

# Older people's experiences of planning and arranging support with a personal budget



## A report on the findings from a study carried out jointly by Westminster City Council and Age Concern Westminster

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## Introduction

As part of the transformation of social care, set out in *Putting People First*, councils are required to make personal budgets (PBs) available to everyone who has ongoing care and support needs so that they will have more control over how the money allocated to their care is spent. A personal budget refers to the amount of social care money that an eligible person has to fund their care and support, calculated on the basis of an assessment of their needs. The person eligible can have control over their budget in a number of ways:

- as a direct payment (a cash payment held directly by the person, or where they lack capacity, by a 'suitable person')
- as an 'account' held and managed by the council in accordance with the person's wishes and 'called-off' by the user in direct negotiation with the provider
- as a combination of the above

The agreed minimum target for all councils is that by 2010-11, 30% of people who have a community based social care package in that year will have taken up self-directed support. To achieve this target councils are in the process of replacing existing systems with a system of self-directed support which includes a number of distinct stages: self-directed assessment, an 'up-front' allocation of resources, and support planning.

Westminster City Council introduced PBs on a phased basis in 2009 initially with people with learning disabilities and then with older people and people with physical disabilities. This paper summarises the findings of a small scale study carried out jointly with Age Concern Westminster to explore the views and experiences of people aged 50 years and over who had received a PB or who were in the process of getting one. The study was approved by the Council's Research Governance Framework process and forms part of the Council's on-going work to capture and learn from users' experiences of having a PB across all care groups.

## Aims

The main aim of the study was to explore the views and experiences of older people with regard to two areas in particular:

- the different stages involved in getting a PB, particularly the extent to which people felt they were in control of each stage;
- the impact that having a PB had had on their overall quality of life (where support was in place).

## Sample

The sample comprised people aged 50 years and over who at the beginning of September 2009 had completed a supported self-assessment form and who had started a support plan but who did not necessarily have the support in place. It excluded people in this age group who had mental health problems or who had learning disabilities as these groups were due to be followed up separately in parallel surveys over a longer time period. After excluding the people in these two groups, and also people who had moved away or who had died since applying for a PB, the total sample comprised 39 people.

Just over half (54%) of the sample were women. Just under a third (31%) were aged 50 to 64 years; 23% 65 to 74, 33% 75 to 84; and 13% 85+ years.

## Method

The study was carried out by postal survey in combination with telephone and personal interviews.

The survey questionnaire asked people about their views and experiences with regard to five areas:

- Getting started on a personal budget
- Completing the supported self-assessment form
- Developing the support plan
- Arranging the help and support set out in the support plan
- The impact of having a personal budget

In the case of the second, third and fourth areas, it asked about six themes in particular:

- The need for help and support
- Understanding the process
- Whether the particular stage had achieved its goal (for example in identifying needs or addressing identified needs)
- Being in control
- Ownership of the output (an aspect of control)
- Overview (how people felt about each stage overall)

The survey questionnaire was developed jointly by the authors with advice from colleagues. Because of data confidentiality issues, the postal survey was carried out by staff from the Council. To allow for data sharing between the two agencies, and also to allow for the opportunity for follow-up, respondents were asked at the end of the questionnaire whether they would be willing for a copy of their completed questionnaire to be passed to a researcher from Age Concern Westminster, and whether they would be willing to be contacted by the researcher to see if they would like to take part in further research about PBs.

The survey was carried out between mid-September 2009 and mid-December 2009. A letter explaining the aims of the survey together with a copy of the survey questionnaire was sent to everyone in the sample with the exception of six people for whom it was not appropriate to include in a postal survey, either because they had a visual impairment or did not read or speak English. So that the views of these six people could be included, each was approached by telephone to see if they would be willing to take part in the survey.

Shortly after the initial mail out of the questionnaires staff of the Royal Mail engaged in industrial action extending over a period of weeks. The net effect of this action was to create considerable uncertainty as to whether or not the selected sample had received the survey questionnaire, or indeed whether they had completed and returned it.

When the industrial action ended, to be sure that everyone had received the invitation to take part in the survey, everyone who had been sent a copy of the original letter was sent a reminder along with a copy of the original letter and a copy of the survey questionnaire.

### **Response rate**

At the end of the survey period a total of nine questionnaires had been returned. In three cases the respondents made comments on the questionnaire which indicated that they did not really understand the context of the questions, or did not see the questions as being relevant to their own experiences.

In the case of the six people who were approached by telephone, only three were able to be contacted, despite repeated attempts in the case of the other three. One of these three asked to be sent a copy of the survey letter and questionnaire. Two others said they would be willing to be contacted by the researcher from Age Concern Westminster and to take part in the survey. Both respondents were subsequently visited at home by the researcher but again both did not make a connection between the questions being asked in the questionnaire and their own experiences of getting a PB.

In summary, eleven people (28%) in the sample responded to the survey in some way. However, five people did not make a connection between the questions being asked in the survey questionnaire and their experiences of getting a PB, leaving only six people who completed a questionnaire – a response rate of 15%.

### **Key findings**

This section looks at the findings for the six respondents who completed the survey questionnaire in full. Four of the six respondents were women. Four were aged 50 to 64 years, one was aged 65 to 74 years, and another aged 75 to 84 years. Four respondents described themselves as White British, one as Black British, and one as Asian British.

**Box 1** Whether respondents agreed or disagreed with a series of statements about the different stages involved in getting a personal budget

	Agree	Disagree
<b>Completing the supported self assessment form (n=6)</b>		
I needed a lot of help to complete the self-assessment form	3	2
I understood all the questions on the self-assessment form	4	2
The form allowed me to talk about everything I wanted to talk about in relation to my needs	5	1
Completing the self-assessment form was a positive step	5	1
<b>Developing the support plan (n=6)</b>		
I needed a lot of help to develop my support plan	3	3
I found the whole process of developing a support plan straightforward	4	2
I had a very clear idea of what I wanted to achieve through my support plan	5	1
The development of my support plan was a positive experience	5	1
<b>Arranging help and support (n=5)</b>		
I've needed a lot of help to range the support in my support plan	4	1
The person who has helped me has helped me to think about lots of different ways I can use my budget	3	2
Arranging the support in my support plan has been a positive step	4	1

### A. Getting started on a personal budget

All but one of the six respondents said that they found out about PBs through a worker from the Council. Together the respondents were evenly divided between those who said they had found the information they had been given on PBs easy to understand and those who said they had not found it easy. Most (four) said that they had chosen to have a PB on the suggestion or advice of a professional worker. Only two respondents said that they had decided to have a PB because they thought it would give them more say over what help and support they got. Two respondents said they had had no other option.

### B. Completing the supported self-assessment form

**i) Need for support.** All six respondents said that they had received help to complete the supported self-assessment form, in every case from a professional worker from the Council. Three respondents said that they had needed a lot of help to complete the form but only one said they had left the task of completing it to the worker who had helped them (Box 1).

**ii) Understanding the process.** Most (four) of the respondents said they had understood all of the questions on the supported self-assessment form; two said they had not understood them all, one of whom indicated that they had had difficulty in understanding the whole process.

**iii) Identifying needs.** All but one of the respondents said that the process of completing the supported self-assessment form had allowed them to look at their needs as a whole and also to talk about everything they had wanted to talk about so far as their needs were concerned. However, only three respondents said that the process had identified all of their needs for support. Another said it had identified most of their needs and two that it identified only a few of their needs. In the latter two cases this was because they felt it had not identified the extent of their illness or had not taken account of the fact that their disability varied from to day.

**iv) Being in control.** Three of the respondents said that they had always felt in control over what answers were given on the

form, with the others saying that they mostly, only sometimes, or hardly ever felt in control of what answers were given. In the last case this was because they had found the whole process difficult to understand. Despite this there was little evidence that there had been differences of opinion between the respondents and the person who had been helping them over what answers to give, though two respondents did say that there were some questions that they did not want to answer as they asked about things that they regarded as private.

**v) Ownership.** The respondents tended to see the supported self-assessment form as a council document. All but one said they thought the form belonged to the Council or to the person who helped them complete the form. The remaining respondent said that they thought it belonged exclusively to themselves. In total two respondents said that they thought the form belonged to themselves either exclusively or jointly with the Council. Most (five) said they did not have a copy of the form or were unsure whether they had a copy.

**vi) Overview.** All but one of the respondents said that completing the supported self-assessment form had been a positive step and all six said that they had been treated with respect throughout by the person who had helped them.

### **C Developing a support plan**

**i) Need for support.** All six respondents said that they had had help from a professional worker to develop their support plan, with three also saying that they had had help from a relative or friend. As with the pattern for the supported self-assessment form, three respondents said that they had needed a lot of help to develop their plan. Despite this only one respondent said that they had left the task of developing it to the person who had been helping them.

**ii) Understanding the process.** Most (four) respondents said that they had found the process of developing a support plan straightforward but two said they had not done

so; both of these respondents also said that they had been unclear as to what they could or could not put in their support plan.

**iii) Addressing needs.** Four of the six respondents said that their support plan addressed all of their needs for support, with another saying it addressed most of their needs. One said that it addressed only a few of their needs. In this last case this was because they felt they had not been involved properly in the process.

**iv) Being in control.** All but one of the respondents said that they had a very clear idea of what they wanted to achieve through their support plan. And all but one said that the person who helped them had a very good understanding of what they wanted to achieve.

Most (four) respondents said that they had always felt in control of what went in their support plan, with the others saying they had hardly ever or never felt in control. In one case this was because they had difficulty in understanding the paperwork and procedures. In two cases respondents said that they had found it difficult to get their views across about what they wanted to happen.

**v) Ownership.** Compared with the supported self-assessment form, respondents were more likely to see themselves as owning the support plan. Four of the six respondents said that they thought the plan belonged to them with three saying they owned it jointly with the Council. Despite this, only one respondent said that they had a copy of their support plan and only two said that they had a copy of their planned budget.

### **D. Arranging help and support**

At the time of the survey five of the six respondents said that they were getting all or some of the support set out in their support plan. This section, and the next one on perceived impact, relate to these five respondents.

**Box 2** Whether respondents agreed or disagreed with a series of statements about the difference having a personal budget had made to their quality of life (n=5)

	Agree	Disagree	No response
Having a Personal Budget means I'm getting the help that's right for me	4	1	-
Having a Personal Budget is transforming my life for the better	2	1	2
I'm finding it a struggle to understand how I can make my Personal Budget work for me	2	2	1
I would strongly recommend a Personal Budget to other people	3	1	1

**i) Need for help.** Four of these five respondents said that they had needed a lot of help to arrange the support in their support plan.

**ii) Being in control.** Four of these five respondents said that the person who helped them had always put their interests first, and three that the person had helped to think about lots of different ways they could use their budget.

**iii) Sufficiency of budget.** All but one of these five respondents felt that their planned budget was sufficient to buy the support they needed, with another saying that it was more than sufficient.

**iv) Overview.** Four of these five respondents said that this stage had been a positive step. All five said that the person who had helped them had treated them with respect throughout.

### **E. Impact of personal budgets**

The respondents were divided as to the impact having a PB had had on their quality of life (Box 2).

Three respondents were positive about the impact, two more so than the other. In each case, all three or all but one said that having a PB had transformed their lives for the better, that it had allowed them to get the help that was right for them, that it had allowed them to do the things that they wanted to do, that they felt in control of their lives, and that they would recommend a PB to other people. All three

respondents had previously been in receipt of services arranged by the Council and all three felt that the support they had arranged through a PB was better, with two saying it was a lot better. As one respondent put it, ". . . it has given me the freedom to be myself as much as my illness allows."

The remaining two respondents were much less positive in these respects; both said that they were finding it a struggle to understand how they could make their PB work for them and both said that they didn't really want to be bothered with a PB.

### **Conclusion**

A key feature of this study was the very low response rate. This was unexpected especially since it contrasts with the much higher response rate achieved in a comparable study carried out in Westminster among older people who were receiving Direct Payments. One factor which may have contributed to the low response was the industrial action during the survey period. Others may have been the passage of time since people started out on the process, and a change of mind about wanting a PB.

But another possible factor, and possibly the main one, is that people did not see the survey as being relevant to them - in that they did not make a connection between their experiences of getting a PB and the questions asked in the questionnaire. This was certainly true for most of the participants included in this survey who had started the process of

receiving a PB but who had not yet completed the process.

Because of the low response rate, it is not appropriate to generalise from the findings but so far as the people who replied are concerned their experiences were somewhat mixed although on balance more positive than negative.

In terms of the overall impact that PB had had on people's lives, the respondents were divided; some (three) were clear that it had had a positive impact while others (two) were much less positive.

In terms of the different stages all the respondents had gone through to get a PB, some had clearly needed a lot of support at each stage but most said that they said that they had felt in control of each stage, that they were clear about what they wanted to achieve through their support plan, and that they had a sense of owning the support plan either exclusively or jointly with the Council.

The two respondents who were least positive about their PB seemed to have had very different experiences; whereas one felt that each step in the process had been a positive step, the other had a very different opinion.

Whether or not respondents were positive about the impact of their PBs, their experiences of the process raised a number of issues which need to be addressed. The main ones were not having all needs identified through the self-assessment process, not feeling comfortable about answering some questions because they asked about what were felt to be private matters, finding it difficult to get their views across, not being given a copy of the planned budget (or not being aware that they had been given a copy) and not being sure what could or could not be put in the support plan.

In general the respondents had not embarked on the process with high expectations, possibly because they did not fully understand what it was trying to do; only two people said specifically that they had opted for a PB

because they thought it would give them more say and more control over what support they got; the rest said that they had opted for it on the advice of a professional worker or because there was no alternative.

### **Lessons**

PBs will only succeed in transforming people's lives if a supporting infrastructure is in place:

- People need to be provided with good quality, accessible information about PBs; this should explain why PBs have been introduced and what they involve, and address the concerns older people are likely to have, for example about the availability of support
- The supported self-assessment forms need to be sufficiently sensitive to identify the full extent of an individual's needs, including needs that vary from day to day
- All recipients of PBs should be provided with copies of any relevant documentation in particular the support plan and the planned budget
- Mechanisms should be put in place to make it possible to identify people who are struggling to manage their PBs and who may benefit from additional support