



Taking a Personal Approach:

A Parents Guide to Personal Budgets



**A brief guide for parents of disabled children
and young people receiving personal budgets**

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Introduction

Being responsible for any child is rewarding and brings both joy and challenges. Being the parent or carer of a disabled child or young person brings an extra element of challenge – unique to each person – but is no less lacking in smiles and tears. The only difference is the level of support that families with disabled children may need.

In March 2011, the Government unveiled proposals for the biggest programme of reform in education, social care and health support for disabled children and young people in 30 years which puts you and your child at the heart of planning and choosing their support.

Who this guide is for

This handbook is for parents and carers of disabled children and young people. Disabled children and young people may also find the information useful, although it is not written specifically for them.

KIDS has been commissioned to carry out this work in collaboration with the following partner organisations: Disability Rights UK, Daycare Trust, NAFIS, In Control and OPM.

KIDS is the national charity working with **disabled children, young people** and their **families** across England.

KIDS' vision is a world in which all disabled children and young people realise their aspirations and their right to an inclusive community which supports them and their families.

How to use the guide

This guide will be supported by a free eLearning package which will be available from March 2013.



What is personalisation?

Personalisation is about putting the individual person in the centre and everyone involved with that child working together as equal partners to support them and enable them to achieve their potential in all areas of life. As equal partners, the child or young person and their family are actively involved.

The idea of putting the child at the centre of planning their care and support is not itself new. What personalisation adds is the active participation of the child and their family in managing their own lives.

What is a personal budget?

A personal budget is the total amount of money per year that children's social services allocate to your family to meet your child's support needs. A personal budget gives you and your child more flexibility, choice and control over the support you use and enables you to make your own decisions as a family about what works best for you.

Your child will only get a personal budget if he has been assessed as being eligible for social care. In the future this will extend to children and young people who are assessed as needing specific education and health support.

What you can spend your personal budget on

- Support in your home, whether it's equipment or help with personal and domestic activities.
- Enabling social inclusion through improving access to services in the community.
- Physical and mental wellbeing through, for example, fitness or cultural activities.
- Short breaks, which give parents time for other things (like spending time with their other children) and give the disabled child an opportunity to do new things and maybe make new friends.

The guidance says that you can buy equipment to make a support package cost-effective, for example, buying a mobile phone for Personal Assistants. You can vary the amount you spend from week to week or month to month and 'bank' any spare money.

Families receiving Personal Health Budgets may also use the funds to pay for therapies, products and services to meet the health and wellbeing needs of their child.



One example of how a family used their personal budget:

Sarah, a 16 year old young woman who has Down's Syndrome and associated learning difficulties, and her family were involved in a personal budget pilot. They chose to manage their budget with the support of a key worker.

The original amount of support she received paid for four hours with her Personal Assistant (PA) and she also attended two youth groups. Following the pilot, Sarah's budget was increased so that she could employ the PA for eight hours per week, giving her mum and dad some time together at weekends. They also used their budget to pay for family gym membership and driving lessons for her older brother. The driving lessons have been hugely beneficial for the family because it means she can rely on her brother as well as her parents and he can help in an emergency, for example if the school bus doesn't turn up. It also means that Sarah and her brother can go out together.

The key worker took the lead on support planning and the social worker worked closely with her to ensure that the support plan was agreed. Both the social worker and the key worker knew the family well before the pilot and had a good relationship with the family.

The family felt that the support planning was very positive and helped them to be realistic. They had not realised the impact of things like the disruption of routine and this helped them to see how the stresses of everyday life could be managed better. The family felt that it was crucial that the person supporting the planning knew them really well and could prompt them and think creatively about how things could be improved.

This family felt that although the key worker would be the appropriate professional to do the support planning, they would need a social worker to complete the figures and get the budget approved.

The impact of the personal budget for Sarah's transition from children's to adults' service was very positive. When she was allocated her adult social worker, the support planning was shared and it enabled the new worker to get a good picture of the family. The budget was agreed quickly when Sarah turned 18

What you cannot spend your personal budget on

It sounds obvious, but you can't spend money from a personal budget on anything that would put your child at risk of harm or on anything that would not clearly benefit your child.

Equally obviously, you can't spend it on anything like alcohol, cigarettes or gambling.

You cannot use a personal budget to buy services from your local authority. However, you can have a budget that is mixed, with

your child's needs being met in part by a local authority service and part by direct payments. In this case, the cost of the local authority service will be deducted from the budget before you receive it.

As a general rule, you cannot use a personal budget to employ a family member who lives with your child, though there may be exceptional circumstances where a local authority will agree to this.

Families receiving Personal Health Budgets cannot use the funds for emergency GP services.

Getting and using a personal budget

There is no standard process for getting a personal budget.

Each local authority has its own way of structuring its children's services and managing the work that has to be done to support children and families.

“In Control” use seven steps to self-directed support for children and young people

in Control

The Seven Steps of Self-Directed Support



Step 1: Need some help

The first step is identifying that your child or young person and your family needs some help. To get a referral to the local authority's children's services, you can phone your local authority yourself or speak to your child's GP, health visitor, teacher, Parent Partnership worker or youth worker. Or you could speak to a voluntary organisation such as a carers' centre or a Centre for Independent Living.

You may feel able to go through the process of sorting out support for your child on your own as a family but it can be really useful to have someone to help you. Local arrangements vary, but local authorities will be able to signpost you to organisations that can support you.



Step 2: What resources have I got?

This step is not just about finding out how much money you might get. It is important to discover what is already available for your child in the local community, whether it is open to all children (a universal service) or is aimed at children with additional needs (a specialised service).

Disability legislation means that universal services should be accessible for everyone and places a legal duty on providers to make reasonable adjustments for individual children who need support to access them. There are some limitations to this; for example, if the cost of making the adjustment is prohibitive. However, many adjustments are simply about people's attitudes and willingness to do something differently.

It is vital for disabled children to be included in their own communities because that is where they have the best opportunities to make friends and build relationships, like everyone else.

This is also a good time to think about what connections and networks do you have in your community? Think also about your family's strengths; how are you coping, physically, mentally and emotionally?



Assessing your child's entitlement to a personal budget

If it is decided that your child is eligible for social care services, they are entitled to services through a personal budget. There are no set rules for local authorities on how they decide whether a child is eligible for support.

Approaches vary, but all local authorities use an assessment process to:

- Assess the need for support.
- Decide what outcomes that support should achieve for your child.
- Agree how the support will be provided.

"We had to go through assessments and these were done at our home. I felt this was done really well as they not only involved us as parents but also my son. We received direct payments and are happy with the support we are receiving as we were involved in planning what suited our son and family."

Parent

The aims of the assessment are to identify what is stopping a child and their family from living an ordinary life and to work out how to overcome these difficulties.

Setting the budget

Local authorities calculate an 'indicative budget' or a rough estimate of how much funding will be allocated to a child, based on the information they get from the assessment. The budget must be sufficient for you to buy the support that meets your child's assessed needs.

If you can't reach an agreement with your local authority about the amount in your child's budget, you can use the ordinary complaints procedure within your local authority to challenge their decision, or ask for help from an advocacy service to try and speed up the process.

Step 3: Making a plan

Local authorities have a legal duty to make sure that your child's assessed needs are being met, regardless of how you choose to arrange support for your child. The support plan must say how this will happen. A plan that does not meet the needs of the child will not be agreed by the local authority.

Local authorities have their own approaches to support planning and your social worker, assessor or other key worker will explain the local process to you.



What is a support plan?

A support plan is a document which is drawn up between your family and a support worker. It should describe what your child or young person wants to do, the support they will need to do it and how you will use the personal budget to make this happen. It enables you to make sure that your child gets the right type of support, in a way that works for you and your family.

Writing a support plan

Many families are now writing their own plans, often with support from a local authority worker, someone from a user-led organisation or another provider, such as a carers' centre.

If the support plan is not written by your family, it is essential that your family is at least an equal partner in the process.

Supporting children's cultural needs:

- All children are individuals and have the right to have their personal, social, emotional and cultural needs met.
- Children must be supported to participate in their religious and cultural activities.
- Share any information that you may feel is relevant to your child's support.

Step 4: Agreeing the plan

This should be quite straightforward, particularly if you have been working in partnership with your local authority. When the plan is agreed, you are likely to have to sign an agreement about how the personal budget will be managed and the arrangements for repaying any surplus.



Some prompts to help you think about support planning:

1. Ask what's working and what's not working – for your child, for you, for any siblings, for anyone else involved? Remember each of these people may have a different view on whether the same support is working or not. You could think about why some things are going well; is it the people involved, or their attitude, or because it's something your child loves to do? Where things aren't working well, do you need to fix them, stop them, or change them?
2. Think about what's important **to** and what's important **for** your child. Personal care and safety, which are important **for** your child, have to be managed, but so too do the things that make life worth living – the things that are important **to** your child. This will be very individual. These are the things that make your child feel happy and fulfilled and safeguard his emotional and mental wellbeing.

Step 5: Managing my support

Looking after the money. Personal budgets can be managed in four ways:

1. You can receive it as a direct payment.
2. The local authority can manage the budget for you (a 'virtual budget').
3. A third party can manage it for you; for example, a service provider, a user-led organisation or a broker
4. You can have a mixed budget which is a combination of direct payments and services provided by either the local authority or an independent provider.

The local authority will carry out an annual review of the support plan and overall budget allocation.

Getting the support you want

It is up to you how you arrange the support for your child. You can decide to do everything yourself or you can pay a provider to do everything for you, or you can do something in between.

Doing it yourself

The advantage of doing it yourself is the freedom and flexibility it gives you, as well as saving on management fees and other overheads that providers have to include in their charges. You have direct control over who supports your child, what hours they work, and how they work. The potential disadvantage is that you will need the time and skills to do it and will be taking on more responsibility.

You could also find someone to support your child on a self-employed basis. This means you do not have to deal with issues such as holiday and sick pay, tax and national insurance. It is important to check this with your local authority as some do not allow this.



Using a support provider

There are several types of support provider, including profit-making companies, not-for-profit companies or registered charities and co-operatives.

The advantage of using a provider is that it saves you time and reduces your responsibilities. The potential disadvantages are the extra costs and the reduced control; you may not be able to have the same person all the time, or you may have to compromise on the hours they work, and you may not have much choice over who is employed to support your child.

“My daughter needed support at weekends and we wanted to access direct payments. However, we were not able to get an assessment done by social services. We had to go through another agency who helped us with all the different stages of managing direct payments. This included help with interviewing and employing a PA, choice of the hours and the pay. It was very important we employed the right person, someone we could trust and who was reliable to provide personal assistance to my daughter. We were more than happy to have outside assistance to make this happen, including help with payments. The agency lets us know how much we need to pay the PA and gave us a chequebook. All we have to do is write the cheque each month for the amounts they have worked out. It’s made my daughter’s life easier and now I have more time and don’t need to stress about going out anywhere and having my own time. I have my peace of mind.”

Parent

Step 6: Living my life

This is the step that makes all the meetings, assessments and planning worth the time and effort. Your child will not only be safe and healthy but also going out and about, enjoying life, achieving things alongside other children, and contributing to the life of the local community by being there and taking part in what's going on locally.

Step 7: Review, change and agree

The support plan isn't meant to be put away in a drawer and not looked at again for a year; go through it from time to time and make notes on it to help you when you come to formally reviewing it with your local authority.

If you are managing a PA yourself, or are involved in a PA's performance review, this is a great opportunity to discuss what's working or not working for your child, for you as a family and the PA.

The review process

Local authorities are required to carry out formal reviews of the personal budgets they allocate and the way they do this varies from area to area.

Reviews may be more frequent when your personal budget is first agreed as you are more likely to need support with it in the early days. The review should be used to learn about how things can be improved, whether through changes in the support provided, trying new opportunities, or using the budget or other resources more effectively.

Part of the review process is the financial audit of the budget which tends to happen separately through the local authority's finance department. They will tell you what evidence you must submit. Your social worker or social care assessor will be told about the outcomes of the audit.

Frequently Asked Questions

What is the difference between direct payments and personal budgets and personal independence payments?

A personal budget is an amount of money calculated as being enough to meet a child's assessed needs.

You could have a personal budget and tell the local authority what services or support you want from them or you could choose a provider to provide your individual services and take responsibility for your personal budget.

A direct payment is a way of taking the personal budget as cash to arrange the support yourself.

A Personal Independence Payment is a new benefit which will replace Disability Living Allowance from 2013.



How do I access personal budgets?

To access a personal budget your child has to be assessed as having a health, education or social care need via your local authority. If the assessment says your child is eligible for support, then he should be eligible for a personal budget which is calculated to meet the identified needs.

What are the criteria for getting personal budgets?

The process varies in different local authorities. Once you have assessed need, however, you are entitled to request a personal budget and to take it as a direct payment if you want to.

How much money do you get?

This depends on your assessed needs. The amount of money should cover the cost of meeting whatever you are assessed as needing.

Who decides how the personal budget money will be allocated?

This is usually agreed through your support plan. Some people have the budget paid monthly into their own account; others have the whole budget paid to a provider of care.

What happens to any money that is not used; can it be carried over?

The policy will be different depending on where you live. Some local authorities will agree an amended support plan for any unused money; others have a 'claw back' policy. Check local policy on this with your support worker.

How does money get clawed back?

Local authorities audit direct payment accounts every year. Unused money might be identified and some local authorities will take this back. This could be done by deduction from your next due payment or they could invoice you.



Do I have the right to appeal? What if I can't afford to pay money back?

Each local authority will have a different system, but speak urgently to your support worker. There will be local advice agencies to help as well; for example your local Citizen's Advice Bureau.

If you do need to pay the money back, you might be able to do it in small instalments rather than one lump sum.

Are personal budgets means tested?

Personal budgets for children are not means tested.

Does receiving a personal budget affect any other allowances and benefits?

No – it is not classed as additional income.

If my child has multiple or complex needs, what is the maximum support or personal budget payment/package they can receive?

There is no cap on how much someone might receive. It must be enough to meet your assessed support needs.

What happens if my child requires 24 hour care?

If the assessment shows that 24 hour care is needed, the budget should cover the assessed need.

Will children who are assessed as having a lower level of need be overlooked for personal budgets?

They shouldn't be! Anyone can ask for a personal budget. If you have an assessed need, no matter how small, you have the right in law to request a direct payment.

If your child does not meet the eligibility criteria, your local authority's local offer should deliver some basic provision.

When children get older, some parents may need more support as they themselves are getting older; will this be taken into consideration?

This should be taken into consideration as part of your review process and your assessment can be changed with changing circumstances.

Do personal budgets support the additional costs of raising a disabled child, for example, heating, water bills, specialised equipment?

Different local authorities take various views on this. Equipment should be fine as long as it meets the outcomes of the support plan. Heating and bills are usually provided for through an enhancement on universal benefits.

If you pay someone to administer the payroll, does the cost of this come out of the budget to meet your child's needs?

The payroll costs should be identified separately in the support plan and specifically covered in the budget – without taking away direct support funding needed.

Do you need a separate bank account for payments to be paid into?

Usually yes. Your local authority will advise on their procedure for this.

Can you use a post office account?

Yes – some local authorities would only allow this if it is separate from other household accounts and only used for the personal budget/direct payment

Some people have trouble getting a bank account; how can this be made easier?

Work is taking place to resolve this issue. Some people have a shared bank account or a trust in place so that the money can be managed by someone other than themselves.

Speak to your support worker if you have difficulties regarding this.

Is there going to be accessible information and training available to black and minority ethnic parents about personal budgets and the process for assessments?

The process for people from black and minority ethnic groups is exactly the same. Some local authorities are better than others at communicating with diverse communities.

If your local authority does not have accessible information, ask them for assistance.

How will assistance from family members be taken into account when assessing for personal budgets?

Natural support from family members is taken into account as generally we all have some natural support that we rely on.

This is part of acknowledging the 'real wealth' of families that extends beyond financial support and will form part of the assessment and support planning process.



What support will be available to black and minority ethnic disabled children, young people and their families to make sure they are supported to fully take part in the assessment process of personal budgets and actively be involved in the decisions and planning?

Your local authority should be able to ensure that all families get the right level of support so that they can fully take part in all aspects of the assessment and decision making process.

If you feel you are not getting enough support, contact a local support organisation such as a Citizen's Advice Bureau, Centre for Independent Living or advocacy service.

What support will be available for disabled children, young people and their families to manage personal budgets?

Support is generally available through the local authority disabled children's team or through a user-led organisation. Ask your local authority what support services are available locally.

Family Information Services and social services should be able to help you.

Can you employ a family member to provide personal assistance under the personal budgets?

This is not common practice, but it has been permitted by some local authorities. You need to check with your local authority on their guidelines for the employment of relatives. If you can prove a genuine need, then they may allow it.

Will PAs receive training to understand and support the traditions and customs of black and minority ethnic service users and their families?

One of the benefits of personal budgets is that you can personalise your training and directly employ people who you choose.

Many people have found they have been able to develop their own training on what is directly important to them and employ their own staff who are able to understand and support their traditions or cultures.

Will there be culturally appropriate and holistic local services available to families?

All children and families should be able to access local services which should operate in a welcoming and inclusive way. People have also built their own culturally appropriate personal support from their personal budget.

At the moment after a certain age, disabled young people are expected to pay their college fees – will personal budgets be able to contribute towards this cost and support them to develop everyday skills and independence?

This is generally a local decision – we would hope yes. There is the flexibility to do this but each local area has their own rules on restrictions about what you can and cannot spend your budget on.

You need to speak to your support worker to find out what your local authority policy is on this.

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