What care users most want to change about their lives, by funding group**

Council funded	Self funder	Direct payment holder
My physical health (49%)	Opportunities for holidays and my physical health (48%)	My physical health (44%)
What I do on weekdays and opportunities for holidays (40%)	My financial situation (38%)	Opportunities for holidays (42%)
Control over my life (36%)	What I do on weekdays (27%)	What I do on weekdays (33%)
What I do in the evenings (28%)	Control over my life (25%)	Control over my life (29%)

- Self funders are least likely to want to change who supports them; just 12 per cent of this group said this, compared with 18 per cent of those with direct payments or personal budgets and 27 per cent of council funded care users.

I would like to go out more and holiday in Ireland.
Irish self funder, age 96

I don't get out enough – I sold the car, the bus takes a long time and the train is hard work.
Indian self funder, age 85

I cannot travel anymore – I miss going on holiday.
Self funder with sensory impairment, age 92

I would like to be in the community more and to go to shops. Find out what is happening locally.
Care user with sensory impairment, age 77

Table 10 **What care users most want to change about their lives, by ethnic group**[18]

White British	White Irish	White Other	Black Caribbean	Indian	Pakistani
My physical health (42%)	My physical health and what I do on weekdays (44%)	My physical health (50%)	My financial situation and opportunities for holidays (58%)	What I do on weekdays (43%)	My physical health and opportunities for holidays (45%)
Opportunities for holidays (35%)	Opportunities for holidays (40%)	Opportunities for holidays and what I do on weekdays (42%)	My physical health and what I do on weekdays (35%)	Opportunities for holidays (41%)	My financial situation (40%)
The control I have over my life and what I do on weekdays (28%)	What I do on weekends and evenings (36%)	My financial situation, what I do on weekends and control over my life (33%)	The control I have over my life (32%)	My physical health (40%)	What I do on weekdays and who supports me (35%)

Differences between what care users most want to change about their lives by ethnic group (table 10) are less pronounced; physical health, holidays and weekday activities are important for all groups, with the exception of Black Caribbean care users who distinguish themselves from other groups by stating that their financial situation is their main concern. It is also interesting that large numbers of this group selected each option, possibly suggesting that Black Caribbean care users want to change more things in their lives than others.

To establish whether people felt that the need to change things about their lives actually necessitated a change to their care packages, we asked a series of questions specific to each type of funding group. We asked self funders whether they would want to change the care and support they receive if they had a chance. We asked council funded care users whether they would

change their care and support if they were to receive a personal budget. And we asked those with personal budgets or direct payments if they had made any changes to their care and support on receiving this form of funding. The answers from each of these three groups are analysed below.

Would people change their care and support?

Self funders

Nearly half (42 per cent) of self funders would like to change their care and support if they could (figure 16). A further 13 per cent did not know, but we must assume that at least some of this group would like to do so on further consideration. An area for further consideration could be to consider what is stopping self funders from making these changes – a lack of finances could be one explanation, given that the data above show that 38 per cent of self funders report wanting to change their financial situation.

Older people are most likely not to want to change their care and support among the self funding group (figure 17).

If we combine these data with our life satisfaction scores, we can see very clearly that those who did want to change their care and support were less satisfied than those who did not – average scores were 2.74 for the 'changers' and 2.09 for the 'non changers' (where a lower score denotes greater life satisfaction) (figure 18). The largest difference between the scores of the two groups is in economic wellbeing – whereby those wanting to change their care and support were significantly less satisfied with their financial situation than those who did not want to change their care. This adds weight to the possibility that financial constraints may be a reason why self funders are unable to change their care and support.

Council funded care users

We asked council funded care users whether they would change anything about their current support package if they had a personal budget. It should be pointed out at first that a large proportion (65 per cent) of care users had no knowledge of

Figure 16 **What would you change about your care and support if you had the chance?**

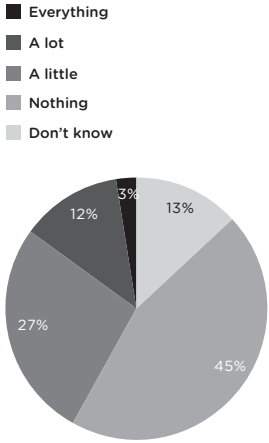


Figure 17 **Self funders who do not want to change their care and support**

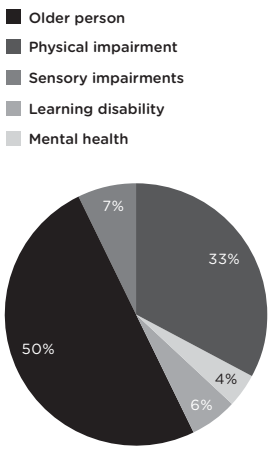
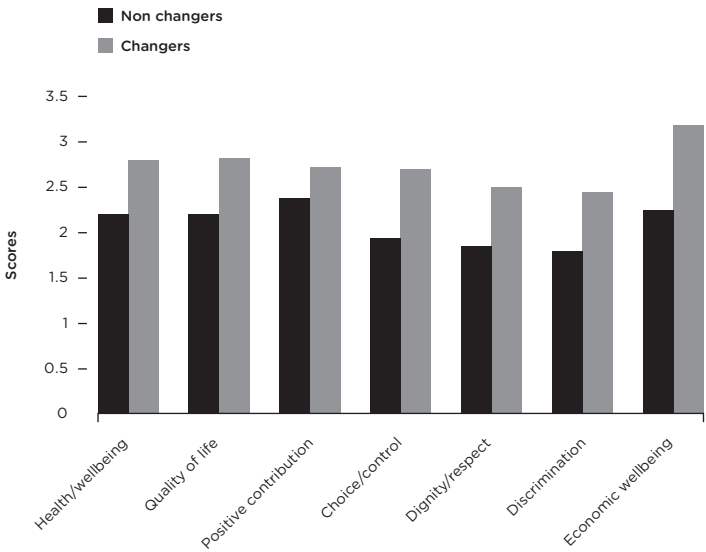


Figure 18 **Level of dissatisfaction with life**



personal budgets at the start of the survey (figure 19). This may present a challenge in that those wholly unfamiliar with personal budgets may not fully understand how they can be used and their capacity for change.

It is interesting to note that these proportions do not represent a large change from our first analysis with 269 care users, reported in *At Your Service*. Those data showed that 62 per cent knew nothing about personal budgets, 20 per cent knew a little, and 16 per cent knew something or a lot.

Part of our survey included an explanation of what a personal budget was and how it could be used. Once this brief explanation was given, we asked council funded care users whether they would change their care and support if they received a personal budget (and by default, were then able to make those changes) (figure 20). Overall, 45 per cent said they

Figure 19 **What do you know about Personal Budgets?**

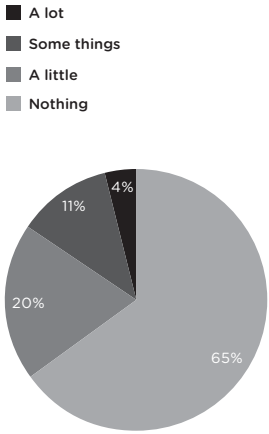


Figure 20 **Would you change your care and support if you had a Personal Budget?**

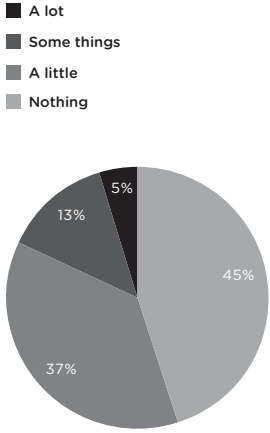
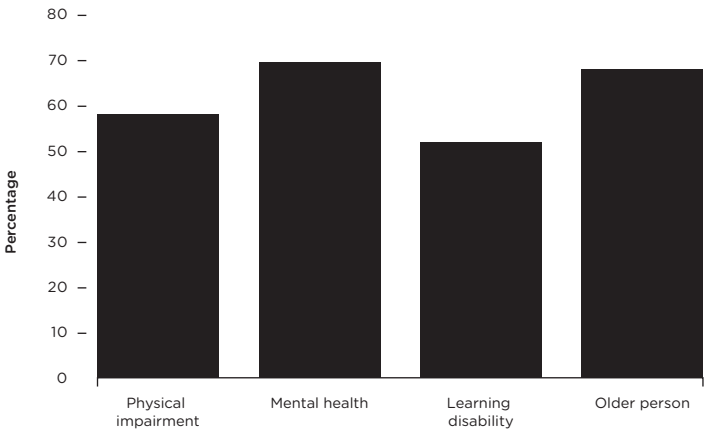


Figure 21 **Percentage of each need group not wanting to change their care if they received a Personal Budget**



would not change anything about their care and support if they had a personal budget, a small decrease on our first analysis, which showed 50 per cent would not change anything. Those with mental health needs and older people were less likely to want to change their care than those with physical impairments and learning disabilities (figure 21).

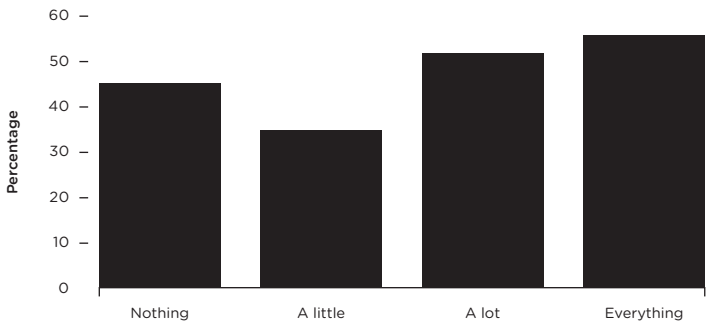
I do not want a personal budget. I am very happy with my day centres. I do not want to organise my own care.

Council funded care user with learning disabilities, age 32

Interestingly, there also seems to be a slight inverse correlation between knowledge of personal budgets and wanting to change one's care and support. As figure 22 shows, a larger proportion of those who know a lot about personal budgets do not want to change their support than those who know nothing.

If we combine these data with our satisfaction scores, we can see that those who do not want to change their care and

Figure 22 **Percentages of 'non-changers' broken down by knowledge of Personal Budgets**

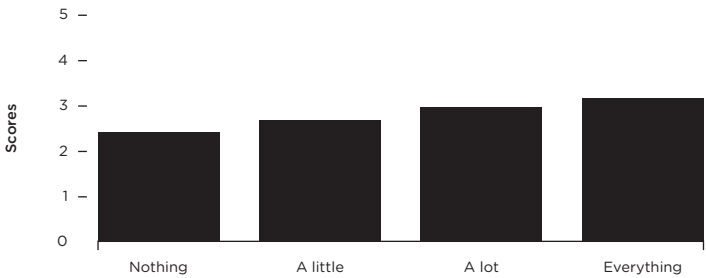


support if they had a personal budget are more satisfied with their lives than those who do want to change – in fact, satisfaction decreases with the likelihood of wanting to change one's care and support (figure 23). The biggest difference in the satisfaction scores of the 'changers' and the 'non changers' is in the area of choice and control – the 'changers' were far less satisfied with this aspect of their life compared with the 'non-changers'. This would support the idea that those least satisfied with the choice and control in their lives are the ones most likely to use a personal budget to make changes to their care and support. It is interesting that among self funders, the area of biggest difference was economic wellbeing – suggesting financial constraint for that group acts in the same way as lack of choice and control does for this group.

Direct payment or personal budget users

As figure 24 shows, 41 per cent of direct payment or personal budget users said they had not changed their care since receiving a personal budget or direct payment, so 59 per cent have made subsequent changes to their care and support packages since having this form of funding. However, there was no correlation

Figure 23 **Dissatisfaction scores by groups wanting to change their care and support**



between the changes made and the length of time a person had had a personal budget or direct payment.

What help do care users need to make changes?

Once we had established what changes care users wanted to make to their lives, we asked what help they would need to action those changes. Figure 25 shows the responses; the most common types of help cited by care users were:

- more information about what I can do (54 per cent)
- more face to face advice (52 per cent)
- someone to speak to in an emergency (46 per cent)

Broken down by need group, we can see that information and advice were the close first and second priorities for all groups. Having someone to speak to in an emergency was third priority for all groups except those with learning disabilities, a larger proportion of whom selected less bureaucracy and more help from the council in doing things with peers. Those with learning disabilities and mental health needs were most likely to select this latter option, with 54 per cent and 53 per cent of these two groups electing this respectively. Older people were least

Figure 24 **Have you changed anything about your care since having a Personal Budget or Direct Payment?**

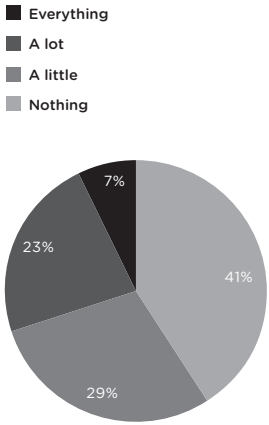
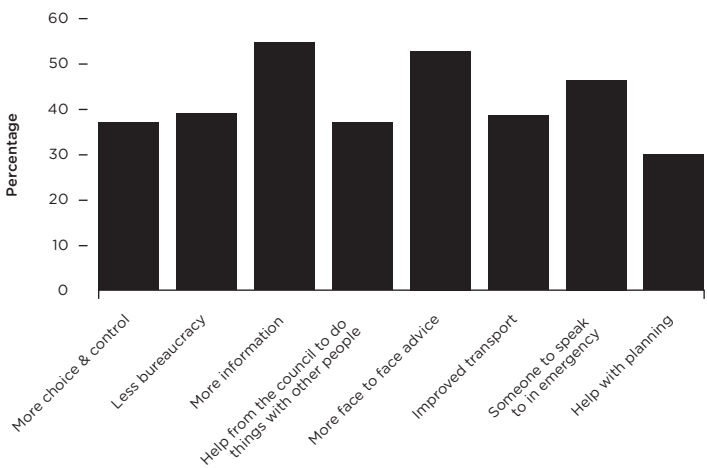


Figure 25 **What help would you need to make changes?**



likely to select this, at 29 per cent. Those with sensory impairments were least likely to think bureaucracy was a problem, with 22 per cent selecting this option.

There were larger differences by ethnic group. Information and face to face advice were the top answers for White British, Indian, Pakistani and Black African groups, but White Irish and Black Caribbean groups placed someone to help in an emergency as their top priority. They also placed face to face advice ahead of information. Black African groups put help with planning their care as their third most important issue, much higher than all other groups, whereas Indian care users' third priority was having more choice and control over their care.

Different funding groups also had different priorities. Council funded and direct payment or personal budget users selected information as their first and face to face advice as their top two concerns, but self funders identified someone to help in an emergency as the most important issue. This was council funded care users' third choice; interestingly, the third choice for direct payment or personal budget users was less bureaucracy.

5 What do people want?

Specific activities

Once we had established what people wanted to change about their lives and whether they would use a personal budget to make those changes, we asked council funded care users specifically what sorts of activities they would like to carry out, and what sorts of services they would like to use, if they were to have a personal budget (figure 26).

The specific activities most council funded care users said they wanted to engage in if they had a personal budget were:

Figure 26 **What activities would you like to do if you had a Personal Budget? (All council funded)**

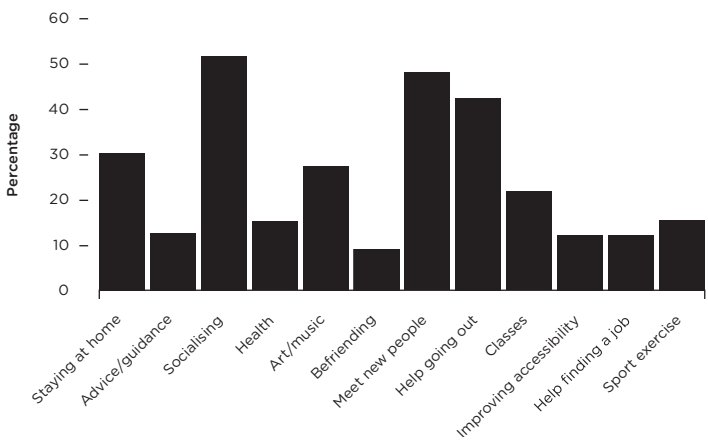


Table 11 **Most common activities people would like to do with a personal budget, by need group**[19]

Learning disability	Mental health	Physical impairment	Older person
Socialising and meeting new people (88%)	Socialising (54%)	Socialising and meeting new people (45%)	Socialising (54%)
Help going out (66%)	Help going out and meeting new people (46%)	Help going out (38%)	Meeting new people (48%)
Art and music and classes (58%)	Arts and music and classes (34%)	Staying at home (29%)	Help going out (43%)
Help finding a job (42%)	Staying at home and sport and exercise (31%)	Art and music (22%)	Staying at home (39%)
Sport and exercise (38%)		Classes (17%)	Art and music (25%)

- socialising (51 per cent)
- meeting new people (48 per cent)
- having help going out (43 per cent)
- activities which allow you to stay at home (30 per cent)

There were some interesting differences when comparing the activities that different need and ethnic groups would like to carry out if they had a personal budget (tables 11 and 12). Although all need groups wanted to engage in socialising and meeting new people, the profiles of learning disability and mental health need groups are quite different from the profiles of older people and those with physical impairments. For example, while the former groups are interested in sports and exercise (37 per cent and 31 per cent respectively), this was far less of a priority for the latter groups; only 8 per cent of those with

Table 12 **Most common activities people would like to do with a personal budget, by ethnic group**[20]

White British	White Irish	Black Caribbean	Black African	Indian	Pakistani
Socialising (53%)	Socialising (66%)	Socialising and help going out (43%)	Help going out and art and music (60%)	Meeting new people (77%)	Help going out and socialising (45%)
Meeting new people (49%)	Help going out (55%)	Staying at home, art and music, accessibility improvement and classes (36%)	Meeting new people, staying at home, socialising, and help finding a job (40%)	Socialising (69%)	Meet new people and staying at home (36%)
Help going out (44%)	Meeting new people (33%)			Art and music (63%)	Sport and exercise (27%)
Staying at home (34%)				Help going out (52%)	
Art and music (24%)					

physical impairments and 14 per cent of older people selected this activity. Older people and those with physical impairments were also less interested in art and music. The differences in the preferences between those with learning disabilities and older people are significant – 41 per cent of those with learning disabilities but just 1 per cent of older people want to find a job. Of those with learning disabilities, 20 per cent are interested in health activities, 33 per cent are interested in advice and guidance, and 58 per cent interested in classes, compared with just 9 per cent, 7 per cent and 9 per cent of older people interested in these activities, respectively. It is interesting that the

differences in preferences between need groups are so marked when the activities different need groups currently engage in do not differ by a large amount. Overall, those with learning disabilities selected the greatest number of activities each, suggesting they were more eager to engage in more activities. They were also the least likely to want to stay at home – just 20 per cent said this (compared with 39 per cent of older people).

Indian care users were most interested among all ethnic groups in going to classes and finding a job, and in sports and exercise. They were also by far the most interested in meeting new people. Black African and White Irish care users selected the fewest number of activities each, though both groups were particularly interested in having help going out, while Indian care users selected the greatest number of activities.

Services

In order to understand whether the pursuit of such activities would also entail a change in service use, we asked specifically what sorts of services people would purchase with a personal budget (figure 27).

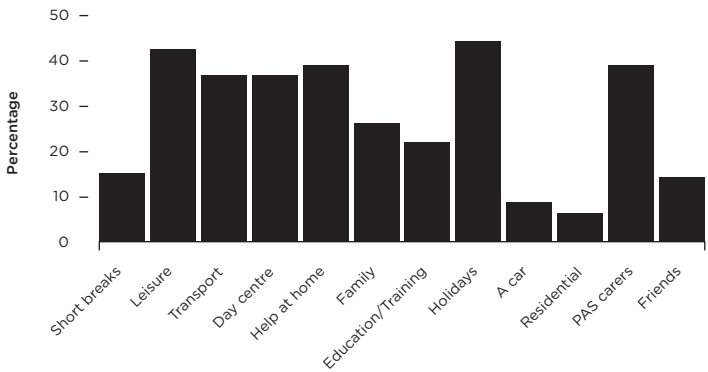
The most popular services all care users would engage in if they had a personal budget were:

- holidays (44 per cent)
- leisure services (42 per cent)
- PA or home carer and home helps (both 38 per cent)
- transport and day centres (both 36 per cent)

The least popular options to spend personal budgets on were residential care (6 per cent), a car (8 per cent), and paying friends for care and support (14 per cent). This is similar to the findings in our first analysis of care users, *At Your Service*, where the most popular services were PAs (44 per cent), holidays (40 per cent), home helps (37 per cent), leisure services (34 per cent) and day centres (31 per cent).

If we consider these data according to need we can see that older people express an interest in the most 'traditional' care

Figure 27 **What services would you use with a Personal Budget?**



services, while those with learning disabilities have far more interest in non traditional and universal services (table 13). This group also has the greatest interest in education and training. It is also interesting to note that a fairly large proportion of those with mental health needs say they would use a personal budget to pay their family to provide support. There are more noticeable differences between ethnic groups (table 14), in particular, the preference for paid family support among white Irish and Black Carribean care users, the interest in education and training among Indian and Black Carribean groups, and the use of personal budgets to pay friends to provide support among Pakistani care users; this group was twice as likely to select this option as the sample as a whole.

I want to go to a hairdresser.

Council funded care user with mental health needs, age 92

I want to be moved to warden control of support housing. I have a three bedroom house going to waste as I cannot go upstairs.

Council funded older person, age unknown

Table 13 **Most common services care users would use if they had a personal budget, by need group**[21]

Learning disability	Mental health	Physical impairment	Older person
Leisure (67%)	Holidays (54%)	Holidays (48%)	Home help (48%)
Holidays (55%)	Day centres (45%)	PA/Carers (47%)	Day centres (46%)
Education and training (44%)	Leisure (42%)	Home help (41%)	PA/Carers (43%)
Day centres (35%)	Transport (34%)	Transport (39%)	Leisure (39%)
Home help (28%)	Paid family support (29%)	Leisure (33%)	Transport (29%)

I would like to go to tai chi.
Council funded care user, age 79

I would like help in the garden and taxis to help me get out of the house.
Council funded care user with physical impairment, age 70

Table 14 **Most common services care users would use if they had a personal budget, by ethnic group**[22]

White British	White Irish	Black Caribbean	Indian	Pakistani
PA/Carers and holidays (41%)	Leisure (50%)	Holidays and transport (53%)	Holidays and leisure (53%)	Holidays (69%)
Leisure (39%)	Paid family support (42%)	Paid family support (46%)	Transport (48%)	Day centre (46%)
Home help (38%)	Holidays (33%)	Leisure (40%)	Day centre (43%)	PA/carers, help at home, leisure (38%)
Day centre (35%)	Home help and education and training (25%)	Home help and education and training (33%)	Home help (40%)	Transport and paid support from friends (31%)
Transport (32%)			Education and training (38%)	

6 The scale and nature of change

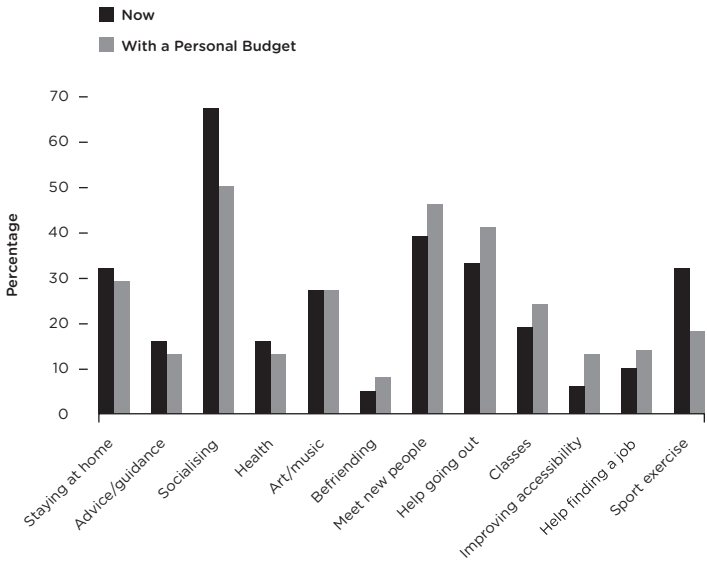
Our survey has given us two sets of 'before and after' personal budget data – among those currently using direct payments and personal budgets, we can compare what they say they used before receiving this form of payment, with what they are using now. Among council funded care users, we can compare what services they are using and activities they are engaging in now, with what they say they would use and do if they had a personal budget.

By comparing these two sets of data we can gain an insight into how demand has increased or fallen for different service areas since the introduction of direct payments and personal budgets, and how it might increase or fall in the future as a result of more council funded care users being offered personal budgets.

How care and support packages will change for council funded care users

If we compare what council funded care users do now with the activities they want to engage in if they had a personal budget, we can see a number of clear trends (figure 28). Perhaps most interestingly, socialising as a generic pastime will fall, as will saying at home. Conversely, meeting new people and going out will increase. If we combine this with data on the services council funded care users would use if they had personal budgets (figure 29), which shows they would make more use of leisure services and have more holidays, it may indicate a shift from generic 'socialising' activities to more specific leisure pursuits. Overall, there are no large changes in the types of activities people want to engage in – most increase slightly. This suggests there may not be a significant change in what people want, but rather how it is

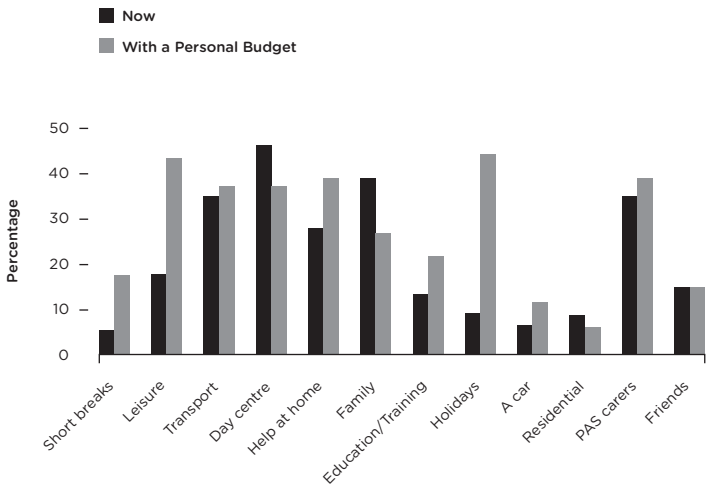
Figure 28 **Council funded care users — activities now and with a Personal Budget**



delivered – this issue will be investigated further below when we consider changes in service use. It is also worth noting that more people in the sample selected the types of activities they wanted to engage in, compared with what they engage in now, suggesting there would be an overall increase in volume of activities.

If we compare the types of services council funded care users currently use with those they say they would use if they had a personal budget, we are able to establish whether changes (or not) in activity translate to any changes in service use (figure 29). It seems, based on the headline trends, that the hypothesis that personal budgets will result in a small change of 'what' but a much larger change of 'how' seems to hold true, in that council funded care users would change their services more than their activities if they had a personal budget:

Figure 29 **Council funded care users — services used now and with a Personal Budget**



- Leisure service use would increase significantly; 18 per cent of council funded care users say they use leisure services now, compared with 73 per cent who say they would use leisure services if they had a personal budget
- Holidays and education and training would also increase significantly, from 9 per cent to 44 per cent and 12 per cent to 22 per cent respectively
- Using family for support would fall, from 39 per cent to 26 per cent, and day centre use would also fall, from 46 per cent to 37 per cent
- Residential care use would only fall slightly, from 8 per cent to 6 per cent

However, these general results hide some variation between need groups. For example:

- Although day centre use decreased overall, it actually increased very slightly among older people – 45 per cent of this group use day centres now, and 46 per cent say they would use one if they had a personal budget. Similarly, home help increases substantially among older people, but remains the same or falls slightly in other groups.
- The inverse is true for use made of PAs and home carers; there would be an increase in the use of these assistants among all groups except older people, where use would fall from 47 per cent to 43 per cent. This may suggest that older people are seeking more practical help (cooking, gardening, cleaning) rather than care in the home per se.
- Although leisure service use increases substantially across all need groups, it decreases slightly (albeit from a higher level than any other groups) from 31 per cent to 28 per cent among those with learning disabilities.
- Although there is a small decrease in residential care use, this hides a large movement in and out of this service – 28 of the 40 council funded care users currently in residential care want to leave, while another 18 not in residential care want to go into residential care.

The most interesting changes in the services care users say they would use if they had a personal budget compared with those they use at present are outlined in figures 30–34. Figure 30 analyses changes in use of day centres if care users had a personal budget by need group; figure 31 analyses change in PA and care use if care users had a personal budget, by need group; figure 32 analyses the extent of reliance on family if care users had a personal budget, by need group; figure 33 analyses changes in leisure use if care users had a personal budget, by need group; and figure 34 analyses changes in residential care if care users had a personal budget, by need group.

There are also variations between ethnic groups, for example:

Figure 30 **Change in use of day centres by need group**

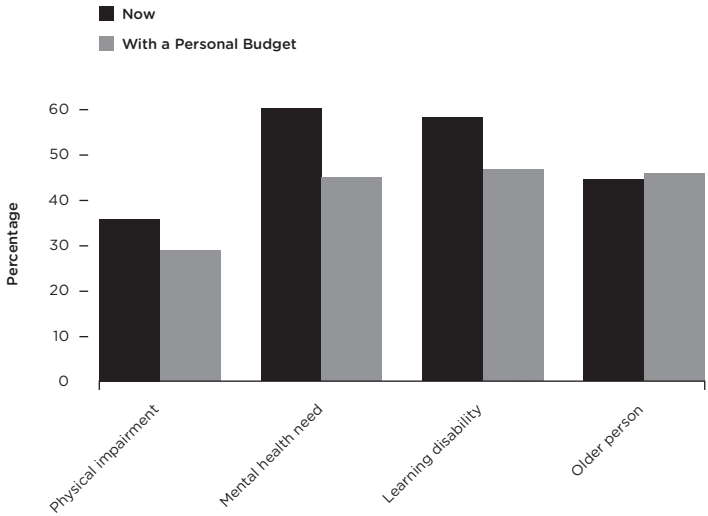


Figure 31 **Changes in PA and carer use by need group**

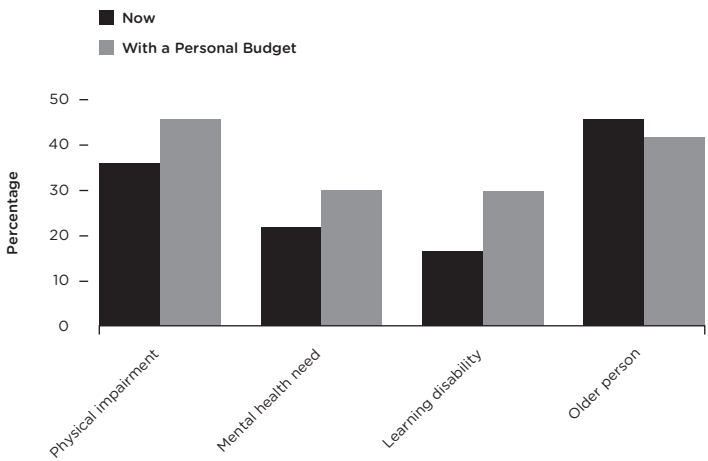


Figure 32 **Reliance on family by need group**

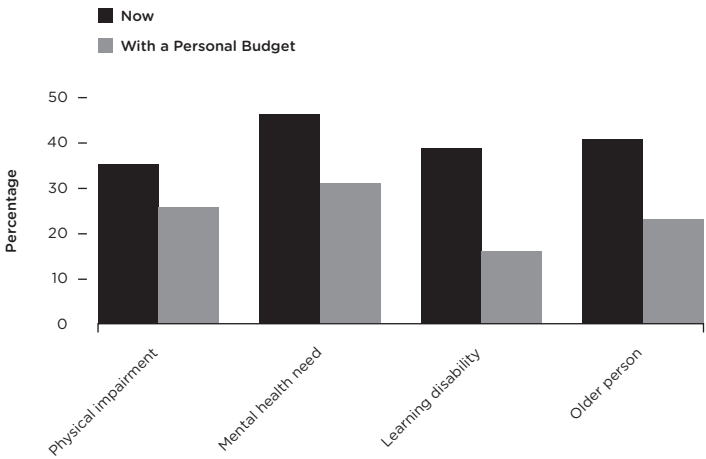


Figure 33 **Changes in leisure use by need group**

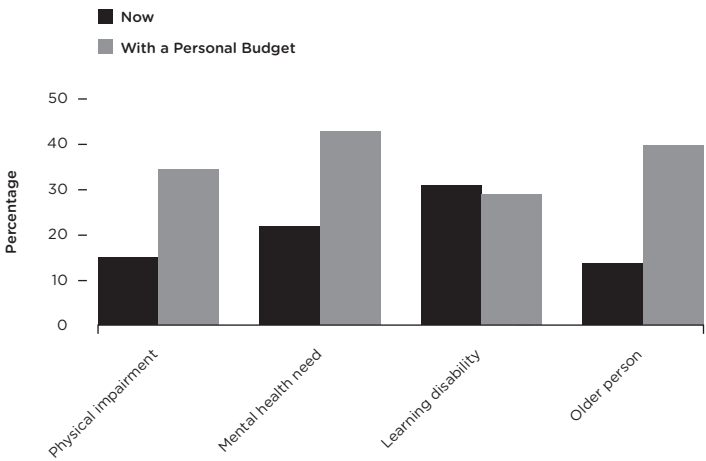
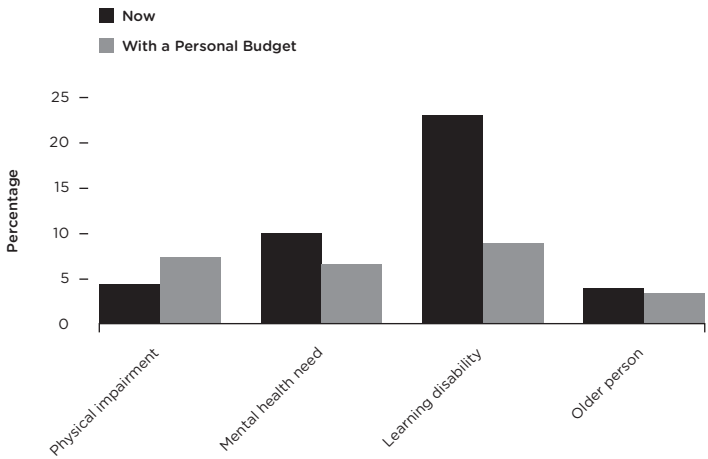


Figure 34 **Changes in residential care by need group**



- Use of home help would increase in all groups except among Black Caribbeans, where it would decrease from 50 per cent to 33 per cent (figure 36)
- Use of day centres would decrease substantially among all groups, apart from Pakistani care users where it would decrease only slightly and White British where it would increase slightly (figure 37)
- Reliance on family would decrease among all groups except White Irish, where it would increase from 29 per cent to 42 per cent

Figure 35 shows the change in use of leisure service by ethic group and figure 38 shows the change in use of residential care by ethnic group.

Figure 35 **Change in leisure service use by ethnic group**

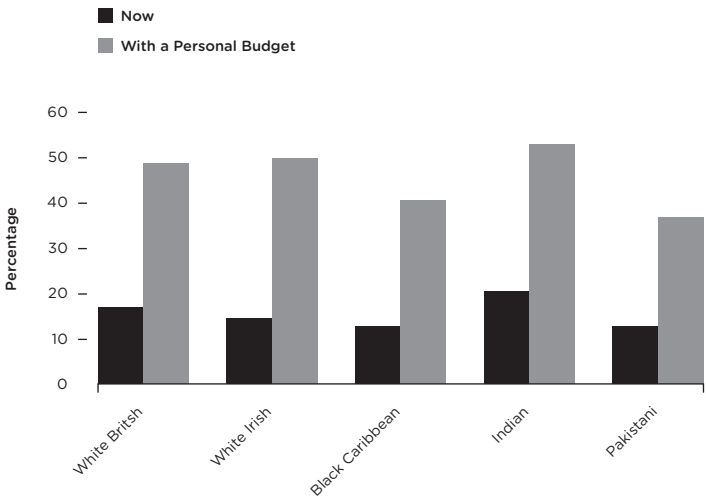


Figure 36 **Change in PA/home carer use by ethnic group**

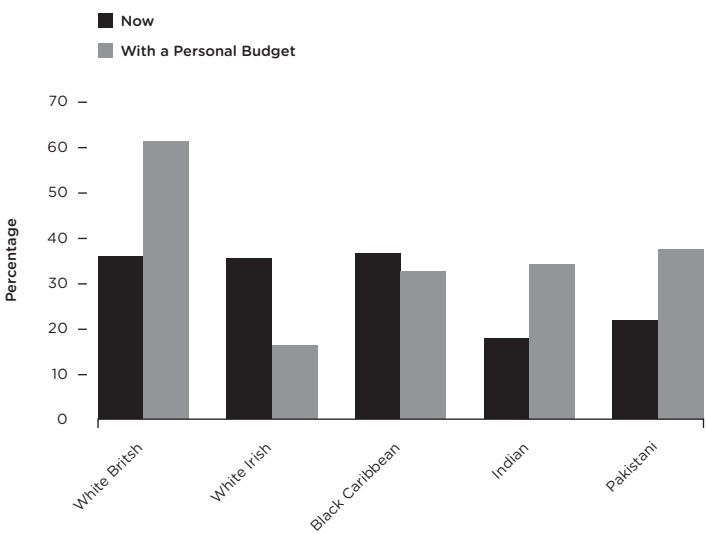
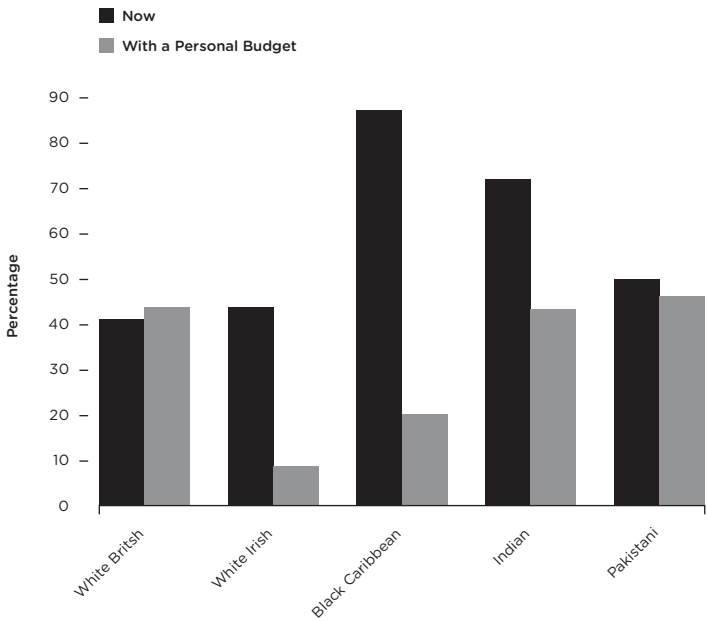


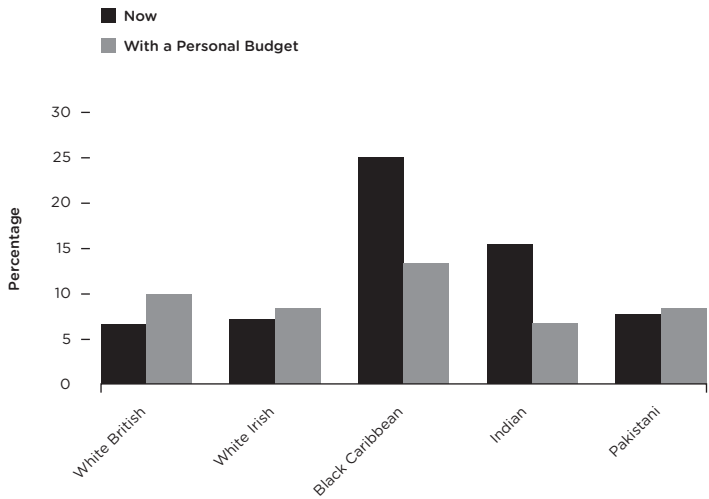
Figure 37 **Changes in day centre use by ethnic group**



Current personal budget and direct payment users – how has their care changed?

We should bear in mind that the data outlined above are potential market trends based on a comparison of what council funded care users use now, and what they say they would use if they were to receive a personal budget. But there may be a disparity between what people say and what they then do. To establish whether the hypothetical preferences among potential personal budget users hold weight once personal budgets are actually used, we need to ask existing direct payment or personal budget users what types of support they spent their money on before and after receiving this form of funding (figure 39).

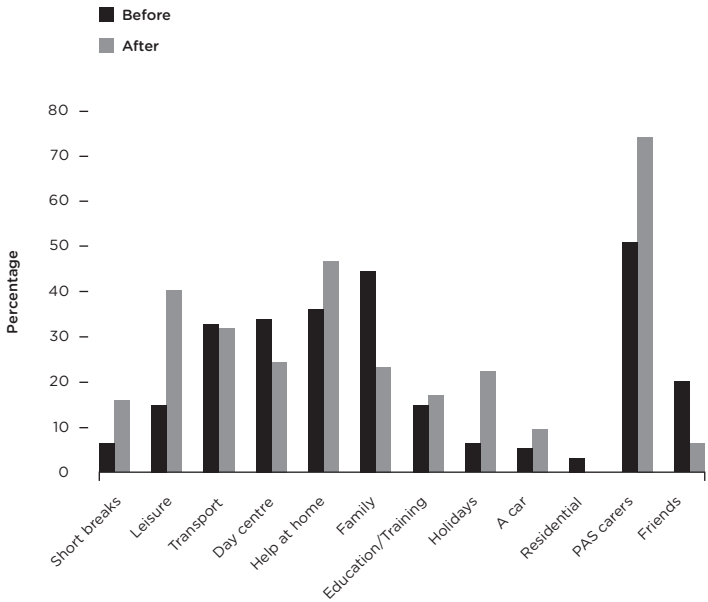
Figure 38 **Changes in residential care use by ethnic group**



These comparative data confirm the general trends seen in the data of hypothetical use outlined above, as care users increased and decreased their use of the same services. The only differences are those of scale: the reliance on friends decreased far more significantly among direct payment and personal budget users compared with what council funded care users predict; and the use of education and training services increased less. Key trends in the direct payment or personal budget user group include:

- Use of PAs and carers has increased substantially among those now with direct payments and personal budgets – 48 per cent of this group used them before having this form of funding, now 70 per cent do
- Leisure service use has similarly increased from 14 per cent to 37 per cent
- Just 6 per cent of this group used their care funding for holidays before having a direct payment or personal budget – now 21 per cent do

Figure 39 **Changes in service use before and after a Direct Payment or Personal Budget**



- The reliance on friends and family has decreased substantially, from 19 per cent to 5 per cent for friends and from 41 per cent to 21 per cent for family
- 2 per cent use residential care before a direct payment or personal budget, now none do

Having had four years with a care agency it has been less hassle. Regular carers turning up on schedule, on time and out of hours in emergency. A much more relaxed system being on the direct payment system. A move forward in social care for the unfortunate people who need it.

Direct payment user with physical impairment, age 64

7 What is important when choosing a service?

Care users funded by the council and self funders were asked what factors were important in choosing a care and support service (figure 40). Their answers give us an insight into what people may 'look for' when spending a personal budget. The most popular answers across the entire sample were:

- staff knowing you personally and continuity of service (47 per cent)
- being locally based (46 per cent)
- professional training of staff (42 per cent)
- flexibility of services (26 per cent)
- cheap price (21 per cent)

However, these averages hide the fact that council funded care users and self funders have very different preferences in most areas:

- Although the average is 42 per cent across the sample, just 28 per cent of self funders selected the professional training of staff as important compared with 57 per cent of council funded care users.
- Similarly, just 5 per cent of self funders felt national accreditation was important, compared with 19 per cent of council funded care users.
- Conversely, 26 per cent of self funders thought other people recommending a service was important, compared with 17 per cent of council funded care users.

Overall, these differences might suggest that self funders look for less objective signs of quality in a service (accreditation, training, and so on) and instead value word of mouth and less

tangible features. Self funders selected fewer features for this question overall, which may also suggest that the features we listed in the survey were not the features they considered important.

I need to trust people to come in to my house.
Self funder with physical impairment, age 66

Being pleasant is more important than professional training.
Self funder, age 91

Interestingly, breaking these data down by need group uncovers relatively few differences – all need groups have the same four priorities: professional training of staff, being locally based, staff

Figure 40 **What do you look for in a service?**

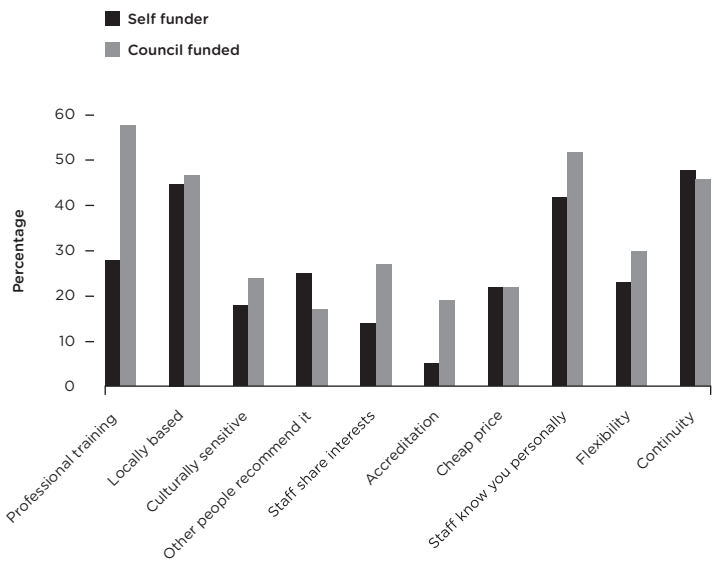


Table 15 **Top priorities for choosing a service, by need group**

Physical impairment	Mental health	Learning disability	Older person	Sensory impairments
Professional training	Staff know you personally	Professional training	Professional training	Staff know you personally
Continuity	Being locally based	Being locally based	Continuity	Professional training
Being locally based	Continuity	Staff know you personally	Staff know you personally	Continuity
Staff know you personally	Professional training	Continuity	Being locally based	Being locally based

knowing you personally, and continuity of service. The order of these four priorities differs for each group, however (table 15).

There are more significant differences in the priorities of ethnic groups, the most significant of which are illustrated in figures 41–43.

Figure 41 **Percentage of care users who believe cultural sensitivity is important, by ethnic group**

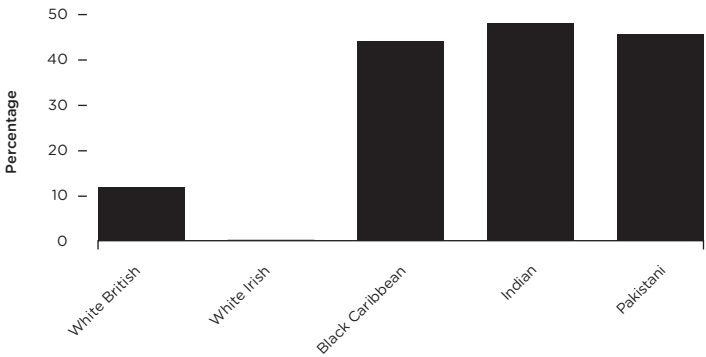


Figure 42 **Percentage of care users who believe staff sharing your interests is important, by ethnic group**

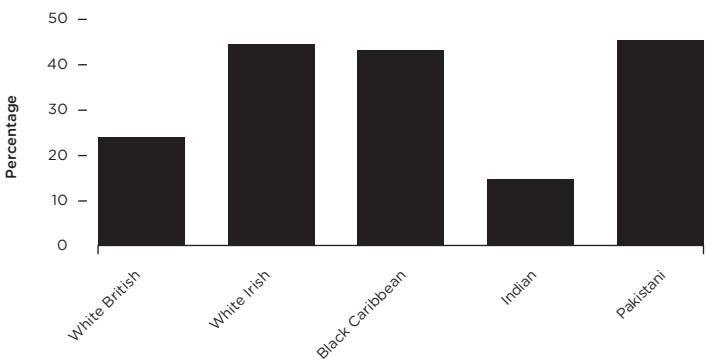
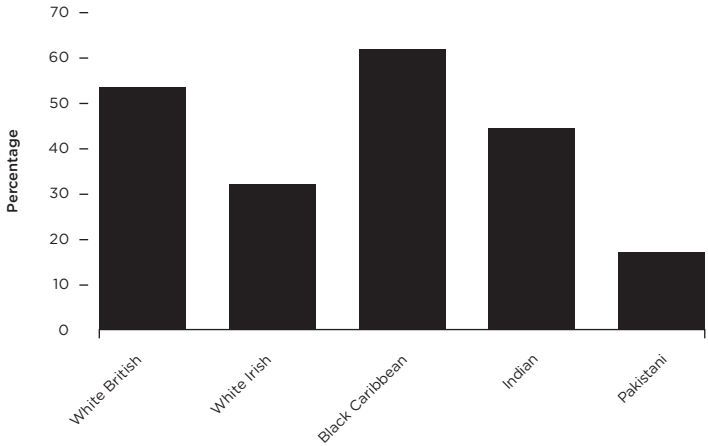


Figure 43 **Percentage of care users who believe professional training of staff is important, by ethnic group**



8 Using a personal budget

We asked those with direct payments and personal budgets (93 people) about how they receive their funding. The majority said they received a direct payment (figure 44). We also asked for how long those with direct payments and personal budgets have received their funding (figure 45).

How easy is it to use a personal budget?

We then asked this group of care users (those with direct payments and personal budgets) how they had found the process of receiving and using a personal budget. Around half of the group said it had been easy to find out about personal budgets (51 per cent), get control over the money (53 per cent), plan the

Figure 44 How do you receive your funding?

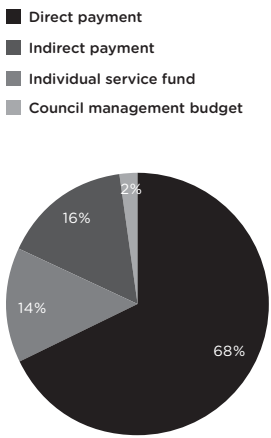
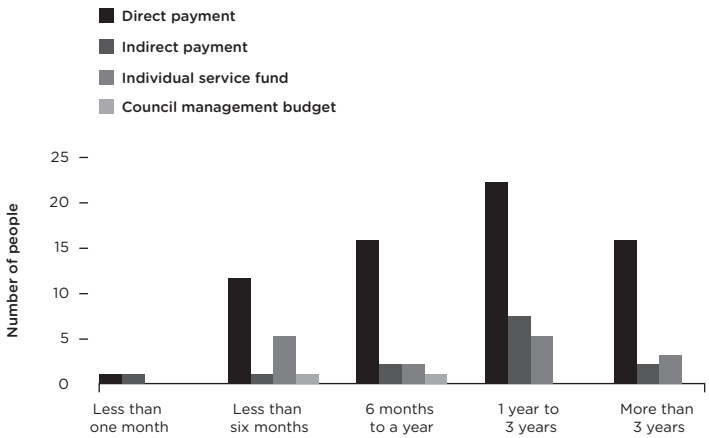


Figure 45 **How long have you had this form of funding?**



support (51 per cent) and get the support (53 per cent). However, only 32 per cent said it had been easy to carry out the self assessment. The fact that half of this group said they had not found it easy to find out about personal budgets may help explain why 65 per cent of the council funded group reported to know nothing about them.

What help do people need using a personal budget?

We asked council funded care users what help they might need if they were to receive a personal budget (figure 46). Just over half (57 per cent) said they would need information on what to spend their personal budget on, but 25 per cent said they would need no help.

Those with sensory impairments were most likely to say they needed no help (33 per cent), followed by those with physical impairments (30 per cent). Only 15 per cent of those with learning disabilities said they needed no help (figure 47). Irish care users were least likely to say they would need no help

Figure 46 **What help would you need with a personal budget?**

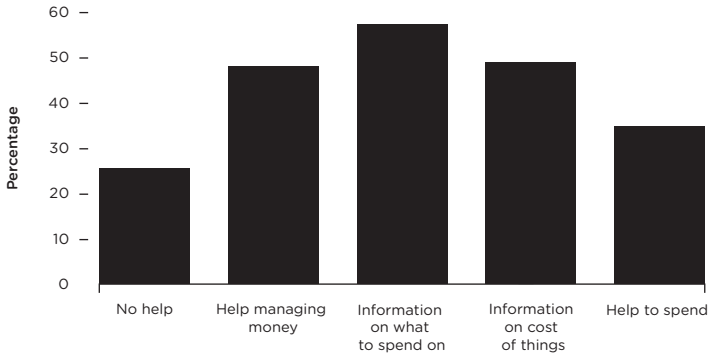
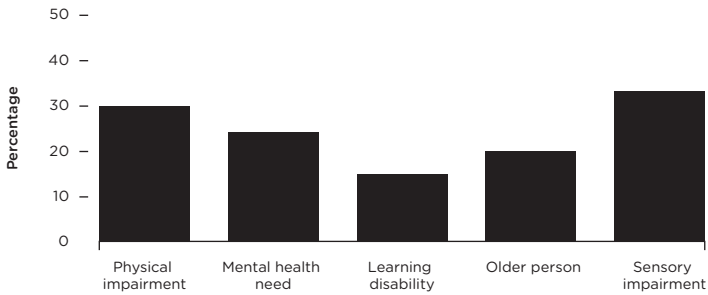


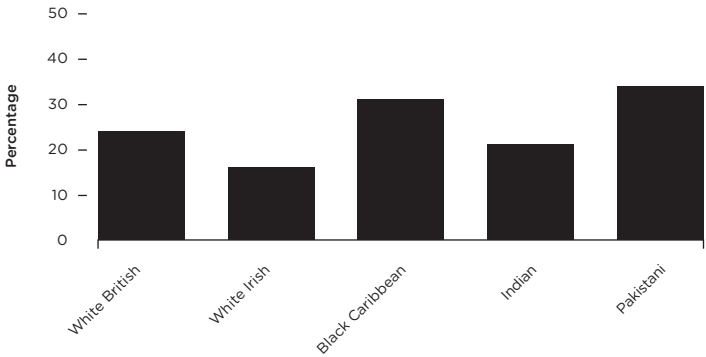
Figure 47 **Percentages of need groups saying they would need no help**



(15 per cent), and the most likely to say they needed help were Pakistani care users (31 per cent) (figure 48). Figure 49 shows the council funded care users who would need help if they had a personal budget, by need group.

I wouldn't be able to do it – my family would have to do it
Council funded care user with a mental health need, age 88

Figure 48 **Council funded care users who would need no help if they had a personal budget, by ethnic group**



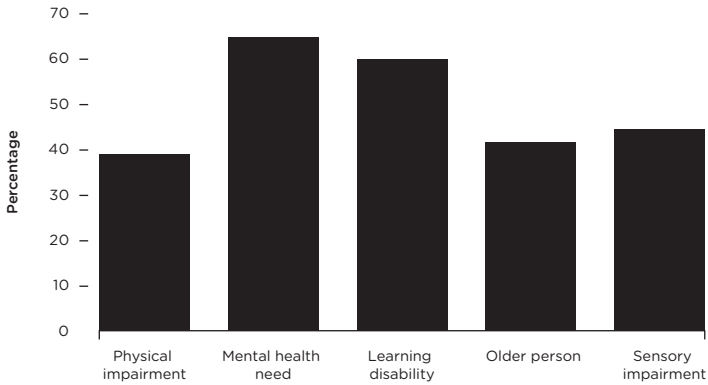
I would need to be taught the value of money

Indian council funded care user with learning disability, age 50

I do not think I cope with a budget and all it entails as well as look after [my husband]

Wife and carer of care users with mental health need, age 80

Figure 49 **Percentage of need groups saying they needed help managing money**



9 Implications and recommendations for ways forward

Key themes

This report is wide ranging and has only provided an overview of the data available, capturing the most interesting trends and findings. With more time and resources, the data Demos now hold could generate extremely interesting and detailed investigations on, for example, the users of one type of service, one minority ethnic group, gender differences, and so on, and the analysis in this report has already uncovered some interesting and unexpected findings:

1 There is a greater difference between funding groups than between need groups when considering the current level of satisfaction of care users in these groups with life and priorities for change, and the services they use and activities they engage in. This suggests that the way in which people's care is funded is more of an influence on people's lives, and the services they use, than is the reason they need that care – for example, physical impairment or learning disability. This seems counter to the purpose of social care and the personalisation agenda, where services should be matched to need.

2 However, comparing the services that different need groups use now with what they select if given free choice (with a personal budget), it is clear that the interests and preferences of different need groups is far more diverse than their current service use suggests. We can only conclude that the way in which care is funded stifles this difference; with the roll out of personal budgets, the full diversity of preferences will be reflected in purchasing decisions.

3 The idea that self funders are in some way 'free' to choose their own care, a situation that we aspire to through the roll out of personal budgets, is too simplistic. Nearly half (45 per cent) of

self funders say they wouldn't change their care and support if they could; and the same percentage of council funded care users say this too. The obstacles to change for self funders could be various – lack of information about what is available, limited access or local availability of services, or resource constraints. The fact that a larger proportion of self funders than other groups want to change their financial situation, and that those wanting to change their care are particularly unhappy with their financial situation, suggests that lack of money must play its part in constraining self funders' choice.

5 Personal budgets seem to be a question of how not what – people want to make more changes in the services they use than in the activities they carry out. With some specific exceptions, care users often want to do more of what they are already doing – socialising, meeting new people, going out, and engaging in specific activities like art and music. But how these outcomes are met looks set to change from traditional care and support services to more universal and mainstream services. This has very significant implications for providers and commissioners alike – an issue we explore below.

The implications for commissioners

Personal budgets represent a challenge for all local authorities. As individuals become commissioners for their own care and support, so councils have to relinquish their role as commissioner and purchaser of services. But as a new market, both consumers and providers might be unaccustomed with their new role. So rather than leaving care users to navigate the local market of providers unaided, and leaving providers to respond to them and develop according to consumer demand, the local authority must now assist both sides.

Local authorities must:

- ensure local markets have the range and volume of services people need at a good quality and price, in partnership with new GP commissioning consortia

- support care users to plan and purchase their own care with personal budgets
- support providers in the transition to a new way of working with their clients
- support care users who do not wish to use personal budgets by still commissioning packages of care

This first role will perhaps prove the most challenging as traditional market shaping tools – acting as purchaser of services – are no longer available. Instead, local authorities must adopt a more nuanced, facilitating role, in encouraging new providers to their area, encouraging care users to shop around, and providing market information and assistance to providers to enable them to respond effectively to consumer demand. It was arguably this last role that prompted local authorities to work with Demos, to help them provide greater insight into the local market for their providers. However, the findings outlined above also provide valuable lessons for local authorities.

Managing change for care users

Our data suggest that 55 per cent of council funded care users would change their support if and when they are given a personal budget. Local authorities must therefore prepare to support over half of their existing clients to make changes, and this will range from a significant reordering of care packages including a change of service and provider, to smaller changes that require negotiation with existing providers. For the other 45 per cent, however, commissioners will have to ensure that services are maintained and remain consistent (continuity was the joint most popular option when we asked people what they looked for in a service, selected by 47 per cent of care users) throughout this period of transition and upheaval. This may mean the local authority still planning, commissioning and perhaps even providing care in some cases, essentially maintaining a dual role of commissioner and facilitator for those with personal budgets. This could prove a challenge organisationally and for local resources.

The lack of awareness of personal budgets in our dataset is a concern and something local authorities need to look into in their own areas as a matter of priority: 65 per cent of council funded care users said they knew nothing about personal budgets at all. This lack of knowledge could hamper take up of personal budgets, or could see people not using their personal budgets effectively. One-quarter (25 per cent) of care users said they would need no help with a personal budget, while the majority selected multiple forms of help, and in particular information on the availability and cost of local services. This supports other data in our report, which found that information and face to face advice were considered to be important ways of making changes in life.

However, personal budgets are not just an informational challenge – 48 per cent of care users (particularly those in learning disability and mental health need groups) said they would need help managing their money, and 35 per cent said they would need help spending it. This implies there is a need for a far more pro-active support and brokerage role, either for local authorities or providers commissioned by the local authority. It is also concerning that only half of current personal budget holders say that finding out about personal budgets and getting control of the money was made easy by the local authority – and just a third said the self-assessment was easy. These processes will need to be looked at if we hope to encourage a wider range of care users – not just the most confident and capable – to make use of personal budgets.

An issue of affordability?

It is important to bear in mind that self funders' current experiences of a local care market could be very similar to the future experiences of those soon to have a personal budget. The data from self funders may therefore hold dual relevance – it may help predict issues arising in the roll out of personal budgets, but it may also be of interest in and of itself to local authorities seeking to ensure the local care and support market caters to all care users, regardless of their funding source.

As outlined above, self funders may be constrained in their choices by a lack of resources – a large proportion said that they would like to change their care if they could, and members of this group in particular were unhappy with their financial situation, suggesting they may not be financially able to do so. More than one-third (38 per cent) of self funders wanted to change their financial situation compared with 27 per cent of those with direct payments or personal budgets and 32 per cent of council funded care users.

This issue could be addressed in two ways – the first is to ensure self funders maximise their income, for example, by claiming the benefits they are entitled to. This may be particularly important for older people relating to pension credit. Only 12 per cent of self funders said that finding paid work was an area they wanted to change. The second is to consider the affordability of the services self funders use – 46 per cent believe they do not get value for money. However, when we consider the top four services they use – transport, leisure services, day centres and home helps – it is not simply the affordability of care services that is in question. Local authorities will need to consider whether all services in their local area – not just traditional care services – are affordable for their self funders.

However, in the current economic climate and with cuts to social care budgets and other related departments imminent, it must be considered whether a downward pressure on social care funding will leave some personal budget holders financially constrained in the way self funders are now. Care users could be in the unfortunate situation of finding the monetary value of their personal budget does not secure the same level (quality and/or amount) of care that they were receiving before having a personal budget. Although we have no quantitative data to substantiate this theory, some of the comments made by those we surveyed suggest this could be a problem, and may become more of a problem in the forthcoming months of austerity:

My [personal] budget is completely spent on carers.
Personal budget holder with physical impairment, age 94

All my [personal] budget is for personal care, and I desperately want a life outside this house.

Personal budget holder with physical impairment and learning disability, age 45

I need help for someone to sew buttons on, someone to take me to a gym or swimming, to make calls for me, write letters, to have wallpaper put up, but it is too dear. I had my passage painted but it cost me £310 from my [personal] budget plus I had to pay for all the paint.

Personal budget holder with physical impairment, age 60

Local authorities will need to think carefully about this possibility, and, armed with their knowledge of the local market and working with local providers, take steps to mitigate it. Could other funding sources be used (for example, housing and regeneration) to stimulate affordable supply? Is franchising of large care brands to achieve economies of scale the way forward? Such difficult questions will need to be considered.

Shaping the market and supporting providers – a shift to universal services

When we consider the data in this report relating to the scale and nature of change, we can see that the most striking direct 'market effect' of personal budgets will be the shift from traditional care services such as day centres and residential care to universal services, such as leisure, education, home help (for example, DIY and cleaners) and holidays. The activities people want to engage in remain relatively similar (although care users, particularly those with learning disabilities, want to engage in more activities overall), which suggests that personal budgets may enable people to carry out the same sorts of activities, but in different locations (for example in leisure centres or gyms) in order to secure more variety and choice.

This poses two distinct challenges for local authorities. The first is in supporting existing care providers in managing this shift. There will inevitably be a reduction in clients for some providers, but ensuring that providers respond positively to this

challenge (changing their service, diversifying, working with others, and so on) could be an important role for the local authority in ensuring the care market remains healthy and responsive to demand. Perhaps more important than a decline in business, care providers will need to deal with disruption to their organisations that personal budgets may bring. What our headline data does not show is that a 'small decline' may hide very significant changes in client use. For example, 40 care users currently use residential care, and 30 say they would if they had a personal budget. It does not hold, however, that ten people will leave residential care – in fact, 28 current users say they will leave, but another 18 say they would want to start using residential care if they had a personal budget. Similar inflows and outflows are likely to be seen in other services. This turbulence in client base, combined with the possible need to make small changes for the 37 per cent of council funded care users who said they would want to change their care 'a little', could mean organisational upheaval for many providers. The support from local authorities in providing advice and practical support to ensure a level of continuity and temporary financial viability could be invaluable in preventing some outstanding and valued providers from being pushed from the market as a result of short term disruptions.

The second challenge for commissioners regarding the shift from traditional care and support to more universal and non-specialist services will be in ensuring that the local market for such services is affordable, accessible and suitable for care users. Local authorities have such an important part to play in this respect because 'being locally based' is the second most common response when we asked care users what they looked for in a service: the availability and accessibility of local provision is a key priority.

Local authorities are best placed to take a strategic overview of the local market – not just of care services but of all services. In the light of the findings in this report, local authorities will have to consider whether there are adequate leisure and cultural services available for personal budget holders to make use of, as well as suitable transport. Home helps

– a big growth area – are also usually a form of non-specialised service, and commissioners will have to consider whether the local market for gardeners, handymen, cleaners and cooks is sufficient in volume and price, and appropriate for those with disabilities or who are old and vulnerable. The potential for a large increase in demand for holidays could also be particularly challenging, and local authorities thinking ahead may want to attract specialist providers to their area to help meet this new market.

This market oversight role will be hardest for local authorities in areas where local provision is expensive (for example providing access to transport and gyms or leisure centres in central London), where providers are not attuned to the needs of care users, or where fewer services are available (such as rural areas). Affordability could be a particular problem: our data show that self funders are constrained in their choices, perhaps because they lack resources, so some services are unaffordable for them. It is likely personal budget holders will face similar problems in the future – although budgetary cuts may lead to care funding levels being reduced, local prices are unlikely to follow suit.

It is vital for commissioners to consider wider 'non care' markets in their areas, and how they might better meet the needs of social care users, if personal budgets are to be a success. If care users cannot afford to access the services they say they would like to use with a personal budget, then choice and control – the raison d'être of personal budgets – will be critically undermined.

Encouraging diversity of provision

Our data suggest that how people's care is funded dictates both the types of activities they engage in and the services they use. However, personal budgets have the potential to change this, by giving people's preferences and needs greater sway.

The data collected for this report includes a far larger proportion of minority ethnic groups than our initial dataset, and also has a better representative balance of different need

groups, including those with sensory impairments and mental health needs. Our data show that there are significant differences between ethnic and need groups, in current life satisfaction levels, priorities for change, preferences for services and activities, and so on. In many areas, the responses of those with learning disabilities could not be more different from those of older people.

It is very difficult, therefore, to talk about care provision in a one-size-fits-all sense when we have seen that those with learning disabilities are three times as likely to be interested in attending classes that those with physical impairments, and nearly twice as likely to use a day centre than those with physical impairments, and when Pakistani care users are three times as likely to want services where staff share their interests as Indian care users. Differences in care needs, age and ethnicity all make up a highly heterogeneous group; providing personal budgets to this group will lead to increases and decreases in demand in different areas.

In taking an overview of the services and facilities available in their local area, local authorities must consider the full scale and breadth of preferences expressed by different groups of users. In order to meet a full range of needs, traditional and non traditional care and support will have to be maintained side by side. It could be challenging for commissioners to maintain the correct balance of diversity and choice with financially sustainable services.

In summary, the data presented here suggest that local authorities face a real and imminent challenge. Potential issues of affordability, a lack of consumer information and hands on guidance, and care related and mainstream service providers unprepared for significant shifts in demand could all combine to create a highly 'imperfect market', where care users cannot secure the services they want and need and where some providers may be driven from the market unnecessarily. It is critical that local authorities rise to these challenges and provide the appropriate support, particularly in the early stages of transition to personal budgets.

The implications for providers

Although personal budgets no doubt create real challenges for local authorities in supporting users and providers, and taking a strategic oversight of local markets, providers of care and support services remain at the coalface of market changes. In this section we consider what the market intelligence gathered here means for these providers.

Market shifts – new opportunities and challenges

The most direct effect on providers will be where care users change the types of services they purchase, and the activities they engage in, once they have a personal budget.

The intelligence suggests that the clearest changes will be:

- a shift towards leisure and holidays
- a demand for a greater range of activities during weekdays
- an increased demand for home helps, PAs and help going out (including transport)

These trends will clearly have variable impacts on the care and support market. Although it is good news for home care providers, who are set to see an increase in demand for their services, it is less welcome news for day centres and residential care providers. Nevertheless, there may be opportunities to diversify and meet new and emerging needs as a means of offsetting potential declines in client numbers.

For example, although the data suggest a general decline in their use, day centres remain a popular service. A third of care users say they will still use day centres after receiving a personal budget, and older people may use them slightly more than they do now. Day centres may then need to consider why some care users would stop using a popular service. One reason may be related to a commensurate increase in mainstream leisure services. This could be because there is more choice and flexibility in the activities on offer – changing daytime activities was a top priority among all care users. Changing activities on weekends and in the evenings also scored highly. There may well be opportunities, therefore, for day centres to offset their

potential decline by offering a greater range of leisure-related activities, escorted group trips (to capitalise on the demand to go out more) and opportunities for socialising and meeting new people. They could also open at different times to meet the demand for activities on weekends and in the evenings. It is worth bearing in mind that care users are looking for services where staff know them personally as well as continuity of service – day centres may well have a natural advantage over mainstream leisure services on both of these fronts and could capitalise on this when diversifying the range of services they offer.

Residential care providers may also wish to diversify and consider meeting the demand for short breaks in registered homes – a market which has increased according to the intelligence of current direct payment and personal budget users, and which is set to increase further according to the preferences of council funded care users. Respite care could also be a growth market as care users clearly wish to reduce the care burden on their family and are prepared to spend personal budgets to do so; reliance on family reduced significantly among current direct payment and personal budget users and the intentions of council funded care users – particularly those with learning disabilities – is the same.

There will be an increase in the demand for the caring services of home care providers, but other opportunities for expansion also exist. They could potentially move into the personal assistant market, and even provide lower level home help (perhaps working with another third sector provider or commercial service) to meet the increased demand for cooking, cleaning and handy-man type services, as they already have positive relationships with their clients and the expertise to provide home-based services. Escorted trips could well be another opportunity for growth for these providers, as care users express an interest in using their personal budgets to enable them to go out more. It may well be that the leisure pursuits they hope to engage in, including participating in educational activities, will require someone to go with them or keep them company. This could be a new role for home carers, who would be well placed to build on existing relationships and expand the services on offer.

However, such diversification – in day centres, home care and residential care – would require new and different skills sets being developed by staff, often to fulfil non-specialist and less 'care related' roles and activities outside the home or day centre. Providers will need to consider cost effective ways of doing this, for example, ensuring qualified nurses and carers are free to fulfil nursing and personal care tasks by hiring other staff to undertake less specialist roles.

Nevertheless, and in spite of these possible opportunities for care providers to cater to new demands, it is very likely that some providers will see a possible reduction in the client base of traditional care services. Adaption and diversification may be a matter of survival. We should bear in mind, however, that the data show care services do not 'die out', rather, for many day centres there may be a decline in use by existing clients rather than a decline in clients per se. Care users with personal budgets may replace some day centre or home care hours each week with other activities, 'bolting on' mainstream services to a 'care core'. This also creates potential challenges for those care providers who seek to create a package of support for their clients, as it could mean having to engage with mainstream providers who do not have an understanding of or facilities for care users' needs. For example, day centres may consider partnerships with a local swimming pool or gym (indeed many day centres already do this to provide more variety for their clients), but it may be a challenge finding good quality, accessible local services that are sensitive to the needs of particular client groups.

In this situation, care and support providers might consider working with these wider, universal service providers to ensure that the services they provide are compatible with a person's care and support needs (perhaps with the help of the local authority). They could also move into these universal markets themselves, and provide their own leisure, transport and generalist 'home help' services in addition to their traditional care service offer. This will of course have implications for staffing and the skills required – as outlined above.

Market stability

We know that although 55 per cent of care users say they would not change their care with a personal budget, 37 per cent said they would change it 'a little'. This could mean 'tweaks' in existing support rather than a wholesale reordering of services. Continuity of service was the joint top response when we asked care users what they looked for in a care service, selected by 47 per cent of care users. Importantly, continuity of service was also one of the few areas where council funded care users and self funders agreed. Both of these facts together could imply a distinct challenge for providers – simultaneously, providers may have to:

- maintain the stability and consistency of traditional services – these will still be sought by those care users preserving their care core while 'bolting on' mainstream services, as well as the care users who do not change their care package with a personal budget
- 'tweak' existing service packages and make small scale changes to meet the preferences of existing clients and the 37 per cent who said they wanted to change support a little
- make more significant changes for the 18 per cent of care users seeking to change their care more significantly, and, as discussed above, diversify the service offering to attract new personal budget holders and offset possible declines in their client base, while at the same time make significant organisational and staff changes to ensure personal budgets can be dealt with administratively and operationally

Maintaining stability for existing clients while driving change is a dual role, which is likely to be the greatest challenge for providers in the wake of personal budget roll out.

New markets

In addition to a shift towards more leisure and activities outside the home and during the day, care users are particularly interested in opportunities for holidays. All of these trends imply an increased demand for suitable transport. Given the potential

limitations of existing mainstream services to meet the specific needs of those with physical, sensory impairments or learning disabilities, it may be that new providers, or existing providers with an ambition to grow and diversify, might consider developing new services to meet care users' holiday, trips, travel and transport needs with the guidance of the local authority. This is already important for day centres (many of which already have their own, or partner with specialist transport providers to bring their clients to them and home again), but may be used further to help day centres, home care agencies and residential care homes diversify to provide escorted trips, short stays and holidays.

Specialist home help services might also be a new emerging market to look into, particularly in areas where DIY, cleaning, gardening services, and so on are not appropriate to meet the needs of care users.

In addition, a wholly new market of personal budget support, where care users may require help spending their budget and managing their care plan, employing a PA, and so on may develop. As we have seen, 75 per cent of care users say they would need help using a personal budget, ranging from consumer information and face to face advice through to more pro-active help with managing and spending the money. There is no reason why those running existing care services, already trusted and maintaining good relationships with their clients, could not expand into these professional support areas and provide in-house personal budget support. Although some feel this would be a damaging conflict of interests, this need not be the case – local authorities must provide consumer information and advice to those receiving personal budgets to help make choices about what services are available and their cost. This must be impartial. However, once a care user has made their choice of provider – or indeed, has chosen to stay with their existing provider – based on this information, there is no reason why those providers could not then offer help to their clients to manage their money, including brokering contract arrangements with other care, third sector or mainstream services to supplement a client's existing 'care core'. Although some may

seek help from their families, the local authority or independent advisers, others may value help from a trusted and familiar source – their carer.

The key to entering all of these new markets will be how providers market themselves. The shift from bidding for local authority contracts to attracting individuals with a budget to spend is a significant one. It requires a greater understanding of the needs and demands of the potential market for different services across a diverse population; the development of a trusted brand and reputation for quality, flexibility and reliability; and initiatives that provide information and increase awareness of the options available. Raising brand awareness and providing service information by providers is vital given the low awareness of personal budgets and the expressed demand among a large proportion of care users for more information about the options available locally. Informing consumers should not be the sole responsibility of the local authority – providers will need to do their part.

Affordability may also be an issue – although 'cheap price' was not a priority area care users identified when looking for a service, we do know that self funders may be financially constrained from making changes to their care and support. In the light of cuts to social care budgets, there is a real possibility that personal budget holders will encounter similar problems. Personal budget holders may need to make their budgets stretch further, with an increased premium on value for money, quality and transparency of costs as a result.

Overall, providers will need a far stronger external focus to engage with care users eager for more choice and control, but possibly unsure where to start. They will also need to be far more responsive to the types of services and activities they offer, and how they offer them. Working with commercial, mainstream and third sector providers is essential if care providers hope to deliver integrated packages of care and support for their clients. Brokering such relationships could be a vital role for local authorities, whose local oversight across housing, transport, health and care, as well as universal cultural and leisure activities, will be invaluable from what these data tells us. An important

first step in this process is for commissioners and providers to absorb and reflect on the implications of the market intelligence generated from this research.

10 Next steps

The Demos national dataset looks set to more than double in size in the next six months, as more local authorities participate. Following on from the ten local authorities already covered here, three new local authorities are already in the process of collecting local data, which we will add to our dataset. We hope to publish a new update in early 2011 with a sample of around 2,000 people, and perhaps yet another update in the summer if more local authorities join the programme. As ever, all of these reports (including our first *At Your Service*) will be available to download from the Demos website (www.demos.co.uk), the Putting People First website (www.puttingpeoplefirst.org.uk/) and In Control website (www.in-control.org.uk).

Notes

1 In the form of a direct payment, indirect payment, individual service fund or council managed budget.

2 Cheshire East County Council, Hull City Council, Nottinghamshire County Council and Lancashire County Council, the London Boroughs of Barking and Dagenham, Havering, Hillingdon, Ealing, Harrow, and Birmingham City Council.

3 DoH, Independence, Well-being and Choice: Our vision for the future of social care for adults in England, Cm 6499 (London: Department of Health, 2005).

4 DoH, Our Health, Our Care, Our Say: A new direction for community services, Cm 6737 (London: Department of Health, 2006).

5 HM Government, Putting People First: A shared vision and commitment to the transformation of adult social care, 2007, www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf.

6 See www.puttingpeoplefirst.org.uk/about/.

7 Using Fair Access to Care Services (FACS) criteria.

8 See '£4 million boost to give patients control of their health care', press release, Department of Health, 15 Jul 2010, www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_117476.

9 See Paul Burstow's speech to the Personal Health Budgets Conference on 16 Jul 2010, www.dh.gov.uk/en/MediaCentre/Speeches/DH_117547.

10 Due on 22 October 2010.

11 D Brindle, 'Boost for "cost-effective" individual budgets', *Guardian*, 28 Jan 2010, www.guardian.co.uk/society/2010/jan/28/individual-budgets-cost-effective.

12 NHS Information Centre, 'Social care and mental health indicators from the national indicator set, 2009–10 provisional, England' (August 2010).

13 J Bartlett, At Your Service: Navigating the future market in health and social care (London: Demos, 2009).

14 C Poll et al, *A Report on In Control's First Phase 2003–05* (London: In Control, 2006); C Hatton et al, *A Report on In Control's Second Phase: Evaluation and learning 2005–07* (London: In Control, 2008); A Tyson et al, *A Report on In Control's Third Phase: Evaluation and learning 2008–09* (London: In Control, 2010).

15 C Glendinning et al, *Evaluation of the Individual Budgets Pilot Programme: Final report* (York: Social Policy Research Unit, University of York, 2008).

16 DoH, Our Health, Our Care, Our Say.

17 Percentage of people selecting this option; multiple answers were permitted.

18 Ibid.

19 Ibid.

20 Ibid.

21 Ibid.

22 Ibid.

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Personal budgets in social care give care users more control over their care by enabling them to purchase their own support according to their needs. A critical element of the previous Government's vision of a more personalised and empowering national care service, the national roll-out of personal budgets was set as a priority for local authorities in 2007. At present, 13 per cent of care users have a personal budget.

But now, under a new government, there is increased momentum for change. The Care Minister, Paul Burstow, has urged local authorities to rapidly improve personal budget take up so that they exceed the target of 30 per cent of care users on personal budgets by April 2011. Personal budgets look likely to form the centrepiece of the Coalition's care reform.

This requires both local authorities and care providers to adjust to rapid change, with large numbers of care users switching to personal budgets in a short space of time. Yet the intelligence on personal budget spending remains limited. Without better information, councils and providers alike risk being unprepared for the change and uncertain how to respond. The data presented in this report goes some way towards filling this knowledge gap, and is required reading for those preparing themselves for a revolution in social care delivery.

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