

at your service
navigating the
future market
in health and
social care

JAMIE BARTLETT

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Any omissions or errors are my own.

Jamie Bartlett
October 2009

introduction

Within the next five years, around 1.5 million people could be using personal budgets to access social and health care services. But without the knowledge of how the public view personal budgets, how they might spend them, and what help they might need, local authorities and provider organisations will be on the back foot.

To help rectify this, Demos and the Centre for Disability Research at Lancaster University undertook an in-depth analysis of the views of people who use social care services, who are likely to become holders of personal budgets as this reform progresses. The research provides important information about how the social and health care market will change and the challenges facing local authorities and providers in delivering the agenda. This report forms the first of a long series: Demos will work with as many local authorities as possible over the next 18 months to build up a bank of knowledge about public opinions and needs. We will publish a new report and data every six months.

The transformation of health and social care

Social and health care are being transformed. The vision is of personalised services; giving people who use services power over what they use. It is part of a general trend towards providing services that prioritise independent living, choice and inclusion.

One of the key aspects of this reform is the introduction of personal budgets for people who use social care services, and in the future for people who use health care services too. Currently people who are eligible for social care funding are assessed by a care manager and allocated a service that has been selected and purchased by the local authority. With personal budgets, individuals are given a budget – often a cash budget – to manage themselves. Individuals will become the commissioners of their own social care services, choosing and buying what they think best meets their needs. People will be 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.

Local authorities are in the process of introducing personal budgets. Around 15,000 people currently hold personal budgets, and by March 2010 the Department of Health (DoH) estimates that number will rise to 200,000. By March 2011, all local authorities are required to have moved at least 30 per cent of all people who use publicly funded adult social care onto personal budgets, and to ensure that everyone, whether they are self-funders or publicly funded, has access to the same information about what support is available locally.¹ Around one-third of local authority sites are aiming to have all people using social care services on personal budgets by March 2011.

Health services are moving in the same direction. The 2008 Darzi report signalled the DoH's commitment to extending personal budgets into health services; approximately 5,000 people will be piloted with a personal health budget from late 2009, mainly those with fairly stable and predictable conditions.² The pilot sites have already been selected, and include people with continuing health care needs, mental health needs, long-term neurological conditions and learning disabilities.³

In addition, there is a growing realisation that the distinction between health and social care is preventing people getting the service they need. The pooling of health and social care budgets is already taking place in a number of local authorities, often on 50/50 funding – 'a little local agreement' between the local primary care trust (PCT) and the local authority. There are at least a dozen areas that have such agreements, which are likely to become more widespread.⁴ This will continue to grow, partly driven by potential cost savings.

The challenges for local authorities

This is a radical and ambitious reform, and many aspects of it are still to be worked through. The central challenge is whether the market can respond to what people want and need. If people are to be given greater freedom and control over the services they use, they need to have genuine choice, control and power, as well as the assistance to make informed decisions. This in turn entails a varied and diverse market supply side made up of large, small, private, not for profit, and public providers competing fairly with each other who can respond in flexible and imaginative ways.

This means that the commissioning role of local authorities will be transformed. At the moment local authorities directly commission and purchase. This will end as people take control, and in some cases that will lead to fairly rapid decommissioning. Local authorities are reviewing their traditional contractual relationship with service providers and will end some of these relationships. Indeed, advice from the DoH is that block contracts should be reduced and short- to mid-term solutions identified where appropriate, although some commissioning will still be required because some level of demand for the old model of service delivery may persist for some time beyond 2011.⁵

On the whole, commissioning, where it does continue, is likely to become more strategic (managing and stimulating markets so people have options to choose from) and more personalised, in the sense that local authorities will use more spot purchasing around an individual.⁶

This, in turn, has major implications for the 25,000 or so organisations that currently provide social and health care services. They range from small voluntary organisations providing personal assistants to very specialist hospital units that work with people with very intense and complex needs. All of them need to work more closely with the people they serve, and make sure they are giving them what they want and need – and change their offer if they don't.

Our research

As the system changes and increasing numbers of people have the power to demand new services to meet their needs in new ways, providers and local authorities need to be ready to meet these requirements. However, it is still unclear what this will mean. There are some exciting cases of people spending their personal budget money on football season tickets or holidays – but how representative is that of the general social care population? Within the next 2–5 years as many as 1.5 million people could be using personal care or health budgets, but providers and local authorities don't know what people think of personal budgets, how they might spend them, and what help they might need.

Demos and the University of Lancaster undertook an in-depth analysis of what people who aren't currently using personal budgets but are using social care services think about personal budgets, where they want to be in their lives, and how they would spend a personal budget to get there. It is based on a sample of 269 people who use social care services, across a range of primary needs in four local

authority areas. A full methodology is available in the annex.

The research provides new and invaluable information about how the social care market will change and what providers, local authorities and families should do to make the vision – better services designed around each person’s needs – a reality.

1 how are people currently spending their personal budgets?

The transformation of social care has been taking place for almost two years, and there are around 15,000 individuals using personal budgets. We have learned a great deal about how they work, what works and what doesn't, and there are early indications of how greater choice will affect the social care market. In this chapter, we review the evidence currently available at a local and national level. However, there are important limitations to the data currently available, which will be discussed at the end of the chapter.

Spending patterns

The social enterprise In Control has carried out two major reviews of the people they helped move onto personal budgets. In Phase I (2003–5) they worked with 30 people, mainly with learning disabilities, across six local authorities. Of the 30, ten were in residential care homes at the start of the process, and all moved out: nine into their own tenancies and one back into the family home. The use of day care centres also fell — the average amount of time spent in day care fell from around 4.5 days per week to 3.5 days per week per person. The biggest increase was in the use of personal assistants: eight people used personal assistants before having a personal budget, 22 people used personal assistants afterwards. Phase II (2005–7) covered 196 people, again primarily with learning disabilities, across 17 local authority sites.⁷ Exact figures for what people spent their money on were not recorded, although In Control reports that most people (82 per cent) changed 'some aspect' of the care they received.

The shift from residential services into supported living was an early finding from this research, and was mirrored, although less intensely, in the Ibsen pilot site evaluation (henceforth 'Ibsen'). Ibsen is the independent evaluation of the 13 DoH funded individual budget pilot sites in 2005–7, and is the most comprehensive data source currently available. The evaluation looked at spending

patterns of the support plans of 282 people holding individual budgets.⁸

Everybody in receipt of an individual budget wrote a support plan setting out what services (and often things that aren't really 'services' in the traditional sense) they wanted. This was used to calculate in what areas people spent their money. There was a strong continuing demand for 'mainstream services', which covers domiciliary care, residential homes and day care centres. Around half of all those surveyed spent some of their money on mainstream services.

A surprisingly large number (41 per cent) of support plans included money being spent on personal assistants, and leisure services were also very popular, although there were visible differences between groups. Older people for example spent the least on leisure services (15 per cent, spending an average of £1,000 a year). The review also showed that there were a number of people choosing to spend their money in innovative and unusual ways: on decking in the garden, arts materials, an IT course, hygiene training, driving lessons, a car harness, a shed, skip hire, a caravan, photography classes and a snooker cue.

In addition to these major national evaluations, some local authorities have undertaken smaller scale evaluations of their own areas. The general pattern again is that people want more choice and control; they are spending less of their money on mainstream services, and more on social support that can help keep them independent and connected to local activities. Worcestershire County Council (73 people), Herefordshire County Council (66 people) and Cambridgeshire County Council (56 people) provided the biggest reviews to date.⁹

In Worcestershire, a substantial minority (13) continue to use day care centres. But no one spent money on a traditional respite centre, and only one person used the money for residential care. Around half of people spent some of their money on leisure, health and fitness-related activities. Leisure was the largest activity area: 34 people spent some of their personal budget on 'leisure' and 21 used money for health and fitness-related activity (including gym, swimming, sports club, golf, rambling). Similarly to the Ibsen evaluation, a lot of people mixed traditional services – to meet their support needs – with other things, including: adaptations to the home, broadband internet access, help with cleaning and ironing, a hot tub, a mobile phone and guitar lessons.

In Herefordshire the dominant trend was also an increased number of people using their budgets on leisure

activities.¹⁰ Many included in their support plans travel training, college activities, access to paid and voluntary work and maintaining tenancies. In Cambridgeshire the most commonly requested types of support were leisure services, personal assistants, help at home, public transport and education.¹¹

Smaller evaluations point in the same direction. Northamptonshire County Council reviewed 39 personal budget support plans in detail.¹² Half the people used some social support, helping them to engage in everyday activities, hobbies or nights out. The most common 'everyday activities' were eating out, shopping, cinema and gym membership. Half the plans included some instances of independent living (assistance with household tasks and administration). Northamptonshire also ran a separate, more focused evaluation of 20 personal budget holders with a mixture of needs and found people either moved into their own homes or spent their money to gain the skills and confidence to make the transition into their own home. Common examples of personal budget spending included employing personal assistants, meeting transport costs, paying for bed and breakfast accommodation to enable overnight stays, accessing mainstream leisure and social activities, and purchasing assistive technology.

Finally, In Control reviewed ten personal budget holders for London City Council.¹³ The study found that older people wanted support to stay in their own homes, while younger people wanted support to leave their parental home. It was common for people to use their money on support and equipment to pursue academic studies, to find work and employment opportunities, to access social and leisure activities, and to gain life skills, learning to drive for example.

Process of using and managing a personal budget

These studies offered some early insight into the diverse ways that personal budgets can be managed and organised. There are a number of different ways that personal budgets are being held. In the Ibsen evaluation, half of personal budgets were delivered as a direct cash payment, and 20 per cent were held by the local authority (the 'care management plan'). But this varies greatly. Worcestershire County Council's evaluation showed even greater diversity; only three people held the budget themselves as a direct cash payment, while 28 people had family members or friends hold it on their behalf. Here,

20 people's budgets were held by independent social care providers.¹⁴

Personal budget holders also draw up a support plan, which sets out what that person wants to achieve, and how they will spend their money. Of the Ibsen sample, around half of support plans were written by the individual budget holders themselves; 35 per cent were led by a care manager; and 18 per cent of were led by an independent broker. In short – there is not one single way to do this.

Conclusion

The research reviewed above offers some useful insights into how people, when given control, might want to spend their money. Some very clear trends emerge. First, many people do seem to want to move out of residential services and into their own tenancies, and will spend in various ways to make that happen, including by employing more personal assistants. Second, many people combine their direct support needs with social support – leisure, training and education. Third, many will continue with what they have now, as there was a strong demand for day care centres for example. There are some very interesting examples of how different people are going about changing their services in ways that work for them, and some exciting stories of how that has changed people's lives for the better.

However, while helpful, there are some weaknesses with the available data, and care is needed in drawing conclusions. First, the size of the sample is small. What is known is based on the small number of people who hold personal budgets and have been evaluated, which is just a few hundred. It is not clear how representative they are of the 1.5 million people who will eventually move onto personal budgets; in truth, probably quite unrepresentative because many of them were the vanguard – selected to try personal budgets because they were unhappy with their existing services. This means there is a 'representation bias'. As a result, many of the sample group benefitted from strong personal networks of support, or considerable assistance and guidance from the local authority, combined with a strong urge to change. It is therefore probable that the changes in spending patterns by those with personal budgets outlined above are more dramatic than the norm.

In addition, the vast majority of the research to date is based on people with learning disabilities. There are many groups of people that we still know very little about – older people, for example, and those with very high level needs

who are outside the 'resource allocation system' (the process by which personal budget levels are set).

The lack of information about how the bulk of people who will potentially use social care services understand personal budgets and what these budgets are likely to mean for them is a major barrier to change.

2 our research – what will people want to do in the future?

Methodology

This research was undertaken to understand more about what people who *are not currently using personal budgets* might want in future; what they were happy or unhappy about in their lives; how they would like to change that; what they knew about personal budgets; and how they would spend their personal budget if they had one. This allows for more accurate conclusions about the impact of personal budgets on the market.

Together with the Centre for Disability Research, we surveyed individuals from four local authorities – Cheshire East County Council, Hull City Council, Lancashire County Council and Nottinghamshire County Council – with a range of needs. They were a mixture of self-funders and publicly funded individuals. We sent questionnaires to over 300 people, and received 263 completed returns between January and July 2009.¹⁵ The most common groups surveyed were people with physical impairments (112 people; 43 per cent), older people (72 people; 27 per cent) and people with learning disabilities (53 people; 20 per cent). A full breakdown of the methodology is in Annex 1, and a list of all questions and responses in Annex 2.¹⁶ Here the key findings are set out; we highlight notable differences in responses between older people and working age adults (people with learning or physical disabilities).

People's lives

The first set of questions were about people's lives – what they want in their lives, whether they were happy with what services and support they were getting now, and what they would like to change.

What do people want from their lives?

We asked people eight questions about how important it was to achieve a number of life goals. The most common areas of life people felt it important to achieve were:

- keeping healthy and well (75 per cent)
- a good quality of life (62 per cent)
- personal dignity and respect (53 per cent)
- choice and control (50 per cent)

There were very minor differences for older people and for working age groups. People with learning disabilities were more likely than other groups to feel it was important to have enough money, to help others and make a positive contribution, for others to treat them fairly and to stay safe.

What do people get now?

We asked people what specific types of support they were using at the moment. There were some differences depending on whether people paid for service themselves, were funded by the council, or were paid for either using a direct payment or a personal budget.

People paying for their own care used a wide range of services, most commonly day centres (55 people; 39 per cent); and least commonly residential or care homes (nine people; 6 per cent). People getting support from the council were most likely to get council support for day centres (75 people; 44 per cent) and least likely to get support from the NHS (four people; 3 per cent) or adaptations to the home (two people; 1 per cent). People using personal budgets and direct payments were unlikely to spend their budget on any of these services.

We investigated whether there were differences in patterns of support that people were paying for themselves across primary need group. Older people were more likely than those with physical impairments or learning disabilities to pay for day centre services (58 per cent vs 30 per cent and 18 per cent¹⁷). In contrast, people with learning disabilities were more likely than people with physical impairments and older people to pay for education and training (32 per cent vs 11 per cent and 0 per cent¹⁸) and to pay for a place in a residential care home (18 per cent vs 6 per cent and 0 per cent¹⁹).

We conducted a similar analysis looking at differences in patterns of *council-funded* support among people with physical impairments, people with learning disabilities and older people. People with learning disabilities were more

likely than those with physical impairments and older people to use council-funded education and training (36 per cent vs 6 per cent and 2 per cent²⁰) and to be living in a council-funded residential or care home (25 per cent vs 5 per cent and 8 per cent²¹).

What do people want to change?

We asked people whether they wanted to change anything about their lives. As figure 1 shows, the five areas people most commonly wanted to change were:

- physical health (113 people; 45 per cent)
- opportunities for holidays (108 people; 43 per cent)
- the money they get (89 people; 36 per cent)
- what they do on weekdays (78 people; 31 per cent)
- control over their lives (76 people; 30 per cent).

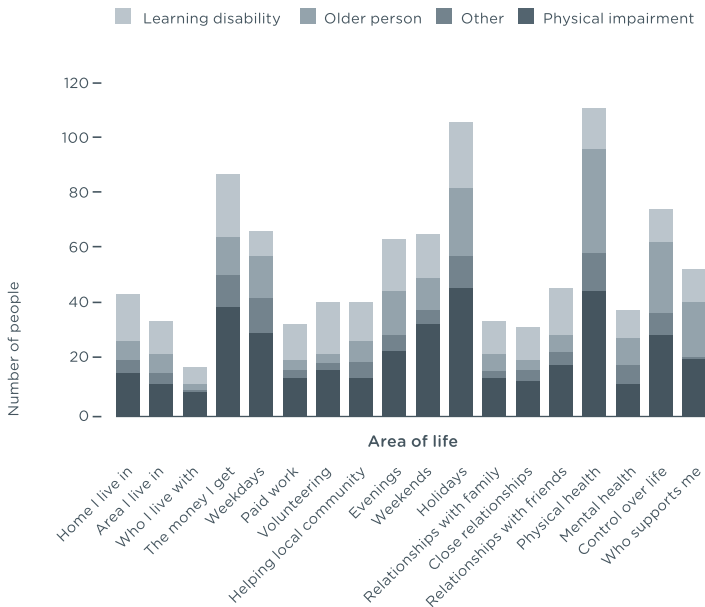
It is worth pointing out the differences across primary need group. The areas older people most commonly wanted to change were slightly different:

- physical health (50 per cent)
- opportunities for holidays (35 per cent)
- things to do during the week (33 per cent) — but interestingly not things to do during the weekend
- control over their lives (32 per cent)

Very few wanted to change their living arrangements (either the home they live in; the area they live, or who they live with). The areas working age people most commonly wanted to change were:

- opportunities for holidays (44 per cent)
- physical health (39 per cent)
- money I get (39 per cent)

Figure 1 What people want to change about their life



People with learning disabilities were also more likely than people with physical impairments and older people to want to change the home they lived in and their opportunities for paid work. They also wanted to be able to engage in volunteering. In contrast with older people, working age adults were far less happy with their living arrangements.

What help do people need to change?

To effect these changes, we asked people what help they would need. The most commonly cited areas where people need additional assistance were:

- having more information about the things that they can do (51 per cent)
- less bureaucracy (49 per cent)
- having someone to talk to for advice (47 per cent)

Given the exceptionally high response rate to these questions, a lot of people still feel that they do need support to change things in their lives. Older people and working

age adults responded to these questions in a similar way, although older people were much more likely to respond that they needed additional assistance of some kind compared with other groups.

Will personal budgets mean different services will be needed?

We asked people who were not already getting a direct payment or a personal budget a number of questions about how much they knew about these services, and how they would change their support if they had one.

What do people know about personal budgets?

Overall, the majority (115 people; 62 per cent) knew nothing at all, and 37 people (20 per cent) knew very little. Only 16 per cent knew something or a lot about them. For older people, the figures are more worrying: 92 per cent reported knowing nothing or very little. Working age adults were more familiar with personal budgets than older people, but still 79 per cent of people with physical disabilities and 73 per cent of people with learning disabilities knew nothing or very little about them.

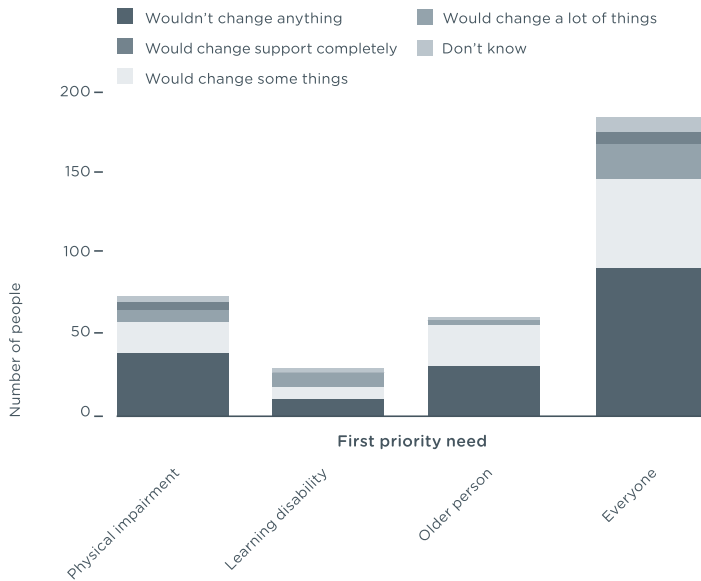
Would people make changes to their support under personal budgets?

We asked whether people would change anything if they had a personal budget and control over how to spend it. As Figure 2 shows, around half (91 people; 50 per cent) reported they wouldn't change anything, with just under half (83 people; 45 per cent) reporting they would change at least some things. A substantial minority would change a lot or everything.

In line with other research, older people were the least likely to change 'everything'. Half of the older respondents said they would not change anything at all if they were given a personal budget. However, it is also worth pointing out that when asked about 'what services they receive now' and 'what services they would buy with a personal budget' the answers were commonly quite different.

Around 45 per cent of older people would change 'some things', but no one responded they would change a lot or everything. This is a significant difference compared with other groups, as Figure 2 shows. People with physical impairments and people with learning disabilities were

Figure 2 Extent to which people would change the support they receive if they had a personal budget



more likely to change either a lot or everything, compared with older people (33 per cent and 17 per cent vs 5 per cent).

In order to understand in more detail how people would spend their money, we split this section into three parts, covering support services, leisure services and sources of support.

What support services would you want if you held a personal budget?

We asked what specific type of support people would want if they held a personal budget; 177 people responded to these questions across all groups:

- day centre services (31 per cent)
- education and training (19 per cent)
- short break services (18 per cent)
- residential care (6 per cent)

Older people's responses were quite different:

- day centre services (33 per cent)
- short breaks (16 per cent)
- residential care (5 per cent)
- education and training (4 per cent)
- Working age adults wanted:
- day centre services (29 per cent)
- education and training (27 per cent)
- short break services (20 per cent)
- residential care (7 per cent)

A slightly surprising finding was the popularity of day care services — two respondents wrote that there were not *enough* day care centres in their local area. It should be stressed that the very low incidence of residential care could be partly due to the fact that not many individuals surveyed currently use residential services (see above). Using day care centres is still a popular way to reconnect with other people, as one respondent told us:

I'd like the opportunity to socialise... a day care in a local purpose-built facility where I could meet other people

Male, 66

What leisure services would you want if you held a personal budget?

We asked what specific leisure services people would spend their personal budget on if they had one, and had the following overall response:

- holidays (40 per cent)
- 'other', including social groups, community activities (34 per cent)
- access to public transport/taxis (28 per cent)

For older people, the three most popular leisure services were:

- access to taxis and public services (23 per cent)
- ‘other’, including social groups, community activities (23 per cent)
- holidays (20 per cent)

A number of older respondents mentioned how they would like to get out more, for example:

... go out and meet people, for short breaks in the park
Male, 79

The responses by working adults were quite different — ‘holidays’ was a more important priority and public transport much less so:

- holidays (52 per cent)
- ‘other’, including social groups, community activities (44 per cent)
- public transport or taxis (33 per cent)

What sources of support would you want if you held a personal budget?

We asked what specific sources of support people would spend their personal budget on if they had one, and had the following overall response:

- personal assistants (44 per cent)
- people to help at home (37 per cent)
- family (24 per cent)
- friends (23 per cent)

For older people:

- people to help at home (57 per cent)
- personal assistants (45 per cent)

- family (27 per cent)
- friends (25 per cent)

It was common for older people to answer that various bits of assistance at home would help them to do a number of other things. One 83-year-old man said if he had a personal budget, he would spend money on ‘washing, dressing, toileting, shopping, cleaning, banking and paying bills’. A number of other respondents mentioned the use of personal help around the house to help with refurbishments, sitting respite and just ‘looking after the house’. This is quite different from working age adults, who were less likely to want help at home. Working age adults wanted the following sources of support:

- personal assistants (44 per cent)
- people to help at home (30 per cent)
- family (22 per cent)
- friends (21 per cent)

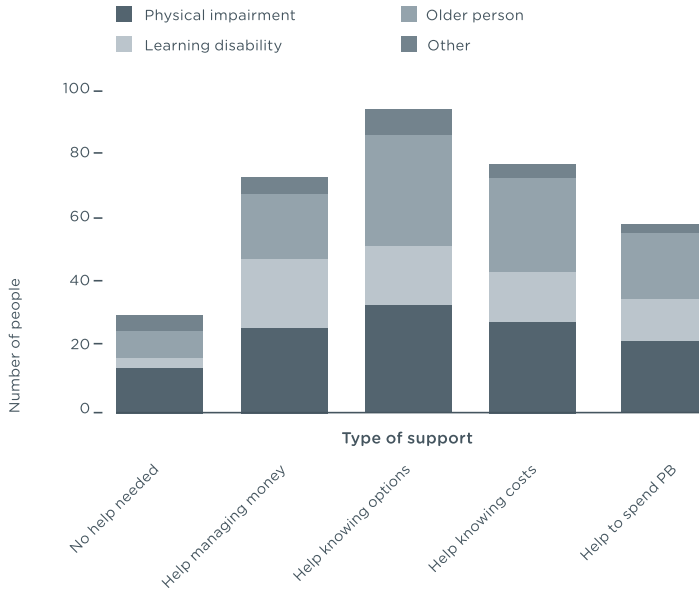
What help would you need if you held a personal budget?

Finally, we asked people what, if any, extra help they would need to manage a personal budget effectively (Figure 3). Personal budgets are a major concern for some people. Of the 163 people who responded, the most common forms of support would be help to know what to spend it on (93 people; 57 per cent), extra help managing it (72 people; 44 per cent), extra help knowing the cost of options (76 people; 47 per cent) and help to spend it appropriately (58 people; 36 per cent). Many people ticked multiple options. Older people most commonly responded that help was required.

People with direct payments or personal budgets now

We also asked a detailed set of questions designed for people using personal budgets, including questions on the form, how long they had held it for, how they spend them, and whether they had made any changes. However, only five people in the survey were holding a personal budget, and so we included responses from people holding direct payments. A total of 47 people answered these questions.

Figure 3 The sort of help people would need if they had a personal budget



Do people change their support as a result of having a direct payment?

We asked people who held a direct payment or personal budget whether they had changed their support as a result:

- changed some things (46 per cent)
- not changed anything (32 per cent)
- changed a lot of things (16 per cent)
- changed everything (5 per cent)

More specifically, we asked what types of support people spent their money on before and after receiving a direct payment or personal budget, and had the following response:

- the use of day care centres fell
- the use of residential and care home centres fell
- participation in education and training increased

- the use of leisure services increased
- the use of public transport remained the same
- the number of holidays increased
- the employment of personal assistants increased
- the use of family members and friends fell

Trends for working age adults

Working age adults are moving out of residential services and maintaining their own tenancies

There was a clear trend towards supported living and people maintaining their own tenancies. However, it is clear from the Ibsen report that there is still a place for traditional services, including residential services.

Working age adults want more personal assistants

All of the data suggests that there will be a large growth in the demand for personal assistants. This is related to the fact that as more people move out of residential tenancies into their own accommodation, they need more personal assistants to help them live independently.

Working age adults want to participate in leisure services

There was a high demand for 'leisure' services. The most common are health and fitness training, such as those provided by a gym; others include going out to eat, shopping, visiting museums, joining clubs and pursuing hobbies. People with a learning disability want to spend significantly more on leisure activities compared with other groups.

Working age adults want more support to help them access whole life activities

There was a sustained increase in the use of services which help people develop personal and professional skills, for example accessing employment, training programmes and debt management.

Some working age adults are innovative

A small but growing number of working age adults want to use small parts of their personal budgets on things entirely unrelated to social care services — for example a snooker cue, skip or football season ticket. There is some indication that the longer people have a personal budget, the more radical they will become in considering ways of spending their budget money.

Trends in older people's services

It is important to stress that there are significant differences between older people and working age adults.

Older people will change the services they use, but more slowly than other groups

Older people seem to be the least innovative spenders. They spend more on mainstream services than working age adults, and less on leisure services, education and training. It remains unclear why. It could simply be a lack of demand for these things, although older people have a lower level of budget — meaning that there is less scope to buy things beyond basic needs. However, half the people surveyed here did want to change the services they received, though not radically. As other research has found, it is often the little things that make a big difference for older people's services.²² As one respondent to our survey living in sheltered housing said, if he had more control over the money he would 'decorate the house, and make it nice to live in'.

However, it does also need to be borne in mind that the next decade will see a large increase in 'younger' older people using support services. It is quite likely that this group — the 'baby boomers' — will have very different aspirations and views about the sorts of services they would like to receive.

Older people want more personal support services

Older people are happy to remain in their homes and would simply like more support around the house in enabling them to stay. All of the data suggests that there will be a large growth in the demand for personal assistants. Older people on the brink of requiring residential services can often be much better (more cheaply) served by focusing on interventions to keep them in their home.

Older people want to spend more on leisure services and transport

The demand for leisure services was still evident for older people, even though it was less pronounced than in other groups. Similarly, older people expressed a very high demand for spending money on transport services, which is often directly related to accessing leisure services.

Older people want more weekday and daycare centres

A surprising finding among older people was a very strong demand for day care centres. At the same time, the single area that most older people wanted to change was ‘what they did during the weekday’ — suggesting there is huge scope for developing new types of services to fit this demand.

A large number of older people would not change anything

Because the publicly available evaluations only look at current holders of personal budgets — and not prospective ones — there is a danger that too much emphasis is placed on the changes that people will make. Our survey shows around half of older people would not change anything about the services they receive if they moved to a personal budget:

I want to stay as I am, with social services!!

Male, 60

Older people want new ways to help them manage a personal budget

Older people were by far the least likely to know anything about personal budgets and the most likely to need help managing and designing them. One of the Ibsen pilot sites noted that as many as a quarter of older people received their personal budgets through a managed account, held by a provider. This allows people to continue to direct their own support, but without having the burden of actually managing it.

Conclusions

Our research has provided a valuable insight into what supports people are using, how they match what people want and don't want, and the impact the introduction of

personal budgets might have on that. There are some very important findings, which providers, local authorities and PCTs should act on as they work to transform health and social care.

In some respects, what people get now does not always meet their aspirations. Substantial numbers of people want to change several aspects of their lives. It is important to recognise that there were differences across groups. For example, people with physical impairments rated themselves as happier than other groups in the choice and control they had over their lives. They were also more likely to want to change their physical health, the money they got, what they could do at the weekends and their relationships with friends. People with learning disabilities rated themselves as happier with their physical health than other groups. They viewed getting enough money and helping others as particularly important and were more likely to want to change the money they got, the home they lived in, opportunities for volunteering, and their relationships with friends. Older people rated themselves as less happy than other groups in terms of keeping healthy and well, and having choice and control over their lives.

In these respects, personal budgets offer great hope. However, there is a worrying lack of knowledge about what personal budgets are, and people will need considerable support to help them manage and spend them. This is particularly worrying because other research has shown that the support services infrastructure does not currently have the capacity to deal with the number of people who use direct payments currently, let alone the prospective number of personal budget holders.²³

When people are given the freedom to choose their own services through a personal budget, changes in the demand for services are likely. Almost half of respondents said that if they had a personal budget they would change some or a lot of the support they use at present.

There are likely to be shortages of the services people will want more of – social support, personal assistance, and education and leisure services. Many people will want more personal assistants, for example, but a UK study found that implementation of the direct payments system was hindered by the limited supply of people to work as personal assistants, which was linked to low rates of pay and high vacancy rates.²⁴

At the same time, though, it is important to recognise that a large number of people – especially older people – will want to keep things the same as they are. In other

words, this is not the end of statutory services, and nor should it be, because people's medical and physical support needs still need to be met. As our research shows, people want support services that directly meet those needs. But they will often want to explore new ways to provide them, combining support and social services. One respondent summed up it well:

[I want] the appropriate level of support to enable me to continue to work and contribute to... the economy in a generic and localised sense. Also to continue to shape and plan for my future as best as I can allowing for impairment along the way.

Female, 42, with a physical disability

3 recommendations and ways forward

At the moment, personal budgets are clearly working well for people who are using them — although that is still a relatively small number. As personal budgets are rolled out across all services there are many other groups for whom the change may be more difficult.

Families and individuals who use services will now be more in control than ever before about the nature and shape of what they get. This brings opportunity and responsibility. People and their families can push for change and take an active role in developing their own services. They must ensure that any care plan they agree to is designed to help them make sustainable and positive improvements in their life towards the goal of full and active citizenship, and give feedback where things can be improved. This means speaking to providers and local authorities, negotiating and working with them towards this joint goal.

This has serious implications for local authorities and service providers. Local authorities need to consider what their role will be in this new environment, and how they will shape, stimulate or guarantee the social care market, meeting their statutory duty of care while helping people realise choice and control. At the same time there are other demands; for example, as a result of the ageing population the demand for residential services is expected to rise. It is equally important that in the next decade the category 'older people' will begin to include the baby boomers: large numbers of people whose views about the services they would like to receive in older age will probably be very different from those of the current generation of older people. Providers have another set of challenges about meeting, and sometimes creating, the changing demand, while maintaining a functioning and sustainable business model. There are a number of things that can be done now by both service providers and local authorities.

Ways forward for service providers

Personalise existing services

Providers should ensure their offer is personalised. This means working with the individual and their family to create service options that respond to their needs and, where things aren't working, providing alternatives to what is currently on offer. In many cases this could mean creating additional add-ons to existing services, combining support needs with social support — this is particularly the case in residential and day care services.

There is no one way to do this, just as there is no one type of person. But all providers must make sure that people who use services and their families play a central role in designing a plan that helps them meet their own goals in life in a creative way, that they know what money is being spent on them, and that they can use that money flexibly. Possibilities range from creating completely new types of service, such as helping someone move into their own tenancy, to being more flexible about the hours that personal assistants work. In other cases it could mean breaking down services that were formerly part of a service package, so people are able to buy the whole of a service, or parts of it (for example management support to a trust circle, or training for personal assistants).

Personalising a service means personalising the contract. People will want to know what they get, and what they are paying for. Providers must make clear what their offer is, how much it costs, and be ready and able to demonstrate this. That entails breaking down the costs of services for each individual (not quoting a generic, average placement cost) and setting out what exactly is being delivered. Every organisation will have its own way to achieve this, and useful guidelines are already available.²⁵

New opportunities in the market

There are a number of secondary services that service providers with established infrastructure and systems in place can offer. These include:

- holding budgets for people; a large number of people don't necessarily want to manage their budgets themselves, and would rather rely on trusted providers to do so
- acting as brokers to design person-centred plans for people, even if not delivering the service itself

- recruiting and managing the administrative aspect of employing personal assistants on behalf of individuals; the marginal administrative costs of expanding would be low, and the provider could provide a covering option for holidays and sickness

New opportunities need new forms of marketing. Providers need to be directly marketing to people using their services and/or families and friends. This means accessing those people (local authorities might assist with this) and then selling the service in a way that makes sense to them, and makes them feel confident about buying those services when they have alternative options.

Get the internal culture right

Physical characteristics such as size and location are less important than the leadership and commitment of individuals throughout the organisation.²⁶ Any health or social care provider organisations should attempt to push people forward, widen their horizons and ambitions, and make positive presumptions about people's capacity.

People who use services are increasingly seen not simply as passive recipients of social care services, but expert parties able to inform and influence the nature and range of care provision.²⁷ They should be directly involved in the design of the services. This has benefits in terms of changing organisational culture as well as making services more tailored to individual preferences.²⁸ Writing a truly person-centred care plan with an individual is co-production at its best — the provider working closely with the individual and their family or friends to understand what they are trying to achieve in their lives, and exploring ways this can be done together. This has another advantage, too, because it helps providers discover what new types of service people might want to purchase. Understanding the possible demand for specific kinds of service that do not yet exist, and how these services should be developed, is something that can only be done with people who will use them.

Look for new partnerships

Providers must take the initiative and engage with local authority and PCT commissioners about moving this agenda forward. All local authorities and PCTs are or will be taking some action and what happens from area to area will vary.

Each organisation must find out what the local strategies and policies are.

Partnerships go beyond just the local authority. Some are already developing educationally focused services involving local colleges, and others are establishing links with telecare and meals-on-wheels organisations, with a view to sub-contracting part of potential personalised packages to these partner organisations. This latter partnership should especially be developed for leisure services and could be crucial for residential services.

Ways forward for local authorities and health agencies **Help people get the most from personal budgets**

Local authorities still have a statutory obligation to meet people's needs. Combined with the fact that the market will take a while to mature, there are likely to be short-term shortages in the supply of certain services. Local authorities must carefully manage people's expectations about what services exist for people to choose from, and that for some people change will necessarily be slower as the market responds.

Given the general level of apprehension and lack of awareness about personal budgets, it is vital that local authorities ensure that people have access to the support and expertise they need to manage their own support and exercise true choice. Various research studies have demonstrated that this remains in short supply – and putting systems in place, including drawing on the expertise of private and third sector providers, is essential.²⁹

If personalisation is to work for everyone, PCTs and local authorities need to cooperate to make sure people with very complex needs who are in receipt of both health and social care money – older people with Alzheimer's for example – are not excluded. This is true even if this is not done through the mechanism of a personal budget. This requires local PCTs and local authorities to work together to commission services around an individual.

Understand what people want and how the market looks

Local authorities will want to know how much commissioning they should continue to do, for whom, and of what type in order to meet the statutory care requirements by guaranteeing a market, while giving people true choice and control. Local authorities and PCTs must recognise that people who use services are not all the same and so the only way to

begin to answer these questions is by generating information about what people are spending their money on, and what they would like to spend it on in the future. That way, they can know where there are likely gaps and difficulties, and develop a commissioning strategy to meet them.

There will be shortages in supply in some areas, and at least in the short term local authorities will have to take measures to stimulate growth. Our research suggests that there will be a large increase in the demand for personal assistants, day care services, education and leisure services. As noted above, direct payments reform was hindered by shortages in personal assistants. Similarly, other research has shown that families of disabled children often feel there are few options for them out of school time, and education for older people is extremely limited.³⁰

Therefore, local authorities will need to stimulate and encourage the market to respond where it is under-developed in those areas. Although this is by nature a local endeavour (in some areas there might be shortages in entirely different areas) there are a number of ways this can be done: pump-prime loans to organisations that supply personal assistants and help around the home; develop new models of care such as extra-care homes and re-ablement services; work with large providers to explore where they can extend their services; and work with other public agencies to establish if they can contribute to the local market in education and leisure activities.

New public—private partnerships

The traditional split of interests between providers and commissioners must end. Information about market trends, gaps and difficulties must be shared. Local authorities do not want a collapse in the health and social care market, as perfectly competitive providers go out of business because of short-term changes to block contracting. To avoid this, local authorities need to work with providers large and small, who are a great source of knowledge and information.

This means sharing information about the local authority's strategy and direction, spending decisions, commissioning vision and emerging market intelligence — including being honest about what is still not known. For example, providers could play an important role in informing and advising people about personal budgets, given the very low levels of knowledge that our survey revealed among participants. For groups for whom personalising services is difficult, local authorities must work closely with providers

and work out options together, even working out a joint new plan for someone when things aren't working.

A new operating model

Local authorities need to establish a new operating system. At the moment there is a strong current – especially when they are at crisis point – where people enter the social or health care system and get moved along quickly, irrevocably, into institutional care. There will be a large group of people who want real change in what they use, and to chart their own course. The way local authorities interact with those people must change, in particular by being accessible online, giving choices and options, and offering opportunity for co-production and user involvement.

At the same time, there will be many people who do not want to take on personal budgets, or at least want varying levels of control and responsibility, which could even change year on year. The lack of awareness and concern about personal budgets – and the resulting levels of assistance people will need – is considerable. Therefore local authorities need to have options in place to help people learn about what personal budgets are, and move them forwards. Those who just want to stay as they are for the moment must not become a forgotten residual group, but continually be given the option to take on a personal budget and given support to make sure they are getting the best for themselves and their families.

annex 1: methodology

We looked at a broad sample of prospective and current personal budget holders across four local authorities – Cheshire East County Council, Hull City Council, Lancashire County Council and Nottinghamshire County Council – with a range of needs, who were a mixture of self-funders and publicly funded. We sent questionnaires to over 300 people, and received 263 completed returns – which was coordinated by leads in each local authority that took part. The questionnaire was designed to explore how the implementation of personal budgets would affect the social care market. The survey was designed by a steering group that was convened for this project. An easy-read and a picture questionnaire were produced. We submitted the research for approval to the research group at the Association of Directors of Adult Social Services; it was granted.

Of the 263 people who returned the questionnaires, 69 were living in Cheshire, 54 were living in Hull, 55 were living in the East Midlands, and 85 were living in Lancashire.

Data from the questionnaires were coded into Excel then transported into the statistical software package SPSS 15.0 for further analysis.

The most common groups surveyed were people with physical impairments (112 people; 43 per cent), older people (72 people; 27 per cent) and people with learning disabilities (53 people; 20 per cent). When asked about their levels of need, the most common response was that people didn't know (97 people; 40 per cent), and relatively few people overall (11 people; 5 per cent) recorded their needs as low. Those who did know most commonly reported that their needs were critical or substantial. There were slightly more women than men, and the vast majority of people were white. Most people either answered the questions themselves (88 people; 36 per cent), or with help from someone else (130 people; 54 per cent); in the remaining cases someone else answered the questions on behalf of the participant. There were differences in these figures across groups.

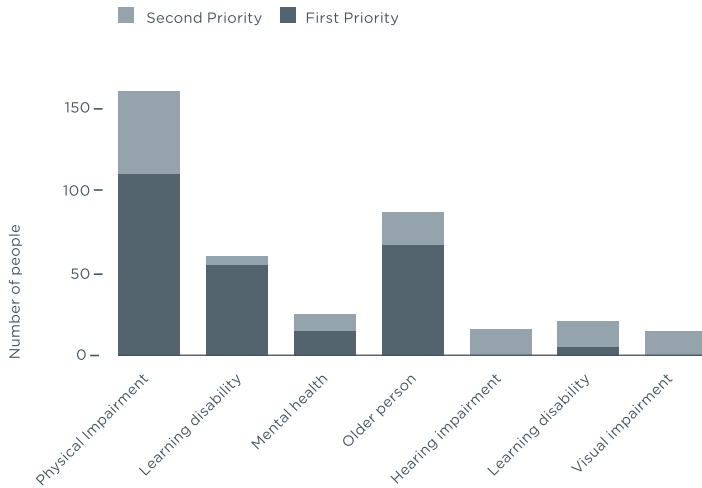
In the questionnaire, we asked people who paid for the support they used; for the 256 people who replied, support was paid for by:

- the local authority (107 people; 42 per cent)
- the local authority and the person sharing the cost (51 people; 20 per cent)
- the person using direct payments (47 people; 18 per cent)
- the person without other help (44 people; 17 per cent)
- the person using a personal budget (seven people; 3 per cent)

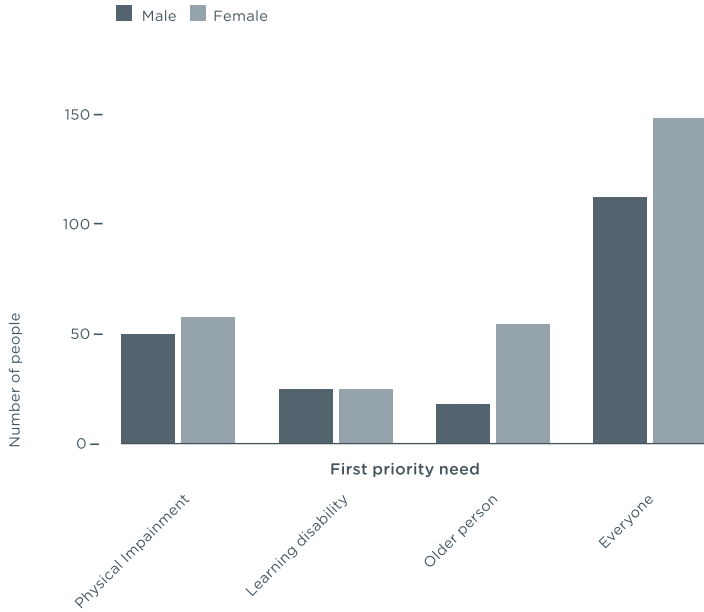
It is important to point out that our research methodology, along with other research in this area, does have a selection bias. For example, our sample did not include a large enough number of people in residential services. There were also some difficulties in ensuring that the questions were clear enough about technical matters (for example, 'What is the level of your need?'). There are still areas to be worked on and we will address them in future versions of this research, which will be part of an ongoing project to generate market intelligence.

annex 2: questions and responses

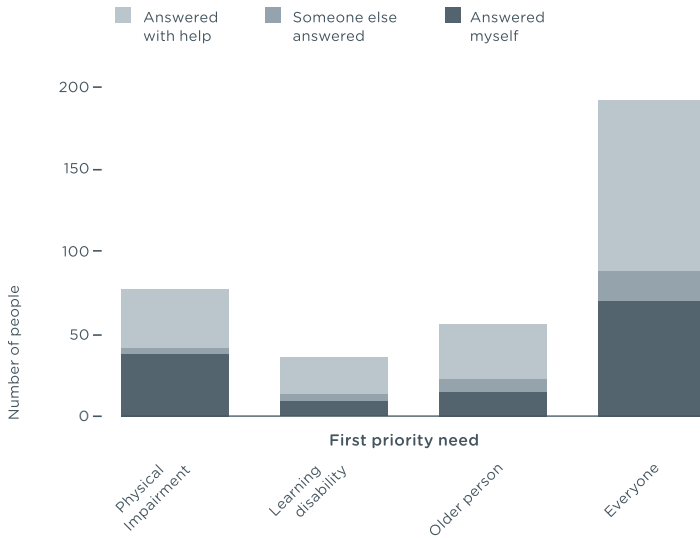
**What are the major needs that you need help with?
(263 respondents)**



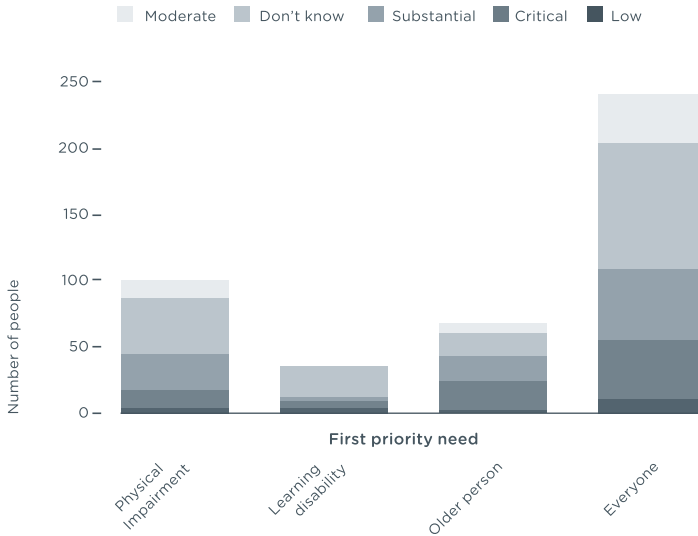
Gender (262 respondents)



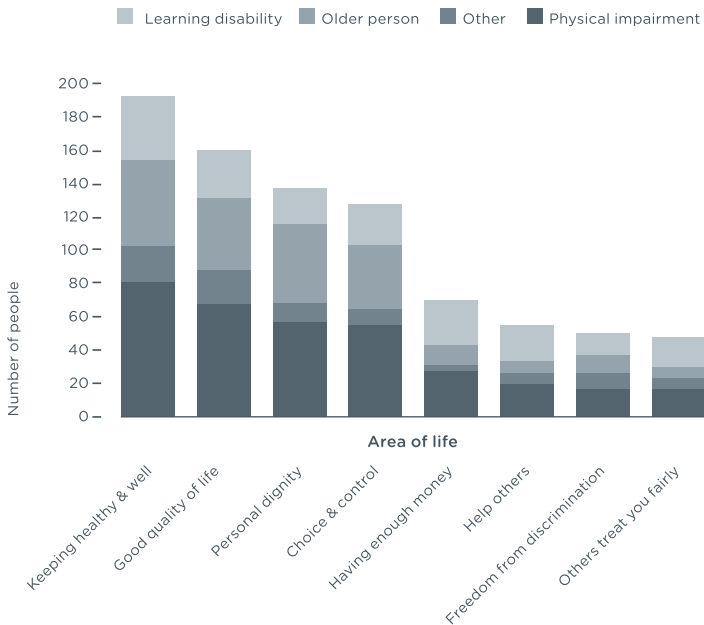
How did you answer the questions? (242 respondents)



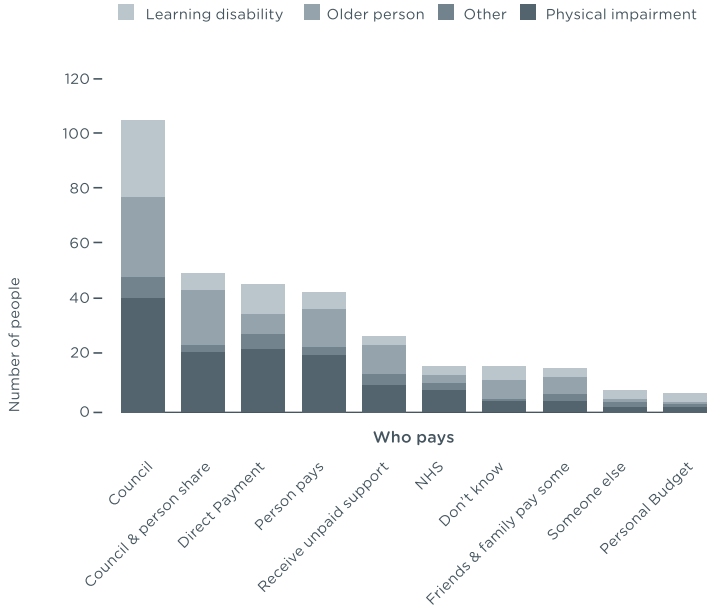
Your local council might have given you a ‘needs assessment’ or a ‘community care assessment’. If they did, what level of eligibility did your local council say you have? (147 respondents)



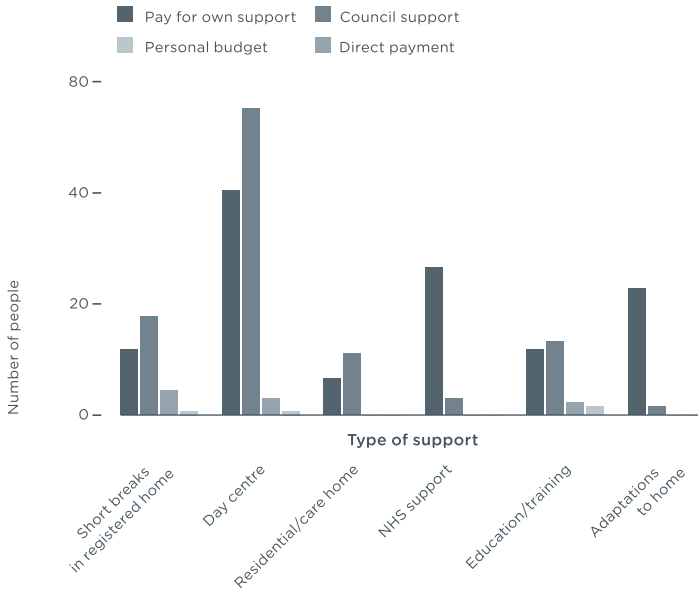
What is important for you to achieve in your life? (261 people responded)



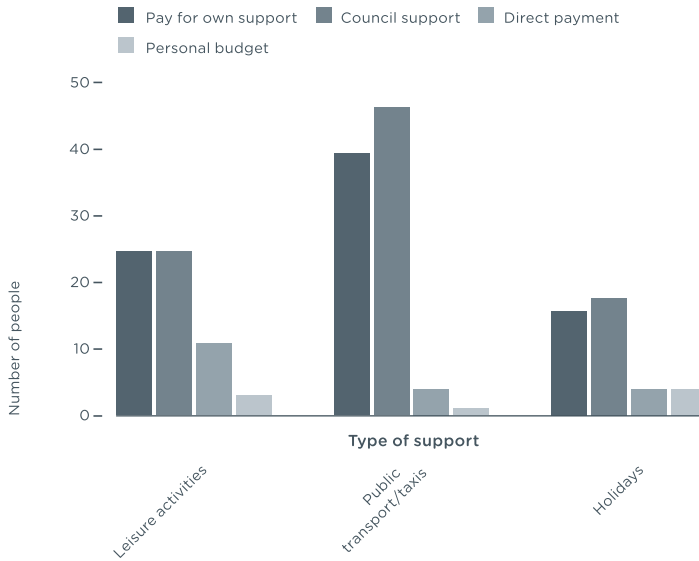
If you receive any help to deal with these needs, how do you get it? (241 respondents)



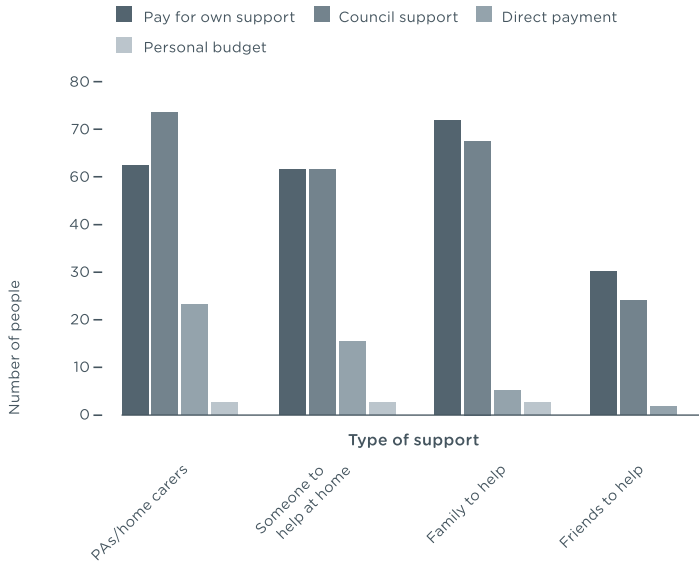
What services and assistance do you use at the moment? (200 people responded)



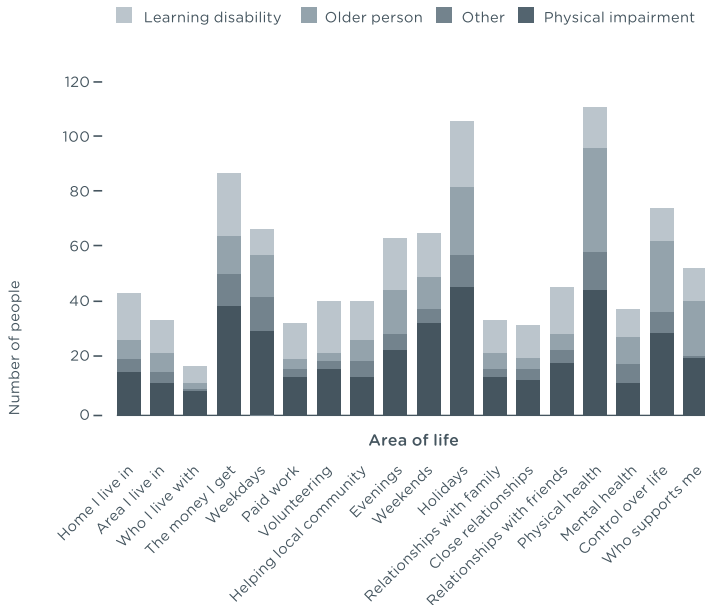
What service and assistance do you use at the moment? (200 people responded)



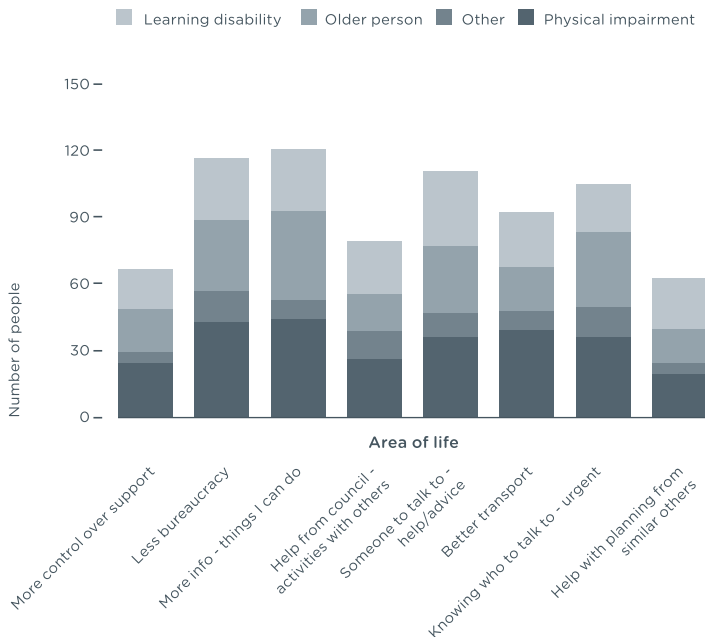
What services and assistance do you use at the moment? (200 people responded)



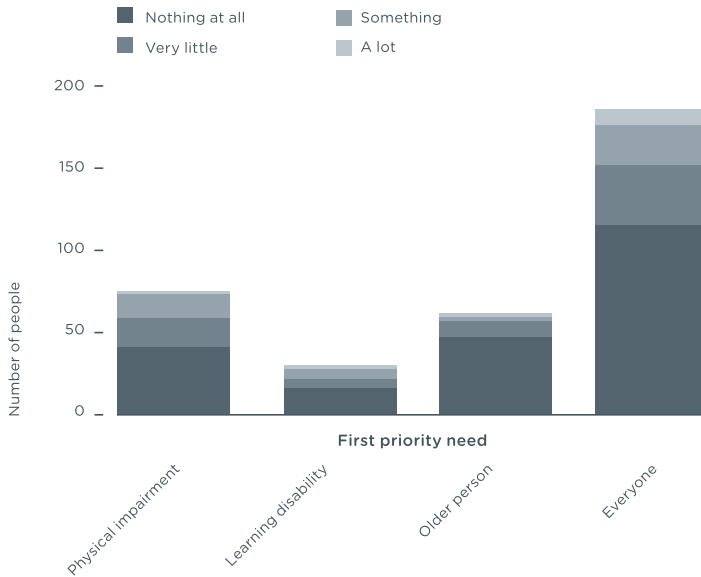
Please look at this list of areas of your life. Can you tick each area of your life that you really want to change in the next year? (251 people responded)



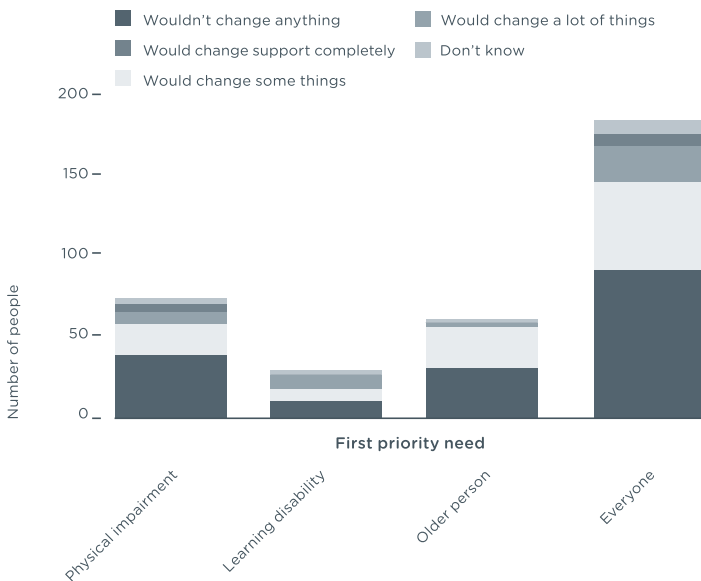
What specific things would allow you to make these changes? (241 people responded)



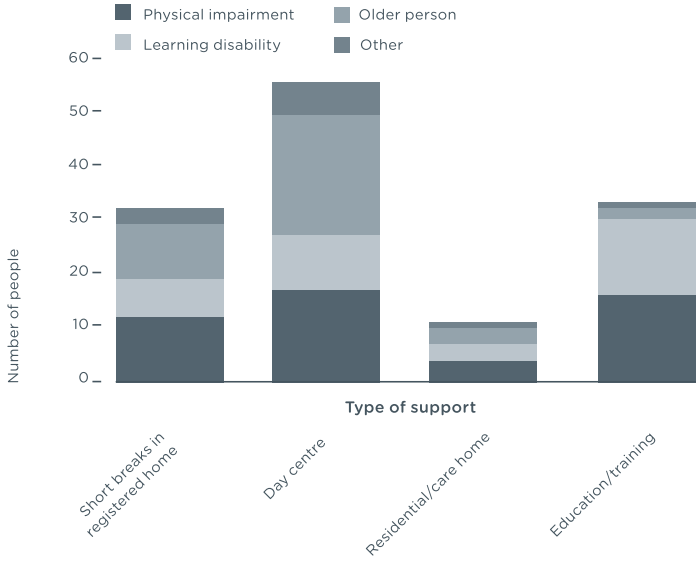
How much you feel you know about personal budgets? (186 respondents)



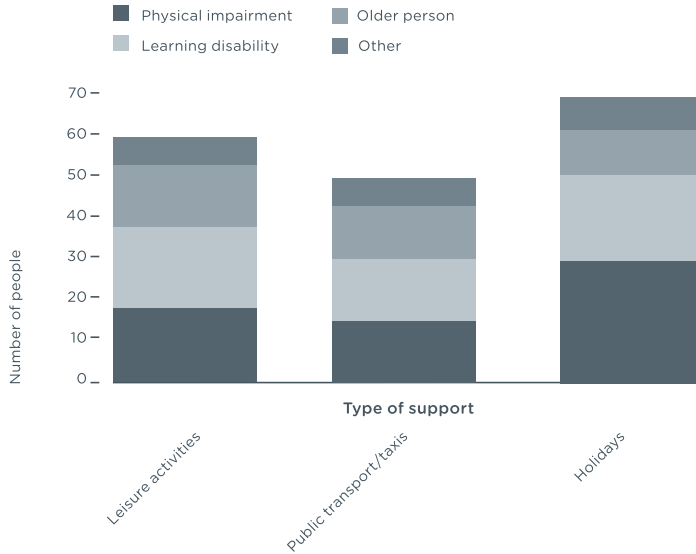
If you had a personal budget, and could spend the money on anything that would help you in life, do you think you would change the support you have? (174 respondents)



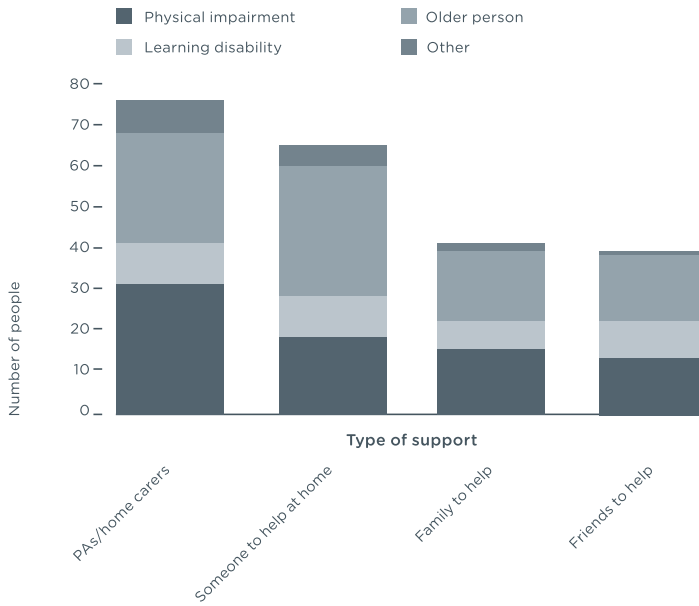
If you were given a personal budget, what would you want to spend it on? (177 people responded)



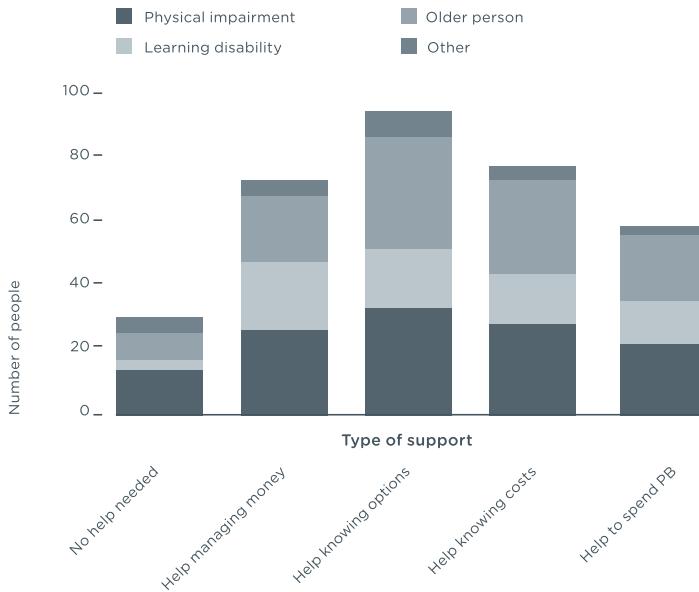
If you were given a personal budget, what would you want to spend it on? (177 people responded)



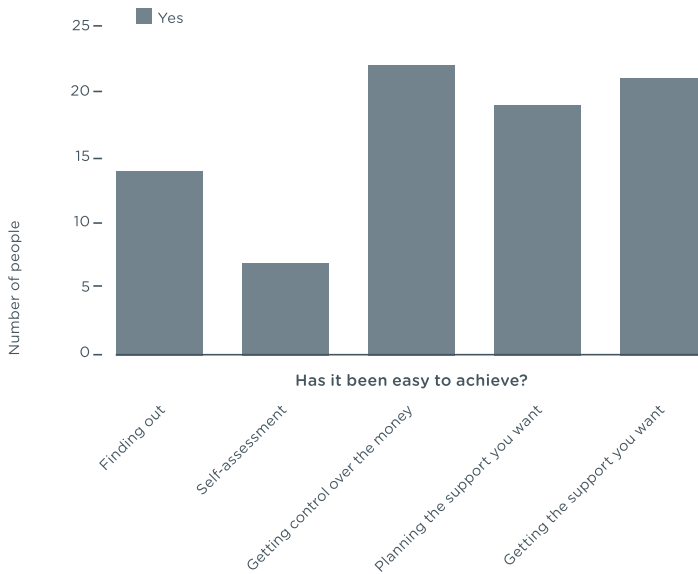
If you were given a personal budget, what would you want to spend it on? (177 people responded)



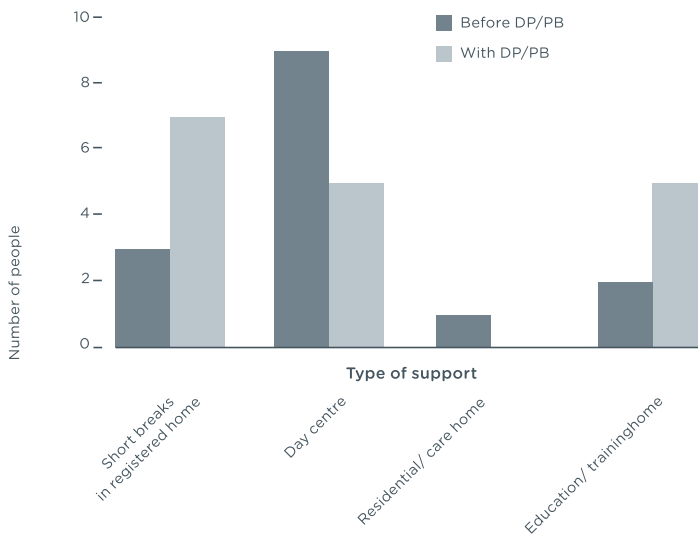
What help might you need if you were given a personal budget and asked to organise your own care? (163 people responded)



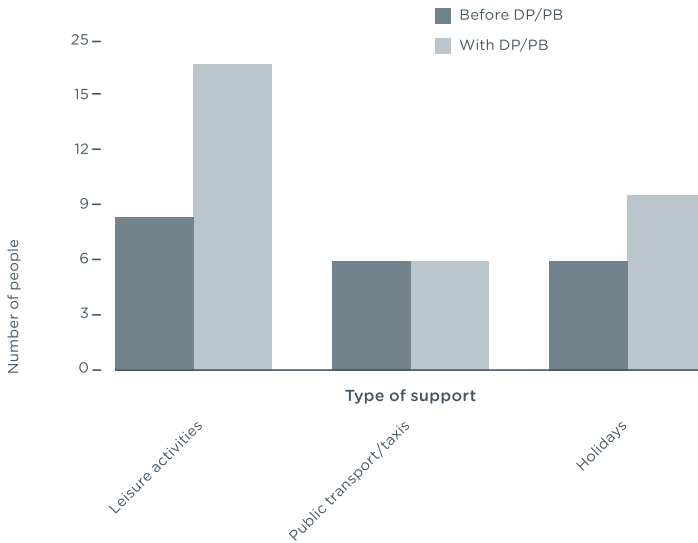
Has your local council made it easy for you to... (36 people responded)



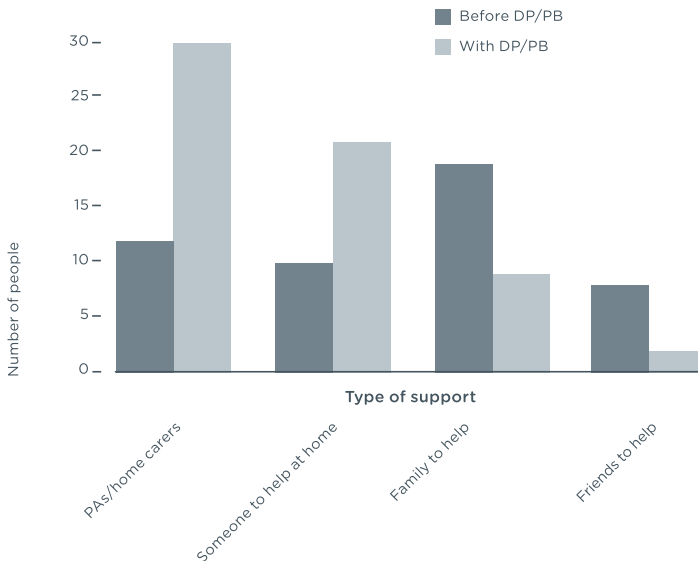
What support did you use before you personal budget or direct payment? / since your personal budget or direct payment started, have you changed the things you use? (37 people responded)



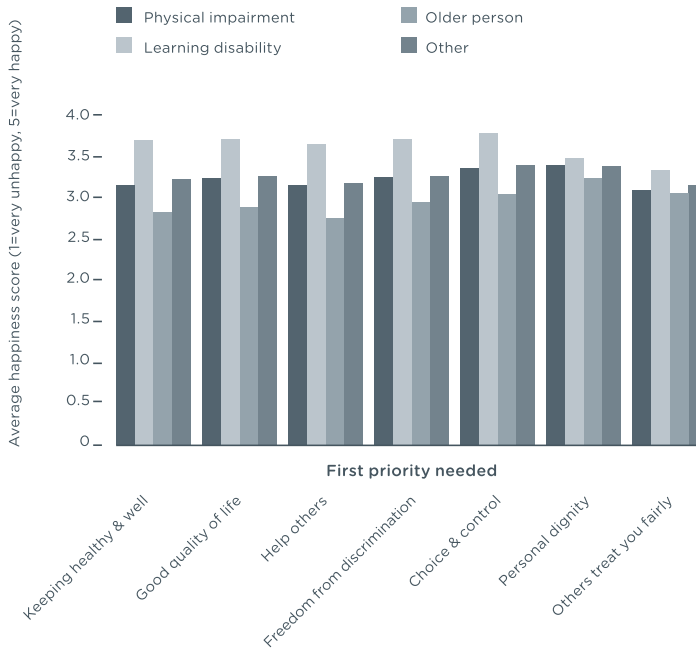
What support did you use before you personal budget or direct payment? / since your personal budget or direct payment started, have you changed the things you use? (37 people responded)



What support did you use before you personal budget or direct payment? / since your personal budget or direct payment started, have you changed the things you use? (37 people responded)



How happy are you with each of these aspects of your life at the moment (248 people responded)



notes

- 1 Department of Health, *Putting People First* and Department of Health, *Transforming Adult Social Care II*.
- 2 Department of Health, *High Quality Health Care for All*.
- 3 A full list of the pilot sites is available at www.dh.gov.uk/en/Healthcare/Highqualitycareforall/DH_090018.
- 4 Henwood and Hudson, *Keeping it Personal*.
- 5 Interview with commissioning lead in one of the local authorities, conducted for this research.
- 6 Department of Health, *Transforming Adult Social Care I*.
- 7 58 per cent of the group had learning disabilities and had spent between six months and one year in receipt of a personal budget.
- 8 See <http://php.york.ac.uk/inst/spru/pubs/1119/>. Individual budgets are budgets which cover non-social care money. Personal budgets only cover social care funds. The latter is what the Department of Health is committed to implementing. The breakdown of service users analysed in the Ibsen report is: 94 people with a physical disability, 72 people with a learning disability, 35 with a mental health condition, and 81 older people.
- 9 Pitts, Soave and Waters, *Doing It Your Way*.
- 10 Herefordshire County Council, *It's Your Life Take Control*. They reviewed the spending decisions of 66 people with a mixture of needs, with an average annual budget of £32,441 (pre-personal budget).
- 11 Cambridgeshire County Council, *Plotting Your Own Course*. This reviewed 56 people with learning disabilities who received personal budgets between 2005 and 2008.

- 12 Northamptonshire County Council, *Self Directed Support Plan Review*. This looked at people with an average budget £22,070 per annum per person.
- 13 In Control, *My Budget My Choice*.
- 14 Pitts, Soave and Waters, *Doing It Your Way*.
- 15 The questionnaire was designed to explore how the implementation of personal budgets would affect the social care market. The survey was designed by a steering group that was convened for this project, and an easy-read and a picture questionnaire were produced. Of the 263 returns, 210 gave us information on which area of the country they were living in. Of these, 69 were living in Cheshire, 54 were living in Hull, 55 were living in the East Midlands, and 85 were living in Lancashire. Data from the questionnaires were coded into Excel then transported into the statistical software package SPSS 15.0 for further analysis.
- 16 People in the physical disability were most likely to answer questions themselves (61 per cent) compared with 25 per cent of people with learning disabilities and 32 per cent of older people who answered the questions themselves.
- 17 Chi-square=12.08, df=2, p=0.002.
- 18 Chi-square=14.55, df=2, p=0.001.
- 19 Chi-square=7.89, df=2, p=0.019.
- 20 Chi-square=24.60, df=2, p<0.001.
- 21 Chi-square=9.73, df=2, p=0.008.
- 22 Department of Health, *Learning the Lessons of Personal Budgets for Older People*.
- 23 Davey et al, *Schemes Providing Support to People Using Direct Payments*.
- 24 'Staff shortages and immigration in the social care sector' and Davey et al, *Direct Payments*.
- 25 Many organisations split the work into three types: Direct support costs include the following: average hourly rate of support; national insurance, pensions and other staff

benefits; direct support expenses; and percentage to cover annual leave, sickness, bank holidays and staff development. Company costs include expenditure on: offices and office equipment; administration and IT teams; payroll section; accounting and auditing; bank charges; legal charges; human resources; recruitment and selection; insurance; the Commission for Social Care Inspection; Criminal Records Bureau checks; and contingency insurance. Service coordination and development include the following: senior management team, staff development team, development officers, team leaders and consultants.

- 26 Harvard, 'Turning on a Sixpence'.
- 27 Needham and Carr, *Co-production*.
- 28 Bradwell, *Making the Most of Collaboration*.
- 29 Davey, *Schemes Providing Support to People Using Direct Payments*.
- 30 Petrie et al, *On Holiday!* and Shelley, *Everybody Here?*

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Personal budgets in health and social care are giving disabled and older people unprecedented control over the services they use. Within the next five years, 1.5 million people could be using personal budgets to commission and manage their own support, drastically changing health and social care provision. This means great uncertainty for both local authorities and service providers, which will need to respond to unfamiliar demands.

This pamphlet looks at how personal budgets will impact the social and health care market, what prospective budget holders know and think about personal budgets, how they would spend it and what difficulties they envisage. It sets out the likely challenges facing local authorities and service providers in delivering the personalisation agenda and contains recommendations about how to make the transition successfully.

Jamie Bartlett is a senior researcher at Demos.

