NHS

PERSONAL HEALTH BUDGETS GUIDE

Advice, advocacy and brokerage

DH Department of Health

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Personal health budgets

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our 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.

What are the essential parts of a personal health budget?

The person with the personal health budget (or their representative) will:

- be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional
- know how much money they have for their health care and support
- be enabled to create their own care plan, with support if they want it
- be able to choose how their budget is held and managed, including the right to ask for a direct payment
- be able to spend the money in ways and at times that make sense to them, as agreed in their plan.

How can a personal health budget be managed?

Personal health budgets can be managed in three ways, or a combination of them:

- notional budget: the money is held by the NHS
- third party budget: the money is paid to an organisation that holds the money on the person's behalf
- direct payment for health care: the money is paid to the person or their representative.

The NHS already has the necessary powers to offer personal health budgets, although only approved pilot sites can currently make direct payments for health care.

What are the stages of the personal health budgets process?

- Making contact and getting clear information.
- Understanding the person's health and wellbeing needs.
- Working out the amount of money available.
- Making a care plan.
- Organising care and support.
- Monitoring and review.

1 Introduction

Brokerage is not just about finding and buying things. If done well, it's about developing a good relationship with the person with the budget, from the start of the process. It's as much about who the person is (their personal qualities and skills) as it is about what they can do. It's not only about connecting people with services and with items, but also about connecting people with peers and with other people within their community.

Personal health budget holder

It's more important to know the person than to aim to have an encyclopedic knowledge of all available services.

Personal health budget holder

The pilot programme

Personal health budgets have been piloted in over 70 locations in England. An in-depth evaluation of 20 sites, published in November 2012,[1] supports the planned national roll out. This guide summarises learning on advice, advocacy and brokerage from the personal health budgets pilot sites, and is aimed at professionals who are implementing personal health budgets in the NHS, and third party organisations.

The guide forms part of the personal health budgets toolkit (www.personalhealthbudgets.dh.gov.uk/toolkit), which brings together learning from the pilot programme and shows how personal health budgets can be implemented well.

How information was gathered

Telephone interviews were held with people involved in the personal health budgets pilot programme. The project team interviewed 12 personal health budgets pilot site leads, three care navigators/facilitators, two support brokers, and five people with their own personal health budget.

2 The purpose of advice, advocacy and brokerage

Good quality advice, advocacy and brokerage functions are a vital part of the personal health budgets system. Personal health budgets are about a shift in power and decision making and sharing risk and responsibility within a clear partnership relationship. They are about recognising and encouraging people's natural skills and abilities and connecting people within their local communities. They are part of achieving sustainable health outcomes. The ways in which advice, advocacy and brokerage are made available need to support these overall goals.

To help us make sense of this, we need to listen to what's important to the people who have, or want to have, personal health budgets, as well as listening to the views of NHS commissioners and health professionals. We also need to think about equity of access to this new way of achieving health outcomes.

Personal health budget planning is an inclusive approach. Under the Equality Act 2010,[2] providers need to understand how to make services accessible to all and meet different people's needs across all protected characteristic groups. In the case of people who may not have capacity to make their own decisions, there can be best interest decisions guided by the principles of the Mental Capacity Act 2005.[3] People with fluctuating health conditions can plan for a time when they may not be able to discuss options or make their own decisions.

If we are to ensure that personal health budgets are made truly accessible in an equitable way, the necessary advice, advocacy and brokerage provision must be in place. This will enable those who may want or need some additional support to write and action their care plan, irrespective of their educational background, knowledge, ability or level of confidence.

At the same time, we must be careful not to assume everyone will need the same kind or level of support. We need to consider advice, advocacy and brokerage in terms of how they:

- can best support the necessary shift in relationships
- complement people's personal strengths and skills
- fit with the natural sources of support within local communities, including peer support
- can be empowering, informative and enabling, and avoid promoting helplessness and dependency.

3 Functions to support decision making

The Department of Health's vision for personal health budgets is to enable people with long term health conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive. When deciding whether advice, advocacy and brokerage support this vision, it's helpful to consider where they sit on a continuum of functions that affect decision making.

Information

Information is empowering. It tends to be more neutral than providing advice, hence its position on the scale. People will need information about what a personal health budget is, and the processes and rules, to make an informed decision about whether it is right for them. They will also need information about their specific health condition, the services and treatments available, and the evidence base for these to help them make good choices about how to use their budget.

The message from all the pilot sites is that it is critically important to get the groundwork right when offering people personal health budgets. Before starting to plan, people need clear, accessible information about:

- what a personal health budget is
- its purpose
- what the deal is, including
  - how much money is in their personal health budget
  - the choice of ways to hold the money
  - the choice and range of support for planning
  - what could be possible (through examples of what others have done)
  - the flexibility of using money to achieve health outcomes.

Capacity issues also need to be addressed in the initial stages of the process.

It is imperative that those with an advice or brokerage role gain a thorough understanding of the local framework governing personal health budgets in their area.

This is a lot of information to take in, and people need to be given sufficient time. Staff need to explore their understanding and provide space for questions and clarifications. Sending a leaflet or directing people to a website is unlikely to be adequate, although it can be a helpful part of a broader approach. Linking people with others who have a personal health budget already in place can be particularly helpful, both in person and via virtual links and forums (such as www.peoplehub.org.uk).

Advice

Advice, whether given by a friend, family member, peer or professional, is about giving an opinion and a suggested course of action. It is therefore more loaded than information. Advice includes a degree of subjective recommendation based on personal experience and knowledge. It may also involve a vested interest.

Importantly, advice forms part of a dynamic relationship between two people – one person seeking help and the other advising. Health practitioners are trained to give advice, and within the personal health budgets process it is often still necessary for people with clinical expertise and knowledge to provide advice.

But this is an area where staff supporting people to make decisions about how to use their personal health budget also need to employ a more complex set of skills. They need to be highly sensitive to the power imbalance between people who are unwell and seeking advice, and their professional health role. They need to hold back on the natural tendency many of us have to want to fix people's problems. While this approach is helpful and appropriate for some people in some situations, over the longer term (and for people with chronic conditions) it can keep people in a passive role where they never gain the confidence to take more responsibility for their health and support. To shift their relationship with personal health budget holders towards a more equal, partnership approach, practitioners need to develop their listening and facilitation skills, enabling people to find their own solutions.

Advocacy

Advocacy has been described as:

Taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.[4]

The Equality and Human Rights Commission has highlighted the importance of improving access to advocacy:

Our overall view now is that there appears to be a postcode lottery of availability of advocacy, and that if this continues it will result in many people not being able to access and use self-directed care such as personal budgets [...] The Commission recognises that for most people good quality information, advice and signposting services will be adequate for them to access and utilise personal budgets. The Commission strongly believes that independent advocacy needs to be available for those people, however, who are at greatest risk of not benefiting from self-directed care. These include people who have limited mental capacity and/or who face sudden vulnerable circumstances, such as onset of severe impairment.[5]

Advocacy was generally seen by pilot site participants as representing another person. Advocates are seen to act on behalf of another and to represent that person's voice. There was recognition that people may be unable to represent their own views for a range of reasons, some permanent and some temporary, such as being too overwhelmed or anxious to be able to speak.

Advocacy was seen to fulfil at least two main purposes: to give a voice for people who don't have the capacity to use words, and to help people in dispute to make their case. Advocacy is perceived to be the most supportive function. It enables self-determination, hence its place at the top end of the scale in the diagram on page 5.

Advocacy ranges from legal advocacy through to informal support and/or encouragement of a friend:

Advocacy is not new and is part of everyday life. People advocate (or speak up) every day for themselves, for their children, for their relatives and for their friends. Concerned individuals advocate for people whose rights are particularly vulnerable and whose contribution as citizens is undervalued.[6]

Although the different forms of advocacy are distinct, there are links between them. No person's needs are addressed entirely by one form of advocacy, and people's needs change. People should have different options available to them to meet their various needs.

Professional, statutory and voluntary advocacy

Advocacy is integral to many roles, but there are instances when advocacy is a distinct function that can be performed only by certain people.

For example, there are professional advocacy roles where people have expert knowledge of the legal, health or welfare system. This service is most likely to be provided by paid professional staff with relevant training and experience.

Conversely, peer support is largely voluntary and recognises the value of an advocate having shared common experiences with the person they are supporting, for example, a person who has faced mental health difficulties supporting somebody with similar experiences.

There are two statutory advocacy roles.

Independent mental capacity advocate

In operation since April 2007, this is a statutorily defined role that was introduced with the Mental Capacity Act 2005. Independent mental capacity advocates should be involved where a person is considered not to have the capacity to make a particular decision, and has no family or friends available to be involved and consulted regarding their care and support. More information on the situations in which the independent mental capacity advocate service should be used is available from the Ministry of Justice.[7] Since April 2009, independent mental capacity advocates should also be involved when deprivation of liberty safeguards are registered.

Independent mental health advocate

In operation since April 2009, this is a statutorily defined role that was introduced with the Mental Health Act 2007.[8] Independent mental health advocates should be involved in defined situations, for example when a person is sectioned under the Mental Health Act or treated under a Community Treatment Order.[9]

Brokerage

Brokerage or "support brokerage" is the help and support that people may need to work out how best they can achieve their health outcomes as set out in their care plan, the support they need to make things happen and thus how to spend their personal health budget.[10]

Brokerage can be empowering or more directive. Whether support is more towards self-determination or towards imposition will depend on how brokerage is understood, commissioned and carried out. Anyone acting in a brokerage role needs to be sensitive to and guided by how far people feel able and willing to make their own decisions, and to appreciate that this may change over time.

David and Dee's story illustrates how people may take more control over decision making as they become more confident.

David and Dee's story

David developed locked in syndrome six years ago. After a long stay in hospital followed by three years in a nursing home, David really wanted to live at home with his wife, Dee, and be able to see his family more often. David and Dee met with their personal health budgets co-ordinator, who provided them with independent information and advice about personal health budgets, how they could offer David more choice, control and independence, and ways in which he could manage the budget. David communicated his wishes by using eye movements to indicate "yes" or "no" and an alphabet and number board to convey words and sentences. David and Dee completed the personal health budget support plan with the co-ordinator. They chose to use a care agency to provide day-to-day support and also bought in the services of a neurophysiotherapist.

One year on, David and Dee decided to interview for prospective staff and have begun to employ their own personal assistants. David says:

It has given me so much more to look forward to being around my family, and I feel that I have improved so much since being in my own environment. Having the support of the personal health budgets co-ordinator helping us with the budget has enabled us to lead as normal a life as we possibly can and I'm extremely grateful for her guidance in all aspects of this.

Example from Personal Health Budgets Support Service, Cheshire Centre for Independent Living

The five key principles of the Mental Capacity Act[3]

- Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.
- A person must be given all practicable help before anyone treats them as not being able to make their own decisions.
- Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.
- Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.
- Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Brokerage and the Mental Capacity Act

Brokers need to be creative and committed to finding all possible ways to enable people to make their own decisions, in line with the principles of the Mental Capacity Act 2005.

Pilot sites were aware of the importance of people being enabled to express their views. One person said:

The most important thing is that the client is afforded any help they need to express themselves in the setting up and review of care plans if they suffer from any impairment that restricts their ability to express themselves clearly.

Alice's story illustrates how well this can work in practice.

Alice's story

Alice, a lady who does not use words and had been assessed by the hospital as not being able to communicate at all, was supported by her husband and the brokerage service to get a personal health budget. She used this to fund two live-in carers who got to know her and found a way of communicating with her, which means that she is now easily understood by most people. This would not have happened if she had not had a personal health budget as she would not have had the continuity of two people only, and the consequent depth of knowledge and sensitivity to how she was communicating would not have been built up.

The broker used person-centred communication and planning methods, for example asking Alice to indicate her consent by blinking – once for "yes", twice for "no". The broker was also present at the three-monthly review meeting in order to contribute to further planning. By this stage, the consistent caring had improved Alice's communication to such an extent that she was able to participate more, using a variety of sounds to indicate approval or disapproval. Crucially, while the main emphasis initially was on continuity of care, by the three-month review Alice was able to indicate that one of the carers frightened her, and that person was replaced.

There were two agreed health outcomes identified around communication. This is what the support and budget plan included about Alice's communication and about how staff could be supported to understand her:

continue on next page >

OUTCOME 2: build up communication by Alice to those around her; Alice's communication has benefited from a small core team of carers and the aspiration is for this to continue	Alice to see NHS speech therapist to improve her communication and vocalisations (to meet outcome 2) Contingency – If NHS speech therapist doesn't work out – Alice to see specialist speech therapist (to meet outcome 2) Partner to support by communicating Alice's needs and wishes to other agencies to ensure that support provided is in line with these (unpaid) (to meet outcomes 1, 2, 3, 4 & 5)
OUTCOME 3: maximise Alice's control over her life, eg over positioning and communication, by using IT equipment	Alice to be referred for a consultant appointment for an assessment for IT eye gaze equipment and to be provided with the equipment recommended (to meet outcome 3) Contingency – Alice to see a private consultant for support purchasing private eye gaze appointment

Therapists also attended the three-month review and agreed to come back and work specifically with the carers to identify what they could do on a daily basis to work on rehabilitation goals.

NHS Somerset

In Alice's case, in terms of support and brokerage, the personal health budget planning process enabled her communication needs to be addressed. The budget holder and her partner highlighted these needs in the agreed health outcomes plan, which was sent to the support and brokerage service, who looked at how they could be met within the budget. The pilot site lead contends that these health outcomes, which were crucial to Alice being enabled to make her own decisions, would probably have been lost in a more conventional approach focusing on her more obvious personal care needs. By having them written into the final support plan, the communication and control-of-life outcomes remained centre stage.

Although there are some powerful stories of how effective and responsive brokerage functions can transform people's lives, pilot sites said at this stage it had not been easy to find good brokerage services. This shows that to roll out personal health budgets, it will be important to make a concerted effort to develop local information, advice and brokerage services.

Functions of brokerage

Brokerage, whether for personal health or social care budgets, may involve a number of functions, including:

- find out what is available
- explore what is possible
- provide information
- give technical advice
- encourage and develop informal support
- co-ordinate support and resources
- assist the person to manage their obligations and responsibilities in relation to their budget
- enable things to happen
- help with support planning and person-centred planning
- help people speak up for themselves or, where necessary, speak on their behalf
- obtain clinical support where necessary.

This is not an exhaustive list, but suggests the wide scope of brokerage. When brokerage is seen as a range of tasks and activities, it becomes obvious that there is no clear boundary between it and other support functions – there is significant overlap with advocacy, information and support. While it is necessary to understand this overlap, it is particularly important to understand the discrete role each has to play.[11] For more on role clarity see 'Learning from pilot sites' (page 15).

Pilot sites described how the functions work in practice. Brokerage has at least two significant dimensions: there is an inherently practical aspect, but more fundamental is the depth of understanding of each person – what matters most to them. Brokers need to be responsive and adaptive because personal health budgets are about tailoring support. Both aspects are illustrated in the following definitions from pilot sites.

Helping individuals identify goods and services that they want to purchase to meet their health needs, and help them cost up the prices of this.

Pricing items, sourcing personal assistants and payroll.

Acting as an intermediary to access or purchase what's required.

Sourcing, understanding, directing, researching, providing options and choices and helping the person to maximise their choices. Use it in support planning, giving the information to make informed choices.

May involve advice. Ongoing support around the care package.

Contract compliance, employment and management of staff.

Finding out what the person wants, researching and sourcing this, offering the information to the person so they can make an informed choice and making arrangements for this to happen.

Brokers and programme leads in personal health budgets pilot sites

There is a danger in immediately translating this range of assistance and help into a specific role or job. The independent living movement has a rich history of disabled

people doing much or all of this for themselves or with the assistance of peers and user-led organisations such as centres for independent living.[11]

There is a danger not only in assuming brokerage functions can be loaded into one role or job, but also in assuming any single organisation will be well placed to meet the diverse needs of a whole population.

The recurring theme in this guide is that it is better to commission a range of brokerage functions within a range of different organisations, including peer support and user-led services.

Tim's story demonstrates how the broker communicated with Tim in the best way for him (via email after the initial meeting), and provided answers to all his questions.

A range of brokerage services, functions, roles and approaches were described by the pilot sites. While there was no simple blueprint offered, there was some tangible learning, which is summarised in section 4.

Tim's story

Tim has a genetic, progressive condition called Friedreich's ataxia, which has affected mainly his nervous system and speech. Tim felt that, with the changes to his condition in recent years, he was losing his identity and control over his life, having previously worked successfully as an accountant. Tim was first introduced to the idea of personal health budgets by a nurse assessor from the local primary care trust, who set up a meeting with the personal health budgets co-ordinator. Tim had a comprehensive list of questions prepared for the meeting, including how could he benefit from a personal health budget and what difference would it make to his life?

Tim was supported at the meeting by a carer who knew him well, who was able to assist him in expressing his views. Tim explained that he wanted to employ a personal assistant who could assist him with taking control of his care and support him to manage a team of support workers.

The co-ordinator provided Tim with independent information and advice, and answered all the questions that he had listed on two sides of A4 paper.

Following the initial meeting where the personalised health budget support plan was discussed, the personal health budget co-ordinator liaised with Tim via email to discuss the finer details of the support plan. This included how to recruit support workers and how to comply with legal responsibilities as an employer, such as having appropriate insurance and using a payroll service.

Example from Personal Health Budgets Support Service, Cheshire Centre for Independent Living

4 What matters most to people with personal health budgets?

Learning from the pilot sites indicates that people with personal health budgets don't care what things are called – but they have very clear views about what support they need in order to create and manage their care plan.

People want to:

- know what's possible and what's available to them
- be directed to people, places or things that might be useful to them
- know about the options, rather than being given one solution
- know how their plan can be practically and successfully put into action, including the price of things and how affordable the plan is
- work with processes that are simple and not too time consuming
- guard against vested interests coming into play
- have support from people they trust
- be able to choose who offers them ongoing support
- receive advice from a range of people – and receive support to find things out for themselves
- have support in putting the plan into action from a person who knows them and their circumstances really well
- know there is someone who will speak up for them, and speak on their behalf if necessary
- have support in co-ordinating services, which are frequently perceived to be fragmented
- share with others what a good thing a personal health budget can be
- have a known individual to inform when everything in their care plan is working well, and to contact if their needs change.

5 Learning from pilot sites

Know the deal

Brokers, especially if they are not within the NHS, need to know the deal – the rules of the local framework.

People who want a personal health budget, brokers, professional health staff and NHS commissioners all need to have a thorough, shared understanding of the local framework of rules.[12]

Brokers need to be clear, before meeting with clients, what the money can and can't be spent on. Without this, clients' expectations are raised and this causes problems later on as people feel the budget has let them down. Brokers need to understand, in detail, how budgets are set so they can explain how this works to clients. Where brokers are offering employment advice, they need to understand that the budget has been calculated to include, for example, tax and national insurance for employed staff, and that the budget includes an amount for training and setting up employer's liability insurance, advertising etc.

Where the rules are still being developed, it is important that brokers have access to people within the commissioning organisation who are making decisions, so that they can advocate for personal health budget holders and bring their own experience into the discussion and decision making process. If patients and brokers are not part of the decision making meeting, then all too often, brokers are just told "no, we don't allow that", without understanding how that decision was reached or having an opportunity to explain the patient's point of view as to why they want to do something different. This leaves the broker as the bearer of bad news, with no way of explaining how the decision was reached or of finding a compromise as they are unsure of the different choices they can offer … If brokers are working across clinical commissioning group boundaries, it is important that they know the rules that apply in each local area.

The most important thing is to ensure from the outset of the process of defining care plans that both the client and the commissioner/health assessor sing from the same hymn sheet in terms of what the personal health budget can be used for.

Pilot site leads

Work with the local authority

An integrated approach for advice, advocacy and brokerage between the NHS and the local authority is really helpful.

The following quotes from pilot sites illustrate this:

The partnership working with the local authority was helpful – we couldn't have done it without them – they are really great.

Without the local authority support we could not have done this. They have been great and there has been no fighting about budgets. People have got the advice, advocacy or brokerage they needed.

Where sites did not have this, it was described as difficult and challenging:

The local authority have been really inflexible and not really helped us at all. They have refused to fund things for people with certain conditions, like stair lifts, wet rooms or hoists, on the grounds of this being too risky for the patient, even when we have risk assessed and this is not the case. They also restrict what people can spend their personal budget on. We have tried repeatedly to work with the local authority but they refuse to co-operate. It's really frustrating.

Recognise differences from brokerage in social services

Acknowledge and be sensitive to the significant differences between brokerage in personal health budgets and personal budgets in social care.

Although encouraging an integrated approach, the pilot sites were also clear that brokerage in personal health budgets has some significant differences from brokerage in social services, and that it's helpful to consider these differences, not ignore them.

Personal health budgets brokerage is very different because of the:

- complexity of many health conditions
- size of some budgets
- number of personal assistants employed, either directly or through a third party, and their interface with NHS health staff and services
- range of technical skills and competencies required by support staff
- level of illness and variable health status of the budget holder
- need for clinical input or clinical advice, including on available evidence.

It can be very frustrating for professional brokers who have been working with local authority personal budgets if they aren't supported to understand these differences. The different history, legislation and culture of the NHS may mean that the NHS appears more risk averse than local authority brokers are used to, but both NHS staff and brokers who are entering this different context need to be able to take time to understand and appreciate each other's point of view and to learn from each other.

Pilot site lead

Promote partnership between NHS and independent brokers

Have a range of brokerage options, not just one provider, and include both in-house and external provision.

Participants expressed the need for independence of the brokerage functions. At the same time, there was also acknowledgement of the need for a brokerage role within the NHS. Total separation is unhelpful. There is no point in having an external independent broker work with people to produce a great action plan if this work is so separate that no-one within the NHS is comfortable to authorise it. This is a danger if no-one within the NHS can see how and why the elements in that plan have been created.

Internal NHS brokers can work with independent brokers in a partnership that helps to secure greater understanding of both internal and external constraints and opportunities.

What has been helpful is having an internal and external brokerage role. Because of the nature of the NHS Continuing Healthcare process, the patient may have been along a rocky road to have been assessed as eligible. Having an independent broker can be a really helpful fresh start. It can offer more creativity. An internal broker can help move things more quickly through the process and can develop understanding within the team. The internal post helps deliver the culture shift. It's vital to have that internal post with the focus just on personal health budgets.

Make sure the team is on board and that the broker is within the team helping to facilitate the culture change.

Pilot site leads

It is important that at least one element is external to the NHS commissioners; this gives a more robust independent system.

I think a broker could be invaluable but I'm also concerned that a broker might not be impartial and may fleece people. … I would need to know they weren't profiting from it … People can sometimes be vulnerable, especially if they don't know about personal health budgets. The person has to be trustworthy.

Personal health budget holders

Clarify boundaries between roles

Develop a shared understanding of the boundaries between roles and explain to people the different roles of clinicians and brokers.

One pilot site lead commented:

It's really important that there is an understanding of the different roles in teams/services so that clinicians, brokers and personal health budget holders are not confused about who is doing what. Clinical commissioning groups and Continuing Healthcare teams, for example, need to think about the roles of the broker carefully before commissioning the service to ensure that whatever they commission meets their needs and expectations. Continuing Healthcare clinicians and brokers need to be clear when one person's responsibility starts and ends. Continuing Healthcare teams need to also think carefully about how they will communicate and put people in touch with any external brokerage service, making sure that they offer choice. They also need to consider what background information a broker may need before they begin working with people to create a care plan, and how and who might collate that information so people do not have to repeat themselves unnecessarily.

Over time, role boundaries can become more blurred when people learn to trust each other and become confident in their roles and relationships.

Pilot site lead

The most important thing is to make sure that people understand what is happening and who they can talk to.

People are being asked to take a leap of faith and do something very different, and we need a safety net. People may not need to use the safety net, but knowing there's the amount of support there, and you can get it if you really need it, is really, really important. For example, if I struggle with this decision – who can I turn to, to not be on my own?

Personal health budget holders

Keep it simple

Don't overprofessionalise or over-complicate things.

It's important not to assume everyone will need to make use of brokerage services.

It's not always required by people – you could empower people to do things for themselves.

Develop different services to give people more options around brokerage.

Support people to do the functions themselves, with encouragement – we can overprofessionalise it.

Pilot site leads

The broker spent an excessive amount of time creating the paperwork. They came to my house more frequently than needed. The support document they produced took so long that it wasn't finished by my three-month review.

Ensure some crossover so that we aren't overwhelmed at the beginning of the process. I almost asked to be removed from the trial because it took so long and required a lot of my time.

Develop an online resource for members of the public to access with information about how to write a support plan and an online calculator for costs of things.

Personal health budget holders

Ensure equal access

Make advice, advocacy and brokerage free.

To ensure fair access to personal health budgets for people with diverse support needs, brokerage support costs need to be paid for by the NHS, or the funding needs to be included in the personal health budget.

Make service-level agreements

Make service-level agreements with organisations rather than paying an hourly rate for brokerage.

This will enable the brokers to meet a range of need flexibly, and is more likely to be cost effective.

Enable choice

Create a range of advice, advocacy and brokerage services.

It is important for people to be able to choose from whom, if anyone, they want support to help them write their care plan. This is a critical role. Pilot sites found that some people are happy and comfortable to plan on their own, particularly when they are given clear information about what is expected of them. But when planning for the first time, many people will want to talk things through with another person, preferably someone with whom they feel comfortable and who they believe understands their situation. This may be their health care professional, but some people may prefer an independent person to guide them through the process and liaise with the relevant parties.

Brokerage support of the kind and quality needed does not appear to be readily available yet, so commissioners will need to work with local clinicians, people who want personal health budgets, and the voluntary and community sector to create the range of support needed. This will include seeking the views of people from groups with protected characteristics under the Equality Act to ensure brokerage advice and advocacy are available in ways that enable equal access to personal health budgets.

Our learning has been that the broker is the lynch pin, and where it is poor quality we have had to pick up the pieces.

When we have got the right broker it has gone brilliantly.

We have lots of people with learning difficulties or dementia who would not be able to access a personal health budget without brokerage support.

Make sure there is adequate access to brokerage especially if someone is employing personal assistants – if you don't do this, people will end up in trouble.

Don't do it cheap, it's a professional service so pay professional money.

Pilot site leads

Get all the facts. For me, the best source of information was the transition worker. I asked everyone and researched things. I also asked my friends. I just gathered as much info as I could, so it needs to be available in different ways and different places. Different people came up with different solutions, so the more info you gather, the clearer picture you get. Other people researched too, so I felt we explored every avenue.

Personal health budget holder

Focus on the relationship

Brokerage works best when it is woven into the whole process, not added on at the end – and when the focus is on the relationship, not just the task.

Brokerage is not just about finding and buying things. If done well, it's about developing a good relationship with the person with a budget from the start of the process. It's as much about who the person is – their personal qualities and skills – as it is about what they can do. It's about connecting people with services and with items, but it's also about connecting people with peers and with other people within their communities.

People with a personal health budget are clear that they want to have support from a person they can trust, who knows them well and understands their care plan. The broker can support finding and buying useful things only if they have a full appreciation of what matters most to the person. It's more important to know the person than to aim for an encyclopedic knowledge of all available services. Rather, the broker needs to know how to research, and to help the person develop those skills if they wish.

Having a single person to provide support throughout the whole process can build trust. The relationship is very important. Draw in specialist advice when needed (eg employment law) – there may also be a co-ordinating role for brokerage.

This is not a task-oriented process – it will not work if the NHS tries to make it one.

Pilot site lead

Brokers need to be impartial and trustworthy. If someone is going to sort out a budget for you, they're going to learn a lot of stuff about you if they're going to be useful. They're getting a look into your life. They need to be friendly and I need to be comfortable with them. In my experience, the only person I had to help me wouldn't have been my personal choice. I had to take the hand I was dealt. If I could have chosen the person, it would have been a lot easier.

I've found that all the services I use are working in isolation. Advocacy and brokerage need to have the independence to overcome those institutional barriers.

For me the three things are all one. They blend together. It could be one person and one conversation, and you wouldn't realise that it included all these things.

Personal health budget holders

Evaluate

An ongoing process of evaluation is needed to check how well advice, advocacy and brokerage are working.

Without the right information to hand and sources of help and advice, people can feel unsupported.

I feel very much on my own, with no information as to how to obtain such services, and wonder whether it is now too late as things are set in stone, and in any case, with the NHS financial situation, I have been told that my personal health budget cannot be increased.

Personal health budget holder

Advice, advocacy and brokerage are essential components of support to make plans work well and to manage risk. For example, if a person has a piece of equipment that needs servicing regularly, where do they go for that?

Personal health budgets are not about dumping responsibility or shifting all responsibility to the person, they are about sharing responsibility and working in partnership. They are also about improving decision making and ensuring people with personal health budgets have ongoing support.

Now that the personal health budgets pilots evaluation has been completed,[1] simple feedback processes need to be put in place. Some of the leading pilot sites have begun to use the POET tool[13] to assess experience of the process and outcomes for people. This will be essential to monitor equity of access to personal health budgets through appropriate and effective support being put in place.

6 Conclusion

There is an important balance to be struck in commissioning advice, advocacy and brokerage services in each local area and ensuring a well trained and confident workforce within a variety of different provider organisations, including information networks, peer support and user-led organisations. These are essential functions to ensure equal access and effective use of personal health budgets.

At the same time, commissioners also need to:

avoid turning advice, advocacy and brokerage into a complicated and expensive industry. It doesn't need to be. If you do, then the benefits to the patient of having a personal health budget will be lost.

Pilot site lead

At its heart, this is about building confident new relationships in order to achieve personal health outcomes. People can use the detailed conversations that are necessary to create a good support plan as a tool for culture change.

Advice, advocacy and brokerage are all about building effective relationships through the use of conversation and communication, and can enable shifts in power. They are about supporting the shift in power from people being passive recipients of care to being active participants, to the extent that they wish to make that change.

7 References

1 Forder, J. et al. **Evaluation of the personal health budget pilot programme.** Personal Social Services Research Unit, University of Kent for the Department of Health. 2012. www.phbe.org.uk

2 **Equality Act 2010.** www.legislation.gov.uk

3 **Mental Capacity Act 2005.** www.justice.gov.uk

4 Equality and Human Rights Commission. **Advocacy in social care for groups protected under equality legislation.** 2010. www.equalityhumanrights.com

5 Equality and Human Rights Commission. **Personalisation in the reform of social care: key messages.** 2011. www.equalityhumanrights.com

6 Advocacy Resource Exchange. **What is advocacy?** 2010. www.advocacyresource.org.uk

7 Office of the Public Guardian. **Making decisions: the Independent Mental Capacity Advocate (IMCA) Service.** 2007. www.justice.gov.uk

8 **Mental Health Act 2007.** www.dh.gov.uk

9 Rethink Mental Illness. **Independent Mental Health Advocates (IMHAs).** www.rethink.org

10 Campbell, N. et al. **Independent Living Strategy: support planning and brokerage.** Office for Disability Issues and Norah Fry Research Centre. 2011. odi.dwp.gov.uk

11 Department of Health. **Good practice in support planning and brokerage.** 2008. www.personalhealthbudgets.dh.gov.uk

12 Brewis, R.K., Stewart, G. and Fitzgerald, J. **Implementing effective care planning. Department of Health.** 2012. www.personalhealthbudgets.dh.gov.uk

13 In Control and Centre for Disability Research, Lancaster University. **POET – the Personal Budgets Outcomes and Evaluation Tool.** 2011. www.in-control.org.uk

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