The Open University

Your Health in Your Hands

How Personal Health Budgets (PHBs) work

Catherine:

This is Your Health In Your Hands, a podcast from the Open University. I'm Catherine Carr.

Personal Health Budgets or PHBS are the next major step towards personalising healthcare. The movement towards personalisation started in the 1970s. Since 2009 a variety of trials have taken place across England, mainly for people living with long term conditions.

The NHS hopes to ultimately offer a PHB to anyone who could benefit.

In this discussion practitioners tell us how PHBs will be rolled out.

I'm joined to discuss PHBS by **Anne-Marie Mason** who's the director of a company called Health Your Way, which provides consulting services to clinical commissioning groups and advice to individuals who have or would like to have a PHB.

Rachel King is the personalisation coordinator for Lambeth Clinical Commissioning Group and **Sarah Little** is a commissioning manager in Islington Clinical Commissioning Group.

So we'll start very basically, perhaps with you Sarah, what is a PHB?

Sarah:

A personal health budget is really a person centred care plan. There are four key aspects to a personal health budget. The first one is that the person who is receiving the budget gets to choose their health and wellbeing outcomes. The second is they get to choose how they want to meet those outcomes. The third is they get to know how much money they have to spend, and the fourth is they get to choose how they want to manage that money.

Catherine:

How is that a shift away from what happens at the moment?

Sarah:

Right now what happens, often times, is your clinician tells you what your outcomes really should be and how those should be met. This is really turning the table, so that the patient is at the centre and is really driving what their care looks like.

Catherine:
Anne-Marie, how would you describe a PHB or personal health budget?

Anne-Marie:
I think a personal health budget is, the basics is, an amount of money to meet the person's health and wellbeing needs. At the centre of it is a support plan, or care plan as it's called, to define someone's health outcomes and the health needs that they have and really look at the support that they need to put in place to deliver those outcomes.

Catherine:
I mentioned a trial period which started in 2009, Anne-Marie who is eligible currently for a PHB?

Anne-Marie:
At the moment people who have continuing healthcare needs which is for adults 18 upwards and there has also been other trials within mental health services and also the long term conditions such as stroke or COPD.

Catherine:
Rachel, mental health conditions, is that something which you've been involved with trialling?

Rachel:
Definitely, so Lambeth was involved in the pilot project for NHS England Department of Health. We trialled it specifically in adult mental health, so 18 to 65. Obviously from our experience we found that it's worked quite well. It's enabled us to give a lot more flexibility about how we deliver services and support to people that they need and definitely the people we've worked with have given us positive outcomes and the responses we've had have been excellent.

Catherine:
What kind of positive outcomes, what kind of evaluations have you done?

Rachel:
Mental health is tricky because obviously every single person presents so differently and by having the flexibility of a personal health budget people can really choose about what they want to do. So instead of having that limited menu of options that somebody might have commissioned for them, they can go broader and outside of that and they can really think

about what sort of things are really unique to them and the things that they're experiencing that they can buy to help them.

Catherine:
Let's just pause the discussion there and hear from one example of an individual who's benefited from a personal health budget. Andrew Voice has schizophrenia, he spent 20 years in and out of asylums before finding a place to live independently in Bexhill. He got a PHB which allowed him to set up a social enterprise, offering things like music sessions and yoga to people living with mental health conditions in his local area.

Andrew:
Can you manage, are the stairs alright?

Catherine:
Yes, no problem.

Andrew:
When I was in and out of the asylums, which was for about 20 years, you were given a bed in a ten-bed male dormitory, a cupboard with no locks on it. Your only privacy was a curtain that was drawn around. You couldn't collect any books, records, you had nowhere to put favourite clothes.

A bathroom, yes, so a bathroom. I've got a shower and a bath which is very good to use.

Catherine:
Tell me when it was first mooted that you might be able to have one of these budgets and how you went about working out how much money you'd get and how you'd spend it simply?

Andrew:
A chap from East Sussex County Council County Hall in Lewes came down to Bexhill. He is a commissioner for mental health services. There were about six of us from Bexhill and we were introduced to the concept of self-directive support and personal budgets. I was allocated just over £500 as, I think the term was, an indicative amount.

Catherine:
What did you say you were going to use that £500 for?

Andrew:
There were four things that I mentioned in my support plan. One was to have a short holiday with my special friend. One was to take her for meals to make our relationship stronger. One

was to buy an electric guitar, and one was to start a social enterprise. I had all four things approved.

[Guitar noise]

Yes, the fuzz box is working.

I mean in a previous life I have had an electric guitar of my own so it was something I knew I could make use of.

Talking about founding the social enterprise, it wasn't just the £35 that I got to register the company with Companies House. What was important was that the County Council felt that I could make it work, make it a success and that I was capable of doing all the necessary to run a social enterprise. That was really terrific to have their confidence.

Catherine:
That was Andrew Voice. You're listening to an Open University podcast series called Your Health In Your Hands.

Now Rachel King, you're the personalisation coordinator for Lambeth Clinical Commissioning Group with a special interest and responsibility for people with mental conditions. That man, Andrew Voice, seems to have made £500 go a long way.

Rachel:
Definitely, I think listening to Andrew, the good thing about that example was that it sounds like Andrew has really used his strengths in his support plan. Thinking historically that he'd been in what he referred to as an asylum for quite some time where, obviously, he'd been stuck and hadn't really been able to progress very far. Obviously something like a personal health budget has given him an opportunity to really build on those strengths. He's had a level of choice and control. He's been really clear about what's been effective and what's going to be effective in helping him.

Catherine:
Andrew did tell me he did his personal support plan as a PowerPoint, animated PowerPoint and a friend of his wrote a poem. It must be quite tricky sometimes to work out what people are actually asking for, Anne-Marie, when you sit down to write those very specific personal plans.

Anne-Marie:
Yes, potentially. I think people have some ideas and maybe they need support to formulise that really. Also sometimes people are a bit concerned that if they ask something that maybe isn't seen as a traditional kind of support is are they going to be rejected straight off or are

they going to be considered that it's inappropriate to ask for that. So there may be some apprehension about that.

I think by speaking to someone like myself before and maybe speaking to a commissioner that actually can check things out and see if that's going to be - it's a safe zone really to ask that.

Catherine:
So let's talk about the beginning of the process towards designing a personal health budget, Sarah, what's the first step and then what's involved?

Sarah:
The first step is really for the patient to want a personal health budget. It's not something that the clinician can really make them have. So the initiative has to come from the patient. Then I think the second thing is really their care planning process and that can happen in a variety of different ways, either with whoever their lead clinician is, with a team of clinicians that have been supporting them or with someone totally independent. Then from there that care plan would get set with a budget and then the person would be able to use that money to fulfil what they had in their care plan.

Catherine:
Is it quite involved and potentially stressful?

Sarah:
Hopefully not stressful but it's definitely involved. I think it's a very different question that all of a sudden people are getting asked. When you're used to going to the doctor and relaxing and letting them control because you see them in a position of power, to all of a sudden have someone ask you what you really want. It's a question that sometimes takes people a little bit of time to figure out exactly what they want and how they would want to fulfil those needs.

Often times people kind of tell their life story, if you will, you kind of go back to what they really enjoy, what they really think they're good at, what they want to give back to the community. It's from those things that you can really start to build a care plan and help someone build a life that they may have lost.

Catherine:
You're nodding there Rachel, is that what you do? You go back to perhaps how they were before the last episode or something they enjoyed?

Rachel:

Yes, definitely, I think what we've neglected to do or not done very well in the past is we haven't seen the people as whole people. We have seen them as somebody with a diagnosis or with an illness. The whole point of personalisation and personal health budgets is seeing someone as a whole and somebody that can contribute and somebody with these strengths in a way that we can use to try and help them overcome their own needs.

Catherine:
I suppose it's not just about the whole person either, it's about the person, the family and the community.

Rachel:
Yes, definitely, I think it's important to consider everybody else who is important to that person around them and who would be worthwhile contributing.

Catherine:
I think we'll just pause there and hear about Jonathan Fitzpatrick. He was diagnosed with Alzheimer's in his 50s. He's now 68 and after a short spell in a care home he lives back at home in Oxfordshire with his wife Anna. Her aim is to look after him at home for as long as she can. So they built a brand new extension to allow him to sleep safely downstairs.

Anna (to Jonathan):
Do you want to go outside, go outside in the garden?

Anna (to Catherine):
If you have a live in carer it's £850 a week for the live in carer. Then after that the live in carer has to have a break of at least three hours a day. So then you have to pay for that relief. Also you get funding for respite. How that was explained, it was things that you wouldn't normally do on a regular basis. So that might be your hairdressing appointment. So you might get money to be able to ask for a carer to come in so that you can go for a hairdressing appointment. That might be the case.

So basically it's a bit like a hospital bed so that you can lift, that needs to be lifted because he chokes.

Say you decided that the relief to care, you were going to do it instead of a carer coming in, then the money that you save for that can go for things like, for instance, music therapy or going to a concert or activities that Jonathan could participate in.

Catherine:

I suppose it's quite nice to have something where you can manage your money like that down to that last £15. It's a bit more like real life.

Anna:
Yes, definitely. Absolutely. You have got to keep track of things and get on top of like, you know, sending timesheets off etc., if you have a personal assistant, which I do have on a Sunday morning. No, it's really flexible, it's lovely, a really lovely way of doing it.

Anna (to Jonathan):
Okay, I'm just going to pull your zip up, that's it.

Catherine:
Are you encouraged to think a long way ahead or are you encouraged to take a very much day by day view?

Anna:
I think very much a day by day view, it's the here and now. So when you write the personal support plan it's about now, not about the future. That is then reviewed so that his needs are continually being met.

Anna (to Jonathan):
It all gets muddled up.

Yes, that's nice.

Catherine:
It struck me when I met that couple that there was an awful lot of administration and some very new skills to appropriate. Is that something that you help people with, Anne-Marie, becoming an employer, filling in the paperwork, deciding whether to use a broker or not?

Anne-Marie:
Yes, absolutely. I think the key starting point is to give people information and advice about what is involved. I think particularly if somebody is looking to become an employer is that they need to know what the responsibilities are of taking on a member of staff or whether it's a team of staff. I think the level of responsibility with that some people will want to take on and some people will not. Perhaps with Anna, maybe she had enough going on and actually chose to use an agency where they will deal with that responsibility. Actually some people start off with using an agency and then as they get used to things being settled at home they actually change their minds and some prefer to stick with it.

Catherine:
Can it be overwhelming at times to sort of not only be dealing with perhaps a health concern or mental health condition but also to then start dealing with the HMRC?

Rachel:
I think definitely it can be overwhelming and it's a discussion that you have to have in the support planning process with somebody sort of outlining what would be involved. I think definitely in mental health we do use agencies quite a lot to try and relieve people of that responsibility, but I know in other areas where personal health budgets are offered that might not be the case at all.

Catherine:
Sarah, as a commissioner is that something which you have to bear in mind that you may have to change your structures actually to allow people to become employers, to allow them to change their tax codes, to take on these new responsibilities?

Sarah:
As a commissioner for the NHS we can really rely on commissioners in the Local Authority who have already gone through all of this and who have experience with personal budgets for the last five or six years or even longer. So in Islington we've really partnered and relied on our Local Authority to provide all of that support, because they really have that expertise there.

Catherine:
So complications aside, it was clear to me at least that Anna and Jonathan had found a way of making it work.

Sarah:
Definitely. I mean there story is a fantastic example of, even though it took a while to get set up and it took them really changing their thinking, they're able to get something that ultimately really works well for them.

Catherine:
Anna did mention that she had perhaps taken on a little bit too much, managing an extension, retiring which I know that she did and moving her husband back home. Those sorts of wider life concerns, are they something you would take into account when you're offering support to individuals?

Anne-Marie:

Absolutely, because the person isn't just about the health needs that they have, or their outcomes, life still goes on as other things are happening. The amount of support that somebody will need will vary depending on what's going on in their life. So perhaps initially at the start where they need support planning help and advice on where they're looking for what support they want to put in place, we might be quite heavily involved with people. Our overall aim is to actually provide very little support ongoing, because the person wants to get on with living their life and actually we shouldn't really need to be involved after so long.

Catherine:
Rachel, you've mentioned often with people who have mental health conditions that you offer an agency option perhaps for greater levels of support, do you find that that extra step and those extra layers of support are essential?

Rachel:
I think definitely they are. I think it is a new thing and this is a new way of thinking as people have pointed out. I think in order to enable people to get their heads around that and be really clear on what they can and can't do with this sort of opportunity is really important.

Catherine:
We heard there from Anna and Jonathan and she explained how she had a choice about where the money ended up. I know that there are three different ways aren't there, in which the money can end up in your hands or available for you to spend as you wish.

Rachel:
The newest way I guess of handling money is something called a direct payment and that means that the money has gone directly from an organisation or the CCG and it's gone directly to the person, whether that's in their bank account or through some other means. I think that's really the big change around personalisation and what we're trying to do here. It really gives people ultimate control because they have that money with them.

There's obviously something called a notional payment as well, which is where funds are moved from one service to another, but not necessarily through a person themselves. The third option is third party, and that's where you can get an agency or an organisation. You can buy them to do a lot of the accounting and money management work for you.

Catherine:
We did hear earlier from Andrew who bought an electric guitar, what checks and balances are there on what exactly you'd like to include in your support plan or perhaps change your mind about further down the line?

Rachel:
Obviously the checks around the management of money obviously we have a finance team that checks in with people when they might have an agreement with people where they provide receipts or whether they provide bank statements. That's really just to make sure that the money is spent in a correct way.

In regards to people changing their mind about how they want to spend money or if they're finding something is not really working for them, that can usually be done in regards to the ongoing payments or if they haven't spent a one off payment definitely. We would call that a review in Lambeth, so we would meet with the people who are involved in creating the support plan or who is responsible for managing it and think about why it's not working and why we want to spend money differently. We can make amendments as necessary and then subject to agreement that can be done.

Catherine:
Let's take another pause and hear from Mathew O'Sullivan. He's 25 years old and has a form of muscular dystrophy called Duchene's. He lives near Reading with his girlfriend Lizzie who has cerebral palsy. They manage their personal health budgets in tandem. Mathew breathes using a respirator and needs 24 hour care.

Mathew:
Hello, who is it?

Paul:
Hello Matt, it's Paul.

Mathew:
Paul?

Paul:
Yes.

Mathew:
Oh hi Paul. I'll let you in, hold on.

Paul:
Thank you.

Mathew:

I was diagnosed when I was five years old and basically it's a condition that severely weakens all of your muscles. So as you get older you severely get weaker and weaker and weaker.

Catherine:
What care do you have and how do you organise it?

Mathew:
I have a mixture of both PAs and agency staff. I use PAs mainly during the day and the weekday nights. We get on with the team and they're really, really good and we wouldn't swap them for the world.

Catherine:
You were sort of ahead of the curve a little bit asking about this is my money, is there a way that I can tweak the way that I spend it and, lo, you got your personal health budget. Has it actually lived up to what you wanted?

Mathew:
It has, I used to do a lot of Excel programming, so I've gone and got the budget on the screen, so that I can change one bit and it'll work it all out.

The good thing is that you can save money. So say if you save a couple of hundred quid a week, you can let it build up to go on holiday or something like that.

We've set up our own shared care rate which basically means that my carers could help my partner as well, because she's got cerebral palsy. It basically means they get paid more but I pay less and then Lizzie pays less. Then we also have a few gaps in care where Lizzie is my carer for a couple of hours just so we can just go away together and do stuff.

Catherine:
The money that you save you said you could spend on going on holiday or whatever, are you really free to spend it on whatever you like? Could you say, "Lizzie, good news, we've saved £150 this month, we can lash out, get taxis, go out for a nice meal, have a date," whatever or are there jurisdictions on it?

Mathew:
I am slightly cheeky about what I claim back for, but as long as you ring up your support broker and ask and just say, "Can I claim back for this?" They usually are okay with it.

Catherine:

That was Mathew O'Sullivan. You're listening to an Open University podcast series called Your Health In Your Hands.

We heard at the end there, it was quite funny he said he's a bit cheeky with his budget but he always runs it passed someone. I guess that's where we get back to the question of not what the money buys, perhaps, but what it achieves.

Rachel:
Absolutely and I think what Mathew said there about checking in with the broker or the clinician, it's just really checking that it is okay, what's agreed in the support plan is what the money should be spent for, but there needs to be an element of flexibility in there.

Catherine:
There was the interesting point as well that they sometimes double up on care for his girlfriend, Lizzie, who has cerebral palsy. She can sometimes act as his carer for an hour or so to relieve the carer and this save respite money. So there are various ways of managing your budget. There are infinite ways.

Rachel:
Definitely, and I think the important thing to remember about personal health budgets is flexibility is key and a person's life doesn't stay stagnant or the same all the time, there's variations. Particularly we see in mental health people as mental fluctuates. If somebody is having a period where they're quite well, they might be able to bank or accumulate some of that money or some of that time that they've got their carers. When they are having a bit of a shaky day or a shaky week where things aren't so good, they can call on those and get the extra support that they need at that time.

Catherine:
Sarah, after a care plan has been designed or been suggested by an individual, at what point does the commissioner get involved to say, "This looks good, let's go with this."

Sarah:
Ideally the commissioner wouldn't have to be involved that much in a care plan. At some point really it is a conversation between the person who's receiving care and the person who's delivering the care. From a commissioners perspective I'm only really interested if the indicative budget that we've given at the beginning of the process isn't going to be enough to meet the person's needs. At that point their clinician would come back to me.

Catherine:

What if they want something off the wall or a service that hasn't been commissioned by Islington before, how do you go about deciding what sort of budget they should receive for something entirely new, and as Rachel was saying, very flexible?

Sarah:
Ultimately their health needs are very similar to someone else's health needs that we've commissioned services for and so we base it on that. Usually we would spend some amount of money to meet those health needs and if they want to meet them in a totally different way they can do that. Ultimately they really only have access to the same amount of funds as anyone else.

Catherine:
How can you see the increase of personal health budgets in your area influencing the kinds of services that you buy in or the kinds of providers that you might do contracts with?

Sarah:
I think it'll be really interesting indication of what services people really want that we may not be commissioning now. So if lots of people in the population want to buy a certain service then there may be an opportunity to use the CCG as a way to buy that more efficiently.

Catherine:
Rachel?

Rachel:
Often people are entirely unhappy with what they receive and there might just be a little tweaks here and there which we spoke about that people might want to do. Within Lambeth we've had some, I guess in mental health it's quite different, because a lot of people might want something a little bit difference. We set money on things like SAD lights for people, bicycles are really popular.

We've have awarded somebody Sky TV package before which, obviously, a lot of people raise their eyebrows at. I think the important thing to remember about some of those things is that everybody's story is different and why they need such items needs to be really carefully considered. So Sky TV package that's suitable for person A might be completely unsuitable for person B and it's about why that person needs it and what outcomes they're trying to achieve by having that.

Catherine:

We are seeing some moves towards national standardisation for personal health budgets but some authorities or areas do seem a little further ahead in getting ready for this than others, is that true?

Sarah:
Yes that's definitely true. Recently there were pioneer sites selected across the country and these are essentially boroughs that are really committed to integrating health and social care.

Catherine:
What are the problems that that can cause if one area is a lot further ahead in being set up in terms of processes and things compared to another area? You're going to end up with people with a very different experience of personal health budgets.

Sarah:
True. Hopefully it creates opportunities though for boroughs to really share their learning with their neighbouring boroughs, because the economies will be quite similar and the problems will be quite similar.

Catherine:
Finally are you optimistic about this project?

Rachel:
Definitely, I think what we've done so far has had some really great results, we've learnt a lot, we've got a lot of challenges still ahead of us, but I think ultimately we can do some really nice things for people.

Anne-Marie:
Absolutely, I think it's the way forward and I think it's not just changing the mind-set of the NHS and those that work within it, it's also about changing the mind-set of the general public. I mean we've talked in the past of the Daily Mail headlines and actually when people really understand why people have been given a Sky package that, actually, people understand that and think actually 'that might potentially work for me if that kind of thing happened to me'. It's a whole society change.

Catherine:
Do you think that's right, Sarah, whole society change is what PHB is precipitating or is that too grand?

Sarah:

No, I definitely think that’s what it will take, but I also think it will take a bit of patience for that whole society change to happen.

Catherine:
You’ve been listening to Your Health In Your Hands, a podcast on PHBs from the Open University.