

Putting you in control?

What difference have Personal Health Budgets made to people in Wigan?

**An evaluation of the impact of Personal Health Budgets
2013-2018**

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In 2013, Wigan Clinical Commissioning Group began to give people control over the money that is spent to help manage their health. Instead of having to choose from a limited range of options, people were allocated a Personal Health Budget (PHB). They were able to spend their budgets on the support that worked best for them.

This report tells the story of what happened next. What worked well? What didn't work so well? And most importantly, what difference did having far more choice and control make for people in Wigan?

We want to share some of the stories that people have told us. We hope that this will inspire others to try Personal Health Budgets for themselves.

What is a Personal Health Budget?

A Personal Health Budget is an amount of money the Clinical Commissioning Group will make available to an individual to support their identified health and wellbeing needs, planned and agreed between the person and their local NHS Team.

The vision for Personal Health Budgets is to enable people with long-term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

Put simply, Personal Health Budgets give you choice. You know what works best for you to manage your health and wellbeing, so it makes sense for you to decide on what support you want.

Why have Personal Health Budgets been introduced? It's about better health for people and better use of public money by doing things differently.

The whole point of a personal health budget is for people to feel better, experience better health and to be able to do more of what matters to them. Personal health budgets are one way to give people with long-term health conditions and disabilities more choice and control over the money spent on meeting their health and wellbeing needs. In this report we can share some of the big differences having a personal budget has made to people in Wigan and celebrate what they have achieved.

We will look at some individual stories and hear from families and carers of people who have been doing wonderful things in Wigan over the last two years.

What difference can having a Personal Health Budget make?

Before we look at some findings from the evaluation, here is what one person said about the experience of Personal Health Budgets.

“My brother used to be a frequent visitor to A&E, often ending up having to stay in hospital for long periods due to infections and other complications from his health condition. This was difficult for everyone.

My brother was miserable, not able to enjoy life at all and just existing. Me and my family were constantly worried about him, doing lots of his care ourselves so we could be sure he was OK. We were always using health services which we knew we shouldn't really need to use, taking up the time of Doctors and Nurses for things that ought to be preventable.

My brother's personal health budget has drastically improved his health and wellbeing. It has meant we can recruit and train a team of staff specifically for him, who treat him just as they would treat their own family members. We can look for people who share our values, who share my brother's interests and who can build up expertise with him so they spot any health issues early.

This means that we now use health services and NHS professionals more productively and much less frequently and can be much more pro-active about getting my brother what he needs to manage his health. The flexibility the funding has given has helped us to buy equipment which has maintained and improved his condition instead of him getting support when things have gone wrong. We now have most of our contact with health professionals via phone call rather than by appointment and the staff we work with see us as equal and as experts in his condition. The overall effect is that my brother spends far less of his time receiving treatment for health issues and far more enjoying his life. He's even been able to go on holiday, something that would never have been possible before.

Having a PHB isn't an easy option. It takes a lot of work and commitment, but we wouldn't have it any other way. My brother's needs are met when it suits him, not when it suits a company providing staff. We are able to spend quality time together without compromise, with my brother being able to make choices for himself and enjoy his days, rather than just living them out. It's enabled him to be a son, brother and uncle again.

I think it's important to say that everything we have done with my brother has been achieved within the budget we were given. Personal Health Budgets don't only change lives; they are a much more efficient use of funds, because the people who know the person best can help make decisions which prevent things getting worse. My brother and family have more control, but the whole thing has been empowering for us too. Having control isn't just about us handling the money; it's about the people who believe in us and the relationships we have built.”

How have we evaluated Personal Health Budgets in Wigan? How do we know what difference they have made?

For this evaluation, everyone receiving a personal health budget was either interviewed by a member of staff from the CCG, or was able to complete a survey with the same questions as in the interview. For people who find it more difficult to communicate, we spoke to a family member or carer about how things had been since receiving their budget.

The interview or survey did not involve box ticking. People providing feedback had the opportunity to say exactly what they wanted, going into as much detail as they wished. The interviews and surveys were invaluable in showing what the personal experience of health budgets was and we thank everyone who participated. We have examined all the responses in detail, looking at the different effects and experiences of Personal Health Budgets and identifying common themes. We looked for where things had worked well, where things had been more difficult and what the impact of receiving personal budgets was for individuals.

The criteria of recipients included in the survey:

50 adults in receipt of Continuing Healthcare where identified to have had a PHB for over 2yrs, 10 individuals where chosen at random (20%).

10 children in receipt of Continuing Care where identified to have a PHB for over 2yrs, 2 were chosen at random (20%).

The questions asked in the interviews and surveys were:

- Do you feel that your personal health budget has helped you to feel better? And if so how?
- Are you using health services differently since receiving a personal health budget?
- Do you feel more in control of your life since receiving a personal health budget? What can you do with your budget that you couldn't do before?
- Have you felt more independent since receiving your personal health budget?
- Since receiving a personal health budget do you feel that your support is more controlled and flexible to suit your needs and lifestyle? If so, could you explain how?
- Do you feel supported with dignity by people who respect you and treat you well?
- Does having a personal health budget assist you to feel safe at home and when you go out?
- Have you been able to choose where you live and with whom you live?
- Since having a personal health budget have you been able to volunteer or undertake paid work?
- Since having a personal health budget have you been able to engage in your community?

- Do you feel your relationship with your friends and family has changed since having a personal health budget? If so how?
- Looking ahead, how confident do you feel that your needs will be met by your personal health budget?
- Do you feel that your budget is enough to buy what you need?
- Did you get the required information, advice and support to understand what you can and cannot spend your personal health budget on?
- Is there anything else you want to say about having a personal health budget?

Who has received Personal Health Budgets?

The people we have spoken to in this evaluation have all had a Personal Health Budget for at least two years. In Wigan, people in receipt of budgets are funded through what is known as 'Continuing Healthcare'. People in receipt of Continuing Healthcare have been assessed through the Continuing Healthcare Process as having a primary health need. This could be a condition they have had since birth, such as a physical disability, a learning disability or a mental health condition. It could be a progressive condition which has developed later in life such as Multiple Sclerosis or Alzheimer's Disease, or it could be something which has resulted from a specific incident, such as an illness or from an injury sustained in an accident.

The first stage of processing a Personal Health Budget is a needs assessment, where a health professional will find out what a person needs support with and how their disability or condition affects them. It is the persons assessed health and wellbeing needs from which the personal health budget is determined. It isn't new money, but a different way of spending health funding to meet the needs of an individual.

This process gives an amount of money – an indicative budget – which can then be used as a guide when developing a person-centred Care & Support plan to manage the assessed health needs. There are some rules to what money can and can't be spent on, but the idea is to give people as much freedom as possible to make their own choices and do what is right for them.

How much money do people receive as Personal Health Budgets?

The amount of money that people receive depends on the assessment of their health and wellbeing needs. What a personal health budget will be spent on will be outlined in their personalised care and support plan, which must be agreed between the person, their representative, the local NHS team and the CCG.

Where does this money come from?

The money that goes into a Personal Health Budget is the same that is used to fund current traditional models of care and support. The difference with a Personal Health Budget is who makes the decisions about how the money is spent. Instead of the NHS spending money on services, which people then use, with Personal Health Budgets the money can be allocated directly to the person to make their own choices in agreement with their local NHS team.

This money can go directly to the person in the form of a direct payment, or can be managed in other ways depending on what suits the person best.

A 'Third Party Budget' would mean that the money is managed by a chosen trusted provider organisation independent of the NHS and supports the individual in meeting their assessed health and wellbeing needs. A notional budget means that no money would change hands but the individual would be informed how much money is available. The individual would work with their local NHS team to identify the different ways to spend the money on meeting their assessed health and wellbeing needs; the NHS team will then arrange the agreed care and support. The idea is to give as much choice as possible in order to find the best solution for each person.

What did our evaluation tell us?

Our evaluation told us clearly that there are three major impacts of Personal Health Budgets.

These are that:

- Personal Health Budgets increase happiness and wellbeing
- Personal Health Budgets help people to have better physical health
- Personal Health Budgets are a help to family and carers

Let's look at these three findings one by one. In each section we have included quotes from the evaluation that show the impact on individual people.

Personal Health Budgets increase happiness and wellbeing

Our evaluation of Personal Health Budgets shows that **80%** of people feel happier since receiving a budget due to this giving them more control over how they are supported.

"She is much happier, more relaxed and more active. She says more words and can let people know what she wants to do. She is living in her own home instead of with Mum and Dad!"

The reasons for the increase in happiness are as varied as the people who have received the budgets, but the evaluation shows that choice and control are critical in making this change. Being able to choose how your support is arranged, who provides the support and when it takes place means that you can:

- Do more of the things that make you happy
- Not have to do things in ways that don't work for you.

The evaluation shows that both are important in increasing happiness and wellbeing. One person we spoke to said that her son was happier as he was no longer tied to traditional hours of support, taking place in the day. Her son had been effectively housebound in the evenings, which was far from ideal for a 21 year old man.

By being able to employ a personal assistant who was of a similar age and outlook, her son was able to do more of the things that mattered to him and live more of the life he wanted to live.

"He can go out in the evening if he wants to, not just 9-5. He even goes on holiday!"

We have found that Personal Health Budgets can transform people's confidence in what they are able to do. When people are worried about meeting their own health needs, or about the health of people they care for, there is an understandable tendency to take fewer risks and to stick to what you know works, even if it isn't precisely what you want.

Control over how support is provided means that there are fewer problems, leading to people being more and more confident and creative in what they do and what they will try.

"He was involved in the Scouts for years. Now they have a Scout of the Year award, which he presents personally. He even managed to go on the Scout's annual camping trip where he stayed for two nights."

Hope for the future contributes greatly to happiness. Our evaluation shows that **80%** of people who received Personal Health Budgets were hopeful and positive about the future for themselves or for the people they cared for.

"The PHB is the best thing that has ever been offered. Disability becomes less of an issue and she is able to live an ordinary life. She can do so much more and her quality of life has improved."

Just under **50%** of the people we spoke to in the evaluation have been able to contribute more to their community since receiving their budget. The extra flexibility available from choosing their own support has meant that they can choose activities that are important to them, including volunteering and supporting others.

"I've started volunteering at a local community centre two days per week."

What have we learned?

Although this is a relatively small evaluation, our findings are conclusive – wellbeing and happiness increase when people have more control over their support. We must remember that it is not enough just to give people money and assume they will be happier, or to think that if someone pays for the same support they are currently receiving in a different way this will make a difference. The increased happiness and wellbeing comes from the ability to make choices and decisions, which in turn requires there to be options and choices available.

In order to make this happen, a detailed, person-centred Care & Support plan is developed with the person receiving the support. This plan sets out what the person wants to do, how they will structure their support and how the money will be spent. This plan is produced with the help of NHS staff, who will stay involved and help keep the plan under review.

Personal Health Budgets help People to have better physical health

“Having regular staff who she knows well really decreases her stress. Less stress means fewer seizures. She’s had stable epilepsy since she got the PHB”

89% of the people we spoke to said they had experienced an improvement in their physical health since having a personal health budget. **80%** of people said they had needed to use health services less often. The same number said the number of times they had been admitted to hospital had reduced – in some cases down to **zero**.

How can receiving funding for healthcare in a different way have such a dramatic effect? The answer is through better control over how support is provided and, as importantly, who provides it.

With a traditional health service you can only get the support other people think might work for you. But what if something different works better?

This is exactly what one local resident did with part of his budget, using it to buy a specialist piece of equipment which meant he could take far more control of his own physical health. The flexibility offered by personal budgets allows people to pick precisely the most effective means of support for them.

“I have improved my fitness, my circulation, my physical health and mental health. I sleep better and I breathe more easily”

“I was involved in a road traffic accident in which I suffered severe spinal cord damage resulting in tetraplegia. All four of my limbs are affected and I require full support with the majority of daily living activities.

I use an electric wheelchair to mobilise outdoors and require the use of a hoist for all my transfers. I was awarded some funding for a Functional Electrical Stimulation Exercise Bike which helps me to remain as well as can be and prevent long term complications of spinal injury. The FES bike has boosted my confidence a great deal. I use it 3-4 times a week to stimulate my arms and legs. It does tire me out and so I do need to rest afterwards.”

Who provides support is critical to how effective it is. Personal Health Budgets have allowed people in Wigan to have far more control over who provides their support. Some have recruited, trained and managed their own staff teams. Some have used a small team of personal assistants (PAs) rather than have staff sent to support them from a service or agency. Some have employed friends and relatives to deliver care, or have had staff work closely with members of their family. A team of people who work closely together with a person they know well can develop this detailed knowledge, so they know how to spot a problem before it becomes serious, getting the right support quickly.

“He’s not had any hospital admissions. Previously he had multiple admissions due to different carers not knowing him well enough to pick up warning signs.”

“The staff pick up on subtle signs of illness starting. This stops her getting really ill.”

“My chest is much better. A better chest makes me feel healthier. Lots of people can spot if there is a problem, not just Mum”

The evaluation shows that, although overwhelmingly positive, there are some challenges in recruiting and managing staff. One participant saw the advantages of having your own team, but also found some difficulties.

*“Recruitment of personal assistants can be difficult, as can retention of staff”
It would be very beneficial if more support was offered, maybe having a register locally where carer can access a list of available people.”*

What have we learned?

The evaluation shows that when a person has the flexibility to choose the right support for them, that health outcomes improve. The evaluation also shows that when a consistent, skilled team of carers are present, then there is a physical health benefit in the majority of cases. We can show that Personal Health Budgets improve health outcomes, increase patient satisfaction and are likely to reduce pressure on health services.

“I’ve had to go into hospital less often since getting the PHB”

More support will be required to help people to set up their own staff teams and to develop the market, increasing the number of people working as personal assistants. But the signs are good, as 100% of respondents said that they had better relationships with staff as a result of receiving their Personal Health Budget, which is great for people using services and also for staff recruitment and retention too.

Personal Health Budgets are a help to family and carers

"It has enabled him to be a son, brother and uncle again."

The evaluation showed that Personal Health Budgets have had a positive impact on families and carers providing support to people with disabilities. **90%** of people interviewed said that pressure on relatives and carers had reduced since receiving the budget. **80%** of people said the budget had increased their independence. **20%** of people with budgets had been able to move into their own home.

The flexibility that Personal Health Budgets allow means that staff support can be provided at the time it is needed, rather than just at standard times. This allows families and carers to provide the support that fits in with their lives, with staff fitting around them.

"I feel less reliant on my family. It doesn't feel like I am a burden and making people fed up."

The evaluation shows that families and carers want to play an important part in caring for the people they love, but also that the pressures of continuous care provision are great. Yet having a break is difficult when you cannot be certain who will be providing care in your absence, or when you know the person you care for is worried about who will be there.

"Mum and Dad can be confident the PAs know what they are doing, so they can take a break."

Throughout the interviews for the evaluation, something we learned from families was that they didn't want the person they cared for to have to rely on them for everything. This was particularly common for parents caring for younger people, where the parents were aware that their children might not always want to do the same things in their spare time as their parents did. Personal Health Budgets have helped people with disabilities to build up their own social lives, explore new interests and hobbies and to live more independently. This has meant parents and carers can concentrate on making the most of time together as a family and follow their own interests without worrying.

"She is much happier, more relaxed and more active. She says more words and can let people know what she wants to do. She is living in her own home instead of with Mum and Dad!"

What have we learned?

The evaluation shows that increasing the choice and control over support can significantly reduce pressure on families and carers. Carers fulfil a vital role in health and social care – the system simply could not function without them. Through allowing support to fit specifically around the person with a disability **and** their family, we can help everyone involved in the person's care.

We have also learned that family relationships, which can be put under strain when carrying out a caring role, can be made less stressful through having more control over support. Families can support each other in the way that makes most sense to them, with staff working around them.

“100% freedom for him and the family. It's changed his and the family's life”

How does what's happening in Wigan link with what's happening elsewhere?

Our work to introduce and evaluate Personal Health Budgets is part of an ambitious national programme to increase the number of people with PHBs. NHS England started to pilot PHBs in 2009 and have plans to increase the number of people with PHBs to around 100,000 people by 2020.

Evaluations of the early pilots found very similar benefits to PHBs as we did in our evaluation. The National Pilot findings were:

- People's quality of life and wellbeing improved
- People benefited more when personal health budgets were implemented in a way that gave them more choice and control
- People with high levels of need benefited more than those with relatively mild needs
- Total spending fell for people with high levels of need
- People in receipt of NHS Continuing Healthcare or with mental health needs spent less time in hospital when they had a personal health budget.

Like the national evaluation, our work locally shows that wellbeing and quality of life improve with the increase in choice and control that a Personal Health Budget can provide.

You can find lots more information on Personal Health Budgets on the NHS England Website, including some stories and videos from people who have received PHBs and wanted to share their experiences.

<https://www.england.nhs.uk/personal-health-budgets/>

What do we need to do next to make PHBs even more successful?

The biggest challenges identified in our evaluation were the availability of suitable staff and access to required training, the practical difficulties of setting up a budget, including how to make payments, monitor expenditure and getting problems resolved. The lack of availability of staff is in part caused by the small number of people who have PHBs, so as the number of budget holders increases, so too will the numbers of Personal Assistants. As a CCG, we can support this by promoting being a Personal Assistant as a rewarding and sustainable career; and by finding ways in which budget holders can make contact with potential Personal Assistants and access the required training.

We can also listen to feedback and improve our processes to make sure people have all the support they need to make the best use of their budget.

To find out more about Personal Health Budgets in Wigan, please talk to your doctor, social worker or other health professional. Alternatively get in touch with Wigan Clinical Commissioning Group (CCG) or visit our website.