

CHAPTER 3

Money matters



We've found that many parents are worried about asking for any financial help in caring for their disabled children. Some of us didn't realise for a while how much extra help our child might need, and how much it was costing us. Things like extra laundry, special diets, endless appointments, not being able to rely on friends or neighbours to help out, not being able to go back to work: all these things can be a strain on the pocket. So where extra money is available, we've found it a great help.

In this chapter we're going to concentrate on the main disability benefits and sources of financial help for parents who have a child with additional needs. There are also other benefits available to families on low incomes; we list these at the end of the chapter. We haven't included much detail about some benefits as rules about entitlement can change. For up to date information about any of these, it's best to ask at your local Citizens Advice Bureau, Jobcentre Plus, the Amaze helpline or a national advice organisation.

DISABILITY LIVING ALLOWANCE (DLA)

What is it?

DLA is often the first benefit which parents claim, and it's also a passport to other sorts of financial help. DLA is paid monthly, and it isn't taxed or means tested, which means they don't take your other income into account. You can claim DLA if your child needs more help or looking after than other children their age because of their additional needs.

Often we don't notice just how much resourcefulness, time and energy we put into helping our children learn all sorts of skills that other children seem to pick up effortlessly. Some of us find it easier to notice the practical help we give our child than the 'thinking' we do to anticipate and manage potential difficulties. Both are important, so don't underestimate the help your child needs. Lots of things count as help.

Many of our children need help to make themselves understood, to make sense of what's going on around them, or to manage difficult feelings like anger or anxiety. Some children need 'hands on' help, or prompting and encouragement with everyday activities like dressing, washing and toileting, or maybe to learn how to play or get along with other children. Your child may need you to monitor a medical condition, give

medication, help them to use special equipment, or to carry out a therapy programme. Or perhaps your child needs your help to get out and about, or needs you to keep an eye on them to stay safe.

Some children need much more help than others of the same age. But even if your child needs extra help with just some of the things we have mentioned, we think it's worth making a claim for DLA. If your claim is successful, DLA is payable in two parts. There are care and mobility components: you can claim either or both and there are rules about what you can claim.

The care component

You can claim this if your child needs help with 'personal care', that is, looking after themselves and this includes things like keeping safe and communication. You can claim this part of the benefit at any time, as long as your child has needed the extra help for at least three months and will continue to need that help for at least another six months. There are three rates at which it can be paid:

The lower rate: if your child needs some help during the day

The middle rate: if your child needs more help during the day or at night

The high rate: if your child needs help day and night

The mobility component

You can claim this part of the benefit if they need extra help with getting around. There are two rates for this:

The lower rate: if your child needs someone around to keep them safe or someone to help them find their way around. It is payable to children from the age of five. Many primary age children are still learning how to get about and stay safe on

streets and in parks near their homes. So, to get this you will need to show how much more help your child needs than others of the same age. Most children meeting the criteria for the lower rate mobility component are likely to have a significant learning or co-ordination difficulty, a communication disorder or some sensory impairment.

The higher rate: if your child's ability to get around is severely restricted by their disability. It is payable to children from the age of three who are unable to walk independently. Children meeting this rule are likely to have a severe physical or sensory impairment, a life threatening neurological, cardiac or respiratory disorder, or the most severe autism and learning disability. If your child is coming up to three years old and already receives the care component of DLA at the higher rate, you should be contacted and asked if you wish to make a claim for the mobility component.

More about the higher rate mobility component

You may not have to pay Road Tax on the vehicle used by your disabled child if your child is awarded the higher rate of the mobility component. You can get a VED (Vehicle Excise Duty) exemption form from the Disability Benefits Unit dealing with your child's claim. Ask for a DLA 404. You will need this Certificate of Exemption from Road Tax as proof that you are entitled to a 'tax exempt disc' from the Driver and Vehicle Licensing Agency (DVLA). Technically the car is only exempt while it is being used solely by or for the purposes of your disabled child. However, this doesn't mean your child has to be in the car. In practice, as long as the car is used 'substantially' for your disabled child, you needn't worry. Your child will be entitled to a Blue Badge. This allows the holder to disregard some parking restrictions, making it much easier to park very close to places you are taking your disabled child.

Only in very exceptional circumstances will Brighton and Hove issue a Blue Badge to a child who doesn't get the higher rate. In these cases, it's worth asking your child's consultant whether they are happy to support your application in writing. It really helps if they can say clearly why they think your child needs a Blue Badge. Make sure your GP is not left out of the loop - ask that they are copied into the letter from the consultant - because the Parking Officer will always write to your child's GP.

The badge is also available to families with children under two who, because of their medical condition, need to travel with bulky medical equipment or be close to a vehicle for emergency medical treatment.

If your child has a Blue Badge, take care to stick to the rules about its use. Do not place it photo side up. If you display the badge back to front, or with the expiry date hidden, you are likely to get a parking ticket. And remember, if your child is not in the car, it is an offence to display the badge, unless you are on your way to pick up your child, or you have just dropped them off. To get a Blue Badge in Brighton and Hove, contact the Parking Officer, Brighton & Hove City Council on 01273 296270. It costs £10.

You can also use this part of your child's DLA to lease or buy a car or a wheelchair, under the Motability Scheme, which we tell you more about later.

How can I get DLA forms?

It's best to get the forms from the Department for Work and Pensions who will stamp the form with the date you phoned to ask for it. As long as you send it back within six weeks and it's successful, the claim can start from that date.

You can download a claim pack by visiting www.gov.uk or call them on 03457 123456 and ask them to send you a copy. You can also text phone on 03457 224433 or apply online. Be clear you are claiming for a child and not yourself. Tell them your child's age, so that you are sent the right claim pack. The application form you need, DLA1CH, is different from the one for adults. If your child is nearly 16, expect to fill in an adult claim form. Since April 2013, DLA for adults has been replaced by a new benefit called Personal Independence Payment (PIP).

MAKING A DLA CLAIM

For both the care and mobility parts of DLA, you have to show that your child's needs for care or supervision are 'substantially in excess' of the needs of other children the same age, who do not have an illness or disability. It's a good idea to send supporting advices from professionals working with your child, because whatever you say needs to be backed up.

The forms are long and detailed and it's worth getting support to fill them in. Ask a friend to help. Other parents who have children with similar problems can be a great source of information about what to say and what not to say, and we can help too.

Amaze has a fact sheet about making a claim for DLA, and more detailed notes of the sorts of things that other parents have found useful to include on each of the pages of the claim pack. You can get these by calling our helpline. But even with lots of advice and a good friend, we know it can still be hard to put pen to paper. If you feel really stuck, rather than giving up, it's worth ringing Amaze, as we may be able to offer more individual help. But to get off to a good start, here are some general tips.

Tips

- **Set aside at least five or six hours to fill in the pack and give it a high priority.** Awards are made for two or three years at a time and most are worth several thousand pounds a year, so this may be the best day's work you ever do! DLA can be a 'passport' to other sorts of benefits and support, so it's worth taking time to get it right.
- **Remember it has to be read by someone who isn't familiar with your handwriting.** Try to keep it legible but don't worry too much about spellings or writing in complete sentences. If you make a mistake, it's better to just cross it out rather than use Tippex.
- **You can apply in lots of different ways:** online or by filling in a paper copy and, if there isn't enough space, typing what you want to say and attaching your notes to the claim pack.
- **Dig out all the most recent advices and reports you have about your child** and read through them. They can often help you understand the underlying reasons why your child, for example, appears clumsy or unable to listen.
- **Tick boxes on every page but don't bother filling in pages that aren't relevant.** When there is plenty to say, fill up the box. If you run out of space, write in the margins or add extra sheets.
- **Don't underestimate the help your child needs;** think through the extra sorts of help they need compared with other children of the same age. This is what matters.

I got so used to helping her I had forgotten that other children her age could do these things for themselves

- **As you fill in each page describe what happens at mealtimes, bath times, bedtimes, at the shops, on public transport and so on.** Say exactly what help or supervision you give. Say what would happen if your child didn't get this help. Even

if some of it feels too painful or too ridiculous to share, get it down; these three steps are key to making a strong case.

- **It can help to make comparisons between younger, able friends, brothers or sisters and your disabled child.** Include anecdotes that illustrate the problems, maybe where your child has misread a situation or been misunderstood. Give examples of what has happened when your child hasn't had the help they needed with a practical task, or were left unsupervised for a short time.
- **And don't forget about glasses and hearing aids,** we often forget these are equipment too. How often are they lost, mislaid, need adjusting, repairing or cleaning?
- **Write about the bad days, even if some of what you say feels very personal and hard to share.** If you gloss over difficult times your child's behaviour can be almost guaranteed to deteriorate the day after you have sent in the form and you'll wish you had been more open. On the other hand don't waste space saying what your child can do - this isn't the time to reveal your child's skill at the piano!
- **Remember the claim needs to be strong enough to convince someone who has never met your child.** Read it back to yourself: is there anything you haven't said? What you read may seem repetitive, don't worry, it's meant to be. The Department for Work and Pensions (DWP) will be looking for common threads running through your claim.

How others can support your DLA claim

The DWP will also want evidence from other people who know your child. So be prepared. First, check that all professionals whose details you include know that you are claiming as the DWP may well contact them. GPs are very often contacted and can find themselves 'out of the loop' as your child is referred onto specialist consultants, so it may be worth making an appointment with your doctor to put them in the picture. The DWP will usually contact your child's school.

Get a supporting statement from a professional who really knows your child well. Whoever you choose must say how much more care or supervision your child needs and why. It's not enough just to give a diagnosis, every disability impacts differently on individual children. Remember that this person may have only seen your child in a clinic or school setting. Make sure they aren't having to guess about how things are at home; ask them to read what you have written, or give them a summary of the main points you need stressed.

Getting supporting advice for problems at night can be difficult so keep a 'sleep' diary for a week or two. Show it to your GP or your child's teacher and include it with your claim. It helps if others are able to say that you report broken nights. So if you have asked your GP for help to manage your tiredness or your child's disturbed nights, or if your child falls asleep or is irritable at school and their teacher can link this to your reports of broken sleep, ask them to include this in their advice. It can support your claim.

Don't rely on a professional to fill in their part and send it off, as it's unlikely to be given a high priority. Ask for it back by a particular date and make an effort to drop it off and pick it up yourself. Don't trust the post - this is your only copy and you've invested a lot of time on it.

It really helps to send supplementary evidence that supports what you are saying. Things like medical reports, speech and language assessments, psychological advices and Statements of special educational needs are often useful.

You should keep a photocopy of all the papers so that you have a record of what you have written. Keep the copies in a safe place; you will need to refer to them if you want a decision looked at again, when the claim is reviewed or if the original gets lost in the post.

Consider returning your claim by special delivery. Doing this is expensive but we think it's worth the peace of mind. You get a receipt, the claim can be tracked and the DWP has to sign to say they've received it. Claims can get lost in the post. If you hand a claim into a Jobcentre Plus, ask for a receipt.

Getting support to fill in the DLA forms

Amaze has notes about how to tackle the claim form. Contact us if you'd like a copy.

Many disability organisations offer useful advice about claiming DLA for children and young people with specific chronic illnesses, disabilities or impairments. Their websites can be good places to visit, especially if your child's needs are just emerging. It can be really hard in the early days to make sense of how a child's diagnosis might have an impact on everyday life. You can get the contact details for these national organisations in the 'Useful contacts' at the back of this book.

You can also telephone Amaze for specific advice about DLA on 01273 772289. If you need more help, we have a small team of trained volunteers who can meet with at your home, to work alongside you to make a claim. However, many of the volunteers are parents, so this service is limited, especially in school holidays.

Many of us found filling in the forms a rather depressing experience because it's really important to concentrate on what our child can't do rather than celebrating what they can! It's important to remember this is a snapshot in time and it's likely that your child will make a lot of progress in the future. So when you've finished, make some time to talk about what you like and admire and enjoy about your child.

What to do if you think the decision is wrong

If your child's claim for DLA is turned down, or you don't get the result you expected, don't give up. Over 50% of decisions are overturned when you ask another decision maker to look at the claim again and over 70% of appeals are successful.

You can also ask for a review if your child is receiving the benefit at a lower rate and his or her condition alters and they need more help, or if the decision was correct at the time but circumstances have changed.

The DWP can look at any part of the award again, even a part you are happy with. So it's important to seek advice before asking for a decision to be looked at again, just to make the best of this opportunity. You can challenge a non-award, or argue that you feel your child should be entitled to a higher rate of either the care or mobility component, or the length of the award.

Asking for a reconsideration

When you ask another decision maker to look again at the claim, this is called requesting a reconsideration. The DWP must do this, if you ask. You must go through this process before you can appeal.

The outcome letter will explain what to do next if you do not agree with a decision and the date by which you need to reply. The first thing to do is contact the DWP: you can do this over the phone.

Say what it is that you do not agree with and why. It may be that you feel your child should be entitled to the higher rate for the mobility component rather than the lower rate. Or maybe you disagree with the length of the award.

If you did not keep a copy of the claim, ask for a copy of everything you've submitted so far, as well as any extra reports requested by DWP. Ask for a Statement of Reasons as well.

You only have 28 days from the date on the letter to tell the DWP that you disagree with a decision but if you ask for a 'Written Statement of Reasons' you get an extra two weeks.

The DWP's statement of reasons felt really patronising. It didn't take on board the amount of emotional support as well as the practical stuff.

Although sometimes these have enraged some of us, having a more detailed written response can make sense of how the DWP came to their first decision. Responding to each of their points, however bizarre, can be a useful way to structure your reply.

Go through all the paperwork carefully. Amaze can help you look again at what you wrote and help you think about what would make your claim stronger. Has any evidence been overlooked? Do you need extra reports to support what you say? Write giving detailed reasons why you disagree with the decision and stick to timescales.

The DWP has 13 weeks to look at the claim again. Your right to appeal a DLA decision only arises once a different decision maker has reviewed all the information and you have the outcome in writing. Hopefully, the first decision will be revised in your child's favour and you won't need to go to appeal. If it isn't, all is not lost!

Whether or not the decision is changed, you will get a mandatory reconsideration notice. You will need this to appeal. You now have one calendar month to submit your appeal.

Appeals

Appeals are made directly to an independent Tribunal. You will need to fill in an SSCS1 notice of appeal. You can download this from www.gov.uk website or by ringing the DWP on 03457 123456 to get one posted out.

Say clearly what part of the decision you disagree with and why. Keep a copy. Send it back within the timescale.

Amaze can give you advice to help prepare for DLA appeals but we can't support parents on the day. You will get a pre-hearing questionnaire. It's best to opt for a face to face hearing, as your chances of an outcome in your child's favour are much greater if you do. You do not need to take someone like a solicitor with you. Experience of DLA appeal tribunals tells us parents and carers are generally best placed to 'tell it how it is'.

If you don't want to attend in person, you can submit an appeal in writing or send a representative to act on your child's behalf. But if you have a campaigning spirit and find it easy to speak from the heart, it's worth doing it yourself.

If you have any more supporting evidence, send it in at least a week before the hearing. If you only get a report the day before, take it with you and explain about this. In our experience the Tribunal panel will accept evidence on the day.

I had visions of standing in a dock being interrogated. But on the day everyone was really nice, put me at my ease and explained everything very clearly. The Panel was kind and respectful and had read the papers. They had grasped the issues: their questions were relevant. There was nothing that I felt was attacking or interrogating. But it is an emotional roller coaster and they were fine when I became upset.

Remember, the Tribunal will want to know how things were at the time you put in the claim. Appeals can take a year to be heard, so make time to read through your 'bundle' of papers several times. What's important is how things were at the time you made the claim so it's worth refreshing your memory.

Time limits for reviews and appeals are short so always get advice as quickly as possible. If you are on a very low income, Money Advice and Community Support (MACS), or the Citizen's Advice Bureau may be able to help you with an appeal. You can look up sources of help at the library or visit Brighton and Hove City Council's website

CARER'S ALLOWANCE

If your child gets DLA for personal care at the middle or high rate you may be able to claim Carer's Allowance (CA). It's a weekly cash payment for anyone who spends at least 35 hours a week looking after someone who gets the care component of DLA at the middle or higher rate but is not paid to do this. Even if your child is at school, it's easy to see that most parents will clock up many more hours than this.

If you are a student, you can claim as long as you are studying for less than 21 hours a week. If you work full time and someone else cares for your child they can claim the benefit instead. CA is taxed. At the time of publication, carers may earn up to £102 a week after taxes and expenses and still claim. Expenses include up to 50% of your child care costs while you are at work and up to 50% of what you pay into a pension. However, the amount you can earn changes yearly so be sure to check what you can earn before you claim.

You can only claim CA for one person. If you have more than one child with additional needs, it may be that if someone else does a lot of caring, they can claim for CA for them instead.

Even though CA is taxable and counted as income if you are on other means tested benefits, there are good reasons to claim. It's worth claiming CA if you are on Income Support, because although CA is deducted from your Income Support, claiming it protects your pension and makes you eligible for a Carer's Premium, so overall you will be better off. If your family claim tax credits, be sure to tell HM Revenue & Customs (HMRC) if you start claiming CA or you may be overpaid.

How do I get it?

You can get a claim pack from the Carer's Allowance Unit on 0345 6084321. You can claim online at www.gov.uk. This is straightforward because you are only asked for basic information. The on-line format takes account of your answers and skips irrelevant questions. You are sent a paper copy to sign and return.

Making a claim

The claim pack is simple and easy to understand. You are guided to relevant pages and it takes only a few minutes to complete. You can make a claim when you apply for DLA and as long as you meet the qualifying criteria, CA will be paid as soon as an award for DLA is made.

Claims can be backdated up to three months, so you can wait and make a claim for CA once your child's award for DLA is agreed.

If your child's claim for DLA is turned down, or they are only awarded the lower rate of the care component, apply for CA as soon as you can, while you challenge that decision. This ensures that your backdated CA is safe if the decision is revised.

CHILD TAX CREDIT (CTC)

What is it?

Child Tax Credit (CTC) is designed to help families with dependent children. If you are on a low income and have only modest savings you are likely to be entitled. You can claim for any children under 16 and for children up to 20 if they are in full time education, studying up to A level or an equivalent standard, or if they are in unpaid, work-based training, as long as you are responsible for them and they usually live with you. This includes children who may be away at school in term times.

If you have a child who gets any rate of DLA, whether this is for care or mobility, any CTC you get will include an extra Disabled Child Element. If your child gets DLA at the high rate for personal care, any CTC will also include an additional Severe Disabled Child Element. These credits are in addition to all the tax credits available to other families.

The extra tax credits meant I could cut down my hours and spend more time with the kids.

CTC is more generous than other benefits. Maintenance payments, fostering and adoption allowances and most other benefits are disregarded as income when HMRC calculate your entitlement to tax credits. An exception is Carer's Allowance, so be sure to tell HMRC if you get this. Student loans are disregarded, as are any student grants relating to dependent children, books, travel or equipment.

If you've only just found out about Tax Credits and your child has been getting DLA for some time, it's worth telling HMRC that you may have been entitled to Tax Credits and giving details. CTC has a little more flexibility than other benefits to look retrospectively at your entitlement.

If your child's entitlement to DLA changes, this may make a significant difference to your CTC award, so it's in your interests to tell HMRC about this as soon as possible.

In the future CTC will be replaced by additional payments within Universal Credit (UC).

How do I get it?

Telephone HMRC Tax Credit help line on 0345 300 3900.

UNIVERSAL CREDIT

At the time this handbook goes to print in September 2014, Universal Credit (UC) has only been launched in a few places in other parts of the country. The plan to roll out UC is behind schedule but on its way.

UC will be an integrated means-tested benefit for people in or out of work. It will replace many familiar benefits, and includes allowances for adults, additions for children, childcare costs, limited capability for work, caring and most importantly housing costs.

At some point, there will be no more new claims for Income Support, income based Job Seekers Allowance, income related Employment and Support Allowance, Tax Credits or Housing Benefit and anyone claiming these and reporting a change of circumstances or a break in their claim will be moved to Universal Credit. But we do not know when this will begin to happen.

Until UC is introduced locally we cannot be sure about its impact, but it is likely that some families will be worse off. If, by the time you read this book, UC is being rolled out in this area, contact Amaze for advice as we will have more detailed

information as soon as it becomes available. Or visit www.gov.uk for more information about Universal Credits.

PARENTAL LEAVE

Parental leave is unpaid. But it gives birth and adoptive parents the right to time off work to look after their children and it is more generous for adoptive parents and parents of disabled children. Not just because it's even more important to strike a better balance between work and home when you have a child with additional needs, but because, from time to time, you are more likely to need to give more time to family commitments. Employers and employees can agree their own terms and conditions for taking parental leave. It's worth checking your own contract: it may be more generous than employers are legally required to offer, for example, it may include a few days paid parental leave.

If there is no mention of parental leave in your employment contract, the legal minimum automatically applies. This is called the Fallback Scheme. For every child in your family getting any rate of Disability Living Allowance or for every adopted child regardless of whether they get DLA, each parent can take up to 18 weeks parental leave. Although any parent can only take up to 4 weeks a year, the leave can be taken on a daily basis, rather than a week at a time. It can be taken at any time up until your child's 18th birthday. So this is a real help if you've ever felt uncomfortable asking for time off to get your child to medical appointments, or attend Annual Reviews and lovely stuff like school plays and concerts!

To take parental leave, you have to be an employee and to have worked for your employer for at least a year. You must also give your employer at least 21 days' notice in writing. In some circumstances your employer can postpone your leave for up to six months, if they feel your absence would significantly disrupt

their business. If this happens to you, or you feel you have been treated less favourably than other employees because you have taken or tried to take parental leave, ring the Working Families free legal helpline for advice on 0300 012 0312.

DIRECT PAYMENTS

Direct Payments are a way of giving more choice and control to disabled children and their families about the services they use. Parents can be given money to pay for and arrange services for their child, as an alternative to those their local authority offers. You and your child arrange how, when and where support services fit best into your lives. Direct Payments for disabled children were introduced in the Carers and Disabled Children Act (2000) and each year more parents are choosing to take them up.

To get Direct Payments your child needs to have been assessed as needing a service. Actually getting social services to agree that you and your child need support can be really hard. Money is limited, so Direct Payments, just like other services, are only offered to families who need it most. In reality, unless there are exceptional circumstances, this usually means your child has to meet the criteria for the local Children's Disability Service.

When you ask for an assessment of your child's needs, ask for an assessment of your needs as a carer at the same time. This won't get you services for yourself but does give you a chance to explain things from your perspective, and if you are feeling at breaking point, social services should see that you, as much as your child, need a break. After all, if you go under, who else would look after your child?

You can use Direct Payments to employ someone to care for your child (often called a Personal Assistant or PA) or to buy into a local service, like a day nursery, after school club, holiday

play scheme or even a residential short break unit, but you can't use it to buy into a service run by Brighton & Hove City Council. Unless there are exceptional circumstances you cannot use Direct Payments to employ a close relative who lives in your household, although you can use it to employ a relative who lives elsewhere.

Are Direct Payments for you?

Direct Payments are ideal for parents who want more control over the support for their child. They are worth thinking about if your child has been assessed for a service but has been on a waiting list and getting no help for a long time. Direct Payments may also be right for you if you and your child don't have a say about how the services you use are run, and you always feel as if you are fitting in with what they can offer, rather than getting your family's needs met.

Finding out more about Direct Payments

In Brighton and Hove, Direct Payments for parents are managed by the Children's Disability Service. To get Direct Payments, your child needs to have been assessed as needing a service. If your child isn't currently getting any services and you think they may be entitled to some, ring the Children's Disability Service at Seaside View on 01273 265825 to get a community care assessment.

If your child is assessed as needing a service, you cannot be refused Direct Payments if this is your choice. Local authorities have a duty to offer Direct Payments: the law says they must tell you about Direct Payments and support you if you wish to take these up. Locally, if you are already getting services, your child's social worker should have told you about this alternative to accepting services run by the local authority.

Direct Payments do mean extra work but the rewards can be very great. These are some of the issues that worry parents about arranging support for their child.

Asking for what you need

It makes sense to make a detailed record of how many hours and what sort of help your child needs on a daily or weekly basis to do the sorts of things that other children their age who are not disabled would expect to be able to do. Be clear how much of this need you cannot meet and how much of a break you and your child need from each other. You may need to do this on a daily, weekly or monthly basis but plan it out for the whole year and remember about school holidays. This will give you an idea of the number of hours you need. All families have different needs: what other families get is irrelevant.

The amount of money you will get should be the equivalent to the cost of that service, run by the council. If there is no local authority service, you may have to negotiate over how much that service would realistically cost to provide. Local authorities *must* make payments at a rate that covers the reasonable cost of buying in a service to meet your family's assessed needs. There should not be a standard rate that is offered to everyone on a 'take it or leave it' basis. You will have legal obligations as an employer and the amount you get must cover things like NI payments, holiday and sick pay as well as basic pay. Remember, you really need to negotiate on the basis of a 56-week year: anyone you employ has an entitlement to 4 weeks paid holiday and you will need someone else to cover while they are away, and they will need to be paid too.

Finding the best people to support your child is really important. You can contact The Fed Centre for Independent Living or the At Home Childcare Service within the Family Information Service, as they both have databases where they

can try to match professional carers and PAs to families. Parents also tell us that good places to advertise for free are www.gumtree.co.uk and the website of the Sussex University Career Development and Employment Service.

You can't meet everyone who replies to an ad but if you ask the right questions, you can tell a lot about a person from their application. It's worth remembering that parents and disabled children and young people have the legal right to disregard discrimination laws, if you want a male carer or a younger person for example.

Being an employer

If writing a job description, advertising and recruitment all feels a bit overwhelming there are some very helpful guides to make the process less daunting for both parents and young people. The Carers UK website (www.carersuk.org) has good information on Direct Payments. 'My Money, My Way' is a young person's guide to Direct Payments and can be downloaded from helpline@scope.org.uk or ring 080 8800 3333 for a copy.

Locally, The Fed runs a comprehensive Direct Payments Service that supports parents of disabled children and disabled adults using Direct Payments. They can help with issues like finding or recruiting a PA, training for a PA, or tax and insurance. They can also give advice and support about being an employer, and payroll services. You can contact them on 01273 296747.

Managing the responsibilities of being an employer is often our biggest worry but this doesn't need to be complicated. Using as little paper as possible is often best. Because you are not being paid and are just effectively receiving and handing out money you don't need to act as a business employer.

Managing deductions for tax, National Insurance contributions, holiday and sick pay is fairly straightforward if you use the HMRC guidance and online system. To find out how to get started, visit www.hmrc.gov.uk. Alternatively, The Fed offers a payroll service that can take care of this for you.

Keeping track of how you are spending the money doesn't need to be a burden. You will need to open a bank account just for Direct Payments and, of course, it's important you keep receipts and bank statements. The law says that local authorities must check that the money you are given is used for what has been agreed. So using Direct Payments does require you to keep accounts and records of how the money is spent. But you should not have to make weekly or even monthly returns if this doesn't make sense in your circumstances

OTHER BENEFITS

Family Fund Trust

What is it?

Lots of us have found the Family Fund a great help financially for one-off payments for specific things. Some families have had grants for washing machines, fridges, beds, telephones, outings and holidays in the UK or even abroad. The fund is for families on low incomes with children aged 17 or under with severe disabilities.

Although the Fund will consider most requests, they give priority to people whose social or financial needs are greatest. The Family Fund cannot help fund equipment or services that are the responsibility of health or social services to provide. You cannot get help for a child who is in the care of their local authority. The Family Fund produces an information leaflet with up-to-date details of how to apply, and who is likely to be eligible.

How do I get it?

You can get an application form by calling the Family Fund on 08449 744099. Or you can apply online at www.familyfund.org.uk. Amaze also keeps copies which we can send to you.

You may want to ask your health visitor, social worker or Amaze to support your Family Fund application. When you apply, you will need to give details about your child, what help you need and whether you've asked for a grant before. The Family Fund will ask you for details of your income and may contact your consultant asking for more information about your child's disability or medical condition. The first time you apply, a family support worker may arrange to meet you and your child at home, to get a better picture of your needs. This meeting is informal and sometimes they may suggest things the Fund can help with, that you may not have thought about asking for. You can ask for help each year and you can ask for help with more than one thing.

The Social Fund

What is it?

Managed locally by Jobcentre Plus, the Social Fund makes Budgeting Loans, Sure Start Maternity Grants, Funeral Payments, Cold Weather Payments and Winter Fuel Payments. There are different eligibility rules for each sort of payment.

Budgeting Loans

A Budgeting Loan is intended to help spread the cost of essential one-off expenses that are hard to meet from weekly benefits. You can apply for a loan if you've been getting income-related benefits like Income Support, JSA or ESA for at least 26 weeks.

Budgeting Loans are interest-free so you only pay back what you borrow. But you normally have to repay the loan within two years so budgeting for repayments can be difficult.

How do I get it?

In practice a Budgeting Loan can be very hard to get; there is no legal entitlement, payments are discretionary and the budget limited. If you are successful the amount you get is decided by the decision maker at Jobcentre Plus. You can find out more and download application forms from www.gov.uk. Or locally, you can contact Brighton or Hove Jobcentre Plus.

The Local Discretionary Social Fund

What is it?

This is emergency help for things you cannot do without and need very urgently, for example food, gas or electricity. You will need to show that something unexpected has happened, like a fire at your home or being burgled, so that you cannot pay for these things yourself. Requests will be assessed within one working day.

The fund may also be able to help with essential items like mattresses, cookers and fridges but you will need to show that your family cannot do without them. Requests are assessed within five working days.

There are no cash awards. To make best use of very limited funds help is given as vouchers. These can be redeemed at supermarkets and stores that recycle furniture and white goods or used to pay for unavoidable journeys.

For more advice, contact the Discretionary Help and Advice Team by emailing dhat@brighton-hove.gov.uk or by calling on 01273 293117.

Council Tax - reduction for people with disabilities

What is it?

If you've had to adapt your home especially for your disabled child, your council tax bill could be reduced to that of a house in the band immediately below yours. If your house is already in the lowest band (A) you get a reduction of one sixth of your bill. The sort of adaptations that might make the difference are:

- additional space for a wheelchair to be used indoors (like widening doors, corridors, removing partition walls);
- an extra room to meet special needs (for example, a downstairs bathroom/toilet).

The Council Tax Discount Scheme

What is it?

Where there are fewer than two adults resident at your home, you can get a discount on your council tax bill. This is worth 25% if there is one adult and 50% if there are no applicable adults. Not all adults are counted for council tax purposes. Young people aged 18 or over getting DLA at the middle or highest rate for care are disregarded. So it's worth checking!

How do I get it?

Call Brighton & Hove's Council Tax department on 01273 291291 to make an application for a reduction in your council tax band or a discount on your bill. If you have missed out in the past, you can ask for either of these to be backdated to the date they first applied.

Fares to hospital

The Hospital Travel Cost Scheme helps with fares to hospital if you're on Income Support, income related Jobseeker's or Employment and Support Allowance and sometimes if you are getting tax credits. If you aren't getting any of these benefits and

your income is very low you may still be able to claim travel costs through the NHS Low Income Scheme.

Hospitals have someone who deals with reimbursing fares on the spot. If you drive, any unavoidable parking charges and a mileage allowance should be reimbursed. You will need to show receipts, the appointment letter and proof of qualifying benefit, tax credit exemption certificate or your certificate showing you qualify for the NHS Low Income Scheme. You can also claim travel costs by downloading form HC5 from www.nhs.uk

If your child cannot travel on buses or trains or using public transport is impractical contact your child's hospital well ahead of the appointment. Your hospital social worker or the consultant's secretary should be able to help you find out whether your child can get an ambulance, hospital car transport, or help with taxi fares. The Family Fund will also consider requests for help with travelling costs to and from hospital whilst your child is in hospital. Amaze produce a fact sheet about 'Help with transport' so ring for a copy if you need more information.

Every weekend, Suzie went up to Oxford and they said 'Do you want help to pay for travel costs', because we had to go every week and we said 'No, it's all right'. I didn't really think about it, and they said 'No, go on, you must - it's going to cost you a lot of money', and they went and did it. They were excellent like that...

Motability

Motability is a charity set up to help disabled people and parents of disabled children buy or lease a car. You can also use your child's higher rate of mobility component to buy an electric wheelchair. To use the scheme your child must have at least 12 months of their DLA award left to run.

For details of the schemes, ring Motability on 0300 456 4566 or visit their website at www.motability.co.uk.

Special grants

Some charitable organisations make grants for specific purposes like holidays, or buying a special piece of equipment. You can find details of these organisations in directories held locally at main reference libraries in Jubilee Street and Hove. The main directory is 'A Guide to Grants for Individuals in Need' published by the Directory of Social Change: it is updated each year. Useful websites are www.disability-grants.org.uk and www.turn2us.org.uk.

Childcare Inclusion Funding for primary aged children

Childcare Inclusion Funding may be provided by the local authority specifically to help disabled children access mainstream childcare. It can't be used to pay for childcare fees, but it can fund a one-to-one worker, training or specialist equipment.

It can only be used in Ofsted registered provision. This is more likely to be an after school club or holiday play scheme, but could be with a child minder or an at home child carer. The application is made jointly by you and the child care provider. Get your childcare provider to apply. There are eligibility criteria and financial limits to the fund. To find out more, contact the City Early Years and Childcare Team on 01273 293523.

FURTHER HELP WITH BENEFITS

Locally, in the voluntary and community sector, Amaze, Citizen's Advice Bureau, The Fed, Brighton Housing Trust, Money Advice and Community Support and the Unemployed

Centre can offer information, advice and support to claim disability related benefits.

Disability Rights UK is a national organisation committed to breaking the link between poverty and disability. They publish 'The Disability Rights Handbook: a comprehensive guide to benefits and services for disabled people, their families, and carers'. It's 'a must' for advisers: we have a copy at Amaze and use it a lot to look up unusual queries from parents. But it's not light reading and gets updated each year, so unless you have a special interest in benefits, it's probably best to look for it in the reference section at your library. Just call Amaze and we'll try to answer your query for you.