

Personal budgets: an introduction

Briefing 1



This is the first of three briefings about personal budgets prepared by In Control* for Together for Short Lives. They have been funded by the Department for Education as part of Together for Short Lives' special educational needs and disability (SEND) project. The briefings are for the trustees, managers and staff of voluntary sector providers of children's palliative care services in England – and for the families who use them. This first briefing is an introduction, the second is aimed mainly at families and the third mainly at provider organisations.

Families of children with life-threatening or life-limiting conditions often say that they are deeply impressed and moved by the compassion, the care and the professionalism of the staff they meet in children's palliative care services, including children's hospices. It is important to acknowledge this and to register our aspiration that personal budgets will help to build on and magnify this care, compassion and professionalism – not dilute it.

This introductory briefing explains a little about the rationale and background to personal budgets, where they come from, how they work and in particular how they sit within the requirements of

the new legislation to support children with special educational needs or disability.

This is important because clinical commissioning groups and local authorities – the local bodies responsible for health and social care – are required to work to this legislation and they will expect provider organisations to understand it and shape what they do accordingly. In introducing this way of working we will also describe some of the opportunities and challenges which it presents.

*In Control a national charity. Its mission is to create a fairer society where everyone needing additional support has the right, responsibility and freedom to control that support.

What are personal budgets?

A personal budget is a sum of money that is made available to someone who needs support. The money comes from their local authority social care or education department or NHS commissioners and is allocated to the individual or family to spend on help and support to meet their assessed eligible needs and to achieve agreed outcomes.

Until recently most personal budgets have been for adults who need social care, but now they are being extended to children and young people with special educational needs or disability (those who qualify for the new Education, Health and Care Plans) and to support some health needs (those

with continuing care needs from 2014, those with long term conditions from April, 2015). When the money comes from the NHS it is referred to as a Personal Health Budget.

To help prepare local agencies in implementing the special educational needs and disability (SEND) reforms in the Children and Families Act 2014, the Department for Education issued a draft Special Educational Needs Code of Practice which defines a personal budget as an amount of money identified by the local authority or health service to deliver parts of the provision set out in their Education Health and Care (EHC) plan.

Families will be able to request a personal budget as they work with the authorities to draw up their EHC plan, or at their annual review. One of the major challenges for the authorities is to agree and join up money contributed by social care, and sometimes now by education and the health service to form a single personal budget that works smoothly for the family.

Where did the idea come from and why?

Personal budgets for adults have been around for quite some time now. The Direct Payments Act 1996 gave local authorities the powers to allocate money in lieu of services to a disabled person who met their eligibility criteria and who preferred this arrangement. This law was the result of many years of campaigning by disabled people who argued that they would have greater choice and control if they had a cash payment rather than a standard service.

It is important to note that a direct payment of this sort is now only one of several management options for personal budgets (see below for more detail) and that whether someone takes a direct payment or not there should be no expectation that families are on their own to arrange and manage their support.

Direct payments for adults with disabilities were successful and popular, but only on a relatively modest scale. In the early 2000s there was a call for a more comprehensive system which might suit a wider range of people. This led to personal budgets as we now know them.

As far as children and young people are concerned, from September 2014 the Children and Families Act 2014 states that where there is a child or young person with higher levels of need their family will be offered a personal budget. It is important to be clear that they do not have to accept this offer: if they prefer they can still receive support in the traditional way, which means services are organised for them.

The two major differences between early-style direct payments and personal budgets are that:

- Personal budgets are only agreed by the authorities when a clear and sensible set of outcomes is agreed. So a personal budget

What the words mean

A **personal budget** is a sum of money allocated to an individual or family to meet their eligible needs and outcomes.

A **direct payment** is a personal budget that is paid direct to the individual or family.

An **individual budget** is the name sometimes given to joined-up personal budgets from different funding streams – education, health and social care

Personalisation is the policy, the whole set of changes which puts the person at the centre.

Person centred thinking is the change in mind-set needed to make all of the above work.

A **person centred plan** is the product of this changed thinking: a plan with the perspective of the child/young person and family at its heart. For those families who are eligible, this is the EHC Plan which sets out the outcomes the family are seeking to achieve and how they will do this.

A fuller glossary in relation to personal budgets is available at www.in-control.org.uk



does not pay for a service, instead it pays for whatever it takes to achieve these outcomes. While this may include traditional services, it might equally be used to pay for taxi fares or admission charges for example; and these may then complement various free things provided by family or community.

- The driving force behind personal budgets is the person-centred planning process. For children and families this now takes the form of the single EHC plan, which incorporates all aspects of the child or young person's life, not just education, health or care. The planning process is designed to be flexible, clear and open to family influence. A personal budget is an option for those children and young people where it is agreed that an EHC plan is needed.

How has it worked so far?

Many people have now benefitted from personal budgets. Here are some of the things they have said:

“Since [we got a personal budget] I have a few hours off each day. I am a far happier person and I feel that because I am more relaxed, in general, my attitude to caring is a far better one, than a few months ago when I began to resent everything I did for my sister. I will also have the ability/freedom to have a few extra hours off once the school holidays come around and be able to spend time with my grandchildren – something I could not do before.”

“The key ingredient to living independently was my personal budget. I am now living as independently as I can, in my own place on an ordinary street with my own personal assistants helping me with my day to day life. I was able to be fully involved in all the planning and interviewed my own personal assistants. They are the same type of age as me and I get on with really well with them.”

“As for personal budgets, I would advise anyone to go for it and change their life. Ask for help if you feel you cannot manage but do not let the opportunity pass you by. I am a person again. I can hold my head up high. I am now giving back and helping others.”

Personal budgets in education, health and care

Most of the short history of personal budgets has been in social care, where the idea grew out of the experience with direct payments.

The first trial of personal budgets for children and families was through a project called Dynamite between 2005 and 2007 which began by allocating £200 “practice budgets” for a variety of interesting self-defined family projects.

Some local authority children’s social care departments then picked up the idea and, with support from In Control, began a process of design, testing and review. In 2011 the Government included the option of personalised funding in the Support and Aspiration green paper and this led in turn to its inclusion in the Children and Families Act 2014.

Subsequently, the concept of personal budgets has been extended to address health issues. From 2014, personal budgets will become available for children and adults determined as having continuing health care needs.

In the field of SEN, where local education authorities are making certain aspects of the high needs block funding available to eligible families as an education personal budget.

Joining up these three funding streams – social care, health and education – is a very real challenge for the authorities given that the funds are provided for quite different purposes and channelled through very different routes. So at this point integration is a work in progress and it would be naïve to expect systems to function completely smoothly.

For example, children’s hospices are funded through a combination of charitable contributions, an NHS England grant and varying amounts of statutory income from CCGs and local authorities.

Given this level of complexity it is probably unrealistic to expect everything to go smoothly from day one: this is not to say of course that families will not (and indeed should not) expect clear information and a seamless service. It is therefore important that all concerned are informed about both what the law now says and about what is reasonable.

What are the options for managing a personal budget?

It is very important that families are given a choice about the ways they receive and manage their personal budget.

1 Direct payment (where money is paid direct to a named person, the disabled person themselves or a family member)

Sometimes, depending on the sums involved and whether it is a one-off sum or an on-going payment (eg a monthly for support costs), A person receiving a direct payment may need to provide a record of their expenditure and possibly consider issues relating to tax, national insurance and payroll.

The local authority or CCG will advise about local arrangements. Each local authority is obliged to ensure that information, assistance and support is available in relation to these issues, often through a centre for independent living or other user led organisation. Such organisations are invaluable resources not only for people seeking to manage a direct payment, but for anyone interested in learning about what is possible locally and how to get the most from them.

2 Requesting that someone else, a named individual or organisation, does it on your behalf

When an individual takes on this management task for someone else, this the approach is sometimes known as brokerage. When a service provider organisation does it, it is known as an individual service fund. Sometimes there may be a separate arrangement with a specialist organisation known as a third party arrangement.

How these different arrangements work varies from place to place: the big advantage that many people describe about them is that they bring a degree of personal control without the worry and burden of being personally responsible for everything.

3 Asking the authorities (local authority or CCG) to manage the personal budget for the individual or family and make all the arrangements

Various names are given to this, including a directly managed personal budget and a virtual personal budget. This approach has the great advantage of being straightforward and requiring minimal work by the person or family; however some people complain that with this comes a lesser degree of choice and control.

4 Combine two or more of the above

This might mean for example some services being funded directly through a virtual budget and some funds going direct to the person as a direct payment – or perhaps to a broker.

In any event the aim is to work towards the outcomes as set out in the person of family's plan.



How do assessment and planning inform personal budgets?

An individual or family will only become eligible for a personal budget in instances where their assessment indicates that their needs warrant it: as a rule of thumb we can say that children and young people who would have had a statement of special educational need under the old system will now be eligible for a personal budget.

However, the way in which the assessment process operates should now be very different: it will be one joined-up process across education, health and care with a lot more emphasis on the family perspective and the means to help the family find their own solutions without recourse to services. For those who are seen as eligible for a personal budget and an EHC plan this approach to assessment will lead directly into (but will be separate from) the process of sitting down together to write and agree that EHC plan.

Although this is still to be worked out in detail, almost certainly the whole of a child's support will not be able to be taken as a personal budget: schooling, medical services, therapy services and much else will remain as now organised separately and open to all – or at least all whose need warrants it.

The other complication is that, as already noted, education, health and social care all do things differently and use different criteria for decision making: in the short term at least some of these differences will continue to apply to the allocation of personal budgets. This may mean for example, a child, young person or family is eligible for (say) a substantial social care personal budget, a modest educational personal budget and no personal health budget. Everyone's circumstances are different and this will be reflected in the response people receive.

The assessment process is always the critical first step in determining this. In part this is to help the authorities decide precisely how much money is available in a personal budget. Most authorities use a system known as the Resource Allocation System (RAS) to do this. There are a number

of different approaches to RAS but they should always be visible, in the public domain and easy to understand. From September 2014 they should be published in the area's local offer. Families should be involved and consulted as the local RAS is developed. The sums allocated in the first instance should also be indicative. This budget can then be fed into the EHC planning process and if it is wrong (too much or too little) to realistically enable the family to achieve agreed outcomes then it can be amended.

If the individual or family do not know how much money they have to plan with (what is sometimes known as an up-front allocation) then it is much harder to make plans that are realistic and capable of achieving outcomes.

The process of thinking through and preparing the EHC Plan itself is an important one and there are many simple but powerful tools to help channel that thinking. Different authorities will suggest somewhat different approaches, that in all cases the child and family should be at the centre.

The plan should take account of their hopes and dreams, their strength and resilience and the challenges they face. These should inform a strong and realistic set of outcomes. If this does not

What are the specific issues for families of children with life-limiting conditions and providers of children's palliative care – including children's hospices

happen, families have the right to complain and question the process.

Personal health budgets are likely to be of particular importance for these families. As this briefing is published (April 2014), the detailed arrangements for these budgets are yet to be set out in many local areas.

What is clear is that CCGs are the responsible bodies for overseeing personal health budgets; and children and adults eligible for continuing health care funding from those CCGs will have the right to ask for a personal budget from April 2014 and the right to have one from October.

The move away from a service which is free at the point of delivery on the basis of need to one which is purchased (or more likely, part-purchased) by those who use it is a major challenge for voluntary sector services.

The clear aspiration is that these changes will give families of children with complex needs much more influence, flexibility, choice and control over their lives.

How this might work in practice we begin to map out in *Briefings 2* and *3* of this series.

Other helpful resources

- The Social Care Institute for Excellence (SCIE) 'Personalisation: a rough guide' provides a good introduction to the concept of personalisation
- For help and support on personal health budgets see the [specialist resources provided by NHS England](#)
- The [peoplehub](#) is a family-led online resource on personal health budgets
- The disabled children's charity KIDS provides a [helpful series of resources on personal budgets](#)
- In Control provides information on personal budgets at www.in-control.org.uk In Control is a membership organisation and about one in three local authority children's departments are members, as are a number of the larger provider organisations. There are also links to health services. Ask your local contacts if they are members as this will mean they can get more information and support.
- [Information and background on person centred thinking and person centred planning tools](#) is available from the consultancy Helen Sanderson Associates.
- Evaluations of the use of personal budgets among the SEND pathfinders are [available here](#)
- The [draft SEN Code of Practice](#) includes a section on personal budgets on pages 114 – 120
- Draft personal budgets regulations related to the Children and Families Act 2014 can be [read here](#)
- The [Council for Disabled Children](#) provides a range of information on the SEND reforms

