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Personal Health Budgets and Maternity Care

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DH 2541

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Summary

As part of the piloting of personal health budgets across England, one site piloted personal health budgets for maternity care. A particularly deprived locality was chosen, where there was a risk of women with social and health problems failing to access conventional antenatal services. Thirty six women were offered personal health budgets; ten were selected for in-depth interview, three months after the birth of their baby. These ten were among the first to be offered a budget for maternity care and may not have been representative of all 36 women.

Interviewees reported that they were first told about personal health budgets by a midwife early in their pregnancies. They subsequently had two or more meetings with a broker to discuss plans for using the budget, based on a list of possible uses. All the interviewees knew the level of their budget although none knew how this had been calculated. They used their budgets to purchase a combination of exercise treatments, yoga, reflexology, and doula birth attendants, both before and after the birth of the baby.

Interviewees were almost wholly positive about the benefits of the personal health budget on their well-being and, indirectly, on their babies and families as well. Their subjective accounts are consistent with the overall findings of the main personal health budget evaluation, that personal health budgets can have a positive impact on care-related quality of life and psychological well-being.

Interviewees appreciated the information and help they had with planning how to use their budget and the fact that they did not have to be responsible for sourcing services or managing the budget. Some suggestions for improving information about the budget were made, particularly to emphasise the fact that it could be used flexibly before and after birth; and that support plans could be reviewed and revised, should health or other problems prevent the budget being used as originally agreed.

1. Introduction

1.1 Background – personal health budgets

Personal health budgets are central to the development of more personalised health care in England; the overarching aim is to create a more patient-centred, responsive NHS (Department of Health 2009). The contribution of personal health budgets to this broader transformation, and the Government's commitment to the policy, was restated in the NHS White Paper *Equity and Excellence – Liberating the NHS* (HM Government 2010) and further reiterated in the Government's response to the report of the NHS Future Forum (HM Government 2011).

Personal health budgets aim to give individuals more choice about the services and support they receive, and greater control over the money that is spent on some aspects of their health care (but excluding primary and emergency care). The process for receiving a personal health budget is that, after an assessment of needs, the patient is told how much money is available to them and draws up plans for using the budget in ways that are intended to benefit their health and wellbeing. These plans are agreed with the primary care trust (PCT), after scrutiny for possible clinical and other risks. The personal health budget money can be held and managed by a health professional; held by another third party on behalf of the patient; taken as a cash direct payment held by the patient; or as a combination of these.

In 2009, the Department of Health invited PCTs to become pilot sites for personal health budgets. Between them, the pilot sites offered personal health budgets to people with a range of long-term conditions including diabetes, lung diseases, mental health problems, stroke, long-term neurological conditions or those eligible for NHS Continuing Healthcare. Personal health budgets were also piloted in one PCT for maternity care and in three PCTs for end-of-life care.

1.2 The evaluation of the personal health budget pilots

Personal health budgets are new to the NHS and involve major cultural and organisational changes for services, professionals and patients. Evaluating the pilot projects is therefore very important and the evaluation will help to inform the subsequent extension of the initiative. Twenty of the PCTs piloting personal health budgets took part in an in-depth, multi-method evaluation of the programme, with the other pilot sites forming a wider cohort and contributing to a less detailed evaluation. The in-depth evaluation examined the impacts of personal health budgets on budget holders, carers and the wider NHS.

The overall aims of the evaluation were to identify whether personal health budgets deliver better outcomes for patients than conventional health services and, if so, how

they should best be implemented (for full details see www.phbe.org.uk). The overall conclusion of the evaluation was that personal health budgets are associated with a significant improvement in care-related quality of life and psychological well-being, particularly for people with higher value personal health budgets (Forder *et al.*, 2012).

One strand of the evaluation examined in depth the experiences of subsamples of patients and carers who were offered personal health budgets. One report was published on patients' experiences of learning about personal health budgets and early plans for using them, around three months after accepting the offer of a personal health budget (Irvine *et al.*, 2011). A further report examined patients' and carers' experiences of using their personal health budget and the impacts on their lives, around nine months after the offer of the budget (Davidson *et al.*, 2012).

This report presents findings from interviews with a small sample of women who were offered personal health budgets for maternity care. The interviews were conducted around three months after the birth of their baby. Only one site piloted personal health budgets for maternity care, with a relatively small number of women. The evaluation therefore focused on obtaining qualitative evidence on the aims of the maternity pilot and on the experiences and outcomes of personal health budgets for some of the women who took part in it. Although small scale, this evidence nevertheless provides valuable learning for other localities that may wish to offer personal health budgets for maternity care, beyond the pilot programme.

1.3 Background to the maternity pilot

Information on the aims and context of the maternity pilot was obtained from interviews carried out by the evaluation team with the relevant personal health budget pilot lead officer, as part of a wider programme of interviews about the aims and organisation of local pilots (see Forder *et al.*, 2012). The maternity pilot was situated in a very deprived part of the pilot site, where women tended not to use standard antenatal or post-natal support services. The pilot aimed to supplement or replace standard antenatal or post-natal NHS maternity care for women who were vulnerable in some way: for example, they were not in touch with maternity and other health services; there were concerns about child neglect; they had previously suffered post-natal depression; or they had previously had a child taken into care. Not all the women involved in the pilot were vulnerable; some just wanted to try different services to the standard NHS services on offer.

The pilot involved a considerable amount of joint working with local health professionals and children's services. A midwife visited each woman shortly after her first contact with maternity services (the 'booking in' appointment) and introduced the idea of a personal health budget. Detailed support planning then took place with

a broker, who was easily accessible to the budget-holders, should they have queries about their budget or how it could be used. A local Children's Centre was also involved in supporting women who might benefit from a personal health budget; providing support for some socially isolated women; identifying potentially relevant services in the community and signposting budget-holders to them; and providing doulas (lay birth attendants) for those women who chose to use their budget for this service. Completed care/support plans were approved by community midwives. The level of the budget, set at £500 for each woman, was based on the estimated costs of NHS antenatal and post-natal support services.

1.4 Selecting and interviewing the sample

A total of 36 women in the early stages of pregnancy were offered a personal health budget and recruited to the evaluation. Subsequently the research team was advised by the local personal health budget lead officer that it would not be appropriate to recontact 12 of these women for interview because of adverse personal circumstances. From the remaining 24 women, the research team selected ten women for interview, three months after the birth of their baby; this time period was considered appropriate to allow reflection on the personal budget experience and its benefits, but without risking significant loss of recall. Because of time constraints within the evaluation timetable, these ten women were the earliest to be offered a personal health budget for maternity care and, therefore, able to be interviewed within the timescale of the evaluation.

Four of the 12 women who the research team were advised not to recontact had had their babies taken into care or were experiencing other serious domestic problems. No information was available about why the other eight had withdrawn from the study. It is therefore possible that the remaining 24 women from whom the ten interviewees were selected were unrepresentative of all those offered a personal health budget for maternity care and, in particular, may have excluded those in very difficult or challenging circumstances. Moreover, because the ten women selected from the remaining 24 were among the earliest to have been offered a personal health budget for maternity care, it is also possible that their experiences may have been different from those offered a budget later in the pilot project.

The ten women were contacted by letter three months after the birth of their baby and invited to take part in a telephone or face-to-face interview lasting no more than an hour. All agreed to this request. Consent to the interview was obtained in writing or digitally recorded at the start of the interview. Semi-structured interviews were conducted using a topic guide (Appendix A). The interviews covered the women's experiences of learning about and deciding how to use the personal health budget; and the impacts of the budget on their own health and wellbeing, their baby and their wider family. Each interview was digitally recorded and fully transcribed. The

transcripts were charted according to the main themes and issues covered in the topic guide.

The sample is small and potentially unrepresentative of all the women offered personal health budgets for maternity care in this site. Caution must therefore be exercised when interpreting and using the findings from this strand of the evaluation. Nevertheless the report offers unique and valuable insights into the potential benefits of personal health budgets in maternity care.

2. Findings

2.1 The sample of personal health budget maternity interviewees

All ten women who took part in the interviews were married or living with their (male) partner. Seven of the women were having their first child; the remaining three already had one or more children. One woman reported her baby had been conceived through IVF treatment; a second had had IVF treatment prior to the pregnancy although her baby was eventually conceived naturally. Two of the ten women reported having long-standing health problems and another four reported having had difficult pregnancies, including severe and persistent sickness, back problems, chest and bladder infections and pelvic problems. One of these four women had to attend hospital daily during the final stages of her pregnancy and her baby was induced early, at short notice. Several of the women were in paid work up to the final weeks of their pregnancy. None of the ten women reported any other adverse social or family circumstances; this, plus the absence of any lone mothers, again suggests the subsample may not be fully representative of all those offered a personal health budget for maternity care.

2.2. Learning about the personal health budget and first impressions

All ten women reported they had first been told about the personal health budget by a midwife early in their pregnancy; some specifically linked this to a 'booking in' appointment at around ten weeks. They recalled their initial response as wholly positive and none had any hesitation in signing up for the pilot:

I don't think anyone would not like it and not appreciate it, so I thought 'This is fantastic'.

I thought it was a brilliant idea ... just offering people more when they're pregnant, that little bit extra that you normally can't do.

I'm somebody who knows generally what my needs are and it's difficult when you know what your needs are and you come across red tape or bureaucracy ... so for me it was a really vital resource.

Two women were under the impression that the offer of the personal health budget was somehow a response to the introduction of restrictions on eligibility for maternity grants (<http://www.bbc.co.uk/news/business-12265665>) that they would otherwise have been entitled to. Other early impressions were that the personal health budget was preventive, helping to avoid postnatal depression and build the relationship between a new mother and her baby; or that it was a substitute for conventional antenatal classes:

I thought it was a very good idea 'cos there are a lot of women that don't go to antenatal classes.

Only one interviewee indicated that she had already been considering purchasing privately some of the service options that were available through the personal health budget.

2.3 Deciding how to use the personal health budget

Once they had been recruited by a midwife to the personal health budget pilot, all ten interviewees then had one or more discussions with a personal health budget broker to plan how they would use the budget. Most recalled being given a list of potential options, including conventional antenatal classes:

They showed me a shopping list of the things I could have and discussed it with me and roughly how much they'd cost.

One or two interviewees recalled also being told how other women had decided to use their budget; and about research on the benefits of one option on the list, reflexology, during labour (*that really swayed it for me*).

Two interviewees experienced painful pelvic problems during their pregnancy and had been referred for NHS physiotherapy services. However, there were local delays in accessing NHS physiotherapy and they were advised to consider using their personal health budget to purchase private physiotherapy instead (one of these women did, the other was eventually able to access NHS physiotherapy faster than had been expected).

All ten interviewees chose a combination of ante- and/or post-natal yoga classes, reflexology, massage, gym membership, ante and/or post-natal swimming and/or a doula. It was widely understood by interviewees that their options were limited to the options on the list, but none of them reported feeling restricted by this and unable to choose something else, not on the list, that they would have preferred. Only one woman chose an item not on the list for part of her personal health budget – hiring a birthing pool for a home birth:

I was kind of a little bit worried initially because I was kind of thinking 'Ooh do I have to pick from this list?'... 'cos that's not really empowering me.

Another interviewee reported that she had wanted to pay for the cost of travel to the gym (her chosen use for the personal health budget) from the budget, but had been told this was not possible. A few were restricted by health problems from choosing some of the options on the list – for example women with back problems were unable to consider some exercise options. Others reported that they were restricted

by paid work commitments (including shift work) from choosing options such as yoga classes that were held during the daytime.

On the whole, the benefits of being given a list of possible uses for the personal health budget seemed to outweigh any potential disadvantages. Interviewees appreciated the suggestions they were given and were entirely happy with the range of options they were offered. One or two women chose options that were not on the list, suggesting that it was not necessarily seen as a definitive list of the only options allowed. One or two also reported being offered 'taster' sessions, particularly for treatments like reflexology that they had not previously experienced, and they appreciated this. Many reported having two or more discussions with the personal health budget broker, with time in between to consider the options. These processes enabled them to feel that '*at the end of the day it was my decision to pick the things that I picked ... I just made informed choices, I suppose*'. The only instance of a choice being less than well informed was one woman who had understood that her personal health budget had to be used before the birth; when interviewed three months after the birth she said she'd '*love [a massage] now*'.

2.4 The level of the personal health budget

All the interviewees were told their budget would be around £500 (some gave a more precise amount of £475 plus £25 administration fee). Many were surprised at the level and felt this was a 'serious amount', not just a 'token' scheme:

That's a lot of money, you can get loads for that.

It was more than I'd expected and it was wonderful to actually think that's all for me ...

None reported being told how the level of the budget had been worked out. Instead they believed it to be a '*random number, what they can afford to test*', or equivalent to the cost of the antenatal classes that they would otherwise have been expected to attend. None of the ten women expressed interest in knowing how the level of the budget had been arrived at.

2.5 Managing and spending the budget

In almost all instances, the personal health budget officer calculated the costs of each woman's chosen option(s) and how many sessions could be afforded from the budget. The only interviewee who reported undertaking her own research into the cost of her chosen use of the budget was the woman who used part of her budget to hire a birthing pool; she used the internet and chat rooms to research different models, contacted the hire company and obtained full details of the cost, which she then gave to the personal health budget broker.

The personal health budget broker was also reported to have sourced appropriate local practitioners – a number of interviewees noted that yoga or massage practitioners needed special licences to be able to treat pregnant women. For a few interviewees, the lack of a qualified, easily accessible practitioner meant that they were not, in the end, able to have their first choice of treatment using their personal health budget.

The ten interviewees reported that their budget was held and managed by the Primary Care Trust. Although other options were available, most interviewees thought they had had no choice over this deployment option. However they greatly appreciated the fact that they did not have to worry about managing the budget and payments from it:

It was all done sort of in-house ... it was far easier them dealing with it. It was like, you know, it's all sorted. There was no worry that I had to pay for it.

I was told that I basically wouldn't have control over any of the sort of money side of it and they would just organise it and deal with like the invoicing and stuff and pay direct ... It was easier for me, to be honest.

The only circumstances in which interviewees would have appreciated more direct control over the resources in their personal health budget was where exercise classes or other sessions had been purchased and paid for, but the woman's health problems or work commitments prevented these being taken up and used:

I think it would have been easier if you was in control of it ... and then whatever you don't use after a certain time you hand back ... it could go on to help someone else. Now I think there's 19 yoga sessions I'm never going to use, it's wasted, they've just profited from it and no one's gonna be able to use 'em.

They appeared unaware that the costs of unused classes would be reclaimed from the provider.

2.6 Outcomes of the personal health budget

A majority of interviewees were wholly positive about the benefits they had derived from the personal health budget. Those who had chosen exercise classes, reflexology, yoga, (private) physiotherapy and a birthing pool all commented on how these had helped them to relax and cope with the pain of labour and delivery:

It was really nice, it was really like a treat and helped me to relax ... definitely beneficial to my happiness.

It helped me to be much more in control because it controlled my pain.

*My labour was brilliant and I really believe that that was due to the reflexology ...
She taught me how to cope with the pain.*

Some women pointed out that these positive impacts had also benefitted their baby – ‘she’s so relaxed and contented’. Partners were also reported to have benefitted - ‘probably ‘cos I weren’t so stressed’ and also because reflexologists had been able to suggest ways in which partners could help the mother during labour. The long-term nature of the personal health budget was appreciated, particularly the fact that it could be used flexibly before and/or after the birth.

About half the interviewees highlighted the importance of the fact that the budget had to be used specifically for their own wellbeing. This gave them a significant psychological boost; sustained their motivation to continue with gym or exercise classes; and avoided the temptation to use the resources for the well-being of the wider family, especially where family finances were tight:

It was something to look forward to each week.

If you have [your own] money, then you ... wouldn’t want to waste it on massage ... I would have felt guilty spending it on massage if I’d had the cash.

There’s so much more else that you could be buying or saving towards... that option there [the personal health budget] says to you ‘Yeah, you’ve got this amount of money and you can do this, this, this and this’.

Because it’s there, it’s easier to use. It’s not like ‘Right, OK, I want to take [children] swimming this week [so] I need to keep X amount back from the wages’.

However, four of the ten interviewees reported reduced or no benefits from the personal health budget. One woman felt she had derived little benefit from having a doula, who had only visited three times since her baby’s birth:

So I think it felt like we was on our own still ... then I didn’t see her and didn’t get to say goodbye and all that. It’s not as good as I thought, I’m afraid.

The other three women had experienced health problems and/or paid work commitments that had prevented them taking full advantage of their chosen budget option. Thus one woman had decided to use her budget to pay for yoga, massage and reflexology. However, she was unable to get to the yoga sessions because she was working and also had numerous pregnancy-related hospital appointments. She was also unable to continue with reflexology because of problems with dizziness; and although she appreciated the massage sessions, she was unable to benefit from the full course because she was admitted to hospital early and induced at short notice:

I'd had enough in the end, I was like 'I just wanna sit at home ... I've got all these appointments.... I don't want to do it any more'.

A second interviewee was also unable to benefit from her chosen gym membership, yoga and massage because these were not available at times she could get off work:

Because I didn't know about dates or times [of classes] or any of that, I couldn't really use it to my lifestyle ... 'cos I was working I couldn't then use the yoga or anything else before [the birth].

2.7. Implementation issues

On the whole, interviewees reported very few of the implementation problems that appeared to have characterised the experiences of some other personal health budget holders (Davidson *et al.*, 2012). The processes of informing potential budget-holders about the pilot early in the pregnancy; taking time to discuss with a broker and decide on potential uses of the budget; and identifying appropriately accredited providers, combined with the PCT's active role in procuring and paying for chosen services, all appeared to contribute to minimising difficulties and delays. As noted above, interviewees particularly valued being given a list of suggested options for using their budget, combined with information about other women's experiences and opportunities for taster sessions; they also appreciated the flexibility to choose items not on the list. Interviewees also valued the broker's role, which meant that they did not have to source potential suppliers and work out how many sessions of different treatments could be funded from their budget. The fact that budget-holders were not responsible for paying providers directly was also widely appreciated because it reduced the burdens on them at a stressful time. One or two interviewees also commented on the accessibility and responsiveness of the personal health budget broker – *'I could just text her or ring her and ask her'*. On the other hand, two interviewees reported that they had had difficulties in arranging meetings with the personal health budget broker because of their own paid work commitments.

Despite the fact that these interviewees were the first to be offered personal health budgets for maternity care in this particular pilot site, only a few minor delays were reported, either in the interval between being recruited to the pilot by the midwife and the first visit from the personal health budget broker to discuss the budget; or subsequently, in finding appropriate practitioners and organising classes. In only one instance were such delays reported to have reduced the benefits of the personal health budget: *'had I had it in place before [32 weeks] then it would have been a lot better.'*

Interviewees were asked about their overall satisfaction with the personal health budget pilot and suggestions for ways in which their experience could have been improved. Around half were so satisfied that they could not think of any possible improvements. Among the rest, there were two broad themes. A few interviewees wanted better, more detailed information on possible ways of using a personal health budget. They spontaneously commented on their reduced capacity to remember things during pregnancy ('*my mind's like a sieve*') and the particular importance of having written information at this time. More detailed information on the location and timing of different classes was also suggested, so that decisions about signing up for classes or courses could be made in the knowledge that they would actually be able to attend:

I was at work up till I was 36 weeks so it wasn't very flexible for me to actually use the things I'd chosen because ... it wasn't on the days when I could use it 'cos I was at work. ... If someone had given me more advice as to what I was choosing ...

It was also important for potential budget-holders to be aware they could use the budget after, as well as before, the birth. This flexibility was appreciated by some interviewees, but not all had realised they had this choice.

The second area for improvement concerned the importance of flexibility and opportunities to amend support plans. One or two women wanted more opportunities for taster sessions funded from their personal health budget, so that they could experience an unfamiliar treatment like reflexology before committing to spending a substantial part of their budget on it. However, the more common arguments for greater flexibility were prompted by unanticipated health problems that had developed during pregnancy or childcare constraints following the birth. Thus one or two interviewees found they were unable to continue with chosen options such as reflexology or yoga because of pregnancy-related pelvic, back or heart problems; early deliveries curtailed the use of purchased classes or treatments; and post-natal classes like baby yoga or swimming had to be postponed until relatives were available to care for other children:

Afterwards [i.e. after the birth] we redid my care plan with more sessions for physio and then swimming for [older child] and I.

However, not all the interviewees had had the energy to, or had realised they could, contact the personal health budget broker to amend their support plan:

She said I could ring her to change it, but it was just too much, the amount I had to sort out.

3. Conclusions

The interviews reported here were conducted with a small (and possibly unrepresentative) subsample of women from one personal health budget pilot site who were offered a budget for maternity care. These women were first told about personal health budgets by a midwife early in their pregnancies. They subsequently had two or more meetings with a personal health budget broker to discuss plans for using the budget, based on a list of possible uses. All the interviewees knew the level of the budget although none knew, or was interested in, how this had been calculated. They used their budgets to purchase a combination of exercise treatments, yoga, reflexology, and a doula birth attendant, both before and after the birth of the baby. In all cases the personal health budget broker had worked out how much of each treatment could be afforded from the budget and had sourced appropriately accredited providers. In all cases too, the budget was managed, and providers reimbursed, by the PCT.

Because personal health budgets for maternity care were only offered in one pilot site, this aspect of the personal health budget pilots was not covered by the main evaluation (Forder *et al.*, 2012). Nevertheless, the subjective accounts of the women reported here are strongly consistent with the overall findings of the main evaluation – that personal health budgets can have a positive impact on care-related quality of life and psychological well-being. None of the interviewees reported their personal health budget had an impact on their use of other NHS services. However, no routine information was collected on the interviewees' use of other health (including traditional antenatal care) or social care services, compared with women who did not have personal health budgets for maternity care, so it is not possible to conclude whether the personal health budget reduced spending on these other services. It is therefore not possible to make any comparison with the costs and benefits of personal health budgets that were indicated by the wider evaluation (Forder *et al.*, 2012).

Overall, interviewees were very positive about their experiences. This conclusion is broadly similar to the findings of the main evaluation of the personal health budget pilot projects, which found that personal health budgets were associated with improvements in care-related quality of life and psychological well-being (Forder *et al.*, 2012). Interviewees appreciated the help they had received with planning how to use the budget, particularly the list of possible options and information about how other women had used their budget. Some appreciated the possibility of being able to choose other items not on the list (although it was not clear how many interviewees realised this was possible). Having written information, plus details of when and where classes and other treatments were available would have been appreciated by a few women, so that better informed choices could have been

made. Interviewees also appreciated the fact that they were not responsible for sourcing services or managing the budget.

Those who had been able to use their budget for reflexology, yoga and other exercise classes felt these had had very positive benefits, helping them to relax before the birth and manage pain during labour. Indirect benefits, for their babies and partners, were reported as well. They also valued the psychological impact of the budget – the fact that it could only be spent on their own well-being avoided the temptation to spend it on more urgent, practical needs, particularly where family budgets were tight.

The minority of interviewees who did not report significant benefits to their wellbeing were mostly those who had been unable to take full advantage of the services funded with their budget. Paid work commitments during pregnancy, unanticipated pregnancy-related health problems, early deliveries and childcare constraints after the baby was born had restricted some women's use of their budget and/or prevented them taking up any or all of the services purchased with the budget. None of the interviewees reported major problems with the implementation of their personal health budget, although a couple reported minor delays in finalising support plans or getting desired services in place.

The experiences of this small number of interviewees are again consistent with the findings of the main evaluation (Forder *et al.*, 2012) in highlighting the importance of providing clear information about the aims of the personal health budget, the size of the budget and the range of options for using it; all these factors clearly contributed to the very positive accounts reported here. In the specific context of maternity care, flexibility in support planning and options to review plans easily and quickly, should unforeseen health problems arise, were also clearly valuable. Thus one or two women had been able to revise their support plans when it became clear that they would be unable to continue with their chosen course or class. However, others had not realised they could do this, or had been too preoccupied to contact the personal health budget broker. It is important, therefore, that personal budget-holders are clearly informed that their budget can be used flexibly, for some time after as well as before the birth. It is also important for budget holders to be aware that they can request a review of their support plan if health problems prevent chosen options being fully used. Personal health budget brokers, midwives and other health professionals in regular contact with pregnant budget holders may also need to be prepared to prompt a review if necessary. Finally, PCT/clinical commissioning group procurement and invoicing systems need to be flexible, so that only those classes or sessions that are actually attended are paid for, should health or other problems prevent women using their budget as originally planned.

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Appendix A: Maternity Topic Guide



Personal Health Budgets Evaluation: In-depth interviews with Maternity users

Early Implementation Issues

Introduction to the interview

This in-depth research is part of the wider evaluation of Personal Health Budgets, which you are already taking part in. We are talking to some of the people who have a Personal Health Budget (PHB) to find out more about their experiences of planning and using the PHB for support before and after the birth of a baby. This will help the government to understand what difference this new approach might make.

I am a researcher at the Social Policy Research Unit, based at the University of York. We are independent researchers, carrying out this project for the Department of Health.

We would like to speak to you today – about three months since the birth of your baby. I'd like to begin with a bit of background about yourself and then focus on:

- How you found out about Personal Health Budgets
- How the decision was made to try a Personal Health Budget
- The amount of the PHB and how you feel about this
- How decisions were made about what to use the PHB for
- How the PHB is being managed
- Your experiences of having tried a PHB

We will finish with a few more general questions about what you think of this new way of supporting people's health care.

There are no right or wrong answers. We are interested in finding out about your own views and experiences.

Taking part in this interview today is entirely voluntary and you are free to withdraw from the in-depth research at any time without giving a reason. This will have no influence over the standard of care or services you receive.

Our conversation today will last for about an hour. It is fine to take a break at any time if you need to.

If you agree, I would like to record our conversation today so that we can then make a full written record of what we talked about. We follow the regulations set out in the Data Protection Act, which means that the recordings and the written transcripts will be stored securely at the University of York and only people directly involved in this research project will have access to them.

We will be writing reports and articles about what we find out from this study. These will include your views, along with everybody else that we talk to, but your name will not be used and we will not write anything that could identify you.

Finally, we will not tell anybody that you have taken part in this research interview. The only time we might talk to somebody else is if you tell us that you or someone else is being harmed or is at risk of being harmed. We would talk to you about this before speaking to anybody else.

Does this sound alright to you? Is there anything you would like to ask me before we begin?

Get signed consent.

Introduction

First of all, could you tell me a bit about yourself:

Was this your first pregnancy or did you have other children already?

In general, how did you feel during this pregnancy?

Probe for:

- General health
- Stress/anxiety and its causes
- Other social circumstances

If appropriate: **Overall, how did you feel during this pregnancy, compared with your previous pregnancy/ies?**

Hearing about PHB and deciding how to use it

Can you remember back to when you first heard that you might be able to have a Personal Health Budget?

Probe: When heard; who heard from?

What did you understand about Personal Health Budgets at this time?

What did you think of this way of providing healthcare, when you first heard about it?

(Probe whether they have any previous experience to contrast it with)

All in all, did you feel you received enough information to enable you to make a proper choice about having a PHB?

Why did you decide to accept the offer of the PHB?

Probe: How did you think a PHB would benefit you?

Was anyone else involved in your decision to accept the offer of the PHB?

Prompt: Partner, family, carer, health professional, social worker, parenting support worker, peer support groups

At the time you chose to accept the offer of a PHB, what did you know about the things you might be able to use the PHB for?

Probe for: Sources of information

At the time you decided to accept the offer of a PHB, what did you hope to use the PHB for?

Amount of PHB

When were you told how much your PHB would be? *(relative to provision of other information)*

Were you told how the amount of your PHB had been worked out?

Probe:

- Was this explanation clear to you?
- Did you feel you understood how the PHB was worked out?
- (If not explained) Would you have been interested in knowing this?

How did you feel about the amount of your PHB?

Probe:

- Was it more or less than you expected?
- Were you satisfied with the amount?

Using the PHB

What did you decide to use your PHB for?

Prompt for: antenatal and post-natal services/support

Can you tell me why you decided to use your PHB for this?

Probe carefully for: Comparisons with previous experiences of pregnancy/births

What information did you have to help you decide how to use your PHB?

Prompt:

- Did you hear about examples of how other people were using their PHB? (e.g. from health professionals [*probe for specific type: GP, midwife, nurse, etc*], other PHB budget holders, support groups, third sector organisations)
 - How did you get this information?
 - Did you think you might be able to use your PHB to pay for things that you would not usually be able to get through the NHS?

Who was involved in helping you decide what to use your PHB for?

Prompt:

- No one; friends or family; health professional(s) (e.g. nurse/midwife/health visitor); social worker/parenting support worker/care coordinator/planners.
- What help did they give?

Was there any help or information that you would like to have had, to help you decide how to use your PHB but that you weren't able to get?

Probe:

- Help they would like to have had/from who?
- Actions taken to try and get that help
- Outcomes of actions to try and get help

Were there treatments/care/equipment that you wanted to use your PHB for but were told you couldn't?

Probe: full details of treatment/care/equipment and who involved.
Any suggestion of risk aversion among health professionals?

Were there treatments/care/equipment that you wanted to use your PHB for but couldn't find what you wanted?

Probe: full details of treatment/care/equipment and who involved.

- Availability of appropriately qualified staff?
- Availability of desired treatment/care/equipment in locality

Were there treatments/care/equipment that you wanted to use your PHB for but didn't have enough money in your PHB?

Probe: full details of treatment/care/equipment and who involved.

Were there any treatments/care/equipment in your care plan that you didn't really want to use your PHB for?

Once it was agreed what you would use your PHB for, did you have any further discussions with any health professionals about how you actually used your PHB?

Probe for: Professionals' involvement in managing risk and/or quality of care/services bought with PHB

Any changes in use of PHB made following discussions with professionals?

Did you add any of your own money to the PHB so that you could buy more of [service/treatment], over and above what the PHB would cover?

Did you talk to anyone about doing this?

Probe fully for any information obtained before decision to purchase extra from own money.

Probe fully for what they've done and why.

Overall, did you feel you had enough help and support in deciding how to use your PHB?

Probe:

- Who from?
- What other kinds of support would have been helpful at this stage? Who from?

One of the aims of giving people PHBs is so that they can tailor the services they want to best suit their conditions, lives and situations. Do you think the PHB allowed you to do this? In what ways?

Managing the PHB

Were you offered a choice about how your PHB was to be managed?

In the end, who held/managed your PHB?

Was this your preferred choice?

If not, probe for details of preferred deployment option and why this was refused

Were you happy with this arrangement?

Did you have any practical problems with the administration of your PHB?

Probe for: any difficulties getting care plan approved; expenditure authorised

Outcomes of the PHB

Thinking back, did having a PHB make a difference to your experience of being pregnant and having your baby?

Probe fully: including feelings of having more support, choice or control.

If appropriate, probe: for comparison with previous experiences of pregnancy/birth

Do you think having a PHB meant a better outcome for the baby?

Probe fully

Did having the PHB make a difference to anyone else in the family?

Probe fully: better outcomes for other children, better outcomes for partner; better relationships within family.

Thinking back, in the long term did the PHB make any difference to how you feel about yourself and your life?

Probe for: feelings of increased choice and control.

Did the PHB made a difference to any health-related problems you might have?

Probe for: any lasting impacts on health or health-related behaviours.

Did the PHB make any difference to your relationships with the professionals you see?

Probe for: Which professionals?

Do you think you see [health professionals] any more, or less frequently since you've had a PHB?

Do you think your relationships with [health professionals] has got better or worse since you've had your PHB?

Did the PHB make any difference to any other services that you receive or that you used to receive?

Probe for: Started to receive new services

Problems of continuity/co-ordination

Overall, were these impacts/outcomes of the PHB what you expected? Better than expected? Not as good as you expected?

Why? [probe fully]
