

PERSONAL HEALTH BUDGETS GUIDE

Third party budgets: the families' perspective



DH INFORMATION READER BOX		
Policy	Clinical HR / Workforce Management Planning / Performance	Commissioner Development Provider Development Improvement and Efficiency
		Estates M & T Finance Social Care / Partnership Working
Document Purpose	Best practice guidance	
Gateway Reference	18053	
Title	Personal health budgets guide: Third party organisations - the families' perspective	
Author	Co-founders of the National Peer Network and Peoplehub - for the Personal Health Budgets Delivery Team	
Publication Date	4 September 2012	
Target Audience	PCT Cluster CEs, NHS Trust CEs, SHA Cluster CEs, Care Trust CEs, Medical Directors, Allied Health Professionals, personal health budgets pilot sites, people with a personal health budget and their families, third party organisations ie independent user trusts	
Circulation List		
Description	This good practice guide is written by people with direct experience of personal health budgets. It aims to capture learning around what works for families who are in receipt of a personal health budget, and share this with those working in the NHS who are implementing personal health budgets and third party organisations.	
Cross Ref	N/A	
Superseded Docs	N/A	
Action Required	N/A	
Timing	N/A	
Contact Details	Personal Health Budgets Delivery Team NHS, Strategy and Finance Directorate Department of Health 79 Whitehall, London SW1A 2NS 020 7210 2787 personalhealthbudgets@dh.gsi.gov.uk	
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The authors thank the families involved, Crossroads Ribble Valley and Solo Support Services Ltd.



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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

This guide is about what works for families who receive a personal health budget and use a third party organisation to manage it. It is written by people with direct experience of personal health budgets. It is based on interviews with family members, a third party organisation and an NHS commissioner. The guide will be of interest to people who are eligible for a personal health budget and their families, and those working in the NHS who are implementing personal health budgets.

This guide describes how third party budgets have been helpful to people who found that traditional services don't work well. It describes how these arrangements work in practice.

The diagram below shows the three options for how a personal health budget can be managed. A third party budget provides an alternative in cases where a person or their family do not want a direct payment for health care or a notional budget (where the NHS holds the money and buys or provides the goods or services the person has chosen).¹



With such an arrangement, an organisation legally independent of both the person and the NHS holds the money on the person's behalf.

The organisation is referred to as a third party because the budget is held neither by the NHS commissioner nor the family. A third party organisation could be an independent user trust (a limited company providing a service to budget holders), or an existing voluntary organisation, user-led organisation or community interest company. An individual service fund is a way to operate a third party budget that is beginning to become more widely available for people who have a personal budget for social care.^{2,3}

Families interviewed for this guide were those seeking positive change for a family member either receiving or expecting to receive NHS Continuing Healthcare. Each family has at least one member (in most cases, the mother of the person with the identified health needs) who has pursued their vision of a better life with a degree of relentlessness. They were driven by the belief that a personal health budget was the only option that could mitigate their feelings of powerlessness, frustration and fear for the future.

Some families had experienced the benefits of a social care personal budget. They were facing the loss of choice and control that is often experienced when making the transition to NHS Continuing Healthcare, where services are traditionally commissioned from a nursing agency. Others were deeply unhappy with the support services they received because they had little choice or control over how the support was delivered.

Some families receive support or nursing services for up to 24 hours a day. The loss of privacy has a great impact on family life – caring is transformed into a public activity. The families reported feeling scrutinised by people who had little understanding of their situation. They were frustrated by the high turnover of agency staff and the lack of control over who came into their home. They struggled to be heard and felt disempowered.

As few families currently have a personal health budget, and there are also few third party organisations providing support, we hope the findings in this guide will encourage further developments in this area. The families and organisations interviewed have learned a huge amount about what works and what doesn't, and are eager to share their learning for the benefit of others.

2 How third party budgets work

Third party budgets are uncommon. Each family we spoke with had created the arrangement with a third party organisation because it was the only way they could gain real choice and control over the health care of their family member. The families have been able to do this through a highly developed sense of what they want and need in order to survive and prosper, and of what the system will permit at this time, together with a significant degree of peer support.

The families we interviewed had made arrangements that worked in slightly different ways, but with a common sequence.

- A health need is identified which the NHS is required to meet. In most cases, the need meets the criteria for NHS Continuing Healthcare funding.
- The standard arrangement for delivery of health care by local community services is not suitable for the family, for one reason or another.
- The family is attracted by the alternative option of a personal health budget. They don't want a direct payment for health care or don't live in a pilot area.⁴
- Some families already have experience of direct payments for social care. Their family member becomes eligible for NHS Continuing Healthcare funding and is no longer able to use a direct payment. As they are unwilling to give up their autonomy and independence, their only option is to use a third party budget.
- The family researches options. By good fortune, they manage to connect with someone who has a personal health budget and is willing to offer peer support. Through this, they learn that a direct payment is not the only management option, and that they may be able to get support from a suitable organisation registered with the Care Quality Commission, which will enter into a contractual arrangement with the NHS.
- The family then seek out an organisation to provide the support they need. At this point, the stories of the families diverge somewhat: some identify a local organisation; in other cases they find an organisation based elsewhere in the country that is willing to work in their area; in one case, the arrangements with the first organisation identified prove unsatisfactory and the family seek out an alternative. NHS commissioners are involved at this stage, but are not the prime movers.
- Precisely what the organisation offers the family varies depending on need. The fundamental arrangement is that the NHS contracts with the organisation to deliver an agreed package of health care support, managing the personal health budget and employing the staff this requires. In practice, the role of the family is central to the ongoing service.

3 Themes important to families

Each family has its own story to tell, with unique perspectives and experiences. A number of themes were common to most. This section describes the most important themes, illustrated with quotes from interviews with the families.

The need to control your own destiny

One of the most consistent messages from families with a member who has serious health problems and needs a lot of professional care is their sense of powerlessness. People often feel their fate is in other people's hands and that they are powerless to make crucial decisions, so they worry about the future, they sleep badly and their mental and physical health is compromised. This was a universal feature of all the families we met before they received their personal health budget. This sense of powerlessness is illustrated by one family member:

Everything was the wrong way round. People who controlled things for us were remote from us. They were coming into our house, and they didn't know us. Decisions were made to serve the needs of the staff, what worked for them, not for us. Some of the decisions were about actively disempowering us.

Another said:

Being dependent on services sucks your energy. Some of the nights I go to bed feeling most exhausted are not attributable to looking after C, because although this is really full on, it's something I do all the time and gradually adjusted to over the years. But the feelings of frustration/anger brought about by other people's lack of understanding or caring of my situation really wear me out. I've never felt so powerless and out of control of so many aspects of my life.

What families say is important here. Is care being provided by someone who really knows and cares about the person who has the health need, knowing them as a person, not just a bundle of needs? It is difficult, and certainly takes a long time, for an outsider to get to know a person with very high support needs in this way. And in traditional services, it is not expected that a professional person should get to know the person to this degree. This is a core part of the problem that all the families identified.

The sense of helplessness among family members extends beyond this: it is often magnified by deep anxieties for the safety of the person with health needs.

One mother said:

It takes a very long time to get to know what's "normal" for A (her daughter). Although other people have knowledge of drugs and therapies or clinical matters, I don't believe they can keep A safe without me being part of the jigsaw.

Families often become competent to perform high-tech procedures that are normally the preserve of qualified nurses. The families we spoke to expressed confidence in their expertise and explained that specialist knowledge and experiential learning was a fundamental aspect of caring for their family member. They believe that becoming an expert in every aspect of a person's health needs is crucial to ensuring their safety and wellbeing. One mum said:

Over time, it became obvious that my husband and I knew more about our son and his ventilator than anyone else. This was shocking at first, but we soon realised that we were indeed the experts!

In this context, becoming an expert doesn't mean emulating doctors; it reflects people's insightful grasp of medical and intuitive knowledge when they have cared for a person over many months or years. It means valuing and understanding their unique perspective and ability to understand instinctively what is needed by the person they care for. It necessitates the highest level of vigilance and the utmost trust in one's instincts, which can be difficult to surrender to other people's control. Families understand that knowing the person very well, thinking

outside the box and relying on a sixth sense can be crucial when caring for a person with complex health needs. C's mum knows she is the only one:

who understands medicine as applied to C. The doctors are helpful in sharing the theory, but they don't know C's peculiarities.

For the families we interviewed, this sense of less than full engagement with traditional services, compounded by worries about health and safety, creates overwhelming feelings of exclusion and powerlessness. All the people we spoke with were inspired to seek out information about personal health budgets because of their wish to change this situation, to take control of their own destiny and to recover a sense of autonomy. One person said he regarded himself as quite a laid-back person, but came to see the need to exercise more control when his father became ill and he saw things were not being done as the family wanted. All the people we interviewed shared the view that they would be more able to achieve the wished-for control and quality of care through use of a personal health budget, rather than through continuing to rely on directly provided services.

The people we interviewed knew about direct payments and would have chosen that option if it was available. But as they explored the alternatives, they could see great advantages in getting help from a specialist third party organisation. This is interesting, as cash direct payments are sometimes regarded as the "royal route" to choice and control, with other options portrayed as more prone to dilution and compromise. The important point to note

here is that once a good third party budget had been established, no-one saw a direct payment as a better route to being in control.

The importance of peer support

The families we talked with had all found themselves in uncharted territory as they endeavoured to move from directly commissioned services to a personal health budget supported by a third party organisation. Although there was limited information available to them, they needed to take a leap of faith and engage with senior NHS staff with the power to make significant decisions affecting the future of their family. They knew they were pushing the boundaries and that the arrangements they were proposing were largely new and untested.

All the families said that support from peers – other families and people in similar situations – was a fundamental factor in giving them the knowledge and confidence to move things forward. Peer support is indispensable because many of these families become very isolated – for families of people with complex health needs, there is no equivalent to chatting at the school gates.

One family member said:

I've got some trusted friends whose sons and daughters have complex health needs. When I ask them for support and advice, I know they'll tell me honestly what they think. They understand where I'm coming from because we speak the same language. They know what it's like to be told that if you don't

accept the carer that's being provided, you'll have to go without care. And they know what it's like to have to leave your child with someone you don't like and trust because you simply can't stay awake 24/7. So, when I told my peers that I wanted to try and change things but was scared to rock the boat, they gave me the help and support I needed. I couldn't have done it without them.

Another, in answer to the question “who has helped?”, listed three peers from other families who had had taken on specific roles:

C helped by describing her story at the partners in policymaking course. L helped by running the partners course and involving me. And J helped by explaining all about how a personal health budget might help and then, critically, by bringing me together with the commissioner, the finance person and the third party organisation to sort out what needed to happen.

Peer support is of vital importance. At the national level there now exists a small but vibrant personal health budgets peer network. An online resource, [peoplehub](#),⁵ aims to connect people with direct experience of personal health budgets, empower people with clear and accurate information and provide an opportunity for their voices to be heard. Several contributors have posted about the power of peer support. One says:

I know the absolute power of peer support! From these amazing folk on here, I've gained confidence, soaked up a lot of love in the room and I now know I am a unique and very human being!

If personal health budgets and third party support are to grow and develop as we hope, then in addition to national and online networks, each local area will need to create the right conditions for active peer support.⁶ This is one of the major contributions that NHS commissioners will be able to make in the future.

Bottom-up, not top-down

Traditionally, planning in the NHS has been done by managers, clinicians and other professionals, with patients and their families on the receiving end. More recently, people have been invited into this picture, but almost always late in the day as respondents to consultation exercises, asked to make known their views in reaction to proposals from the managers. An approach of this sort does not reflect the intention of personal health budgets.

The families we met were the major players in designing the care and support services they use, they continue to lead and manage these services alongside third party organisations, and they retain by far the biggest stake in the success of the arrangements.

It is the relationship between the family and the third party organisation that is particularly distinctive and critical in this respect.

As one family member put it:

We learned quickly that this relationship with the third party was going to be the key one, so we worked closely and directly with them, and did all the negotiations about practical issues.

It became clear just how important this relationship was a little later in the process, when things started to go wrong for this family.

It felt like a power struggle. We needed a new laptop to help us manage things. We employ 12 staff and needed a laptop for the rotas, record keeping and communication. We also wanted to access e-learning modules. We didn't know until much later that our third party went straight to the primary care trust and told them "we don't think they should have a laptop". The company didn't value the training or expertise of our existing staff team, asking people to repeat courses unnecessarily. There was a lack of trust both ways. There was no choice. They used the Care Quality Commission as a stick to beat us. They were making around £20,000 a year from the arrangement with us, for annoying us. We got into a battle for control. They imposed things on the family. They had poor systems and record keeping, not based on B's needs or circumstances, a one-size-fits-all service. We developed our own systems that worked for B. It was very stressful and disappointing. There were two systems running. We did what we had to do, and they tried to make us conform to their system. Possibly they were overanxious about B's needs and the risks to them as a company.

It was daunting for the family to go back to the commissioners and explain that things weren't working. The family were worried that the arrangement would be perceived as a failure, and the personal health budget would be taken away from them. For this reason, the family were perhaps even more forthright and

assertive in seeking out and engaging an alternative local provider. On this second occasion, they were much clearer about what they were looking for:

We negotiated. By then we knew the questions to ask, based on our experience.

The fact that the second company immediately understood what the family needed helped enormously. But the point of this story is that it was the family making the running, setting the parameters and defining the measures of success. They knew what they needed for a good life, and they went out to get it.

Not all families will want, or be able, to sustain a role as active as this. And although the initial third party budget didn't work for this family, it might still be successful for others.

Personal health budgets (and personalisation)⁷ are about a redistribution of power and responsibility. People who use health services and their families are asked to play a more active role on a continuing basis, on the understanding that sharing responsibility is a good thing. It leads to better outcomes and reflects a more mature relationship between health professionals and the public.

The importance of developing trust

For many families, the need to gain or regain control is rooted in a sense of vulnerability and broken trust: a much loved family member has serious health problems and relies on others,

sometimes just so they are able to go on living. The disengaged nature of the relationship with health professionals means that levels of trust are often low, while levels of stress are correspondingly high.

For our families, one of the most attractive features of personal health budgets and support from a third party organisation was the opportunity to start on a new footing and build a new type of working relationship based on mutual respect, common sense and trust.

The family member quoted above described the way the relationship with the second third party organisation was initiated as "like a courtship". The family had already had one bad relationship with a third party, so second time around they were more experienced and prepared.

We knew the questions to ask, based on our experience with the first organisation. Trust in the relationship was critical. They needed to trust us, that we would do a good job. We showed them our policies and how we operated. I trusted them because of their values. Ultimately, it was a marriage made in heaven, an equal partnership.

Trust is, of course, a two-way street. An interesting feature of the arrangements we heard about is the contrast between the formal and informal agreements that govern them. A formal agreement is a contract between the NHS and the third party, which states exactly what services are provided, over what period, in return for what sum of money. The services usually include employing a team of staff to provide care and support, entailing

responsibility for a whole range of legal and regulatory duties (employment and tax law, health and safety, Care Quality Commission requirements).

Informally, what we heard about in all cases was a very high level of trust between the third party and the family, so that many of the tasks were, in effect, delegated to them. In one case, the family is almost entirely responsible for staff recruitment, management and supervision, despite the fact that this is formally (and legally) the responsibility of the third party. This is precisely the sort of arrangement that the family wants so that they can take control. They have the reassurance that they can call on expert back-up from the third party if they need it, which is very important to them. A couple of instances were cited where they have called on back-up from the third party, including one involving a disciplinary issue where the third party issued a written warning to a staff member.

The consensus from families is that this approach works well and mitigates the sense of powerlessness they feel – at difficult times the family can say to the third party, as one mother put it: “don’t leave us on our own, guys”. But there is a sense of precariousness about the informal nature of the relationship. Far better, several people commented, if there could be something formal as a back-up, perhaps a letter of agreement between the family and the organisation, in effect an addendum to the contract between the NHS and the third party. This could outline the respective roles and responsibilities of the third

party and the family. These will no doubt vary greatly, but will include staff issues – supervision by the family, whistle blowing, access to training and development opportunities, and so on.

Who co-ordinates the service?

Most of the families we interviewed included a young person with complex health needs, and one involved an older man with dementia. The support needed by all these people is highly sophisticated, involving the use of assisted ventilation. There is a need for many consultations with clinicians from different disciplines. There are frequent and often unpredictable crises or emergency situations, the cause of which may be unclear. The necessity for good co-ordination, both clinically (across specialists) and in terms of the day-to-day service, is paramount.

One of the main criticisms families had of directly provided services was that they are often poorly co-ordinated. Traditional services rarely take account of the specific needs, requirements and wishes of a particular family. In crisis situations, they can revert to a medical model more suited to hospital care than to treating a person in their own home. A difficulty several families encountered is the challenge of co-ordinating services when a person has very complex health needs. The families reported that a personal health budget enabled them to co-ordinate all the day-to-day support, allowing them to take a whole-person, whole-family approach that works extremely well.

The third party budgets we heard about were enhanced by robust care plans, clear roles and responsibilities and, especially, agreeing measures that mean the family has real influence and oversight over their family member's health needs. There are a number of variations in how this can work.

In one case, a family member is actually employed (using the personal health budget) to work for a few hours a week to co-ordinate the team, plan rotas, make appointments and other practical arrangements. One third party organisation we interviewed said it is particularly keen on such arrangements, which mean the aspects of the service that need detailed attention are the responsibility of someone with detailed knowledge of the person and their home situation, and with an incentive to get things right. In other cases, the family takes on this responsibility unpaid. Another option is to pay a team member as a senior to co-ordinate things.

None of these arrangements takes away the need for a lead clinician. A well run personal health budget will enable a more normal life and improve health outcomes, but it will not eliminate the need for clinical input. We can mitigate the impact of long term health conditions by having robust emergency and contingency plans, but everyone with a personal health budget who has complex health needs will require the support of knowledgeable, empathic and holistic clinicians, backed up by a 24-hour on-call service. For many people eligible for NHS Continuing Healthcare, the complexity of their condition is not well served by scheduled

(three-monthly or six-monthly) appointments. As one clinician noted:

they need to see doctors when they need to see them, rather than when the service dictates.

Getting the right staff, and paying them for the job

Finding and supporting the right staff for a person with health needs and their family is critical. This varies from person to person, and from family to family, and this is why we talk about personalisation, an approach with personal circumstances and choice at its heart. One family member, a mother, told us about the kinds of people she wants to support A, her daughter:

I want people who see the big picture and who are able to understand A's life. In essence, I'm not looking for carers, I'm looking for people to be A's responsible friends. If A left home, I might want a person in a more traditional caring role, but at the moment I do the caring/managing bit. I want A's personal assistant to tell me she's had a good day, not that she's had a seizure.

This mother went on to talk about the importance of building a team with the right attitudes, and also with the right mix of personalities and approaches:

The team complement each other. One is reliable and flexible ... more like us than the others. If I didn't have Mrs Flexible in the team, it wouldn't work.

Some specialist health expertise may also be needed. One young person has multiple

health needs: he has a tracheostomy and a gastrostomy, and uses continuous positive airway pressure to support his breathing at night. The team needs to include people who are confident in working with these issues. They don't all need to be qualified nurses, whose skills may cover a broader range, but who may lack experience with the particular procedures needed here. In this instance, it is important that there is one trained nurse to provide some day-to-day clinical leadership and to take an overview of health needs. This will be true of many families who opt for personal health budgets and third party support in the future. There will be an increasing need for trained and specialist staff in these roles, and third party organisations will need expertise to support families to recruit and manage them.

So building the team is complex, a matter of getting the right skills, attitudes and personalities together in the right combination. Third party organisations have been able to help in advising and assisting families to draw up personal specifications and job descriptions, placing adverts and managing a recruitment and selection process. One organisation told us:

We start by getting the family to think about what their ideal staff member would bring and working up a job description and personal specification. This sometimes brings up issues in relation to the Equality Act (eg "we don't want support staff with children of school age"), so we have to advise them about what is lawful and what is seen as good practice. A traditional competency-

based approach to recruitment doesn't work here because the important factor has to be how comfortable the person is with their staff, and they need to find a way to judge this ... Not everyone needs detailed support with recruitment, but most do.

A central issue in the relationship between the three parties – commissioners, families and third parties – is setting and reviewing pay rates and other conditions of employment for staff. In strictly contractual terms, these are matters for the third party (which must take account of employment law and minimum wage regulations). Families point out that good pay and conditions are the main ways to attract and reward staff, and also the way to shape the service around the family's requirements.

One family we talked with wanted to offer pay rates commensurate with the complexity of supporting a person with high needs in the community. In agreement with the NHS commissioner, they set their pay rates in line with NHS pay scales which enabled them to offer the same terms and conditions as the local NHS long term ventilation team. Families are very insistent that they must be granted access to these levers if control is to mean anything at all.

Managing and supporting the staff

Some families bring experience of managing staff from the world of business or elsewhere; others have less experience and confidence. The important point is for arrangements to be flexible and amenable to tailoring to different circumstances and wishes.

The approach should always reflect the family's wishes and personalities. We would not expect, or wish, that each personal health budget arrangement looks or feels the same, nor should they attract staff with the same attributes. Some people operate best in an environment with more structure and rules, some with less. Some people want to be doing active things out of the home, others prefer to be quieter and spend more time indoors. It is important that the third party organisation is sensitive to these issues and, where necessary, provides advice, assistance and hands-on management.

Direct staff supervision is very important in care and support services, particularly in circumstances where staff are intimately involved in a family's life and provide personal care within the family home. Supervision needs to be given a high priority and its purpose needs to be clear to all. It needs to be regular and uninterrupted, and a record should be kept to which each party has access. Many of the families interviewed are keen to provide supervision themselves, and there is certainly a case to be made for a direct line from the family to staff. Many staff will also need specialist advice and oversight, as well as the right to raise and discuss issues with their employer (the third party) from time to time. What is most important here is a process to ensure third party organisations are open and responsive to a variety of situations, and are mindful of both the needs of the person and family, and their legal and good practice responsibilities as an employer.

The representatives of third parties we interviewed had some clear views about their management role in relation to that of the family. One framed this as a distinction between the organisation's role in providing the conditions for success, guiding the family and intervening as needed along the way; and the role of the family in taking responsibility for day-to-day management (such as setting up rotas and finding staff to provide cover).

Expectations regarding training and development, and the opportunities made available to staff, are of central importance. Again, third parties have been able to help and advise on this, sometimes offering imaginative, person-centred approaches to training that involve the person with health needs, and sometimes basing training in the family home.

The important point for many families is that they are involved as (at least) equal partners in all the processes that involve staff. This includes setting the probationary period and signing it off as passed by a member of staff, and disciplining staff who break the rules.

Importantly, although the contract is between the NHS and the third party organisation, the family is very much in the driving seat. The third party provides advice, assistance and reassurance. Both families and third parties interviewed told us they were happy with this arrangement, but this approach does require a particular management style by the third party, as well as a very clear vision in relation to what personal health budgets are actually for. Not every organisation will approach things in this manner.

Managing risk

We know from experience with personal budgets in social care that one of the keys to success in achieving good outcomes is the right attitude to managing risk. The same applies to people with personal health budgets, albeit in circumstances where, for some at least, there are continuous and serious risks to health. The families we interviewed were very clear in their views: what they want for the person they care for is a good life, not simply a safe life. They strongly assert that they know their family member better than any professional can, no matter how skilled, and it is in their fundamental interest as a family to ensure he or she is happy, safe and well. This isn't achieved by avoiding risk; rather it is done by taking risks in sensible and planned ways.

One family member said:

No-one can have the same experience of knowing A as me. No-one has seen as many seizures or as much mania. ... They don't have the knowledge to keep her safe and healthy ... she'd be over-medicated; she'd have a gastrostomy; she wouldn't be alive today.

One third party organisation described its approach as follows.

We take a very common-sense approach to risk, starting from the perspective that the person or family know what's best – they know how to live their life and they are motivated to stay safe. Risk-averse behaviour

puts unnecessary barriers in people's way, and traditional risk assessments add to costs. We had a recent example: a mother and her daughter wanted to use a hotel in London to attend a conference, but the agency supporting them said this was not allowed because they had no risk assessment of the overhead tracking for the hoist. This seemed to us to be both silly and unnecessary, particularly as the daughter is light and the mother is very used to moving her at home.

The terms and conditions of this organisation state clearly that they are there to support the service user in their home, or wherever they may be. This is a clear indication that the personal health budget holder is in control, and the function of the third party is to assist them in getting what they want and need, while ensuring they stay safe and well.

This approach – risk enablement – is supported in social care by a range of person-centred planning tools,⁸ which help the family think through what they want to achieve, how to achieve it, and how to stay safe; and by policies and procedures of local authorities to assess, scrutinise and sign off "risky behaviour" and, where necessary, to propose action to help the person mitigate and manage the risks they are taking to live a good life.

The personal health budgets guide 'Implementing effective care planning'⁹ puts it like this:

When people use personal health budgets, they plan how to use their budget creatively,

to tailor their care and support to improve their situation and to achieve their personal health outcomes. Part of that planning process must include weighing up benefits against any possible risks of particular aspects of their care plan.

People will want to discuss the merits of different treatment options with their clinicians. When considering a choice of care providers and third-party organisations, they may also want to seek information more widely, and to consult with other people (for example friends they trust) and perhaps with people who have similar health conditions.

Some people will use their budget to continue to purchase traditional services that they find work well for them; some will want to use it to meet their health outcomes in different ways. It will not be possible simply to rely on existing regulations and protocols to manage risk, and it could be argued that the regulations were not working well enough in the old system. NHS commissioning organisations will have to devise processes that balance protection of the person and the organisation with the person's right to self determination.

These processes should also take account of the contribution of third party organisations in their role of supporting people and families to use their personal health budgets to live the life they choose, without eliminating all possible risk.

Commissioners' role

The staff responsible for commissioning personal health budget arrangements will be within clinical commissioning groups under the NHS reforms. These bodies play a critical role in ensuring the success of personal health budget arrangements, particularly at this early stage and for people who are keen to use a third party. How might commissioners help?

The local commissioners we met and heard about were, for the most part, open-minded, helpful and flexible. They listened to families and demonstrated commitment to understanding their difficulties and anxieties, particularly in relation to their experience of directly provided services and their fears for the future.

Commissioners also demonstrated a degree of pragmatism: where families were saying existing arrangements weren't working, but made suggestions to improve matters, commissioners were mostly happy to try these out.

Commissioners lacked a body of experience (or detailed policy and procedures) to guide their practice in relation to personal health budgets and third party models. It is to the credit of the commissioners we came across that while they may have known little about personal health budgets initially, they were willing to do the necessary research and take a leap of faith to support the family and the third party organisation to construct a new arrangement. They did so while paying due regard to existing rules and regulations and the need to manage budgets carefully.

Two families (in separate locations) told us that the commissioner agreed to support a third party budget so long as costs were contained at roughly the pre-existing level.

This point raises important issues of equity. At the time of our interviews, NHS commissioners working with families had to use the cost of existing services as the basis for calculating personal health budgets. A national framework is in place which provides guidance on eligibility for NHS Continuing Healthcare,¹⁰ and advice is available in the personal health budgets toolkit on ways to set a personal health budget.¹¹ Families will no doubt welcome clear and fair rules. However, the NHS needs to learn from the experience with resource allocation systems in adult social care, many of which are unduly complex and restrictive, and in some localities took a long time to develop and agree.

Interviews with families and others suggested the following additional points for consideration by commissioners.

- Co-ordination of the support arrangement is critical in terms of both effectiveness and efficiency. Commissioners need to consider their own role, along with that of clinicians and others, in determining how best to develop robust arrangements.
- The cost of putting in place a third party budget must be included in the personal health budget, so that people are not disadvantaged or excluded when choosing the best way to hold and manage their budget. There will need to be clear

information about the costs of third party budgets as well as the benefits they bring. This will ensure third party budgets are a viable option for people who can't have, or don't want, a direct payment, promoting equal access for all.

- The formal documentation supporting third party arrangements varies enormously in its scope and level of detail. The families we spoke with favoured formal arrangements that clearly set out the roles and responsibilities of all concerned, including themselves – hence the suggestion of a letter of agreement (see page 11). Formal documentation needs to be clear, unambiguous and in plain English. It should focus on the objective of securing better health outcomes through enhanced choice and control.
- The way a personal health budget arrangement is reviewed, in terms of its success in achieving outcomes for the person with health needs and in terms of value for public money, is also important. Review processes varied significantly among the families interviewed. There is now considerable experience in the field of social care personal budgets about what is important in the review process. This suggests developing protocols that include all parties (commissioners, third party organisations and families) and that regard the review as a learning experience about how well things are working and the steps needed to make improvements.

4 Making third party budgets work well

This section illustrates the outcomes families can hope to achieve if personal health budgets and third party budgets are working well. It draws on the learning gained by one family whose first third party budget failed. They learned that the core values of the organisation, and their willingness to let go, are critical to the success of a third party budget.

Here we suggest some questions that people can ask to determine whether a third party budget is a good fit for them. A case study illustrates how the answers to those questions, and the subsequent approach taken by a third party organisation, can help achieve the purpose of a personal health budget – to ensure people with long term health conditions and disabilities have the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them.

Before their personal health budget was in place, all the families interviewed saw their situation as pretty hopeless, with the prospect of a bleak future for the person they were providing care for. One mother described herself as having experienced years of “absolute struggle”. The NHS staff she dealt

with seemed to recognise this and perhaps to share her sense of desperation, and treated her son as an exception in agreeing a new arrangement: a personal health budget supported by a third party. This is commendable, but now we need to move beyond exceptions if we are to make the system changes needed.

Before and after

The families described life using a directly commissioned service, and how life changed when they started to use a personal health budget held by a third party. They were willing to take more responsibility for ensuring a good outcome in return for being able to choose their staff team, have direct input into staff training, and develop trusting relationships. They wanted greater autonomy, better life chances for their whole family, and a more ordinary home life.

Family life using a directly commissioned service	Life using a personal health budget held by a good third party
<i>There always used to be a crisis on a Friday night when everyone was going home.</i>	<i>My third party's great at sorting out niggles before they escalate.</i>
<i>There was a very high staff turnover.</i>	<i>Our staff team has been with us for three years now. It's made such a difference.</i>
<i>There was minimal training related to our situation, but lots of generic tick-box training.</i>	<i>Our third party helped us find new opportunities for developing our staff team. Two people have just done some postural care training.</i>
<i>It wasn't all bad because some of the carers were really nice, but they were in such high demand from other families that we hardly ever saw them.</i>	<i>I no longer feel I have to look after people when they're in our house. It feels relaxed and natural now we've chosen the team ourselves.</i>
<i>Some of the night staff were irresponsible – they slept on shift and some even smoked. It seemed to be difficult for the NHS to take disciplinary action.</i>	<i>Our team has really gelled together; there's lots of continuity and everyone is taking responsibility for making it work. We know we can rely on them.</i>
<i>The office staff seemed to be invisible when you needed them.</i>	<i>Our third party trusts us and we trust them. It's a great working relationship.</i>
<i>I was forever picking up night shifts at short notice because someone had made a mistake on the rota.</i>	<i>Our new team are much more reliable and flexible and we can sort things out if they go wrong.</i>
<i>I was always chasing things up to make them happen.</i>	<i>Our systems are clear and simple.</i>
<i>Changes would be made to the rota and I wouldn't be informed.</i>	<i>Communication is really easy. We all access the rota on Google calendars, which keeps everyone in the loop.</i>
<i>My son's carers were told not to get involved with us as a family because they were only there to do health-related tasks.</i>	<i>Recently I've had my own health problems and I've felt really supported by the personal assistants.</i>
<i>There was a lot of form filling which didn't serve any useful purpose.</i>	<i>I wouldn't go back to the old way of working EVER.</i>
<i>The staff had to wear uniforms that made them stand out.</i>	<i>My son's personal assistants fit in with our whole family.</i>
<i>I felt totally powerless in our own home.</i>	<i>At last our home isn't overrun with people we don't want to be there.</i>
<i>I felt my life was passing me by. Sorting out my dad's care was a full-time job.</i>	<i>I've been able to return to paid work for the first time in years.</i>
<i>I had endless people coming through the house checking on us.</i>	<i>I have fewer meetings with professionals but I know where they are if I need them.</i>

The role of care planning in choosing the right third party organisation

From the development of personal budgets in social care, and from our experience to date with personal health budgets, we know the process of thinking about and drawing up a care plan is central to getting it right for people with complex needs. Person-centred thinking and planning tools,⁸ that recognise what is important to the person as well as what is important for them, are transforming our thinking about care and support services. For this reason we sometimes talk about care planning as lying at the heart of self-directed support.

The planning process also represents an ideal opportunity for people to explore what matters most to them when choosing a third party organisation. It's a chance to think about what decisions they want to make and how to make them. It's also a chance to think more about the process and practicalities for recruiting a staff team, to explore whether the family wants (and is able) to conduct recruitment interviews themselves or whether they want the third party to do this, or whether there is a middle course where the organisation helps them. And it's an opportunity to begin to map out the most important aspects of service design and management and the respective roles and responsibilities involved: who provides staff supervision and how; what arrangements are needed for staff cover; what happens if something goes wrong? People need to be

empowered to make decisions about the management style and qualities of their third party organisation, and these discussions can unearth issues and help ensure everyone is clear about what is expected and how the future is likely to unfold.

It is important for the person to be able to choose who, if anyone, they want to support them to plan. This is a critical role. Sometimes people are happy and comfortable to plan on their own, particularly when they are given clear information about what's expected of them. But when planning for the first time, many people will want to talk things through with someone else, preferably a person they feel comfortable with, who understands their situation.

People need to feel it is possible for useful change to happen, and hopeful that their day-to-day life can be improved. This is necessary even when a person has a deteriorating health condition or is nearing the end of their life. Having the chance to hear about real-life examples of what others have done differently, and talking with peers, are two useful ways to share creative thinking and generate new possibilities.

How to recognise a good third party

The following questions are intended to help people develop their own criteria for judging whether a third party organisation is a good fit for them. They were developed from the knowledge gained by the family whose first third party budget was unsuccessful (see page 9).

They said:

When we entered into our first third party budget we made a lot of assumptions because they'd said all the right things. They talked about being person-centred and how families are the experts in the care of their family member, so we assumed they'd respect our wish to make decisions and to manage the day-to-day care of our son. With hindsight, there were a lot of clues to the fact that we saw things very differently, but we didn't recognise them at the time – we were probably a bit naïve. We learned a lot from our mistakes, so when we approached a new third party organisation we knew the right questions to ask.

Questions to ask a third party organisation

- Do you have a track record in health? Can you describe or talk me through a personal health budget you've held that's worked well?
- If you're new to personal health budgets as an organisation, what do you think are the three most important things to bear in mind, or that will guide your working practice?
- How do you hold the money? Is it in a named account to be used only by me?
- Who chooses who will be employed?
- Who writes the job descriptions?
- Who writes and agrees the adverts?
- Who decides the rate of pay and hours of work?
- Who does the interviews?
- Who decides how outcomes will be met?
- Are you happy for me to recruit my own people?
- Can I recruit family members?
- How will I know what has been spent and what's left?
- Will you come to meetings with my NHS commissioner and myself?
- Will you make sure I'm fully included and copied in to all correspondence with the NHS commissioner?
- What do you offer?
- How much will your services cost?
- Will your fee vary depending on how much of your service I need?
- Who will write my risk assessments?
- Do you have a nurse who will help with risk assessments and signing off competencies?
- What do you see as your responsibility?
- What do you see as my responsibility?
- If things go wrong – what do you suggest we do?
- Whose money do you think it is?

Everyone has different priorities, and what matters most to one person may differ for the next. The way organisations respond to the developing market and to the need for more third party organisations will also vary.

The following case study (in which the name has been changed) illustrates a responsive and flexible approach to personal health budgets.

Personal Support community interest company

Personal Support community interest company aims to empower personal health budget holders and their families to manage care and support arrangements in their own way. The company is commissioned by the NHS to do this, and is clear in all its documentation that many functions normally considered the responsibility of the organisation will be delegated to families if they so choose. Their publicity says they:

aim to ensure people have real choice in all aspects of their care and support [and that they] start from the premise that things work best when individuals and families have control.

They have some standard policies and procedures, but it is made clear that these provide benchmarks only, and that the support arrangements for each person will need their own detailed paperwork determined by individual circumstances. They work to help the family decide what they need in terms of a support service. They work with the family to prepare profiles of the staff, the skill mix needed, and the personality types that will work best, taking into account any particular issues for each family member. These profiles are translated into job descriptions and adverts. The family's role in the interview process depends on their experience and confidence. They may take the lead, or Personal Support may do this; the family always have the final say in who is appointed.

The family provide day-to-day staff supervision, with guidance from Personal Support, which is the legal employer. It is made clear that staff can always talk to Personal Support if they have difficulties or concerns. Staff training and development are tailored to the needs and circumstances of the person and family, and the family will usually be involved in some way in delivering training.

Personal Support and the family meet and review progress regularly and provide joint reports to the primary care trust. Any changes needed, including requests for additional funding, are agreed between the family and Personal Support, and are put to the NHS in a joint submission. Personal Support charges a simple fee on a sliding scale depending on the level of support people want. Records of all financial transactions (including management fees/profits) are provided for the family.

Future developments

Personal health budgets and third party budgets will help to bring real choice and control for people with health care needs in England. However, some major challenges remain.

This guide concludes with some pointers based on what families have told us about their experience to date, and how this might affect a future implementation programme.

- To date, third party budgets have been proposed by families themselves, who through luck, persistence or good search skills have unearthed a solution that works for them. In the future, NHS staff need to have knowledge and confidence about all the options for managing a personal health budget, and to be in a position to put families in touch with appropriate local organisations. The organisations need to be both third party and local peer-led organisations.
- For this to happen, the few sapling third party and peer-led organisations that now exist need assistance to develop and grow, and more seeds need planting and nurturing. A similar process has happened in the world of social care since the take-off of personal budgets, and there are lessons to be learned, both positive and negative, from this short history. There is an important role for commissioners in finding ways to stimulate the local market.
- Third party organisations face a number of challenges. At this stage, most NHS staff have a limited understanding of the ethos and values of this new approach. Sometimes they have a limited understanding of the Department of Health's own policy, and of the role third party organisations can play. One organisation described some inflexible approaches, giving the example of an NHS commissioner spending £40,000 a year on taxi fares, but who would not consider purchasing a vehicle at much lower cost because this breached their rules on asset building. Commissioning practice is very variable across the country. Some NHS organisations add layers of monitoring to satisfy internal audit demands, while others don't see this as necessary. The NHS reforms provide an opportunity to introduce common sense and standardisation here.
- The Care Quality Commission plays an important role in regulating and monitoring organisations that provide personal care services. One family had struggled to get accurate and consistent advice from the Commission. The impact of personal health budgets and new ways of working will need careful consideration. One organisation made the point that for micro-providers in particular, the cost and complexity of the regulatory process are disproportionate to the impact.
- Families regard it as very important that contracted third party organisations are permitted to delegate many of their functions to families in order to facilitate choice and control. To reflect this, and to promote the health, welfare and integrity of all parties (commissioners, organisations, families), formal arrangements need to reflect this reality. This should include letters of agreement with families, setting out their roles and delegated responsibilities.

5 Recommendations from families

These recommendations from families are to those developing personal health budgets locally, regionally and nationally.

Theme	Recommendation
The need to control your own destiny	That all available steps are taken to ensure third party budgets are available as an option to everyone taking up a personal health budget; and that these arrangements are supported by robust policies and procedures that devolve every decision concerning the family to the family.
The importance of peer support	That the NHS invests in peer support and recognises its value in helping people and families make good decisions about their choice of third party.
Bottom-up, not top-down	That families are expected to be actively involved in planning and establishing their service. The degree and nature of involvement will vary, and families will be supported to contribute in their own way.
The importance of developing trust	That there is a formal letter of agreement between the family and the third party organisation setting out roles and responsibilities, which is appended to the contract between the NHS and the organisation.
Who co-ordinates the service?	That robust arrangements for co-ordination (medical and care) are always agreed as an important aspect of the personal health budget agreement. The precise nature of these arrangements should be agreed with the family.
Getting the right staff and paying them	That families can recruit their own staff and offer terms and conditions that attract the right staff (eg pay rates commensurate with the designated role and tasks and that recognise the complexity of supporting a person with high-level needs). Decisions such as pay rates need to be agreed in advance with the NHS commissioner.
Managing and supporting staff	That third party organisations are sensitive to the different capabilities and wishes of families in relation to staff management issues, and they respond appropriately.
Managing risk	That the NHS provides advice on risk management that seeks to enable a good life, and that balances protection of the person and the organisation with the person's right to self-determination.
Commissioners' role	That the NHS is charged with playing an active role in promoting and supporting third party organisations as a viable option for personal health budget holders.
Making third party budgets available to all	That the NHS takes steps to stimulate the supply of a range of viable, local third party organisations.

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Personal health budgets team

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