Personal budgets: a guide for families

Briefing 2

together for short lives

in Control®

This is the second 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; this second is aimed mainly at families; and the 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 acknowledge this and register our belief that personal budgets can help to build on and magnify this care, compassion and professionalism - not dilute it.

This briefing does not provide all the answers that families will want or need. 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 – and certainly that is true in relation to voluntary sector providers of children's palliative care, including children's hospices.

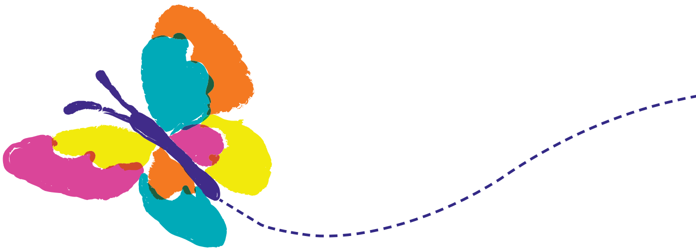
This means that while there are many examples of exemplary practice in palliative care services few of them involve personal budgets at this stage.

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.

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 and 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.



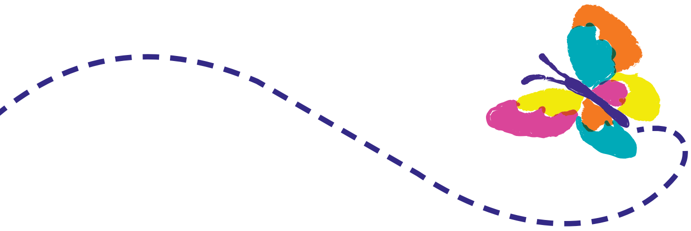
Family-led personalisation and personal budgets

Joe Tomlinson was the first young person in England to have a personal budget as we now understand the term. His mother, Caroline, speaks movingly about the family's experience and has written about it on In Control's website: "Our son, Joe, had contracted meningitis at six-months old which had left him with complex learning disabilities.

Our path was very different to the one we had planned, we had one of two choices - do we sit and wallow in self-pity or do we take control? We chose the latter. The main issue for us was not creating a person centred whole life plan, but actually making the plan happen…we had been planning with Joe for years, but it was like the plan had to fit into the service system - but the service system didn't work well for people like Joe who expressed many challenges.

"Joe was in a minority, of a minority…he was one of those people the system has struggled with for years. If we accepted what had always been done we would get what we have always got - a society that still can't welcome or celebrate difference... we also knew that the system would make Joe increasingly anxious, which would inevitably lead to his challenges becoming significantly worse and potentially spiralling out of control.

"We were willing to play our part - we had no expectations of others having to do it for us, but we needed some real help. Help in terms of a partnership approach to making fundamental changes happen. What we needed was a new way of working with families, a way that was much more equal, a way that encouraged people to take more responsibility, a way that indeed helped those who were willing to help themselves."



Caroline goes on to describe the ways in which she and her family were able to persuade local services to do things differently, and how they went on to use their personal budget so to help Joe get an appropriate education, have fun, and eventually – as a young person - get his own home and make a contribution by working with others to set up a business.

The thing that made the biggest difference for Caroline, Joe and family was the new way of working that she refers to: a way of working that gives families a measure of responsibility and control.

Part of this is about personal budgets – we all know about purchasing power. However, it was much more about a shift in thinking, a new approach that sees families providing one another with mutual encouragement and support, alongside professionals who understand that they do not have all the answers.

There are now many thousands more families across England who have benefitted from person-centred approaches and personal budgets. The scope of personalisation is being further extended by the SEND reforms and the introduction of personal health budgets for people with continuing health needs.

Jo Fitzgerald and her son Mitchell were among the first to have a personal health budget: "When my son, Mitchell, was born twenty years ago, I joined a 'community' of people whose lives have been transformed by the birth of a child with complex needs. Feeling powerless and scrutinized in your own home is a familiar experience amongst individuals who rely heavily on the support of home care staff. The experience has been described as 'a double-edged sword'.

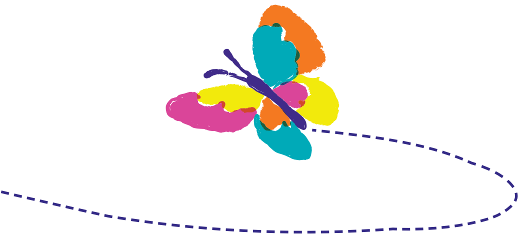
"Although support staff can enable someone to remain at home with their family, having little or no control over who fulfils that role can be immensely challenging. One mum I spoke to said, 'There are times when your home isn't your home. It's not really. It's so invasive isn't it? You pretend to be someone you're not.'"

[After much discussion and a certain amount of pressure it was agreed that a personal health budget would take effect from 1 September 2008.] Jo: "Four years down the line, whilst much has changed, much has stayed the same. Mitchell still has weekly physiotherapy from the home care therapist who reviews his daily care records. Likewise, he still has the services of the key clinicians. Having a personal budget has not meant cutting all ties; rather we have taken a pragmatic approach to maintain clinical involvement and oversight whilst exercising choice and control.

“Professional clinical input has not changed; Mitchell continues to be reviewed on a regular basis and accesses acute services when he is unwell. When I asked his physiotherapist to comment, she told me that despite once feeling sceptical she is now confident that the quality and safety of care hasn’t changed.

“What has changed is the way Mitchell is supported. His team has been carefully chosen and personal qualities were valued over experience. We looked for intuition, commitment, enthusiasm and fun. What we found were people who also embraced our aim of providing continuous, person-centred and high quality care. Flexibility and adaptability are high on our agenda.”

Developing and testing these approaches is challenging: both Caroline and Jo are pioneers. There are still relatively few examples to cite of young people or families using a personal budget to pay for using children’s palliative care services.



Kaddy is a parent who currently uses hospice services to provide breaks for her son Elijah. She is hopeful that getting a personal budget will help to improve and personalise that care. Elijah has severe body-shape distortion which is life-threatening and he needs effective suctioning, which means he must have people around him at all times who understanding and can respond to these needs.

“Although he receives one to one during his time at the hospice, when it comes to taking him out during our stay we need to have an additional person and this needs to be someone who knows him,” says Kaddy, who is hoping to use a personal budget to make this happen. It will also make it more possible to do other more ordinary things like take Elijah with her to church.

A further positive experience is set out by Carol-Anne and her daughter Amber: “Amber is a personal health budget user of one year. As a family our lives have been transformed. Personal Health Budgets have enabled Amber, a child with no physical voice or means of communication in a conventional sense to have control over who she wants to be, what she wants to do, how she plays.

“It sometimes can seem inconceivable how a child who is profoundly affected by a disability can make their wishes known. But she does just that to great effect. PHBs have enabled a professional and relationship-based connection to her carers which in turn has led to her accessing the wider community unsupported by her family which is great as it means she’s seen as an individual.”

None of this is without its complications. One which provider organisations sometimes worry about is the skills and abilities of staff who may be independently employed by families: who will oversee these staff, how do they work alongside professionals providing children’s palliative care - and who is responsible if something goes wrong?

It is important that young people and families who hold a personal budget have early discussions with independent personal budget brokers (where they are in place) and their children’s palliative care provider(s) to determine how a personal budget will work for a particular child in a particular setting. Personal budgets will not be for everyone.

Local authorities are only obliged to offer a personal budget to those families where the child qualifies for an education, health and care (EHC) plan (roughly the same group who would have had a statement of special educational need in the past). And some families, including those who do qualify, will always prefer to be supported in the traditional way.

When considering these issues it is very important to reiterate a point made in our first briefing *An Introduction to Personal Budgets*, that families should have a choice about the ways they receive and manage their personal budget.

A personal budget does not necessarily mean a direct payment, which is money paid directly to a family who are then responsible for the care and support it purchases. *Briefing 1* describes the personal budget options available to families in some detail.

Personal Budgets: Step by Step

Caroline Tomlinson was also responsible for pulling together an *Essential Family Guide to* personal budgets. Although this booklet is now several years old, almost all of the advice it contains remains relevant and up-to-date: this is because the personal budgets arrangements which local authorities and now health commissioners use are largely based on those which were developed and tested by In Control in the early 2000s.

There are **seven steps** for a family who wishes to use a personal budget.

1 Finding out if young people or families are entitled to a personal budget - and if so, how much

In recent years local authorities and clinical commissioning groups (CCGs) have spent a lot of time working on resource allocation systems (sometimes abbreviated to RAS). RASs are designed to make sure that individuals are allocated money on a fair and equitable basis in order to meet their needs and their aspirations.

The detailed criteria and the forms used will differ from locality to locality but the principles are much the same across England. Young people or families are asked to complete an assessment (or self- assessment) which the authorities then use to arrive at a sum of money, sometimes referred to as an indicative allocation. This is the amount of money they think is fair and which young people or families can use as the basis for setting goals and planning how to achieve them.

At this stage, young people and families are encouraged to have an open mind about how they will achieve them and what their support options are. If they feel strongly that the indicative allocation is unrealistic, then this is the time for them to say so.

2 Making a support plan

For those who qualify, this is the EHC plan: making a support plan in this way is useful even if the family doesn't qualify for an EHC plan and a personal budget. The plan is for the child or young person, but it clearly has major implications for parents, siblings and the wider family too. It is not a complicated process and families are advised to keep it simple.

The plan needs to set out:
1. Who the child is and what is important to them
2. What they want to achieve
3. What support they will need to achieve these things
4. How they will stay healthy and well
5. How the family will stay in control
6. How the support will be managed
7. What the support will cost

Local areas will tell young people and families where they can get help to write a plan in this way: every area now has local organisations or brokers to help. There are also formats and guides on-line to help.

Young people and families are advised to be as creative as possible with a plan and consider:
- traditional services and approaches
- general and specialist services
- their family and friends
- professionals who provide their care

Families are also advised to consider what is working well in their child's life and what is not - and how it could be done differently. For some families, this will be the point at which they hold a preliminary conversation with the organisation(s) who are providing palliative care to their child. Families are encouraged to bear in mind the pressures on public budgets and to be realistic in what they include in their plan.

3 Agreeing to a plan

This should be fairly straightforward from the family's viewpoint and local areas should follow the basic rules of support planning described above.

Local areas will be concerned about a plan (and will want to discuss it again with families) if it:
- seems over-costly
- may expose a child to undue risk
- will not meet the outcomes which a young person or family has set out to achieve.

4 Making arrangements to manage the money

As these briefings set out, young people and families have a variety of options for managing a personal budget.

A family can:
1. take their money as a direct payment, paid into their bank account
2. ask an independent broker or to hold the money on their behalf
3. ask commissioner(s) to hold the money

In her *Essential Family Guide* Caroline Tomlinson says that the main thing is to be responsible in using the money; although a direct payment goes to the young person, parent or independent broker, local areas remain responsible for checking that it is used for its intended purpose.

Local authorities and/or CCGs may well ask families to account for how they are using a personal budget, so good record keeping is essential.

5 Deciding how to get the support children and young people want and need

There is a wide range of ways to arrange and receive report. All depend on:
- the needs, wishes and preferences of the child, young person or family
- what options are available locally
- how good and how appropriate these services are
- how much they cost
- how reliant children are on special services
- the extent to which children are able draw on family, friends and general public services (schools, public transport and leisure services, for example)

For some families, it will be sensible to appoint a specialist support provider to manage the whole package, or perhaps just some of it. This could be a provider of children's palliative care. Families may access other means of support: these could include networks of other parent carers or directly from local NHS services or the local authority.

6 Enabling children and young people to live the life they want

Ultimately, this is what personal budgets are seeking to achieve. There are different ways of thinking about this and determining whether this is happening. For a child or young person who needs palliative care, this will include medical and nursing care, in addition to those providing support for learning and having fun.

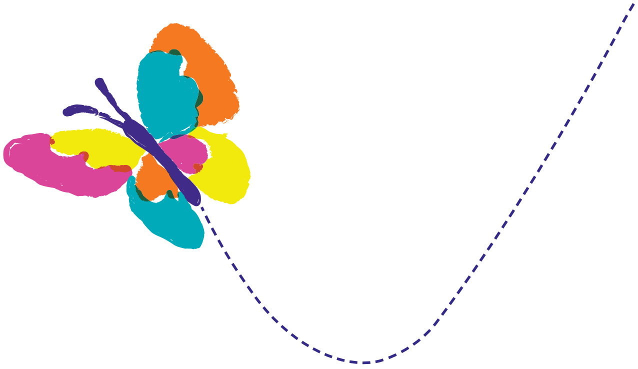
There are many simple but powerful person-centred ways to determine what children and young people want and need. One is to consider what constitutes a good day for the family – is a good day for the child or young person also usually a good day for their parents and siblings? Is a good weekday the same as a good weekend day? Is a good day for a five year old the same as a good day for a ten year old?

Another approach is to consider what the balance is between what is important for a child or young person and what is important to them. There are a lot of ideas and suggestions available on person centred thinking, from Helen Sanderson Associates.

7 Check how things are going. It is not always possible to get personal budgets right first time

Local areas should talk with young people and families on an ongoing basis about what is working, what is not and how the process should be improved. This is what is generally known as the review process.

Further details about getting and managing a personal budget are available in the Essential Family Guide or on the In Control website.



Dilemmas and challenges for personalisation in palliative care services

It is important to note that, to date, personal budgets have achieved varying levels of success for different families. For many families of children who need palliative care, personalisation and personal budgets are a brand new concept. They also challenge the ethos of services which, until now, have regarded themselves as free at the point of delivery.

The problem with this perspective is that when applied crudely, the free at the point of delivery model can fail to facilitate the sorts of choice and control we have come to expect in life today: the danger is that services appear old-fashioned, blunt and not able to do what we now need them to.

The important thing here is not to throw out the baby with the bathwater: 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. We say more about this in *Briefing 3* for providers of support.

A related issue concerns the funding arrangements voluntary sector providers of children's palliative care services are subject to. These are complex, subject to change and differ somewhat from one part of the country to another.

It is also the case that organisations vary in terms of the services they provide, in their charitable objectives and in the levels of statutory income they receive. All of these things mean that different services will take different approaches to personal budgets.

Helping to help others: connecting and looking ahead

Families accessing palliative care services are often under great pressure, emotionally, physically and sometimes financially. Personalisation and personal budgets are designed to make life easier, better, to bring choice and control for all and to promote equality and social inclusion.

But it would be naïve to suggest that this is always what these changes lead to. Personal budgets are still in the early stages of being implemented and the way which they are used will continue to evolve and change.

For this reason it is really important that families join together for mutual support. Many children's palliative care services help to ensure that this happens by running family support groups.

Some families will prefer to find their support through local family centres or other family carers' organisations.

Some local authorities commission programmes such as In Control's Partners in Policymaking (a suite of leadership training courses for disabled children and adults, parents and carers and professionals across education, health and leisure), or All Together Better (which advocates a community health champion model, promotes learning and develops support networks between families, disabled adults and professional and clinical staff).

It is by building supportive networks of this sort that families will join together and in so doing will hold politicians and authorities to account to make a success of personalisation and personal budgets.

From September 2014, the government-funded SEND Independent Supporters will be another source which young people and families will be able to draw support on personal budgets.

Other helpful sources

- The Department for Education has allocated £30million until March 2016 for a pool of 1,800 independent SEND champions to be recruited, managed and trained by the voluntary sector. These Independent Supporters will help parents of disabled children to navigate the new SEND system through independent, one-to-one advice to families. DfE's aim is for up to 12 supporters in every local authority area to be in post and giving advice from September 2014. The Council for Disabled Children (CDC) have been asked to oversee the process of recruiting the champions and establishing this new programme; they have published a series of frequently asked questions and answers at http://bit.ly/19Pq3Cc.

- 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.

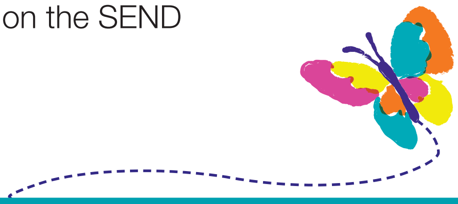
- Information and background on person centred thinking and person centred planning tools is available from the consultancy Helen Sanderson Associates.

- 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.



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