

# Users of Social Care Personal Budgets

Ipsos MORI report for the National Audit Office  
study on the Department of Health's regulatory  
oversight of care markets

29 July 2011

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# **1. Summary of Findings**

# 1. Summary of Findings

**1.1** This report presents the findings from a research study commissioned by the National Audit Office (NAO) which aimed to examine the experiences of users of personal budgets in Adult Social Care. This research was designed to feed into a wider study on the Department of Health oversight of care markets currently being undertaken by the NAO.

**1.2** The research was conducted using a qualitative methodology. It included 48 face-to-face depth interviews with users of personal budgets and/or their carer, and a further 6 telephone depth interviews with the professional lead on personal budgets in each of the local authorities involved.

## Choice and Personal Budgets

**1.3** Not all budget holders interviewed were offered the choice between a direct payment, a managed account, or a combination of the two. When a choice was offered, managed budgets were chosen when the benefit of a direct payment was outweighed by the **added responsibility** and **work** involved. Direct payments were chosen by people who wanted to have more **choice** and **control** over the care they received, and wanted to benefit from the added **flexibility** a direct payment offered.

**1.4** Personal budgets are designed to encourage a greater choice for service users, but on the whole, the most frequently used services were day centres, and visits from professional carers, especially among people receiving managed budgets. Budget holders who received direct payments made more creative use of their budgets, for example purchasing personal training sessions. Many recipients of direct payments employed a personal assistant, which no participants in receipt of a managed budget did. **Effective support planning** played a key role in enabling budget holders to use their budget in a creative, tailored and personalised way, which seemed to lead to better outcomes. Some recipients of direct payments were not sure about what they could and could not use their budget for, which made them concerned that they could inadvertently misuse their budget.

## Choosing, managing and switching providers

**1.5** Managed budget holders were generally unaware that they could choose providers, and were not offered any choice of providers. On balance, it appeared that only direct payments offered a **genuine choice** to budget holders.

**1.6** Little evidence was found of a real shortage of providers that could limit the choice available, though in rural areas the choice was often limited, and choice for managed budget holders was sometimes restricted to approved suppliers. While there seemed to be a well developed supply of **care agencies**, both the professional leads and budget holders highlighted shortfalls in the availability of less common types of services or providers. Some participants only had one applicant when recruiting a personal assistant.

**1.7** Many budget holders relied on word of mouth or on their social workers as their main source of information to help them choose between different suppliers. Participants wanted to see lists of potential providers with feedback from other users to help them choose. Online tools are being developed by local authorities to address this need, with lists of providers including quality accreditations and ways for users to leave feedback.

**1.8** Budget holders found the management of their budget relatively straightforward, though many were getting help from relatives to do so (e.g. writing cheques, checking invoices). Support was available from local authorities for the more difficult or technical aspects of this, such as working out tax and national insurance for people employing personal assistants using direct payments. Aspects that proved troublesome included ensuring a good **quality of service**, and **managing personal assistants**.

**1.9 Dissatisfaction with the services** received was most frequently cited as a reason for switching providers. Switching often appeared to be easier for budget holders using a care agency rather than a personal assistant. Furthermore, some budget holders were reluctant to switch, often saying that they were willing to put up with inconveniences as they were uncertain whether they would be able to get better care from another provider – this was particularly the case for providers of personal care services.

**1.10 Support to manage and switch providers** was crucial to ensure all users were able to exercise choice and get the most out of their personal budget, but it was not always available, or not always of the right quality. While some budget holders felt comfortable managing their budget without much support or were very positive about the support available to them, quality and availability of support were an issue for some budget holders who used their direct payment to employ their own staff, and wanted support with employment law, their responsibilities as employers and training in how to effectively manage personal assistants. Social workers and third party organisations were the most common sources of support, after families and friends.

## Managing Risks

**1.11** The most common risks mentioned by budget holders and carers were **budget misuse**, and the risks associated with **budget holders becoming employers**. Awareness of the risks and responsibilities associated with becoming an employer were mixed – while people who were hiring personal assistants were all aware of the need to have a contract in place, sort out taxes and national insurance, many did not fully realise what they were getting into until things went wrong and they faced legal action. In addition to these risks, professional leads were also concerned with the training of personal assistants. They mentioned some systems and tools that their local authority had put in place to manage and mitigate these risks. Overall, the risks mentioned were similar to those identified in other studies on personal or individual budgets.

**1.12** Budget holders' experiences of monitoring and review seemed to be focused primarily on **financial audit**, which mostly involved collecting receipts and invoices. However, their experiences of this, in terms of ease of understanding the process and how often it would occur, varied between authorities.

**1.13** As budget holders move away from traditional services to use a wider range of suppliers, and in particular venture further into mainstream services, the screening and accreditation of suppliers become more difficult for local authorities. Their response to this seems to be focused around **information provision** and collating **user feedback**, to help budget holders make informed decisions.

## Impact of Personal Budgets

**1.14** Participants who had experienced traditional forms of service provision before moving on to a personal budget mentioned the positive impact of this change. Key ones included: **more personalised support, increased choice** (of activities, or of suppliers), **increased control** (over the care and support provided, when, and by whom), **increased satisfaction with care and support**, and **increased amount of support**. These types of impact were similar to those mentioned by professional leads in local authorities, and in line with the impact identified in the IBSEN evaluation and the POET study.

**1.15** There were few examples of negative impact. They related to the **poor quality of care received**, and **the stress, upset and confusion** caused by inadvertent misuse of budget and problems with personal assistants.

**1.16** The impact for relatives and carers of personal budget holders were also mostly positive, including getting a **break from their caring activities, peace of mind and reassurance**. However, personal budgets and direct payments in particular also placed an **increased burden** on carers and relatives, especially in situations when the budget holder could not manage the budget themselves.

## **2. Background and Objectives**

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### Personalisation and adult social care

**2.1** The drive to increase personalisation of adult social services has taken on particular importance since the publication of 'Putting People First, a shared vision and commitment to the transformation of adult social care'<sup>1</sup> (Department of Health, 2007). Putting People First established a framework for both central and local government, along with other partners in the social care sector, to work together in transforming the provision of Adult Social Care. It recognised the need for service users to shape the social care services they receive. Personal budgets were seen as an instrumental element in achieving this:

**Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders. The state and statutory agencies will have a different not lesser role – more active and enabling, less controlling.**

Putting People First

**2.2** A personal budget is a pot of money allocated to an individual by their local authority to cover their social care needs; aiming to give more choice and control over how their social care needs are met. People who receive a personal budget can opt to receive a direct payment, leave it to their council to commission and arrange services on their behalf (but still retaining choice over how their care needs are met and by whom), or have a combination of the two. To get a personal budget, people need to go through a number of steps which are: assessment of needs and eligibility, indication of resources available, support planning, deployment of resources, commissioning of services or equipment, monitoring and review.

**2.3** It is estimated that 15% to 18% of users of social care currently receive a personal budget. However, there are wide geographical variations: for the financial year 2009-2010, take-up ranged from 3% in Somerset to 59% in Manchester<sup>2</sup>. In line with Putting People First, the current government supports the roll-out of personal budgets by local authorities, and set a target whereby 30% of users of adult social care are to have been in receipt of a personal budget by April 2011, with this target rising to 100% of users by 2013.

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<sup>1</sup>[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_081119.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf)

<sup>2</sup><http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/social-care-and-mental-health-indicators-from-the-national-indicator-set--provisional-further-analysis-england-2009-10>

**2.4** The roll out of personal budgets will only prove to be worthwhile if effectively implemented. In ‘think local, act personal: a sector-wide commitment to moving forward with personalisation and community-based support’<sup>3</sup>, representatives from across the social care sector have identified some key success factors for the delivery of personal budgets, including:

- Personal budgets not taken as direct payment should be offered as a managed account, but this arrangement must be authentic in affording people real choice and control.
- Personal budget holders need reasonable discretion in use of their fund.
- Help to plan, organise and secure support arrangements should be available for all who need this.
- Risk management and protection/safeguarding should be addressed in a balanced way across all sections of the community.

**2.5** These success factors were also identified in research already conducted on personal budgets<sup>4</sup> and in the evaluations of other personalisation initiatives such as **individual budgets for disabled adults<sup>5</sup> and for families with disabled children<sup>6</sup>**.

In this context, the NAO is currently undertaking a study on the Department of Health’s regulatory oversight of care markets, with the aim to:

- Find out if the regulatory oversight of personal budgets takes account of the risks and seeks to mitigate them, and
- Assess if the risks are being controlled and if personal budgets are operating effectively.

**2.6** The NAO commissioned Ipsos MORI to conduct some research with users of personal budgets in social care, to feed into its wider study.

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<sup>3</sup>

[http://www.thinklocalactpersonal.org.uk/\\_library/Resources/Personalisation/TLAP/THINK\\_LOCAL\\_ACT\\_PERSONAL\\_5\\_4\\_11.pdf](http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/THINK_LOCAL_ACT_PERSONAL_5_4_11.pdf)

<sup>4</sup> <http://www.scie.org.uk/publications/reports/report36/files/report36.pdf>

<sup>5</sup> <http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>

<sup>6</sup> [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_089508.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_089508.pdf)

## Research objectives

2.7 The objective of this research was to gather robust information on the following topics:

- **The experience of personal budget holders**, with a focus on users' experience of managing their budget, the process of choosing, contracting and managing suppliers, and how budget holders deal with poor quality service;
- **The extent to which personal budgets provide real choice to budget holders**, including an examination of any mechanisms or support that may have been put in place by local authorities or user-led-organisations to help users exercise choice and make decisions regarding their care, the availability of providers in the local area, and provision of accessible information;
- **The risks involved in holding a personal budget**, including users' awareness of these risks, and how local authorities are managing these risks;
- **The impact of personal budgets on disabled people and carers' independence and quality of life**, compared with more traditional forms of service provision they may have used in the past; and
- **How personal budgets could be improved for budget holders.**

# 3. Methodology

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**3.1** The research objectives called for a qualitative approach to enable us to explore the issues and gather the depth of information required. It involved:

- 48 in-depth face-to-face interviews with personal budget holders and/or their carers across six local authority areas in England (eight in each local authority), and
- Six telephone depth interviews with the member of staff leading on the implementation of personal budget in each of these local authorities.

**3.2** All the fieldwork was conducted by permanent research staff at Ipsos MORI, all of them had experience of conducting research on sensitive topics with vulnerable audiences. Interviewers were also fully-briefed beforehand on how to obtain informed consent from vulnerable adults. Fieldwork took place between **19<sup>th</sup> April** and **15<sup>th</sup> July 2011**.

### Local authorities

**3.3** The Association of Directors of Adult Social Services (ADASS) provided a list of potential local authorities to the NAO, to ensure the study included local authorities with different experiences of personal budgets. From this list, the NAO recruited six local authorities, taking care to ensure that local authorities included came from across England and from a range of levels of deprivation. The local authorities took part voluntarily.

**3.4** The table that follows shows the profile of the six local authorities who took part.

Local Authority	IBSEN Pilot area	Right to Control Trailblazer	Personal Budget take-up <sup>7</sup>	Rural/Urban
Local Authority A	Yes	No	20% or under	Urban
Local Authority B	Don't know	No	20% or under	Urban
Local Authority C	No	No	20% or under	Rural
Local Authority D	No	Yes	Greater than 20%	Urban
Local Authority E	Yes	No	20% or under	Both
Local Authority F	No	Yes	Greater than 20%	Rural

<sup>7</sup> Data on take up and proportion of direct payment/managed are from National Indicator 130 in 2009-2010.

**3.5** It is important to note that some local authorities involved were more ahead than others when it comes to the personalisation of adult social care in general, and the roll out of personal budgets in particular. This was particularly the case among local authorities that took part in the IBSEN study, or who are a Right to Control Trailblazer<sup>8</sup>.

### Interviews with local authority staff

**3.6** These interviews were used to build a detailed picture of the **local factors** shaping the implementation and delivery of personal budgets for users of social care in each of the local authorities. They were conducted before the interviews with personal budget holders in the local authority<sup>9</sup>. This enabled interviewers to build some local knowledge before they interviewed personal budget holders, and helped contextualise budget holders' experiences.

### Interviews with personal budget holders

**3.7** The six local authorities provided us with contact details of personal budget holders for the study. The sampling and recruitment processes with the local authorities were as follows:

- i. Ipsos MORI and the participating local authority established a Data Processor Agreement;
- ii. The local authority transferred an anonymised list of all their personal budget holders;
- iii. Ipsos MORI analysed the profile of budget holders, by type of personal budget, age, and gender;
- iv. Ipsos MORI selected a sample of 50 budget holders for the study, and sent their unique ID number to the local authority;
- v. The local authority appended the contact details for the 50 budget holders, and securely transferred them to Ipsos MORI;
- vi. Ipsos MORI sent out an advance letter and information sheet, on behalf of the local authorities, to the selected budget holders. They included a contact name, number and email address at Ipsos MORI for more information or to opt-out; and

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<sup>8</sup> The Right to Control is a new initiative designed to give disabled people increased choice and control over the support they receive to go about their daily lives, integrating funding from six different sources. It is currently being piloted in 7 Trailblazer areas across England. For more information see: <http://odi.dwp.gov.uk/odi-projects/right-to-control-trailblazers.php>

<sup>9</sup> The topic guide used for the interviews can be found in the appendices to this report.

- vii. An Ipsos MORI recruiter called selected service users to address any questions they may have about the research, invite them to take part in an interview, and arrange a convenient date and time if they agreed.

There were, however, two exceptions to this process.

- i. Local Authority F requested an opt-in approach. Letters and information sheets were sent out to 100 budget holders, and 8 of them opted in to participate in the research; and
- ii. Local Authority A sent out the advance letters themselves to the 50 selected budget holders, and transferred their contact details file to Ipsos MORI following the removal of any opt-outs.

All participants were offered a £20 cash incentive for taking part in the interview.

### Achieved sample profile

**3.8** The table below illustrates the achieved sample profile for the 48 interviews conducted, along with the quotas that were set. The quotas were set to ensure that the findings could be analysed by important sub-groups, such as type of personal budget. With the exception of personal budget type, the quotas set were broadly aligned with the demographic profile of the personal budget holders sent by the participating authorities.

	Quotas	TOTAL
<b>TOTAL</b>	48	<b>48</b>
<b>Number of interviews in each local authority</b>	8	<b>48</b>
<b>Gender</b>		
Male	15 to 23	<b>23</b>
Female	25 to 33	<b>25</b>
<b>Age</b>		
aged 70+	15 to 25	<b>25</b>
aged 50-69	10 to 15	<b>9</b>
aged up to 49	10 to 15	<b>14</b>
<b>Type of personal budget</b>		
Direct payment	At least 20	<b>18</b>
Managed by the LA or by a third party	At least 20	<b>22</b>
Combination of the two		<b>8</b>

**3.9** The profiling information in the above table is based on the demographics of personal budget holders, as indicated on the samples. This information was not always 100% accurate. For example, one respondent had recently moved onto a direct payment but was still recorded as receiving a local authority managed budget.

## Topic guides

**3.10** Topic guides were developed jointly with the NAO for the interviews with local authority staff and personal budget holders. They can be found in the appendices to this report. They provided an aide-memoire, to shape the discussion, and ensured that key topics were covered in all interviews.

## Analysis

**3.11** All interviews were recorded using digital voice recorders, where participants consented to this. A small number of respondents did not wish to be recorded. In all cases, the interviewers took field notes to aid interpretation of results.

**3.12** An analysis database was developed utilising Microsoft Excel, into which interviewers entered their interviews when they returned from fieldwork. This database had been developed based on the research objectives. This provided a transparent and consistent way of analysing the data. The database could be interrogated to help answer the key research questions.

**3.13** In addition, the project team held debrief meetings during the fieldwork period. Members of the NAO research team attended two of these. The debrief meetings enabled interviewers to discuss the emerging themes and hypothesis, and to identify gaps in the evidence to focus on for the remaining interviews. These meetings enabled the development of a shared understanding of the findings within the team, and helped develop the analysis tool.

## Interpretation of the findings

**3.14** Unlike quantitative surveys, qualitative research is not designed to provide statistically reliable information. It is **illustrative** rather than **representative**, and therefore does not allow conclusions to be extrapolated to a higher level. Qualitative research gives a more detailed insight into why people hold particular views, and helps build a picture of how these views are shaped by people's characteristics and personal experiences.

**3.15** To highlight the feelings and attitudes expressed, verbatim comments from the interviews have been included in this report. Names of participants and local authorities have been changed throughout the report to guarantee anonymity.

**3.16** Only eight interviews were conducted with personal budget holders in each local authority, so the differences by local authorities are **indicative** only.

## Acknowledgements

**3.17** Ipsos MORI would like to thank Peter Langham, Charles Nancarrow and Charlie Gluckman from the National Audit Office for their help and assistance in the development of the project. We would also like to thank the local authorities who provided samples of personal budget holders, and all of the staff and customers who took part in the depth interviews, without whose input the research would not have been possible.

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# **4. Choice and Personal Budgets**

## 4. Choice and Personal Budgets

**4.1** Choice is one of the central tenets of the personalisation agenda. Regardless of whether a user receives their budget via a direct payment or a managed budget, personal budgets are designed to empower the user to exercise **choice** and **control** over their care. The experience of personal budgets was far from homogenous across the six local authorities involved in this research project. This chapter first explores budget holders' aspirations for choice over their care and support, then moves on to discuss how budget holders were able to exercise this choice, and the support they needed to do so.

### Aspirations for choice

**4.2** Aspirations for choice varied significantly among budget holders. Some had no desire for choice. They were satisfied with the care they (or the family member they cared for) were getting or just wanted to get good care rather than choice. Thus they were content not to take on a direct payment, and the added work and responsibility that they thought it would bring.

**4.3** Other participants welcome having **some choice** over their care arrangements, but many did not want the **responsibility** of organising and coordinating their own care. There was some trade-off taking place, between **convenience on one hand** and **choice on the other**. The perception was that the having choice brought additional responsibilities, such as finding suppliers, organising and coordinating the support.

**When they changed companies they said either if we want to stay with the same company we can do so with a direct payments because they lost the contract with the council but I wasn't terribly keen on going on direct payments, I wasn't used to it. It looked as if I would have to do quite a lot of my own research and find carers and having four carers every day is not so easy. I mean if it was just one carer you could employ somebody yourself and have somebody spare but this was almost impossible.**

Carer, personal budget holder aged 70+, direct payment, Local Authority B

**4.4** Finally, some personal budget holders wanted to be in complete control of all aspects of their care, usually in an attempt to get better care and support. This issue will be revisited later in this chapter, when we examine the rationale for choosing one type of personal budget over another.

## Awareness of personal budgets

**4.5** Participants' awareness of personal budgets varied greatly, **between** local authorities as well as **within** local authorities. In particular, participants living in local authorities who were more advanced with personalisation tended to be more aware of what personal budgets were about than participants from other local authorities.

**4.6** Many participants who were in receipt of a managed budget knew very little about personal budgets. They were unfamiliar with the term "personal budget", and some did not know that they were receiving one, despite being considered by their local authority as a personal budget holder. From the process they described, it was unclear how much choice they had been offered with regard to their care and support. Reasons for this could be the way local authorities define personal budget. This is explored in the last chapter.

**4.7** Awareness and understanding of direct payments was slightly higher. Most direct payment recipients were aware of the fact that they had to keep all the receipts for their services, and that they could be audited. However, this was not the case in Local Authority C, where some people on a managed account were in the process of applying for direct payments, but were not aware that they would need to account for the money spent in one way or another, and that there would be restrictions on what they could spend the money on. Indeed in one instance the recipient was under the impression that the money received via direct payment could just be added to their household budget and did not see it as being restricted to spending on care.

**It wouldn't have a specific role, I would have it in a box, which is 'extras for John's care', and then take it from there. God forbid, but I don't think you can, I think it's unwise to put it into a slot. I would put it in with the general house [expenditure], for my wife to spend on looking after me and the house and herself. It would be used for our benefit.**

Personal budget holder, aged 70+, managed budget, currently applying for a direct payment, Local Authority C

**4.8** In addition, many participants on direct payment were unclear about what their direct payment could and could not be spent on.

**No we're still in doubt exactly. We've been told what you can't spend your money on.**

Carer, personal budget holder aged up to 49, direct payment, Local Authority D

**I don't know if it's a new idea that they're doing rather than funding everything, they give you the money and you decide where you want to put it to best use. I don't know but, you can buy days at the day care centres can't you?**

Carer, personal budget holder aged 50-69, managed budget, currently applying for a direct payment, Local Authority C

**4.9** Awareness of personal budget was higher among people with a good support network. The support network usually included close family members, such as a spouse, parent(s) or child(ren), who acted as carers. Overall, they had a better understanding of personal budgets than participants without a support network, whether they were receiving a direct payment or a managed budget.

### **Choosing a personal budget**

**4.10** Service users reported a range of experiences when it came to being offered a personal budget, and in terms of what types of personal budgets they were offered. Importantly, not all budget holders were offered the choice between a direct payment, a managed account, or a combination of the two. In Local Authority F and Local Authority A, most participants did not recall being offered this choice.

**4.11** In Local Authority C, all of the service users interviewed were in receipt of managed personal budgets and had very low levels of knowledge about the alternative options, let alone what a personal budget was about. In this authority, the policy is that all new users of adult social care receive a personal budget, whether a direct payment or a managed budget.

**They can refuse a direct payment but they can't refuse a personal budget.**

Personal budget professional lead, Local Authority C

**4.12** Most importantly, a few budget holders in Local Authority B and Local Authority C struggled to move onto a direct payment, either because of waiting lists, or because they were discouraged from taking a direct payment by the local authority.

**They said it would be about 14 weeks.**

Carer, personal budget holder aged 70+, managed budget, currently applying for direct payment, Local Authority C

**I spoke to this older people's department and said I wasn't happy with the carers and a couple of incidents that happened, and [I asked] could I go on to direct payments. I was told that it wasn't something that they generally do and I'd have to keep a log of what I wasn't happy about and what was happening, which I did and then I put it in writing. I think it took about a year before I got passed to take direct payments.**

Carer, personal budget holder aged 70+, direct payment, Local Authority B

**4.13** Participants who were offered the choice between a managed budget and a direct payment explained how they made up their mind. The reasons provided, laid out below, help understand the perceived barriers to take-up of direct payments.

### **Reasons for choosing a managed budget**

**4.14** Of the budget holders interviewed who had been offered the choice between a direct payment and managed budget, one of the main reasons for choosing a managed budget seemed to be a desire to avoid the responsibility of managing a direct payment. Some participants described this responsibility as a burden, and said they were not confident about taking it.

**It's a lot to ask people to take on.**

Carer, personal budget holder aged 70+, managed budget, Local Authority B

**You know I don't want to be responsible for having money given to me. I was quite happy with the old system. And at this moment in time I'm fairly happy, I am happy with the new system because it doesn't seem to have made a change for me.**

Carer, personal budget holder aged 70+, managed budget, Local Authority D

**It sounded as if it [direct payment] would be difficult**

Personal budget holder, aged 70+, managed budget, Local Authority B

**4.15** When choice was offered, those who chose a managed budget felt that the responsibilities that come with having a direct payment outweighed the potential benefits. This was especially the case among older participants. Some lead professionals at local authorities also argued that older people tended to use traditional services (day centre, care agency), and with few providers on the market there was little to be gained from opting for a direct payment.

## Reasons for choosing a direct payment

**4.16** Personal budget holders who chose to receive a direct payment can be divided into two groups, each displaying different rationale for their decision.

**4.17** Firstly, some participants had already been in receipt of social care before they moved to a direct payment. Their main reason for choosing a direct payment appeared to be that they wanted to have more choice and control over their care and support, and over who supported them. In some cases, this was because they were unhappy with the care they were receiving from their local authority, or because they wanted to use a care agency that was not on their local authority approved suppliers list.

**You know we can do what we want, that's what I like about direct payments, that I can say what I want.**

*Carer, personal budget holder aged up to 49, direct payment, Local Authority F*

**Well there is a possibility if they drive you mad that you can change agencies without having to ask anybody. You can sack them and move on. Not that the others are [better], from what I gather the problems are endemic. But still knowing that you can walk out, you hope that they'll treat you better.**

*Carer, personal budget holder aged 70+, direct payment, Local Authority B*

**4.18** Participants new to adult social care services who chose a direct payment tended to do so because of the additional choice and flexibility it provided them with: they could get services that they would not have been able to receive without a direct payment – reflecting an underlying concern that a managed budget does not offer real choice, or does not offer as much choice and room for innovation as a direct payment.

## Uses of personal budgets

**4.19** Many professional leads in local authorities mentioned that one of the key benefits of personal budgets, and direct payments in particular, was that they enabled budget holders to access services that they could not receive under the previous commissioning framework. They provided examples to illustrate their claim. In contrast, only a few budget holders reported very innovative uses of their budget.

**4.20** The most common uses of personal budgets were for day centres and visits from professional carers, once or twice a day, to assist with personal care. These are fairly common types of care and support services. A few participants also used their direct payments to buy or maintain equipment such as wheelchairs or computers.

**Basically to make sure that she's looked after within the home.**  
Carer, personal budget holder aged 70+, direct payment, Local Authority B

**4.21** A few examples of innovative use of personal budgets were mentioned. This included the employment of a personal assistant, instead of using professional carers from a care agency. Participant who used their direct payment to pay for a personal assistant wanted to be able to choose who would look after them, something they were not able to do when going through a care agency. However, the care provided by personal assistant was not so different to what might have been received from a professional carer from a care agency, except for being more personalised and flexible. None of the participants in receipt of a managed budget had a personal assistant.

**4.22** In addition, direct payments were also used to purchase a variety of goods or recreational activities. Examples included; reimbursing family or friends for petrol/transport or other costs accrued on trips/activities, holidays specifically tailored to the budgets holder's individual needs or interests (where before the only option might have been to attend a group holiday), commissioning adaptations to allow wheelchair access to the garden, purchasing or running a PC to aid communication, wheelchair purchase or maintenance, purchasing equipment for hobbies such as gardening, or for personal training sessions.

**I asked about, could I get him a personal trainer? It wasn't mum telling him what to do so it was seen more as an exciting event for him, and he was doing that twice a week and Local Authority D were more than happy that that was a creative thing to do with him and it was good for him.**

Carer, personal budget holder aged up to 49, direct payment, Local Authority D

**When we've looked at what the people with mental health problems are buying, the biggest thing they're buying is personal assistants and, after that, it's very much mainstream services. So, instead of going to a day centre, they're going to gyms, they're buying bikes or they're going out in that sort of way and using ordinary facilities.**

Personal budget professional lead, Local Authority F

#### 4.23 Key factors influencing the use of personal budgets were:

- Whether the participant had gone through support planning or not. A few participants had benefited from independent support planning, and they seemed to make a more tailored and personalised use of their budget. This is explored in further detail later in this chapter;
- The type of personal budget received. Overall, innovation appeared more frequent among participants receiving direct payments;
- Understanding of how the budget could be used. Many people felt they were restricted to spending their budget on the services listed in their support plan, or to achieve the goals listed in the support when no services were listed. They did not know how much flexibility they were allowed within the support plan;

**I kept asking John [at The Trust], asking what I could do with it. It wasn't easy was it really. They didn't give me any idea.**  
Personal budget holder, aged up to 49, direct payment, Local Authority E

- Local rules and guidelines about use of personal budgets. For example, in Local Authority F, recipients of direct payment were told that they could save their budget over time in order to pay for a more expensive item, whereas in Local Authority E, some participants said this was not possible.

### Support planning

4.24 Support planning is an essential part of the personal budget process, as it is during this stage that personal budget holders decide how they will use the funding they receive to best meet their goals. Support planning should show genuine change from the previous system, moving towards an outcome driven approach.

**4.25** Often it seemed that either support planning did not take place, or that if it had taken place, it was not tailored enough and the services provided did not fully meet participants' needs (Case Study 1). This was particularly the case amongst older participants, those with complex needs, and those on managed budgets. When a budget holder had moved from commissioned services to a personal budget, either in the form of a managed budget or a direct payment, there was often a continuation of their previous support plan, without formal support planning.

**When Lisa came out of hospital we had Local Authority D's initial care team who worked out the package that was needed for her care and we've just run off that basically.**

**Carer, personal budget holder aged 50-69, direct payment, Local Authority D**

**Case Study 1: Personal budget holder, aged 70+, managed budget, Local Authority C**

Sue lives in a home for older people, where she receives two daily visits from a professional carer, one in the morning and one in the evening. She does not actually need help with her personal care. In fact, she gets up before the carer arrives to make sure she is dressed and washed before they turn up. She doesn't want to be found in bed, and takes pride in being able to look after herself, despite being in her 90s.

When the carer comes, they have a chat and have a laugh. Sue feels lonely and really looks forward to these visits, even though they are short.

When Sue sees how much it costs to get two visits a day from a professional carer on her monthly statement, she wonders if she really needs their visits. On one hand, she wants some company, but on the other she is able to look after herself. Could there be a more suitable way to meet Sue's aspirations to socialise?

**4.26** Participants who went through support planning stood out from others: the support planning stage made them aware of the options available to them, it helped them think creatively about the use of their personal budget, and helped them access the information they needed about suppliers. Some examples also showed that they achieved better outcomes (Case Study 2). The support planning stage was usually conducted with an independent support broker from local user-lead organisations, but participants were not always able to tell who their support broker was working for.

### **Case Study 2: Personal budget holder and carer, personal budget holder aged 50-69, managed budget, Local Authority A**

Tim has some severe mental health issues, and, along with his social worker, has decided that he should move to a personal budget. The previous support package he received to manage his anger and anxiety classes hadn't been working for him. Together with his social worker, Tim identified his goals: becoming socially involved, and increasing his independence. Tim's social worker then found a centre where Tim could work toward his goals. At the centre, Tim participates in art classes, and undertakes ad-hoc training courses, all funded through his personal budget.

Attending the centre has a genuinely positive impact on Tim's life. Tim feels that the centre is helping him immensely:

**To me the centre is my sanity**

This is also having a positive impact on Tim's wife. She has noticed a huge change in his behaviour. She finds that he has more confidence, less anxiety, and has something to live for. Tim has actually moved on from being a **client** to being a **volunteer** at the centre, helping other people with severe mental health issues to get better.

**4.27** This finding is in line with the findings from the National Personal Budget Survey<sup>10</sup>, which shows that budget holders and carers who are involved in the support planning process are more likely to feel that their support plan fully reflects their needs and desired outcomes, and are therefore more likely to get the most out of their personal budget.

**4.28** Budget holders and carers who did not think they went through support planning often did not reflect negatively on this: many still felt that they or the person they cared for were getting the care they needed. However, they did not realise what they were missing out on, or were not aware of the range of options they could choose from to plan their support.

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<sup>10</sup> <http://www.in-control.org.uk/media/92851/national%20personal%20budget%20survey%20report.pdf>

# **5. Choosing, Managing and Switching Providers**

## 5. Choosing, Managing and Switching Providers

**5.1** Personal budgets aim to give those who use them more choice and control over the providers they use. However, to be able to exercise choice and control, budget holders or their carers need to be able to choose from different providers, and manage them. This chapter first explores the choice of providers (availability of providers locally, and information and guidance available for people to exercise choice). It then looks at personal budget holders' experience of managing a budget and managing staff, and the support they needed to do so. Finally, it looks at users' experience of switching providers.

### Choosing providers

#### Awareness of the right to choose providers

**5.2** Among participants with a managed budget, **awareness** of their right to choose providers was low, reflecting the earlier finding that some did not know that they were receiving a personal budget in the first place. Most of those receiving a managed budget received in-home support services from a care agency but had not had any choice of suppliers, and many did not know they could request a different supplier if they were unhappy with the existing one.

**5.3** Budget holders on a direct payment were generally **aware** that they had the right to choose a supplier. Indeed, for many this choice was a key factor in their decision to opt for direct payment. This research suggests that in effect budget holders generally only feel they have real control and choice over their care and support if they opt for direct payment – reflecting the call for managed budgets to offer real, authentic choice in 'think local, act personal'. It could also result in people choosing a direct payment when a managed option might suit them better in other ways.

#### Availability of providers

**5.4** There were no reported shortages of care agencies to choose from, but some concerns were raised about the quality of the service provided, which is explored later in this chapter. Professional leads highlighted a number of concerns regarding the availability of providers in their area. In particular there was an issue with the availability of services that allowed budget holders to be creative with their personal budgets, or to receive overnight or out-of-hour personal care.

**I think choice has also been limited. Perhaps there's not enough providers who are either aware of personalisation or haven't changed their business to be more flexible in approach. So I suppose in terms of menu I still don't think there's like an extensive menu to choose from.**

Personal budget professional lead, Local Authority A

**Yes, they still need traditional care. There's very little other option. If you don't have home care what do you have? So it is about helping providers to make different services available.**

Personal budget professional lead, Local Authority C

**5.5** Many participants using day centres or attending organised group activities said that while more choice would be welcome, they had found activities that interested them. Occasionally a lack of choice meant that some were or had been attending activities that were not an ideal fit in terms of their ability or age. For example, a participant in her early fifties in rural Local Authority E explained that while she was happy with the day centre she attended in some respects, it was not ideal because most of the other clients there were elderly people. She would have preferred a centre attended by people of her age, but there were none suitable in the local area.

**5.6** Finding accessible facilities for independent activities was also problematic in rural areas such as Local Authority E, where a lack of suitable swimming pools was mentioned by a couple of people. A participant explained how she would like to go swimming to help her mobility, but that there were no longer any NHS hydrotherapy pools in the area, which meant she would have to pay more if they decided to use private facilities.

**5.7** Some participants mentioned difficulties when recruiting for a personal assistant. On more than one occasion, participants placed some adverts locally but only received one application - their only options were to hire that applicant or go through the whole process of placing adverts again, with no guarantee of a different outcome. Most felt happy enough with the individual who did apply to employ them, but this did not always work in the long term.

## Information and support to choose providers

**5.8** The quality of **information available to help budget holders make an informed decision** about providers varied. Importantly, participants were largely unaware of the providers available locally, and their main source of information was word of mouth - getting recommendations from friends or family, from a social worker or from the council. Many did not have access to the internet, relied on someone else to look up on the internet for information, or were too busy caring to have time to look for information on the web. Some councils said they had lists of approved suppliers on their website, and said they could provide a print out to budget holders who requested it, though participants did not necessarily know that they could request it.

**5.9** Beyond contact details of providers and the services on offer, participants wanted to be able to see information on the quality of services provided, and ideally feedback from other users (particularly for care agencies). Some professional leads in local authorities mentioned that they were in the process of developing tools for this.

**5.10** Participants who wanted to employ their own personal assistant usually got support from their local authority or from a third party organisation. This could take various forms: help with drafting and placing an advert, obtaining references or CRB checks, and attending interviews. However, the quality and the availability of support varied greatly from one area to another. Participants in Local Authority F said they **would like more support and/or training in conducting interviews and how to decide who to employ**. In Local Authority E, it was suggested that the support during the interview could be more effective, for instance by ensuring that all key questions are asked. The key factor in choosing a personal assistant tended to be a 'good feeling' about the individual and a sense that they would 'get on' with the budget holder – often this personal connection was seen as more important than other factors such as qualifications or references. In many cases this 'gut instinct' worked out well, but in others the relationship was not successful in the longer term.

**5.11** Overall, there was a feeling that finding a good supplier, whether a professional care agency or a personal assistant, had often been more due to luck than judgement.

## Personal assistants or care agencies

**5.12** The main driver for choosing to employ a personal assistant rather than a care agency was to have choice and control over the individual or individuals who would be providing care and support; the times they would visit; and the consistency of care. Other factors included; negative experiences of care agencies, the option to pay lower hourly rates (and therefore be able to afford more hours of care) and the possibility to employ a friend or relative, including, in one case, a friend who had been supporting them free of charge in the past.

**Well I had to rely on my friends to come and help us. And I didn't like it. I couldn't pay them anything, so I just had to rely on people fitting us in really. There is a big difference now because I feel like they're not doing it for nothing. I don't feel as guilty because they're getting something.**

Personal budget holder, aged up to 49, direct payment, Local Authority A

**5.13** Those who needed significant support with their personal care often preferred to choose a care agency rather than employ their own personal assistant. This gave them peace of mind that there would always be a professional carer available when they needed someone, and this system was easier than them having to recruit, train and manage a personal assistant.

**If you're only employing one person, you don't have that option [of back-up care]. That would be a problem because you would have to have backup.**

Carer, personal budget holder aged 70+, combined budget, Local Authority D

**5.14** Those who opted for a personal assistant often had family members who could step in and support them if their personal assistant was unavailable at short notice. To avoid this issue, a few participants employed more than one personal assistant to ensure there would always be at least one available.

**5.15** Some participants had been put off employing someone directly because of concerns about becoming an employer, and lack of support to do so. In contrast, some participants who had decided to employ a personal assistant were not fully aware of the implications of being an employer. For example, they had often considered the immediate practicalities of managing someone (e.g. in terms of contracts and timesheets) but were not well aware of their potential liabilities as an employer if something went wrong, although some did mention having insurance as part of their budget.

## Managing a personal budget

**5.16** Most participants who opted for managed budgets did not raise any issues regarding the management of their budget – their local authority or the third party handled things for them, including paying suppliers, although some budget holders were billed by their council for a financial contribution towards their care. However, some participants would have liked more information or transparency, for instance how much money was left in their managed budget.

**5.17 Participants in receipt of direct payment found the practical administration of the budget relatively straightforward**, such as keeping receipts, writing cheques for suppliers, making sure they did not over-spend etc. However, in many instances the budget holder was supported by family members. The help they provided ranged from help understanding letters/paperwork when needed, to writing cheques, or looking after everything on their behalf, for example where the budget holder had severe learning disabilities, conditions such as dementia, or where they simply did not feel they could cope with or wanted the responsibility (which was fairly common among older people). Without this support it seemed unlikely that some personal budget holders would have been willing or able to manage the direct payment themselves.

**5.18 None of the budget holders who took part in this research were working out tax or national insurance themselves - this was taken care of by a third party** such as an accountant or specialist organisation contracted to offer this service, paid for as part of the personal budget. Typically the budget holder submitted time sheets signed by them and their personal assistant; a payslip was then produced by the local authority or third party for them to give to their staff.

**5.19** Those using the services of organised activities or day centres payment also seemed to find the actual budget relatively easy to manage, either paying per session or writing a cheque when invoiced.

## Support to manage a personal budget

**5.20** Although the practicalities of personal budgets were found to be fairly straightforward, some participants still needed some support to manage their personal budget, beyond the day-to-day support that family members provided. This was more frequently the case among people receiving a direct payment.

## Support required

**5.21** Participants wanted to be reassured that there was someone they could speak to if they did not understand anything, had any questions, or needed advice or assistance. This made them more confident about taking up a direct payment, rather than a managed budget.

**I've got a phone number direct to one person at the finance team and I just ring her up and she'll talk through it. If I'm still not happy she'll come out to us and go through all the paperwork so that puts your mind straight at rest really.**

Carer, personal budget holder aged 50-69, direct payment, Local Authority D

**5.22** Next, it seemed that once budget holders had got to grips with the administrative tasks required to deal with direct payments, they were essentially left to get on with it, with little support or monitoring after the first few weeks, apart from a phone number to call if needed. Many participants would have liked **more regular support visits with a chance to ask for advice or discuss any issues** – and for reassurance that they were managing the budget properly. Indeed, some participants had receipts dating back months that had never been collected or checked, which they found a little disconcerting.

**I think they [The Trust] are more geared up to getting people to take up the budget and going through the motions of starting people and getting them on to the payroll and whatever else and then they abandon you it seems. So the payroll's the only person I've had dealings with really.**

Carer, personal budget holder aged 70+, direct payment, Local Authority E

## Sources of support

**5.23** For the management of personal budgets, the main source of support mentioned by budget holders was social workers. The accountancy service in Local Authority D, and the The Trust in Local Authority E, were also mentioned as sources of support, though views on the quality of the latter were mixed. Professional leads at several local authorities mentioned other sources of support, in particular the role of the voluntary sector and of peer-support in helping users to manage their personal budgets.

**We've got people from the voluntary sector on our personalised partnership board so they have all the information and advice to support people who go to the voluntary sector as well.**

Personal budget professional lead, Local Authority A

**We've got an information project that's led by disabled people and delivered through our Centre for Independent Living which is rooted very much in the idea of independent living and supporting people to get the information they need to be able to make effective choices.**  
Personal budget professional lead, Local Authority D

5.24 Social workers were also seen as still having a role in managing the budget, especially in the first stages of trying to choose providers.

**It's mainly still us doing that, it's the social workers who are managing that bit [obtaining quotes for services].**  
Personal budget professional lead, Local Authority F

### **Satisfaction with support received**

5.25 Budget holders expressed mixed views with regard to the support available to them. Some were positive about it, other were less so. In Local Authority D, the social workers were often cited as being very helpful and supportive.

5.26 Clearly the level and nature of support required varied from person to person, depending on the personal support network that budget holders had, and on how they were using their personal budget (those hiring their own staff usually needed more support, and this is explored later in this chapter). Some felt sufficiently supported by simply having a contact they could approach as and when required.

**They [the older people's department at the civic centre] said, if any situation arises and you need any help or advice or assistance contact us and tell us the situation and we'll...work together to resolve any issues. They've always been very supportive.**  
Carer, personal budget holder aged 70+, direct payment, Local Authority B

5.27 Ideally, an assessment of the support needs should be made and the approach tailored to take this into account.

## Managing providers

**5.28** Many participants, whatever their type of budget, raised issues about the **quality of service supplied by care agencies**, and the persistence required to get complaints dealt with, perhaps raising questions about how well the local authorities concerned were managing suppliers, or supporting budget holders in this. Common concerns included; carers rushing to get to the next patient and cutting appointments short, too little time being allowed for each appointment (given the tasks required), carers arriving too late or too early and, perhaps most importantly, inconsistency in terms of actual carers; many reported not knowing who would be coming from one day to the next. A desire for consistency was one of the drivers for those opting for direct payments. Participants who used a care agency still liked to have a small number of regular carers allocated to them (e.g. two to four). Importantly, complaints seemed to take a lot of time and effort to get addressed – some participants described having ‘battles’ with the local authority and/or care agencies to get a service they were happy with.

**5.29** Perhaps more worryingly, for some there seemed to be a reluctance to complain unless an issue was perceived as serious, so issues such as those noted above were ‘put up’ with as inconveniences, even though they were clearly having an impact. Reasons for not complaining included; simply being grateful for receiving care, not wanting to get staff into trouble, being happy with the actual care, but less happy with the systems in place, or perhaps a feeling that little could/would be done to address the issue.

**Well, I wouldn't stop anybody's job. I wouldn't like to upset anybody.**  
Personal budget holder, aged 70+, receiving care through local authority – has enquired about personal budgets, Local Authority E

**I do find if there is a difficulty it's usually from the office girls not from the carers. They all seem to be very competent, but I sometimes feel it would be a good idea if they actually came out and realised how long it takes from one side of their area to the other especially if the girls are using public transport. You know apparently they don't give them time for travel... If I've got something to say then I'll definitely say it but not over anything trivial. It's got to be something that's really important.**  
Personal budget holder, aged 70+, managed budget, Local Authority B

**5.30** Encouragingly, many participants who hired their own staff were very happy with the services their personal assistant(s) were providing. A few mentioned small things that they would change in an ideal world, such as more flexibility in terms of the hours their personal assistant was doing, or less time off due to sickness, but they felt that on balance they had a good personal relationship with their personal assistant.

## **Support to manage providers**

**5.31** Managing personal assistants was not, however, always straightforward. Again, there did not seem to be much proactive practical support or training available from local authorities or third party organisations on how to manage staff, beyond completing the necessary paper work. While participants were usually happy with their personal assistant(s), aspects which participants found challenging included addressing poor performance, asking someone to leave, and employment law.

**5.32** When advice was given on specific issues, it was not always up to the expected standard: for example, one budget holder in Local Authority E was asked by her PA whether or not she had accrued extra holiday pay for the additional hours she had been working. Their individual liaison officer at The Trust said she was not. However, when the PA queried it again, because she had heard differently from elsewhere, they called The Trust again and a senior officer said she would in fact be entitled to this, so they passed this information on to the PA. However, this turned out to be incorrect. Similarly, another carer in Local Authority E received conflicting advice when seeking help with regard to a dispute with their Personal Assistant.

**I was getting advice from the Employment Law specialist and certain things from The Trust and they would often conflict so I was caught in the middle again. You know can I do this or this and I was getting more confused and things were so drawn out.**

**Carer, personal budget holder aged 70+, direct payment, Local Authority E**

## Switching providers

**5.33 The primary reason for switching providers was dissatisfaction with the service being delivered.** A common problem with agencies was a lack of continuity of care, where most participants would prefer a consistent carer, or if necessary, a consistent team of carers who they could get to know and trust. Where care was provided by multiple carers some were very good, while others were less than satisfactory. Other issues felt to be beyond the control of individual care agency staff were, as noted; rushed appointments (caused by too little time allowed in the first place and/or too many appointments scheduled for one carer in one day), inconvenient appointment times, not being informed about which staff member was attending on which day, occasional cancellations and difficulty getting complaints addressed. Problems with PAs employed directly tended to include a lack of flexibility in terms of timings as well as not carrying out the tasks required, in the way, or to the standard that the participant wanted. Other less tangible factors such as the relationship between the personal assistant and budget holder just not really 'working out' also seemed to be a factor.

Cost was not generally mentioned as a driver for switching providers.

### Experience of switching

**5.34** Some of those who were dissatisfied with the personal assistants they were employing felt able to ask their personal assistant to leave, with apparently relatively little difficulty.

**5.35** Others had experienced a period of friction which they felt hard to address at the time and the end result had been the personal assistant deciding to leave, which was sometimes quite difficult for all involved. In one case this had resulted in serious problems and the PA was threatening to take legal action, as described in the chapter on risk.

**5.36** Switching from a care agency to another care agency or to a personal assistant seemed to be more straightforward, perhaps because it is less daunting to cancel a contract with an agency than having to make someone redundant.

### Barriers to switching

**5.37** Personal budget holders who were offered no choice about their care provider in the first place were largely **unaware** that they could switch.

**5.38** Many participants were largely happy with the support services they were receiving and therefore had no desire to switch. The importance to budget holders of having support from a personal assistant or carer(s) who they felt comfortable with was reflected by the finding that they were sometimes happy to live with issues such as lack of flexibility in terms of working hours or having to manage without support when their personal assistant was unavailable.

**5.39** There were, however, some budget holders who were not completely satisfied with their care but were still **reluctant to switch**. Often (though not in every case) these budget holders were older people receiving more traditional care from an agency via local authority managed budgets. They tended to be grateful for support and felt they should not or could not make too much fuss about perceived 'inconveniences'. However, the issues raised, such as time keeping, rushed appointments and continuity of care were clearly having an impact on participants (Case Study 3).

**5.40** The reluctance to go beyond complaining and actually request a switch stemmed from the fact that they at least knew what they were getting from the current provider, and that it met their basic needs. Some had also built up a bond with at least some of the agency carers. However, any new provider would be completely unknown to them and they could end up worse off. This relates back to the lack of user feedback which might potentially help budget holders to make more informed decisions about whether or not they would be better off switching.

### **Case Study 3: Personal budget holder, aged 70+, managed budget, Local Authority B**

Maureen has three care visits daily to help her with essential personal care and household tasks, supplied through an agency via a managed personal budget. The care meets her immediate needs and she had built a rapport with two of the regular carers, whom she really likes. However, it took a few complaints initially to get the morning visit scheduled for a suitable time, and there are on-going issues with the way the care is managed: the carers are often rushed because too little time is allowed for the tasks required and for travel between appointments. She also needs to explain the ropes when new carers come. Despite the service being less than ideal in these respects she does not feel it is serious enough to warrant making a complaint.

**You've got to fit in. Well no I wouldn't be intimidated oh no. If I've got something to say then I'll definitely say it but not over anything trivial. It's got to be something that's really important.**

She would not want to switch suppliers because she got on well with two of the regular carers, and because of the risk another agency may be no better.

**I think it's like everything else. If something's working don't mess about with it you know. Rather than going to the unknown you're better to stick with what you know.**

# 6. Managing Risks

## 6. Managing Risks

**6.1** There are various risks associated with the uptake of personal budgets, and in particular with direct payments. This section looks at the risks identified by personal budget holders and by local authorities, and how these risks are monitored and managed.

### Awareness of risks amongst users of personal budgets

**6.2** The risks identified by personal budget holders predominantly revolved around direct payments, rather than managed budgets. They related to the responsibilities of being an employer, and the risk of inadvertently misspending their budget.

**6.3** Most participants were aware of the risks involved in hiring their own staff, and some actually decided not to hire a personal assistant because they did not feel able to take these risks. Others thought they were aware of the responsibilities involved in employing their own staff, such as the need to have a contract in place and pay the associated taxes. However, they sometimes realised later on that they did not have a good enough understanding of employment law, made some ill-informed decisions, or got into real trouble (Case Study 4).

**I wouldn't have any problems whatsoever with that [becoming an employer], because I phoned up Local Authority F Council, and I explained if there's a possibility at any time that I might want to change, and there's no problem with it as long as they keep, you know, the tax side of things and they've got a basic insurance type of stuff what you need.**

*Carer, personal budget holder aged 50-69, direct payment, Local Authority F*

**The problem has been unexpected really, the fact that I am suddenly an employer. Now I'm 71 years of age and I had no experience in my working life of ever handling staff, so I have had problems with staff. In fact, two staff have left and that's been quite traumatic because I had to deal with this.**

*Carer, personal budget holder aged 70+, direct payment, Local Authority F*

#### **Case Study 4: Carer, personal budget holder aged 70+, direct payment, Local Authority E**

Sylvia is the full time carer for her elderly father who lives with her. She and her father have had a distressing experience when they tried to hire a personal assistant.

It was difficult to fill the personal assistant post in the first place. After two rounds of advertising only one person arrived for an interview. Then, over time, various problems emerged including doubts about the accuracy of some the information the personal assistant had included on her CV/application form, a lack of references, concerns over her ability to keep the budget holder safe and alleged attempts to alter timesheets after they had been signed. The situation came to a head and the personal assistant left. However, this is now in dispute and the personal assistant also made some accusations and involved the police.

Sylvia didn't feel she got adequate support when things went wrong:

**It comes back to not really getting enough support I think. I think they're more geared up to getting people to take up the budget and going through the motions of starting people and getting them on to the payroll and whatever else and then they abandon you it seems.**

She still thinks direct payments are a good idea in principle, but feels people need to be made more aware of the possible pitfalls. She personally daren't take the risk again, and is now using a care agency.

**I thought it would just be a case of filling in the timesheets and making sure that it's sent off to payroll and she gets paid properly. I didn't foresee anything going wrong really, even though I'd had warnings about from the social worker saying carers can sometimes alter timesheets, and about where people do fall out and then demand another carer and it's not that simple. I suppose she informed me, well given me other instances of things where they'd gone wrong. And you get a full booklet from The Trust; standard things about what to do if someone's off sick or how to fill in annual leave things and then the grievance procedure if things do go wrong. But I didn't even dwell on that too much because I hoped it would never happen.**

**6.4** Some service users and carers mentioned the risk of the budget being inadvertently misspent, or of expenditures not budgeted correctly over time. This was a particular concern amongst budget holders who were not entirely sure about how flexible their budget was and what they could spend it on – an issue explored in the chapter on choice and personal budgets. While some budget holders said their support plan clearly specified what they should spend their personal budget on, they sometimes wanted to spend money on other things following a change of circumstances, but then faced the risk of being accused of misspending their budget, even when they received a verbal approval from their local authority before they did so (Case Study 5).

**Case Study 5: Carer, personal budget holder aged 70+, managed budget, Local Authority E**

Pam cares for her husband who has Alzheimer's. Around three or four years ago Pam was encouraged to apply for a direct payment by her social worker, which she was told she could spend on a variety of things, including furniture.

**You know they said Pam it's for you to enjoy, go on holiday, buy what you need for James and for yourself, which we did. She said to me 'Pam, you'll be able to have things like furniture' because we needed it, the flat was nearly empty.**

She spent a substantial sum on furniture but she was then told she had to pay the money back. She was very upset about this.

She was moved to third-party managed budget. She felt very confused and ill-informed about how the managed budget is being spent, and why some of the claims they had submitted for things like petrol were not paid in full. Attempts to get someone to visit them to explain appear to have been unsuccessful.

**It makes me feel sick. It makes me feel there's nothing discussed with me and the only thing is what I thought were doing right they said I were doing wrong and I paid The Trust £800 out of my money.**

**6.5** The **availability** and **visibility** of the support made available by the local authority to help users mitigate these risks was crucial. These are discussed later in this chapter.

## Risks identified by local authorities

**6.6** Professional leads at the six local authorities identified risks that were similar to those mentioned by budget holders, focusing on direct payment recipients becoming employers. These concerns were centred around the potential for budget holders to unwittingly break contracts, or to make ill-informed decisions having received poor advice around employment issues.

**There have been a couple of occasions where people are using a direct payment and have perhaps broken the terms of their contract with the provider. And there have been a couple of threats of legal action which we've managed to work with the individual to manage.**  
Personal budget professional lead, Local Authority D

**6.7** Other risks mentioned included budget holders misusing their budget by purchasing services or equipment that they were not supposed to, and lack of training for professional carers or personal assistants, meaning that individuals' personal safety could be at risk. Other research Ipsos MORI conducted for the Department of Health has indeed shown real concerns about the lack of regulation, training and CRB checks for personal assistants, and the IBSEN evaluation found similar issues<sup>11</sup>.

**Say you've got a personal assistant and they've not been trained appropriately around a piece of equipment.**  
Personal budget professional lead, Local Authority E

**6.8** The overall feeling was that a certain level of risk was inherent and unavoidable within personal budgets, especially for direct payments. However, personal budgets were not considered a great deal more risky than traditional social care provision, especially with regard to safeguarding and abuse.

**We've hardly had a proud history of being free from abuse in the past, have we, in a sense, with traditional services.**  
Personal budget professional lead, Local Authority F

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<sup>11</sup> <http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>

## Risk management and safeguarding approaches

**6.9** The approach the local authorities have taken to addressing the risks associated with personal budgets aimed to mitigate these risks, rather than eliminate them – based on the view that risks are an inherent part of self-directed services, and that a balance needs to be struck between controlling the risks and allowing budget holders to have choice and control over their care and support. This view fits in well with the way forward recommended in ‘think local, act personal’<sup>12</sup>

### **If you give people more choice then they take more risks.**

Personal budget professional lead, Local Authority F

**6.10** Local authorities have developed some risk management systems or risk monitoring tools to mitigate the risks associated with personal budgets. Examples include:

- To minimise the risks of budget holders misspending their personal budget, Local Authority B have created an electronic payment card scheme, whereby the direct payment is loaded onto a pre-pay bank card.

**Some people we work with may be alcohol dependent, for example, so there are certain restrictions that we can put on the electronic payment card. And I think that’s where the electronic payment card is really, really helpful, because we can restrict where or what the person is able to be spending their budget on.**

Personal budget professional lead, Local Authority B

- Local Authority A developed a risk assessment tool that social workers can use to decide with service users and carers what type of personal budget is most suitable for their circumstances.

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<sup>12</sup> ‘Risk management and protection/safeguarding should be addressed in a balanced way, avoiding an approach that views people in receipt of social care funding s most at risk’ (‘think local, act personal – a sector wide commitment to moving forward with personalisation and community-based support’, January 2011)

**We designed a tool to help social workers weigh up with their clients and carers about, there's like different shaded parts to it and if you're in the red it means you're not really suitable at all to manage a personal budget. If you're in the amber you could with support if it's structured and if you're in the green you're definitely a dead cert as it were.**

**Personal budget professional lead, Local Authority A**

- Local Authority E and Local Authority D developed initiatives to assist budget users who want to hire their own staff. In Local Authority D, the support was provided in house: social workers helped users with things such as having a Criminal Records Bureau (CRB) check run on potential personal assistants. They also made an accountancy service available to budget holders, to assist with the aspects of becoming an employer.

**What we've tried to do is use council resources. We've got an HR department. We've got a legal department and so where people are experiencing difficulties that they can tap into our expertise really.**

**Personal budget professional lead, Local Authority D**

- Local Authority E, took a slightly different approach, forming a partnership with the charity The Trust, which offers third party managed personal budgets.

**6.11** The risk management tools, such as the above, appeared to make a genuine difference to users. In Local Authority D, a user whose condition affected her memory at first tried to manage the budget herself, but was unable to cope with the payroll aspect and this was subsequently handled by the accounting service.

**I was doing timesheets and I had to then send it to payroll and I was forgetting to send it and, you know, things like that. So that was when it was put to me I could have an accountant and it would be a lot easier for me so that's what I wanted.**

**Personal budget holder, aged up to 49, combined budget, Local Authority D**

**6.12** However, there did appear to be some issues with awareness and understanding of these support services. In particular, one personal budget holder and carer in Local Authority D said that if they had taken up this accountancy service they would have had to pay for it, and this dissuaded them from taking up the offer of help. Also, users' experiences of a managed account were not always entirely positive, and some found the third party did not have a good customer service.

## Review and monitoring of personal budgets

**6.13** Monitoring and review are important elements of personal budgets in that they help ensure that users are making good use of their budget and are progressing toward the goals and outcomes identified in their support plan. The electronic payment card scheme set up in Local Authority B helped the council monitor spending. In addition, some budget holders in receipt of direct payments mentioned that they were, or could be, audited. In Local Authority D, Local Authority F and Local Authority E, recipients of direct payments knew that they needed to retain their receipts as evidence of their spending. In Local Authority C, awareness was mixed: a recipient of direct payment knew that he needed to keep receipts, but two service users who were applying for direct payments did not know that they would have to.

**6.14** Experiences of monitoring varied greatly. In Local Authority D, auditing appeared to be a straightforward process: direct payment recipients expected to be audited on a quarterly basis, and this did not cause them any undue concern or stress.

**Every three months they audit you so obviously they look at all the receipts and that side of it and bank statement. So the simpler I can keep it it's going to be easier to look at.**

*Carer, personal budget holder aged up to 49, direct payment, Local Authority D*

**If you've got effective audit and monitoring processes in place the risks are minimal really. We always have a six week audit, because if things are going to go wrong they go wrong in the first six weeks.**  
*Personal budget professional lead, Local Authority D*

**6.15** In Local Authority E however, a few direct payment recipients reported that they had not been audited in almost four years, and one recipient and carer said that they had never been asked for receipts.

## Screening and accreditation of suppliers

**6.16** A key expected benefit of a personal budget is that it enables the service user to access services and choose suppliers that they could not access via traditional care provision system. In particular, some participants moved to direct payments to be able to continue using a provider that was no longer on the local authority commissioning framework. The range of providers used made it difficult for local authorities to actually monitor the quality of the services personal budget holders were receiving. Quality of care was definitely an issue for many budget holders – in line with the IBSEN evaluation findings, which showed issues with providers' standards and regulations for users of individual budgets<sup>13</sup>.

**6.17** The main way in which local authorities tried to address this was through information provision. A number of authorities, including Local Authority F, Local Authority D, and Local Authority E were in the process to create “e-marketplaces” where users could go to find services and providers. Whilst these were still beginning to take shape when fieldwork was conducted, generally the intention was that they would cover a number of functions. For traditional services such as care homes, information on quality and accreditation would be quite easy to provide in the form of the Care Quality Commission (CQC) ratings and reports. For other services and providers, users would be able to post their own feedback, in a similar way that is common already for many mainstream leisure and tourism services such as hotels.

**When the e-marketplace comes online there has been talk about having some sort of customer feedback and so sort of looking at the eBay model. It's hopefully something that will be there in the future.**  
Personal budget professional lead, Local Authority E

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<sup>13</sup> <http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>

# **7. Impact of Personal Budgets**

## 7. Impact of Personal Budgets

**7.1** This chapter looks at the impact of personal budgets as reported by participants, whether professional leads or personal budget holders. It explores what the perceived impacts of personal budgets are, rather than measures or quantifies these impacts. Overall, the impact varied greatly depending on budget holders' circumstances. Few examples of negative impacts were brought up, and most budget holders were either positive or neutral.

### Differences by circumstances

**7.2** Budget holders' ability to reflect on the impact of their personal budget largely depended on their prior experience with care services.

**7.3** First, some participants had experienced a change to the way their social care needs were met as a direct result of the swap to a personal budget. They had experienced traditional forms of service provision before moving to a personal budget, and could therefore compare the two. For them, the impact of personal budgets was usually clear. Many of these people decided to move to a personal budget because they were unhappy with the traditional service provision.

**7.4** Next, the majority of budget holders in the study were new to adult social care services, following a change in their personal circumstances. The take up of a personal budget coincided with receiving care and support for the first time. It was therefore difficult to disentangle the impact of the personal budget from the impact of receiving care and support. All those who started receiving care found they were better off than without any care and support, so the precise impact of the personal budget was less clear.

**7.5** This situation was frequent. Indeed, many professional leads explained that new entrants were being encouraged to consider personal budgets – and in some local authorities such as Local Authority C, personal budgets were the only option available.

**They can refuse a direct payment but they can't refuse a personal budget. That's simply the financial allocation that we set that says this is the basis on which we make your support plan.**

Personal budget professional lead, Local Authority C

**7.6** Finally, some participants were unable to say what difference having a personal budget made to their lives, because they did not know that they had a personal budget, or because they received a managed budget, which did not really offer choice and control. The issue comes from the way local authorities define personal budgets, which vary greatly – reflecting concerns raised by local authorities regarding the reliability of the national indication NI130.

**All customers are set a personal budget or given a personal budget, new customers and existing customers when they have their annual review. So the numbers themselves are not particularly difficult to achieve. What is much more difficult to achieve is changing the impact that that has or making an impact on quality of life or on the services that people receive or in the choice and control that they're able to exercise. (...)**

Personal budget professional lead, Local Authority C

**Some councils I've heard had boosted their personal budget figures. They had just really transferred people who had been in talking booths to a personal budget. Well to me that's not personalisation.**

Personal budget professional lead, Local Authority A

## Impact on budget holders

### Positive impact

**7.7** Budget holders mentioned different types of impact, which reflected the impact mentioned by professional leads. These impacts focused on:

- **More personalised support.** Some participants reported that their care and support were better suited to their needs, interests and aspirations.
- **Increased choice, for instance choice of activities, day centres, care agencies, adaptations or equipment.** This was usually the case among people who were using their budget in a more innovative way, possibly as a result of good support planning. Some participants started new activities that suited them well. Those who had a personal assistant could choose exactly what to do with them, be that help with shopping or personal care, working on a hobby at home, or going out. They could go out more easily, without having to be accompanied by a family member. Being able to do activities independently of their partner, children or parents was very important to them. In turn, this **improved their quality of life and their independence** (Case Study 6).

- **Increased control over the care and support provided, for instance about who provides personal care, and when.** This control resulted in more convenient times for care visits and/or consistency of care – something particularly important for people with conditions such as dementia. Having the freedom to choose someone they could get on with was very important to budget holders and their carers. They wanted to be able to trust the person supporting them. Some budget holders and their family explained that their personal assistants had become close friends. Other chose to be supported by a family member or a friend, instead of a stranger.
- **Increased satisfaction with care and support.** Though all was not perfect, personal budget holders who could compare their situation with previous service provision were usually more satisfied with the support they were getting, as a result of the increased choice and control they benefited from.
- **Increased support.** A couple of people who were employing their own personal assistant said this allowed them to pay for more hours of care than if they had used a care agency, by paying the minimum wage. This was particularly useful for those who felt that the numbers of care hours allocated in their assessment was not sufficient to meet their needs.

#### **Case Study 6: Personal budget holder, aged up to 49, direct payment, Local Authority A**

Sarah has physical disabilities and had been employing a personal assistant, using direct payments, for over 10 years. When her personal assistant went on maternity leave a few years ago she was able to pay her mother to take over on a temporary basis. Since her personal assistant came back from maternity leave, she and her mum share the role, which works well as they can be flexible and cover each other when needed. Sarah prefers this arrangement to using a care agency as it ensures continuity of care and is also less expensive per hour.

Having this support makes a massive difference to her - she used to be tired all the time as household chores took a lot out of her, as did getting in and out of adapted car and carrying shopping alone. She is able to do more as a direct result of the help and because she has more energy. She also got a dog which was only possible because her personal assistant helps her clean after it.

**7.8** The types of impact identified in the research are similar to those that were identified in the IBSEN evaluation of individual budgets for disabled adults<sup>14</sup>.

### **Negative impact**

**7.9** Other participants mentioned that while personal budgets had a positive impact overall, they were by no means perfect. The issue more frequently mentioned related to the **poor quality of the care received**. Examples included personal assistants not fully meeting expectations (but the idea of addressing this was daunting), or care agencies perhaps being better than the previous one but still not up to the expected standards. Despite this, most felt that a personal budget was still the best option for them, or the person they cared for, and did not want to give up the choice and control it offered.

**7.10** A handful of participants reported a bad experience with direct payments, which resulted in **stress, upset, and confusion**. In one case, a personal assistant had threatened the budget holder's daughter (who managed the budget) with legal action, apparently for unfair dismissal. She had therefore reverted back to having three short care calls per day, via an agency, to help with her father's care, and was very stressed and worried about the potential for legal action (Case Study 4).

**7.11** In another case, the budget holder (with dementia) and his carer (his wife) had been accused of misusing their direct payment, and had to pay the money back. They were moved onto a third party managed budget, but the way it was managed lacked transparency. They could not get any explanation, they did not know how much their budget was and felt very confused (Case Study 5).

**7.12** Overall, the impact are in line with the findings from the Personal Budgets Outcomes Evaluation (POET) survey which found that 'significant majorities of personal budget holders reported positive experiences of the impact of personal budgets on their lives, but experiences of the personal budget process were in many cases deemed unsatisfactory'<sup>15</sup>.

**7.13** The impact also matched what professional leads aimed to achieve with personal budgets, or what they had already observed:

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<sup>14</sup> 'When polling data across the sample as a whole, we found that the IB group were significantly more likely to report feeling in control of their daily lives, the support they accessed and how it was delivered.' Evaluation of the Individual Budgets Pilot Programme, Summary Report, <http://www.york.ac.uk/inst/spru/pubs/pdf/IBSEN.pdf>

<sup>15</sup> <http://www.in-control.org.uk/media/92781/national%20personal%20budget%20survey%20summary%20findings.pdf>

**[I want] people to genuinely feel as if the outcomes that they've got are better than they would have had through a normal traditional service. [I want] people to genuinely say that they have the types of lives that they'd like to live, not one that they have to live, that it's one that they'd like to live and that the choice is real not just pretend.**

Personal budget professional lead, Local Authority A

**I think we have seen really meaningful improvements and outcomes for a number of people on personal budgets, particularly those who have taken the direct payment route. But I don't want to give a false impression that it's been life changing for everyone who's been offered a personal budget. It tends to be for people who perhaps were quite, are quite aware of alternatives, are articulate or are supported within an organisation or within a family that understand that.**

Personal budget professional lead, Local Authority D

**There have been some really inspirational stories about the difference it's made to people's lives. One guy who I initially came across because he was leading the opposition to the change and was very vehement in his hostility to the council and our treatment of disabled people, he's gone from that to being an absolute spokesperson for personal budgets in terms of the life changing difference it's made to his life.**

Personal budget professional lead, Local Authority D

## Impact on relatives

**7.14** While personal budgets aim to benefit disabled people, they also impacted on carers and other close family members, who were very concerned with the wellbeing of the budget holder. When personal budgets worked well for the budget holders, they provided carers and relatives with:

- **A break from their caring activities**, and some spare time to go out or do things they were not able to do while caring (Case Study 7);
- **Peace of mind and reassurance** that their loved one was safe, and was probably having a good time; and
- **Reassurance that their loved one could manage without them.** This was an important concern among parents of grown-up children with significant physical or

learning disabilities, who sometimes wondered how things would work out for their child if one day they could no longer care for them full-time.

### **Case Study 7: Personal budget holder and carer, personal budget holder aged up to 49, direct payment, Local Authority E**

Stephanie has physical disabilities and is hearing impaired. She uses direct payments to employ a PA for five hours a week to assist and accompany her with a range of mainly social activities, like shopping or visits to National Trust properties.

#### **She would do anything. Whatever I want to do she'd do it...**

She also uses direct payments to help with the cost of activities, running her PC (printing, paper etc.), which is important as email is a good way for her to communicate, and maintaining her outdoor electric chair, which allows her to pop out on her own when she likes. The main impact of the budget for Stephanie is independence, including having the option to go out without her husband if she feels like it.

#### **It's really good now, we get girlie, you know. You don't want men shopping without looking at boys stuff. I'm a little bit more independent**

Her husband agreed that it is good for them both to have some freedom, and the choice to do some activities alone if they prefer.

**It's made a good difference to me, I've got a choice like some days Stephanie and Jane, her support worker, may decide to go out somewhere and it'll be a case of 'do you want to come along or not?' and I'll say 'well no' or another time I'll say 'yes'. So I can do what I want to do. It works for us both that way because it gives us both a break from each other, because you know the position was I took an early retirement and so basically you know it [caring] is 24/7 isn't it?**

**7.15** Personal budgets, and direct payments in particular, also had some less positive impacts on carers and family members. Indeed, while the practicalities of accessing and managing personal budgets appeared to be fairly straightforward, some carers were fully responsible for the administrative side of things and for organising and coordinating support services from family members, for instance when the budget holder lacked capacity. Some carers were responsible for managing personal assistants, which they found challenging, reflecting the findings in the chapter on managing providers. Despite this, most carers who took part in an interview were happy with the decision to opt for direct payments.

### **Impact on take up of personal budgets**

**7.16** As personal budgets are being rolled out, examples were mentioned showing that they may be appealing to people who never used to ask their council for support (despite meeting eligibility criteria) or to people who used to pay for these services themselves.

**Before I received a direct payment I was paying for some of it [groups and activities] out of my own personal finances.**

**Personal budget holder, aged up to 49, direct payment, Local Authority D**

**7.17** For example, the couple mentioned in case study 7 heard about personal budgets through the local press and decided to look into how they might help them.

**7.18** Similarly, a participant who had been receiving unpaid support from a neighbour was told by her social worker that she might be eligible for a personal budget, and that she could use this to pay her neighbour for care and to help fund social activities. She got a personal budget, and it made her feel less guilty about asking her neighbours for help. It also enabled her to have a say over who supported her, while previously she just had to accept to be supported by whoever was willing to do this voluntarily.

**7.19** Such instances were not mentioned by professional leads, who had another take on the costs implications of personal budgets, emphasising the limited resources currently available in adult social care, and the potential cost effectiveness of personal budgets.

**We want to afford choice for people but it's also within the resources that we have, and legally what we have to provide as well.**

**Personal budget professional lead, Local Authority A**

**In the environment that we work in at the moment where there's an awful lot of emphasis on saving money, personalisation could be perceived as a means of saving money. When it was originally introduced it was never seen as saving money or costing more money. The notion was that it was cost neutral or that you had that potential of getting better outcomes for less money. And I think the evidence has been that when people are able to take full control that they do achieve better outcomes for less money.**

Personal budget professional lead, Local Authority E

## **8. Conclusion**

## 8. Conclusion

**8.1** This research has found that **managed budgets do not currently represent real choice**; care provision often continues in the same way as it would have under the previous system, sometimes without the budget holder even being aware they receive a personal budget. Only direct payments seem to offer budget holders real choice and control over their care.

**8.2** Many people are primarily interested in getting good quality of care, rather than **choice** – but they do not necessarily know what they miss out by not being given more say over their care and support, or by not having access to support planning. Indeed, examples were found of people who were well supported in their journey through the personal budget process and achieved much better outcomes with their personal budgets than would have been possible with traditional forms of service provision. To this effect, **effective support planning is instrumental in helping budget users get the most out of their personal budgets**, though it does not seem to happen consistently, reflecting concerns raised in the social work sector that personalisation represents a major cultural shift for the workforce and will take many years to fully implement.

**8.3** Supporting budget holders and carers throughout their journey with the personal budget – and not just at the start – is important in mitigating risks. The experience described by participants in some local authorities shows that support could be improved, in particular with regard to the availability and consistency of advice. **Practical support or training on choosing and managing a personal assistant** would make it more attractive for budget holders to use their budget to hire their own staff. Similarly, some of the negative impact of personal budgets could be pre-empted or reduced with a more robust **monitoring and review system**. **Further developing information provision**, advice, and guidance, including ways of collecting and disseminating users' feedback, is also likely to have a positive impact: this could make budget holders more confident about switching providers, reduce their confusion, and improve the quality of care received – something that was important to participants.

**8.4** Despite the small number of interviews in each local authority, **important differences between local authorities were found**. Those who had experience of personalisation initiatives such as Right to Control or individual budgets appeared to be more ahead of the game, and contrasting experiences were reported. There may be other factors accounting for these area differences, such as the way personal budgets are defined. **A shared**

**delivered** and personal budget holders supported could help reduce these geographical differences.

# Appendices

# Appendices

## Appendix 1: Topic guide for personal budget holder interviews

Topic guide – FINAL VERSION  
Face-to-face in-depth interviews with personal budget holders  
25 March 2011

### Objectives

Explore the experience of individuals using personal budgets for social care in order to establish:

- the extent to which people in receipt of personal budgets have been offered choice, their ability to exercise this choice, and the factors affecting this (e.g. information provision, availability of a range of suppliers, attitudes/support of social workers/others), and the difficulties involved in making decisions;
- the impact of personal budgets, e.g. on quality of care/services, choice, control, independence, overall quality of life; and
- how the personal budget system could be improved for users.

Key Questions	Notes	Appro x timing
<b>Section 1: Introduction and warm up</b>		<b>5 min</b>
<p><b>INTRODUCTION:</b></p> <ul style="list-style-type: none"> <li>○ Thank respondent for taking part.</li> <li>○ Introduce self, Ipsos MORI (including role – independent research organisation), explaining conducting research about their experience of receiving a personal budget for the NAO</li> <li>○ Check they received and read the info sheet (give them a copy if not), and ask if they have any questions about it</li> <li>○ Reassure respondents of confidentiality and anonymity – information will not be personally attributed, it will not affect the amount they receive for their personal budget.</li> <li>○ Gain permission to record and sign consent form (if participant cannot sign, record verbal consent on the digital recorder)</li> </ul> <p><b>WARM UP</b></p> <ul style="list-style-type: none"> <li>○ <b>When did you begin receiving a personal budget?</b></li> <li>○ <b>How is your personal budget managed – do you receive direct payments or does the</b></li> </ul>		

<p><b>council/another organisation manage it on your behalf</b> (or a combination of both)?</p> <ul style="list-style-type: none"> <li>○ <b>What do you use your personal budget for?</b></li> </ul> <p>Prompt for services vs one off purchases (equipment etc)</p>		
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Section 2: Enrolling on a personal budget		20 min
<ul style="list-style-type: none"> <li>○ <b>Please can you talk me through the stages you went through to get a personal budget, starting from how you first found out about them?</b></li> </ul> <p>Prompt with stages if needed:</p> <ul style="list-style-type: none"> <li>- how you first found out about personal budgets?</li> <li>- what happened after you were told you were eligible?</li> </ul> <p><b>REASONS FOR TAKING UP A PERSONAL BUDGET</b></p> <p>I'd like you to try to remember how you felt about the personal budget when you first got one.</p> <ul style="list-style-type: none"> <li>○ <b>Were you given the option to refuse the offer of a personal budget?</b> What options were you given?</li> <li>○ <b>How was the decision that you should have a PB made?</b> Was it your decision? Was anyone else involved in making the decision?</li> <li>○ <b>Why did you (other) decide to take a personal budget?</b> What difference did you think it would make to you? What did you expect from a PB back then? How did you think it would affect the support that you get?</li> <li>○ <b>Did you have any concerns about it back then?</b> What concerns did you have? Why? Did you express these? Who to? What was the response?</li> </ul> <p><b>SUPPORT PLANNING</b></p> <p>Now I'd like to hear more about how you decided what you would use the personal budget for, and how you agreed your support plan with the council.</p> <ul style="list-style-type: none"> <li>○ <b>How easy or difficult was it to think of what you wanted to do with the personal budget?</b> And how easy or difficult was it for you to think of how you could spend the budget to achieve these things? Why? What made these things easy/difficult?</li> <li>○ <b>Did you get any support to help you think about your goals and how you could achieve them?</b></li> </ul>	<p>Keep it brief, this is just a warm up question.</p> <p>Focus on extent of choice/ personal decision making at key stages</p> <p>Direct questions to recipient rather than carer. Be sensitive to any special needs which may impact on recall. If recipient can't remember the whole process then ask them if you can speak to their carer later to get more details, if they have one and he/she is present during</p>	

<p>Whom from? What did the support consist of? IF EXTERNAL SUPPORT, E.G. PROVIDED BY LOCAL AUTHORITY OR ULO, ASK How did you hear about this support? Was it offered to you or did you ask for help? How helpful was this support? What did you get out of it?</p> <ul style="list-style-type: none"> <li>○ <b>Were you able to spend the money on everything you wanted to?</b> IF NOT ASK Were you told why you couldn't spend your personal budget on these things? How did this make you feel?</li> <li>○ <b>Has your support plan been agreed now?</b> How satisfied or dissatisfied are you with it? Why?</li> </ul> <p>DECIDING HOW THEY WOULD RECEIVE THE PERSONAL BUDGET</p> <p>You told me you get your personal budget via &lt;INSERT AS APPROPRIATE direct payment/third party management/combination&gt;. Now I'd like to discuss how this decision was made.</p> <ul style="list-style-type: none"> <li>○ <b>What options were you given to receive your personal budget?</b> Are you aware of other options that you were not offered? Were you given the choice between different options? How well were these explained? IF WAS NOT GIVEN THE CHOICE BETWEEN ASK Why do you think you were not given the choice?</li> <li>○ <b>Who decided that you should receive your personal budget by &lt;INSERT&gt;?</b> Was it a difficult decision to make? Why?</li> <li>○ <b>Why did you choose this option rather than the other ones /why do you think they choose this option?</b> Back then, what did you think would be better about this option?</li> <li>○ <b>Were you given all the information you needed to decide how to receive your personal budget?</b> IF NOT What information would you have liked to receive to help you make up your mind?</li> <li>○ <b>Did you receive any support to help you decide which options would best suit your needs?</b> IF YES From whom? What did it consist of? How helpful was it? IF NO Would you have liked some support to help you decide?</li> </ul>	<p>the interview.</p>	
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Section 3: Managing a personal budget		20 min
<p><b>CHOOSING SUPPLIERS</b></p> <p>Now I'd like to discuss how you chose what suppliers to use.</p> <ul style="list-style-type: none"> <li>○ <b>Were you involved in choosing suppliers?</b> IF NOT Why not? ASK ALL Was anyone else involved in deciding which suppliers you should use? E.g. carer, family, friends, ULOs, Council.</li> <li>○ <b>How did you find out who were the suppliers available in your area?</b> Probe for looking on the internet/websites, information provided by ULOs/Council, etc</li> <li>○ <b>How many providers were there to choose from for the services or equipment you needed?</b> Was there enough choice, or would you have liked to have more choice? IF WANTED MORE CHOICE What was missing?</li> <li>○ <b>How did you choose which organisation to buy products/services from?</b> Was any info on price/quality/capacity provided (by whom)? How accessible was this? Was there any user feedback available? What else did you use to help you choose? IF USES PB TO PURCHASE EQUIPMENT did you ask for some quotes?</li> <li>○ <b>Did you have all the information you needed to decide which providers to use, or not?</b> What other info would have been useful?</li> <li>○ <b>How easy or difficult was it to choose providers?</b> Why? What could have made it easier?</li> <li>○ <b>Did you feel in control of the process of selecting the provider of services/equipment?</b> If not, why?</li> <li>○ <b>Do you think this was a good or a bad choice in the end?</b> What do you attribute this to?</li> </ul> <p><b>MANAGING PROVIDERS</b></p> <p>Now let's talk about the providers in more detail.</p> <ul style="list-style-type: none"> <li>○ <b>Who generally deals with managing your service/equipment providers? By this I mean telling them what to do, when to come, how to support you, etc.</b> Prompt for - self, council, family, friends, care worker.</li> <li>○ IF NOT SELF ASK Would you like to manage them yourself? What is stopping you? Is there anything that could enable you to manage suppliers yourself?</li> </ul>	<p>Make sure you adapt the questions to the respondent's context, i.e. find out what they use their PB for and relate to these suppliers. The respondent may find it easier to talk of how they choose a personal assistant, a wheelchair, or a provider for an adapted shower than about choosing 'suppliers' in general.</p>	

<ul style="list-style-type: none"> <li>○ IF SUPPLIERS ARE MANAGED BY PB RECIPIENTS OR BY A CARER/RELATIVE, ASK <b>How easy or difficult is it to manage suppliers?</b> Why? What makes it difficult? What could make it easier?</li> <li>○ IF MANAGED BY A THIRD PARTY <b>How well do you think your personal budget is managed by XX?</b> How good are they at dealing with providers on your behalf? What could they do better, if anything?</li> <li>○ IF USES DIRECT PAYMENT <b>How easy or difficult is it to contract with providers?</b> Prompt for – checking and paying invoices, collecting receipts. <b>What makes it easy/difficult? What could make it easier?</b> Do you need any support with these things? IF YES Do you get any support? IF YES From whom?</li> <li>○ ASK ALL WHO USE THEIR PB TO BUY HOME HELP OR PERSONAL ASSISTANT <b>What happens/would happen if your usual home help/personal assistant is off sick or on holiday?</b> How do you/third party handle this? Has it ever been an issue so far?</li> <li>○ ASK ALL <b>How happy or unhappy are you with your supplier(s) overall?</b> Why/why not? Have you/a third party tried to address any concerns? What was the outcome of this?</li> </ul> <p>SWITCHING PROVIDERS (PRIMARILY APPLIES FOR PEOPLE WHO USE THEIR PB TO BUY REGULAR SERVICES, RATHER THAN AS A ONE-OFF TO BUY EQUIPMENT)</p> <ul style="list-style-type: none"> <li>○ <b>Have you/would you ever consider switching providers?</b> Why/why not?</li> <li>○ IF HAVE SWITCHED - How did it work out? What triggered the change? Who made the decision to switch (you, council, care worker, family etc)? Did anyone else get involved to help you do this? How did the change make you feel (e.g. relieved, stressed, anxious)?</li> <li>○ IF HAS NEVER SWITCHED PROVIDER <b>How would you go about switching providers if the need arises?</b> Do you think swapping providers would be possible? Why/why not? PROBE FULLY e.g. lack of alternative, too much trouble to switch, support needs too complex to train another person, etc. <b>What kind of thing might make you want to switch? What kind of help/support, if any, would you need to be able to switch?</b> Who might be able to help with this?</li> <li>○ ASK ALL <b>What do you think could make switching providers easier for people who get a personal budget?</b> PROBE FULLY What else?</li> </ul>	<p>Look out for potential case studies</p>	
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Section 4: Impact of a personal budget		10 min
<ul style="list-style-type: none"> <li>○ <b>How have things changed for you since you have been receiving a personal budget?</b> PROBE FULLY Has anything else changed as a result of the personal budget? IF ONLY RECEIVING A PB FOR A VERY SHORT TIME ASK <b>How do you expect them to change?</b></li> </ul> <p>Prompt for impact on – overall well-being/quality of life, independence/sense of control, administrative burden, difficult decisions to make, anxiety about things going wrong, etc</p> <ul style="list-style-type: none"> <li>○ <b>What impact does the personal budget have on other people in your family – if any?</b></li> </ul> <p>Prompt - requires more time looking into options, admin, dealing with providers, concern about making the right decision etc.</p> <ul style="list-style-type: none"> <li>○ <b>Do you think the care/service/equipment you receive now is better or worse than it was before – or no different?</b></li> </ul> <p>How? Why is it better/worse? IF WORSE What could make it better? Probe for specific examples.</p> <ul style="list-style-type: none"> <li>○ <b>Does receiving a personal budget allow you do things you couldn't before?</b></li> </ul> <p>What things? How has the personal budget made this possible? Probe for specific examples.</p> <ul style="list-style-type: none"> <li>○ <b>Are you achieving the goals you were aiming for when you first received a personal budget?</b></li> </ul> <p>In what ways? Why/why not? What needs to change for you to be able to achieve the goals as in your support plan?</p>	<p>If respondent has just started to receive a PB and impact has not yet fully developed, ask about expected impact.</p> <p>Look out for possible case studies</p>	

Section 5: conclusion and summing up		5 min
<ul style="list-style-type: none"> <li>○ <b>Would you have made different decisions about your personal budget at the start given the experience you have had so far?</b> What is it that you would have done differently? Why?</li> <li>○ <b>What could make the personal budget system better?</b> For you? For others? How would it work in</li> </ul>		

<p>an ideal world?</p> <ul style="list-style-type: none"> <li>○ <b>What support, if any, do people need to get the most out of their personal budget?</b> Who should provide this? Why?</li> <li>○ <b>What information do people most need to get the most out of their personal budget?</b> Who should provide it?</li> <li>○ <b>Would you recommend a personal budget to a friend?</b> Why/why not? In what circumstance? Who would they suit/not suit?</li> <li>○ <b>Is there anything else you would like to add?</b></li> </ul> <p><b>Recontact question</b></p> <p>The NAO may be doing more research in future about personal budgets, would you be happy to be contacted at some stage in the next 12 months again by the NAO or another research organisation working on their behalf to be invited to take part in further research?</p> <p>Thanks and close, hand out incentives.</p>		
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## Appendix 2: Topic guide for interviews with personal budget professional leads

Topic guide – FINAL VERSION  
Telephone depth interviews with professional leads  
on personal budget in local authorities  
25 March 2011

### Objectives

These interviews aim to provide information to contextualise the findings from interviews with personal budget holders, and add a local authority perspective to the findings. They will ensure that findings from personal budget holders are interpreted within their local context, rather than in isolation.

The detailed objectives of these interviews with lead professionals on personal budgets are to explore:

- how successfully personal budgets have been implemented locally – and the factors affecting the roll out;
- the perceived risks associated with personal budgets, and how these are managed;
- the extent to which people in receipt of personal budgets can exercise choice, and the factors affecting their choice (e.g. information provision, accessible information, support available, availability of a range of suppliers, public attitudes e.g. from social workers or carers/families);
- the perceived impact of personal budgets on outcomes for personal budget holders; and
- how personal budgets should or could be improved for users to ensure a successful roll out.

Key Questions	Notes	Appro x timing
<b>Section 1: Introduction and warm up</b>		<b>2 min</b>
<p><b>INTRODUCTION:</b></p> <ul style="list-style-type: none"> <li>○ Thank respondent for taking part.</li> <li>○ Introduce self, Ipsos MORI (including role – independent research organisation), explain conducting research about personal budgets as part of a review for the NAO (also interviewing people who receive a PB).</li> <li>○ Your responses will remain confidential <b>to NAO and Ipsos MORI. If the NAO and your local authority agree that the NAO could benefit from visiting your local authority, the interview transcript will be passed to the NAO to inform their visit and avoid duplicating the ground covered in the interview.</b></li> </ul>		

<ul style="list-style-type: none"> <li>○ <b>Ipsos MORI and NAO guarantee to keep your participation anonymous.</b> This means that the information you provide will not be personally attributed (to you or your LA) in the NAO report, and participating local authorities will not be named in the NAO report.</li> <li>○ Ask permission for recording</li> </ul> <p><b>WARM UP</b></p> <ul style="list-style-type: none"> <li>○ <b>How long have you been in your current role? What are your responsibilities overall and in relation to personal budgets more precisely?</b></li> </ul>		
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Section 2: Context		5 min
<ul style="list-style-type: none"> <li>○ <b>Where does your LA stand in the roll out of PBs?</b> Is it ready for the roll-out to 100% by 2013? Why/why not? How mature do you think this local authority is on personalisation?</li> <li>○ <b>How easy or difficult is the roll out in your local authority?</b> Why? What is making it easy/difficult? PROBE FULLY What else?</li> <li>○ <b>Could you tell me roughly how widespread take-up has been so far, just to give me an idea?</b></li> <li>○ <b>Are PBs easier to implement for some groups of service users than others?</b> Which are harder/easier? Why?</li> <li>○ <b>Is there anything preventing social workers from offering personal budgets more widely?</b> What? PROBE FULLY Anything else? How is this being addressed/how could this be addressed?</li> <li>○ <b>Now looking at users' reactions to PB, are any client group more willing to have a PB than other?</b> Which group? What makes PB attractive to them? Which group are less willing? What makes PB unattractive to them?</li> <li>○ <b>What prevents service users (if anything) taking up a PB?</b> PROBE FULLY What else? How are you dealing with this? What else could or should be done to address this issue?</li> </ul>	<p>LAs may be reluctant to share information on take up rate. We just need this for context. We have some information from NI130 and ADASS but it's probably out of date.</p> <p>Ask this question to inform</p>	

<ul style="list-style-type: none"> <li>○ <b>What are the options available to budget holders to receive their personal budget?</b> PROBE FOR DIRECT PAYMENT, LA MANAGED, THIRD PARTY MANAGED, ETC</li> <li>○ <b>What is the balance of take up regarding direct payments, managed by LA or third party, or combination?</b> Is it in line with your expectations? What do you attribute this balance to?</li> </ul>	<p>discussions with PB holders</p> <p>LAs have very different figures on % of PB taken up by DP or third-party managed. We need to understand why – e.g. is this related to the LA's perceptions of risks associated with DP?</p>	
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Section 3: Choice and personal budgets		5 min
<ul style="list-style-type: none"> <li>○ <b>In practice, from what you can see, do PBs achieve their objective to give budget holders more choice and control over the social care services and equipment they receive?</b> Why/why not?</li> <li>○ <b>What factors make it easier/more difficult for budget holders to make choice about their social care needs?</b> How could these issues be resolved? What could make it easier for users to exercise choice about their social care needs?</li> <li>○ <b>Are any stages of the PB process more challenging than others for budget holders?</b> Prompt for - support planning, identifying and choosing providers, managing suppliers, budgeting over time.</li> <li>○ <b>Do any particular groups of users struggle with certain aspects more than others?</b> Who? Probe for specific issues and user groups.</li> </ul>		

Section 4: Supporting choice, facilitating PBs process and management		5 min
<ul style="list-style-type: none"> <li>○ <b>What is being done locally to support service users while they...</b> <ul style="list-style-type: none"> <li>a) <b>take up a PB (esp. during support planning)?</b> Do they need support while they enrol? What for in particular? Is the decision on type of PB (Direct payment, LA or third party managed, combination) a difficult one to make for service users? What does the support available during take-up consist of?</li> <li>b) <b>manage a PB once it has been approved</b> Prompt for - when getting quotes, collecting receipts, planning their budget over time.</li> </ul> </li> <li>○ <b>Who provides support?</b> If necessary prompt - LA, User Led Organisations (ULOs) such as Centre for Independent Living? IF NOT THE LA: What do they bring that your social workers cannot bring? How did you decide who should support PB recipients?</li> <li>○ <b>How do you decide who needs support to take up and manage a PB?</b> Any client groups in particular? Is there enough support available for everyone who needs it? Probe for possible waiting time/list, bottleneck during support planning.</li> <li>○ <b>What impact does this support have on PB recipients?</b> How essential is it for a successful roll out of PBs in your LA?</li> <li>○ <b>Should or could anything else be done to support people while they take up and manage a PB?</b> What for? What difference would it make? How important is that? What's stopping your LA from implementing it?</li> </ul>		

Section 5: Providers market and information provision		10 min
<ul style="list-style-type: none"> <li>○ <b>Are there enough providers locally for PB holders to buy the services/equipment they want?</b> IF NOT Why not?</li> </ul>	This is a key section. Make sure you have	

<p>IF YES What has your LA done, if anything, to help develop the market locally (e.g. encouraging new entry)? Are there any area of the market where there is no choice of providers at all? How do you think this affects PB holders?</p> <ul style="list-style-type: none"> <li>○ <b>Are there any types of services or equipment where is a shortage of providers compared with the demand?</b> What for? Why do you think this is happening? What could be done to help regulate this? By whom? What are the implications of this for PB holders? (e.g. higher fees if monopoly situation, waiting time, poor quality of care...)</li> <li>○ <b>Is the providers market in your area static or are new providers also entering the market?</b> What impact does this have on PB holders?</li> <li>○ <b>What if anything has been/is being done locally to inform the providers market of PB needs, and by whom?</b> How successful is it? How important is this for the successful roll out of PB?</li> <li>○ <b>Where and how can PB holders access information about what services are available in their area and potential providers?</b> Prompt for - internet, paper etc. From LA, third parties (e.g. ULOs) etc.</li> <li>○ <b>What information about service providers is available to PB holders?</b> Prompt for - contact details, quality standards such as Care Quality Commission (CQC) ratings, feedback from other users, anything else? Are you aware of any unmet information needs?</li> <li>○ <b>Has anything done locally to help personal budget holders access reliable information in accessible format to inform their choice and decisions?</b> IF YES How successful has it been? What else should be done? IF NO Is there a need to do anything?</li> <li>○ <b>From what you know, how practical is it for PB holders to switch providers?</b> Why? Does this vary depending on the type of PB</li> </ul>	<p>enough time to ask all the questions</p>	
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<p>(direct payments, LA or third party managed, combination).</p> <p>Is that an issue for PB holders? Does it affect the roll out of PBs in your LA in any way?</p> <ul style="list-style-type: none"> <li>○ <b>How could the barriers to switching be overcome?</b> What is the LAs role in this? Who else has a role to play?</li> </ul>		
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<b>Section 6: Perceived risks</b>		<b>3 min</b>
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<ul style="list-style-type: none"> <li>○ <b>What do you think are the risks in PBs compared with traditional service provision? PROBE FULLY</b> What else? IF THE FOLLOWING RISKS ARE NOT MENTIONED, ASK IF RESPONDENT FEELS THEY CONSTITUTE A RISK: budget misuse, poor quality of services/providers, users' personal safety, managing a set budget over a certain period of time.</li> <li>○ <b>Which risks have the most/least impact, which are most/least likely to occur?</b></li> <li>○ <b>How do social workers feel about these risks? How do these risks affect the roll out of PBs in your LA?</b> Do these risks slow the roll out of PBs in any way?</li> </ul>		
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<b>Section 7: Management of risks</b>		<b>3 min</b>
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<ul style="list-style-type: none"> <li>○ <b>How are the risks identified and managed (if at all)?</b> What is being done to manage these risks? By whom (LA, specially created panel, ULOs...)</li> <li>○ <b>What is making it easy/difficult to manage them?</b> Why? What could make it easier to manage them? Is risk management getting better/worse over time and why?</li> <li>○ <b>In practice, what happens when the risks identified above occur?</b> Probe for real life examples/case studies</li> </ul>		
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<b>Section 8: Conclusion and summing up</b>		<b>2 min</b>
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<ul style="list-style-type: none"> <li>○ <b>What do you think are the main outcomes of PBs for those who have one?</b></li>   <li>○ <b>What is producing good outcomes for service users in the way PBs are implemented in your LA?</b>  What has worked well in your LA that could be useful elsewhere? What have you picked up from the experience of other LAs?</li>   <li>○ <b>What else should or could be done in the implementation of PBs to ensure that they produce the best possible outcomes for service users, locally or nationally?</b></li>   <li>○ <b>Do you have any concerns about the roll-out of PBs not already discussed? PROBE FULLY</b> Any other concerns?</li> </ul> <p>Thank and close</p>		
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*Note: Timings in brackets are indicative: if respondents have more relevant things to say we will continue the interview for longer. The timings primarily reflect the relative importance of the sections.*