

Personal budgets: a guide for children's palliative care providers

Briefing 3



This is the third 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 the families who use them. The first briefing is an introduction to personal budgets; the second is aimed mainly at families; this third briefing is mainly for provider organisations.

Families of children with life-threatening or life-limiting conditions often say they are deeply impressed and moved by the compassion, the care and the professionalism of those who provide children's palliative care. We believe that personal budgets can help to enhance good care - not dilute it.

This briefing for providers explores in a little more depth the opportunities and challenges for the sector that are presented by the introduction of personal budgets and a personalised way of working.

It aims to make it clear how these opportunities and challenges impact on different people within the system: from the trustees and senior managers who are responsible for leadership and strategy, through the operational managers who are charged with delivery and oversight of care regimes on a day-to-day basis, and on to those liaison and care staff who work directly with families and children.

This briefing does not provide all the answers. It is very early days in the implementation of personal budgets and personal health budgets and the impact is yet to be felt on many of the services that support children. That is certainly true for

voluntary sector providers of children's palliative care, including children's hospices.

This means that while there are many examples of good practice in the movement, few of them involve personal budgets at this stage. There is, however, a good deal of experience of personal budgets in the world of adult social care and (increasingly) in services which provide short breaks for disabled children. Lessons learnt from these areas are instructive and this briefing is based largely on this experience.

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).

The evidence from this experience suggests that the opportunities for a better life for a family with a child with a life limiting condition are great - and the challenge is to learn how to grasp these.

*In Control is 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.



A context of change

This is a time of great change for the health and social care services that support disabled children and their families. In policy terms the Children and Families Act 2014 presents a number of opportunities to better integrate assessments, planning and services for children with life-threatening and life-limiting conditions.

For example, the Education, Health and Care (EHC) planning process and the drive towards joint commissioning should mean that services are better integrated around children's needs. The extended reach of these plans to age 25 should also improve arrangements for transition to adult services.

The introduction of personal budgets in social care and in health is part of this same drive. The intention is that the child looks first to their immediate family to provide the love, care and support they need, next to those in their wider network (extended family, friends, neighbours, others in the community) – and only after that to professionals, clinicians and specialist care staff to provide specialist help.

A personal budget, allied to a full assessment of the needs of the whole family and a robust EHC plan, can help with all of these aspects.

The personal budget can be used in a variety of ways:

- to make life easier in the home through the purchase of the equipment of choice
- to help a child with restricted mobility to purchase the means to access his or her community in ways that are most comfortable - physically and emotionally - for them; and
- and (potentially) to enable the family to select those aspects of care that the child will benefit from the most.

This is the approach that the Department for Education is promoting for all children who are categorised as having SEND. It may be that the model will have to flex somewhat when it comes to the care and specialist help needed by the children with highly complex conditions.



But the aspiration of greater choice, control and ordinary support applies to all: the key for all families of children with significant support needs will be a high-quality, person centred plan which is co-produced with them. The plan will specify outcomes to be achieved through means that make sense to that family in their particular circumstances.

One of the most helpful things a provider might do for a family is to help them think about the outcomes they are looking to achieve: outcomes need to be realistic and they need to have a time-frame attached (short, medium and longer-term). If families do not get increased choice and control the actual outcome is usually worse, so this is a critical issue. Where families want one, a personal budget will be available to help make this happen.

Person-centred approaches to planning and providing services are, of course, integral to the children's palliative care sector. As many working in children's palliative care will also know, personalisation is not a new concept in the wider health and social care sector either. Personal budgets have been around for many years, although some of the terms used to describe them are now different.

The real change for voluntary sector providers of children's palliative care - including children's hospices - is the fact that it will be the norm for a family to have access to a personal budget, rather than the exception.

The case study below is taken from a report by the organisation Mott Macdonald which is evaluating the introduction of the new arrangements for children with SEN or disabilities (Mott Macdonald, 2013): it concerns the family of Amy, a young woman living in West Sussex, who are receiving a personal budget with elements of both social care and education.

Case study: Amy's mother

"Before the combined social care and education personal budget we were constantly frustrated because the school did not send staff on training. The PA from the agency knew our daughter regarding her personal care needs but not regarding her communication or learning needs.

My daughter was excluded in many ways due to staff with lack of skills and confidence. It was very stressful for me and I could never go far for fear of the dreaded phone call for me to go into school.

With the budget from education and social care I can now employ a full time personal assistant (PA) for my daughter because I can guarantee them a good amount of hours. I employed an experienced carer from an agency who was already trained and experienced with health and safety, manual handling, hygiene, meds etc, and then trained her at home during the holidays, sent her on courses, taught her how to use the wheelchair etc. By the end of the holidays she was ready to go into school.

For the first time in my daughter's life I felt peace - she was in school with a fully trained PA. The PA could show the school how it should be done and my daughter came home with work that she owned and not work done by her assistant. The school say she has made so much progress.

The PA is very experienced with supporting my daughter out and about so can support her on school trips. I know that it is the school that have learned as their eyes have been opened and they have been shown the way to unlock her potential.

Due to continuity of care, the home school communication is great. There is a proper handover regarding timings and volumes of feeds and times and doses of medicine. Due to proper handovers and one committed attentive member of staff who provided personal care, we realized that my daughter's pain was due to water retention (thought to be due to her scoliosis). This very painful condition took a long time to figure out.

Since I have been able to let go, I have been able to get involved with the West Sussex Parents Forum and attend meetings where I can put my experience to good use. I would like to return to work. I have been a full time carer for over 15 years and would like to be free to have my life back.

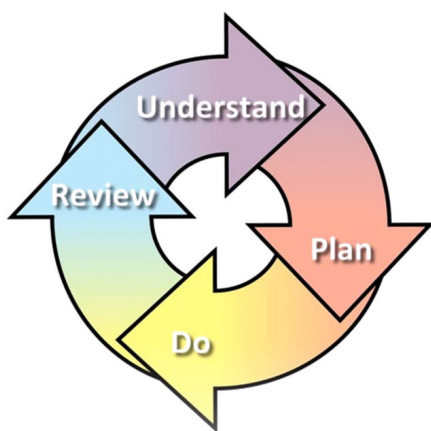
I want to be known for me and not as Amy's mum. Since having a personal budget I can for the first time envisage a future for me too."



The challenges for voluntary sector providers of children's palliative care

1. How palliative care is commissioned and paid for

Commissioning as we use the term here is the process by which local areas make use of resources to plan, specify and pay for services to meet a particular set of needs - including palliative care for children. Commissioning is now often described in terms of a cyclical process: understand, plan, do, review:



In all systems there are three levels of commissioning: strategic, operational and individual (personal budgets). To complicate matters, the commissioning of palliative care for children is a matter for NHS England (for specialised health services), clinical commissioning groups (for general health services) and local authorities (for the social care elements) working together.

The arrangements and closeness of such joint working vary across the country, which makes it more difficult to be definitive about how precisely things work today and will work tomorrow in any given locality.

What should be the case everywhere now is that commissioners will be considering how the new arrangements set out in the Children and Families Act 2014 will impact on the ways they address the four phases of the cycle; and particularly how the right of families to take part of their support as a personal budget or a personal health budget will sit alongside higher-level (strategic and operational) commissioning activity.

What this means in practice is a consideration of how much of the local budget is used to commission statutory services such as NHS community children's nursing teams; how much is used to commission services as a block, that is as contracts for specified off-the-peg services with named providers which might include children's hospices; and how much is allocated to the pot for personal budgets for families affected by these issues.

Even this is something of an oversimplification in that the SEND reforms and the personalisation agenda introduce the possibility of a number of mixed approaches which combine elements of standard off the peg arrangements together with the option for more personalised elements.

So for example, a family might be invited to make use of a number of weeks of short breaks care in a children's hospice as part of a standard package. Alongside this they will have a set personal budget which they can use as they choose. They may want to buy more short break provision, or other services that the children's hospice might provide - an organised activity break for a group of children or access to additional sibling support, for example.

As services know, the questions of if and how to fund children's palliative care have exercised health authorities, primary care trusts, local authorities and now clinical commissioning groups over several years. The fact that voluntary sector providers receive the majority of their funding from charitable sources (unlike many other services that the NHS or local authorities commission) makes it challenging for services to secure statutory funding.

The relatively small number of children with life-threatening and life-limiting conditions in local areas also means that it can be difficult to persuade the NHS and local authorities to commission children's palliative care as a priority.

While these are significant challenges, they also mean that personal budgets could provide greater opportunities for children's palliative care providers to secure statutory funding. The reputations which voluntary sector providers - including children's hospices - have as providers of person-centred, high quality care - are often recognised by children, families and wider communities.

However, the move towards greater use of personal budgets also poses a number of challenges voluntary sector children's palliative care providers. Services will need to consider how they market their services to young people and families who hold personal budgets - and if they do not do so already, how to start.

In doing so, services will need to factor in the contribution of families as well as that of commissioners: there are implications in this for communications and marketing, for invoicing and accounting systems and potentially for staff recruitment and employee relations practice.

It may be of some comfort to record that all of these are issues which have confronted providers in the adults sector; all provoked initial concerns; and work has been done which, which for the best providers at least has led to better, more person-centred services which have gone on to thrive under the new arrangements.

There are now many examples of providers in adult services managing the transition to a personalised approach: one is the organisation, a national provider for people with learning disabilities: their experience is written as the second case study quoted here, in Scown and Sanderson (2011). There are also many tools to help. Probably the best source for these resources is the Commissioning and Provider Development section of the Think Local, Act Personal website (www.thinklocalactpersonal.org.uk).

A few questions which voluntary sector providers of palliative care working in the new commissioning environment may wish to ask themselves are as follows:

- What do you offer to children and families?
- Do the services you offer reflect the needs and preferences of local families - and local commissioners? How often do you review this?
- Do you offer good value for money? Are you perceived as offering good value for money by health and social care commissioners - and parents? It is important to be aware that health and social care services are under huge financial pressure and that some commissioners view children's hospice care as high-cost.
- Are you clear about who you are marketing your services to? This may very well be more

than one set of people (commissioners, families and other third party individuals/organisations providing brokerage advice to families). Are you tailoring your messages accordingly?

- Are you communicating what you do clearly and with conviction - and with different approaches to suit different audiences? For example, in person, on-line, in meetings with specific interest groups?
- Have you researched alternative models to enable your financial systems to respond to personal budgets? You do not need overly complex systems, but they do need to be fit for purpose, which may include accounting for income from multiple sources.
- What is your approach to recruiting and supporting staff? You will still need staff with the same high levels of skill and competency and the same caring and compassionate attitude; but there may be new or additional skills needed in relation to person-centred thinking and working across traditional service silos.

2. What needs to change and what stays the same

One of the biggest challenges for voluntary sector providers is that posed by an ethos and value-set which sees services as absolutely free at the point of delivery. Many see this as something to be proud of, something that sets our national health service ahead of that of many others.

The problem with it is that when applied crudely it does not tend to facilitate the degree of choice and control we have come to expect in other aspects of life: the danger then is that services appear old-fashioned, blunt and not able to do what we now need them to.

One of the lessons from the implementation of personal budgets in adult services is that it is eminently possible to put in place new arrangements that reinforce and build upon progressive and cherished values and to do so in ways which do things even better.

What might this mean in practice for voluntary sector providers of children's palliative care? Services may wish to ask themselves the following questions:

1. Are you clear about your mission in this new environment?

This is not an issue only for trustees and senior staff, but for all who have a stake - in particular the families of children with life-threatening and life-limiting conditions. Personalisation is closely allied with co-production, an approach which seeks to include those who might otherwise receive services without having much say in the way they are provided. If providers are to form a new sort of relationship with their users, one mediated to some degree by families' purchasing power through personal budgets, then it will be vital for service leaders to engage effectively and honestly with families from the off. This will be important in ensuring that children's palliative care providers can reflect families' greater choice and control over the care they receive in ways that preserve and build on what is good about the service.

2. Does your organisational culture need to change?

How your organisation will need to operate when some or all families have personal budgets may not be the same as it was under the pre-existing arrangements - although there will be much to build on, and there is no doubt many children's palliative care services already provide excellent care which is focussed around the child and their family. The main features of such practice is that it will:

- Recognise that every child, their condition and their palliative care need is different.
- Recognise, reinforce and work with the strengths and assets that a family brings. This is the concept of 'real wealth', which grows in communities where people are better able to see one another's capacities and can discover practical ways to look out for each other (<http://bit.ly/1hSvnVW>). Real wealth may come in many forms, including personal qualities, skills, resilience.
- Ensure that people are clear - as best they can be - about what is going to happen when families have access to personal budgets. This really is a situation where information is power and lack of information is its opposite. If we don't know, then say so.
- Is your organisation in a position to be nominated by a child's family or young person to receive direct payments on their behalf? The [draft SEN \(Personal Budgets and Direct](#)

Payments) Regulations 2014 state that a local authority may make direct payments to another person or an organisation who has been nominated in writing by the child's parent or young person.

- Help people make choices, or if they want to be told what to do then recognise and respond to this. The worst thing that can happen is to make assumptions about people and their wishes. Would your organisation want to become a recognised provider of advice on personal budgets? The SEN regulations state that children, parents and nominees will be able to use direct payments to pay for advice and assistance on direct payments from organisations; would you charge to provide advice and assistance?
- Look for networks of support and make use of them. For most people, their informal networks (family and friends) are most important to them at times of crisis and stress, but not so for everyone. We all need support and we find it in different ways. A personalised approach recognises and responds to this diversity.
- Recognise that who is dealing with someone is as important as what they do. In the past we have not always seen choice of support staff as something we need to consider, but the reality is that there are some individuals whose approach and interests are more compatible with our own than is the case for others. Again, there is a growing body of literature from the adult world to build on here (see for example the case study in Scown and Sanderson referenced below).

3. How will you work with your staff to help them to understand the move towards personalisation and personal budgets – and to help them appreciate how it could affect the way they work?

Much of this is about a change of mindset and approach - and an opportunity to ask the following questions:

- are we working alongside families, as equal partners?
- to what extent are we providing a social model rather than a medical model of care?
- what does personalisation mean to me in my personal and family life, and how can do I draw on this insight in my working life?

In answering these questions, providers will get to the heart of what is different about this new way of working. While the reforms are challenging,

the impact they will have on services are not prescribed. Providers have an exciting opportunity to work with families to shape the way in which children's palliative care is accessed and provided.

3. Learning and mutual support

There is a range of support available for children's palliative care providers as they adapt to the reforms. Together for Short Lives is keen to draw attention to examples of personal budgets working well in children's palliative care; highlight learning from incidences where implementing the reforms has proven to be challenging for services; and

provide opportunities for services to share their advice and experiences with others in the sector. There are many approaches to support learning - some formal and some less so - which have helped in other parts of the health and social care sectors and which services may wish to consider using.

These include written resources and training materials, taught programmes and courses, e-learning programmes and mentoring programmes; services can buy support to facilitate action learning sets or problem solving circles.

Other helpful sources

- For more on ordinary support and In Control's real wealth model, go to www.in-control.org.uk and search on real wealth. See also resources on asset-based community development at www.abcdinstitute.org
- For more on a new approach to commissioning in children's services see the 'Making it Personal' guidance for commissioners on the KIDS website
- For help and support on personal health budgets see the [specialist resources provided by NHS England](#)
- 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
- The first case study referred to above is available from: <http://www.sendpathfinder.co.uk/> search for SEND Pathfinder Information Pack, Version 2, 2013
- The second case study is available from: Steve Scown and Helen Sanderson, 2011, Making it Personal For Everyone: From Block Contracts towards Individual Service Funds, HSA Press, Stockport

