



In the driving seat



direct payments for your child



In the driving seat

Direct payments for your child

scepe

About cerebral palsy.
For disabled people achieving equality.

department for

education and skills

creating opportunity, releasing potential, achieving excellence

Acknowledgments

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How to use this guide.

This guide has been written to give you a good idea of what direct payments are and how to use them. Most information will be presented in the format you are now reading. There are several other types of information in this guide which you may find useful. They are explained as follows:

A box with this image of a judge in the corner contains government advice on direct payments. This outlines what rights you have and what you should expect from other bodies, such as social services.



A box with this image of a lightbulb contains useful ideas.



Boxes with a question mark in the corner contain commonly asked questions about direct payments.



If you have a disabled child and feel you need support, direct payments may be able to help you. Instead of help directly from social services, you get money to buy the support that you need.

Direct payments are a relatively new way for disabled people, and parents or carers of disabled children, to receive the support they are entitled to from social services. Instead of getting services arranged by the social services department (such as an overnight stay with another family, or someone coming to your home to help out), an equivalent amount of money is paid to you each month. You can then use this to buy the support you need. People often find that this gives them more control over what they get, and that they are able to arrange their support flexibly, in a way that is convenient to them.

“Before, there seemed to be a different person each week to help with my son, and I was never sure whether they’d turn up or not. The strangest excuse was the one who didn’t mention till that day that he couldn’t come because it was his wedding!

The carer we have through direct payments is like part of our family, almost living in our house. She’s happy to do some cleaning and cook African food. She’ll take the kids out together to go swimming and things, so it keeps the family together.”





Aren't direct payments something to do with benefits?

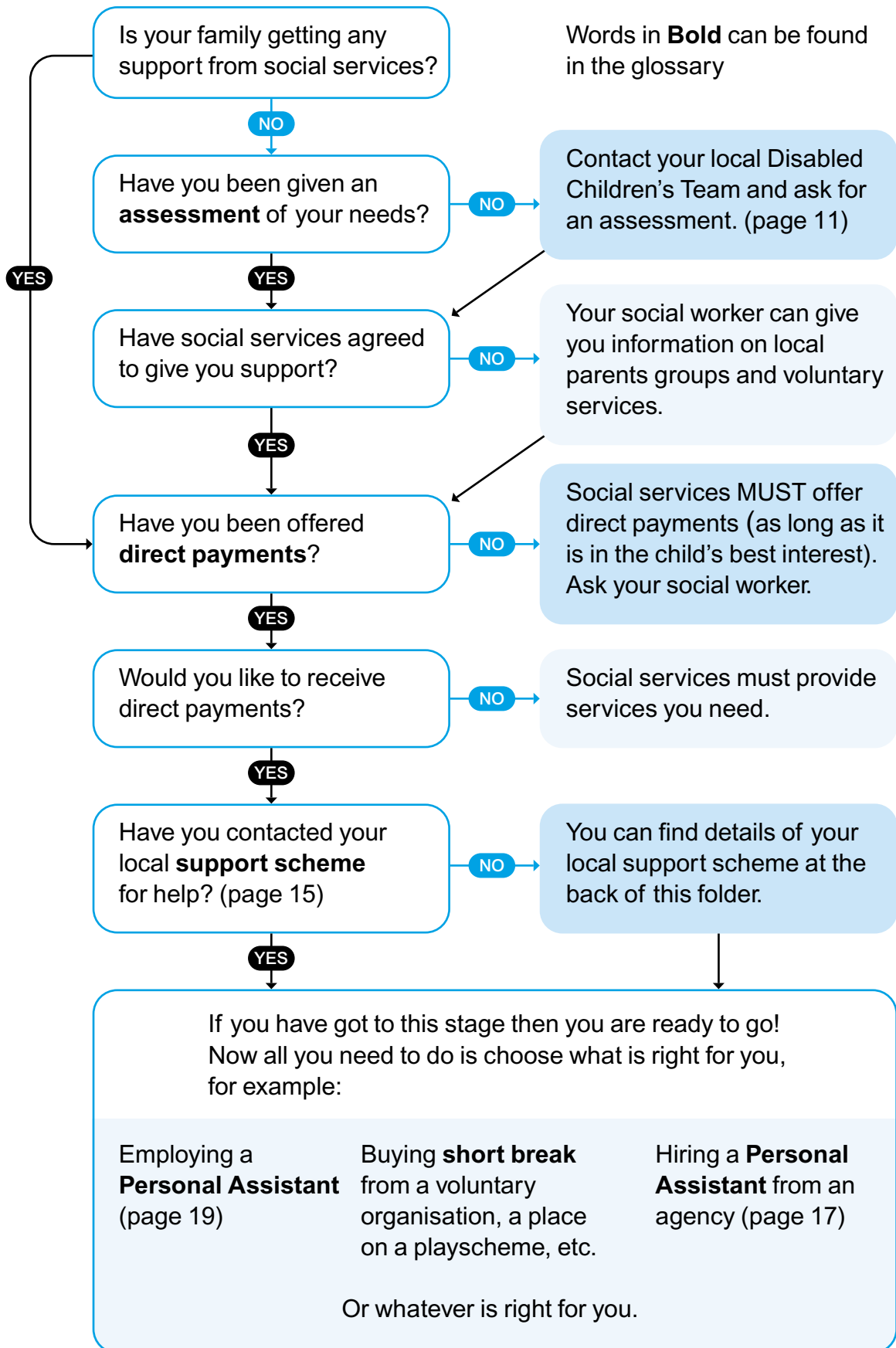
That's the other sort of direct payments!
At the moment there are two kinds.

One means getting benefits such as child benefit paid straight into a bank account instead of having an order book.

The one that this guide is about is where you get money instead of support that social services would otherwise provide. This money is only available for you to meet those needs – not for general household expenses like food.

To try to sort this problem out, the direct payments we are talking about (the social services kind) will soon be changing their name from direct payments to something else. Watch this space...!

How to get direct payments for your child.



Parents have used direct payments in many different ways. These are just some examples:

- To pay a personal assistant to support a child in community leisure activities like going swimming or to the cinema.
- To employ someone as an 'extra pair of hands' at busy times of day such as getting ready for school.
- To enable the whole family to go out for the day together.
- Overnight respite care with another family.
- To pay to attend a local playscheme accessible to disabled children.
- Where mainstream afterschool childcare is not appropriate for a disabled child, direct payments can pay for this so a parent can go to work.
- Where direct payments are given for respite, this can be saved up for a holiday, e.g. Riding for the Disabled.
- An example of creative use of direct payments is pooling them with another family to hire a private hydrotherapy pool occasionally.



“Because of direct payments we have more choice of when and how we use respite. Direct payments make family life easier as we have another pair of hands available when we want it and the children have direct input into who they want to help and enable them.

We can use a personal assistant to enable us all to attend a varied assortment of different leisure activities e.g. swimming, cinema, bowling and McDonald's. Due to direct payments I now have more time to spend with my other child, so he doesn't feel so left out.”

Will they affect my benefits?

No – direct payments are not extra money to spend as you want on things like food; they are in place of help from social services. They don't affect the benefits you get.



Getting started. If you haven't already, contact social services – they are there to help you. If you can, try to speak to a local organisation that knows how things work and can help you.

To get direct payments, you have to first get an agreement from your local social services that your family is eligible for help with its extra needs. Because of the limited resources available to social services departments, those thought to be most in need are given priority.

First ring your local support scheme (an organisation that helps people manage direct payments), organisation of disabled people or group for parents/carers of disabled children. The contacts at the back of this pack are a good place to start. These people can help you work out what support you need, tell you how things work in your local area, and often give other assistance in dealing with social services and other professionals.

It's a good idea to write down some notes to help you explain why you need extra help. To explain properly, make sure you don't underestimate any problems – for example, think of the worst days you experience.



The phone number for your local social services department dealing with disabled children should be at the back of this folder. Alternatively, look in your phone book under the name of your local social services and if in doubt ring the number for 'All enquiries'.

Let the person on the other end of the phone know that you need support to look after your disabled child at home. At this point you may just be told that someone will ring you back within a certain number of days, but you may be asked questions over the phone that will decide whether they think it is serious enough to send someone to your home for a full assessment or not.



To make sure you know where you stand, ask:

- Am I being assessed now?
- When will I hear from you?
- How long will it be until my assessment?

It may be useful to ask your health visitor, GP or another professional to write to social services and explain what support you need.

Social work teams are often small, consisting of six or seven social workers, some of whom may be part-time, and it is likely that more than one person will deal with your case.



When you speak to anyone on the phone make a note of the date you made the call, their name, job title and phone number, and anything they have agreed to do. Always ask if you are unclear about anything.

The next step is an assessment. You explain to social workers why you need extra support and they decide whether they can help you.

There may be a delay, even of several months, between social services agreeing to carry out an assessment and this actually happening. The initial assessment will probably consist of a social worker coming to your home to talk with you and other family members and to meet your disabled child and any other children. Expect to be asked lots of questions about your child, what you have to do to look after him or her, and how you are feeling.

Talk to your local support scheme beforehand. You might find it helpful to keep a diary for a week before the assessment, recording what you do and how long it takes.

Try to have a friend, family member or advocate with you at the assessment. They can give you support and maybe take some notes about what was said at the meeting.



Social services may also wish to contact other professionals such as your doctor. If your circumstances are not straightforward, the social worker may decide to carry out a core assessment, which looks at these in more depth.

If it is agreed that you can have help from social services, the assessment will result in a care plan where your agreed needs will be set out in writing. You should be offered the choice of receiving either services arranged by your local authority or direct payments. If not, and you feel that direct payments could meet your needs better than the services you have been offered, then ask about them!



The decision may be that you are not eligible for any help from social services. If you disagree with the results of an assessment, raise this with your social worker as the first step. If you feel that the assessment was not carried out properly, for example that you were not listened to, or important facts are incorrect, social services will have a formal complaints procedure which you can use. Remember, if your circumstances change, increasing your need for help, you can go back and ask for a reassessment.

If you have been offered help from social services or are getting it already, you can choose to have direct payments instead.

Everyone eligible for social care services such as respite care or help in the home is entitled to direct payments. This includes people with parental responsibility for a disabled child.

The only exceptions are people who are unable to manage them even with a lot of help, and people covered by certain mental health/ criminal justice legislation.

Direct Payments Guidance, 2003 *



If you are getting local authority services, but want to change to direct payments, contact your social worker and he or she will then visit you to discuss this.

There is no reason why you could not keep using services that you are happy with, and replace others with direct payments. You could also do this if you would like to try out direct payments, but are not sure whether they are right for you. When you are receiving direct payments, you are always free to go back to directly provided services if you want.

Direct payments can only be used to meet those needs that social services have already agreed that you can have help with, and the social services must be satisfied that the services bought with direct payments safeguard and promote the welfare of the child. However, within these limits, government guidance to social services states that “by exploring innovative and creative options, people should be encouraged to identify alternatives that meet their needs more effectively”.* So don’t be afraid to suggest to your social worker ways that direct payments could be better used to meet your child’s needs.

*Government guidance on direct payments was published by the Department of Health in September 2003. See page 29 for how to get a copy.

What can I use direct payments for?

Depending on what you have been assessed as needing, you **can** use direct payments for...

- Help with your child's personal care, e.g. dressing, eating, washing
- After school care
- Respite care
- Assistance to access leisure services, e.g. cinema, swimming pool
- Household tasks, to free up time to care for your child
- Some practical things, such as a mobile phone for a PA to be able to ring you when they take your child out
- Equipment that would be provided through social services (depending on where you live - as yet this can only be bought with direct payments in a few areas)

You can't use them to...

- Buy permanent residential care
- Buy services run by your local authority
- Buy health-related services or equipment that should be provided by the NHS
- Make major adaptations to your home that would come under the Disabled Facilities Grant
- Use direct payments to employ a partner or a close relative who lives in the same household **unless** social services are satisfied that someone's needs could not be met any other way. One reason why this may be allowed is if it is the only acceptable solution for cultural reasons

You can get help from your local support scheme with managing direct payments and employing someone (contact details at the back of this folder).

Support schemes provide information, advocacy and support to people who use direct payments. Most offer a payroll service which will sort out paying wages, tax and National Insurance. Many people on direct payments who employ someone directly (i.e. not through an agency) use a payroll service to cut down on the amount of paperwork they have to do.

Support schemes that are managed by people who use direct payments and are independent from social services are called user-led.

There doesn't seem to be a proper support scheme in my area /or it's not very good. What should I do?



A local organisation of disabled people will probably be able to give useful advice even if it is not the official direct payments support scheme. Some of these are listed at the back of this pack. There is also help available from national organisations, such as the National Centre for Independent Living. Your social services department should be able to put you in touch with local sources of help, such as a payroll service.

You can use direct payments to pay an organisation to help you, like a nursery, or an agency that can send someone to your home. Or if you prefer, you can pay someone directly – in other words, you are the employer. There are good points and bad points about both; it depends what suits you.

You may choose to use your direct payments to pay for a service such as a private nursery, a childminder or respite care. The only restriction on this is that it cannot be a service, for example a nursery, run directly by your local social services.

However, nowadays many social services pay voluntary organisations to provide these sort of services for them, and there is no reason why you should not use these. The social services department will be able to give you a list of services and childminders registered with them.

Using an agency to provide someone like a childminder:

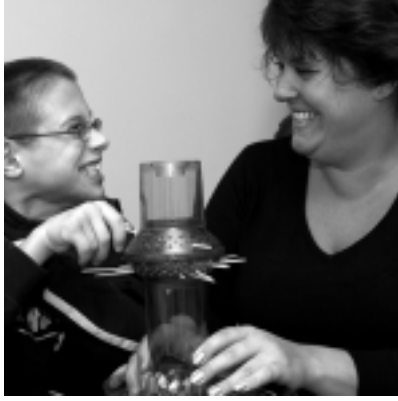
- May be necessary to meet any special medical needs.
- No responsibility for employment issues.
- More expensive.
- You may have less say in who turns up.

Employing them yourself:

- More control over who looks after your child.
- You may already have someone you know who would be good at the job.
- More paperwork and responsibility.

Visit any places you are considering to get a feel for them, taking your son or daughter along to make sure they are happy.





“We had been assessed and awarded respite care with a foster respite family. They were a lovely family but my son did not understand why he should be going home to another family instead of his own. I also found it difficult because of the inflexibility of the way the nights were allocated. Six months of advance dates with little choice of nights did not allow for things that might crop up at short notice. We stopped using this respite and went without until I heard about direct payments.

At that time it had only just become available for parents so my local Social Services Team were not familiar with it and appeared to drag their feet. I decided to learn as much as possible about it, and with this information I approached Social Services with a new determination. The rest followed fairly easily.

I had decided I needed flexibility – a babysitter at night so I could go to the cinema, after school care so I could work longer hours, help during the school holidays etc. I also wanted someone to come to my home so he was in his own environment.

The perfect solution was a local agency who had an excellent reputation from other families that used them and could offer exactly what I wanted. At first we were offered a selection of carers, all who were lovely, but eventually we settled on one carer who now comes weekly. I phone her as and when I need her and if she is unavailable I just ask the agency direct and they send someone. If they have him for more than a few hours they'll take him out for the day.

Each month Social Services pay our pre-agreed money into a separate bank account and the agency sends me an invoice, which I pay by cheque. I just have to keep all this in a file and complete a simple monthly form for my records.

Direct payments for me is to get in from work and find my son fed, bathed, in his pyjamas and happily playing his favourite games. Bliss!”

You may want to pay someone directly with your direct payment. It's important to find the right person. The steps below will help you do that, but for more information you should get help from your local support scheme.

Stages of employing someone:

1. Write a job description.

What will the job consist of? What hours will they work and how much money will they get?

2. Write a person profile.

What sort of person you are looking for? What must they be good at?

3. Decide what you want people to do when they see your advert.

Write a letter with their CV or fill in an application form? It is important to get the names and addresses of two people who can give them a reference.

4. Advertise.

The ad should have: a brief description of your child in positive terms; what you need the person to do; hours and pay and how to contact you.

Good places to advertise might include: the staffroom of schools, nurseries, day centres, local newsletters for carers, the local community college, the jobcentre...



5. Interviewing

Your local jobcentre may have rooms that you can use to interview people.



Make questions open-ended, e.g. 'Can you tell me about...?' You might want to include scenarios: 'What would you do if...?'

6. Checks and references

You need to write to the person's two referees to ask for references, and the local authority will carry out a criminal record check on your behalf (called a CRB check). These steps are important even if you know the person you are employing.

7. Drawing up a contract

It is important to have what you want an employee to do, and what they can expect from you, set down in a contract, in case you have any problems in future. Ask your local support scheme for help with this.

If you employ someone you have some legal responsibilities. The easiest way of getting these right is to get help from your local support scheme.

Some people find it easiest to use a payroll service to pay people they employ; others get someone to help them with the paperwork.

Because when employing someone you have to pay tax and National Insurance, many people find the simplest way of doing this is using a payroll service. Your local support scheme may provide this, otherwise they or social services should be able to give you contact details of other payroll services in your area. You may have to pay for this service from your direct payment.

If you have any questions about your responsibilities for paying tax, or if you think that the person working for you may count as self-employed, speak to your local Inland Revenue office. There is also a national helpline for new employers on 0845 60 70 143.

Employees are entitled to the equivalent of four weeks' leave a year. For example, someone working two days a week who took four weeks off would miss eight days of work in total, so they are entitled to eight days paid leave per year.

While your regular employee takes a holiday, you will need to employ someone else, so a small amount should be put aside each month for this and ideally a bit more for emergencies.

Insurance

Employers' liability insurance covers you if someone you employ is injured while working and claims compensation from you. Public liability insurance covers you if your employee harms someone else (or their property) while working for you. Ask your support scheme if you have any questions.

It is worth asking the company that does your home insurance whether they also do these types of insurance. Another option is Fish Insurance, at the moment the only organisation that specialises in providing insurance for disabled people (tel: 01772 724442, www.fishadministration.co.uk).

Some things will need to be sorted out before you start. There are rules about how much money social services should give you. You will need to plan in advance how you are going to spend it and you will have to keep any receipts that show how you have spent it.

How much money should I get?

The amount of a direct payment should cover the cost of obtaining a service of the same quality and quantity as social services would otherwise provide to meet those needs.



The direct payment should be sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service to which the payment relates... In estimating the reasonable cost of securing the provision of the service concerned, local councils should include associated costs that are necessarily incurred in securing provision, without which the service could not be provided, or could not lawfully be provided.

Direct Payments Guidance, 2003
(paras 82-83)

This means that if you plan to use your direct payment to employ someone directly, social services should give you enough money to pay them a reasonable hourly wage and also pay for costs such as those involved in finding a carer/assistant, paying National Insurance, four weeks' holiday pay, statutory sick pay, employers' liability insurance and public liability insurance.

If your child has complex needs, your direct payment should cover the cost of purchasing appropriate care for him or her.

Other things that you could reasonably expect your direct payment to cover include training for someone you employ directly, such as lifting and handling training; their sleeping arrangements if staying overnight and their expenses such as entrance fees to a swimming pool assisting your child.

It is worth discussing this with your social worker in advance as rules vary between different areas.

As an example, the social services department in one area states that to calculate the amount of a direct payment they add on to the hourly wage:

- 12% National Insurance
- 15% Holiday pay
- 11% Sickness pay
- 12% Insurance costs
- 15% Enhancements (covering increased wages for overtime, bank holidays etc., recruitment etc.)

Amounts paid in direct payments per hour of care vary considerably between social services in different places, but it is worth remembering that if you received, for example, £10.50 per hour from social services, these extra costs would mean that you could only offer someone you employed perhaps £7.50 an hour.

Direct payments give you a lot more flexibility, for example to save up hours to use in the school holidays or for emergencies. Local rules should not prevent you from doing any of this, but you should check if there is a limit on how much you can carry over from one year to the next.

Paperwork

You will need to give social services some information about how you have spent your direct payment. Usually you will have to keep bank statements and receipts for anything you spend the money on. They will tell you what paperwork they need to see, but ask if you are unclear about anything.

You will need to open a separate bank account before payments start, so the money can be kept apart from your other money. This makes it easier to keep track of how it is spent. Direct payments money should not be included in any assessment to see what benefits you are entitled to.

Social services may ask you to sign an agreement before you start on direct payments. This agreement would say that the money can only be used to meet your child's assessed needs and set out any other conditions. Make sure you are clear about everything in the agreement before you sign it.

Disabled young people aged 16 or over can manage direct payments themselves, if they want. Even doing a small part of this for themselves can help them get used to being independent.

Young people can choose to receive direct payments in their own right from the age of 16, although parents can continue receiving direct payments for their child until they are 18.

Scope is publishing another guide, 'My Money, My Way', for 16- and 17-year-olds who might consider this. Not all 16-year-olds whose parents receive direct payments would want to take over entirely, but you should discuss this option with them. Although teenagers and their parents naturally have different views on many issues, being involved whenever possible in decisions about how direct payments are spent can help them make the transition to being more independent.

Where a young person does decide to have direct payments in their own name to manage themselves, family and friends can give as much assistance as is needed with paperwork.

A young person already receiving services is likely to go through a more formal 'transition planning' process arranged through school, and direct payments should be considered as part of this. Again, your local support scheme and/or organisation of disabled people should be able to help.

Another issue around this time is that once a young person reaches the age of 16 different rules apply around benefits. It is a good idea to get advice from an organisation such as Disability Alliance or Contact a Family. The Transition Information Network (contact details are on page 30) can also provide information about transition planning and getting what you need from your local authority.

Checklist before direct payments start

Have you set up a separate bank account?

Things to make sure you know:

How much you are getting each month

£ _____

When it will be paid into your bank account

What is the purpose of the direct payments
(e.g. help with personal care, respite, social)

How many hours of care it is supposed to pay for

and what else you will need to pay for out of it

The information you need to keep to show social services how
you are spending the money, e.g. receipts, bank statements

How often they will ask to see this information

How long you need to keep it for

What help (e.g., support scheme, payroll service, friend) you will have to manage direct payments, particularly if you are employing someone directly.

The date when your direct payments will be reviewed

Social worker contact details

Name

Tel no.

Address

Finance department contact details

Name

Tel no.

Address

Glossary

Assessment – The process where the needs of your child and family are assessed, and out of these, it is decided which you are entitled to get help with.

Care package – A collective term for all the services arranged.

Care plan – This records what it has been decided in your assessment that you need, and what you should get.

Children in need – A term used by social services to describe children who need extra help, including disabled children. It doesn't mean the child is in need of protection.

CRB (Criminal Records Bureau) check – A check to make sure anyone you employ does not have a criminal record (agency staff will already have been checked). This will be offered by social services and is strongly recommended even if you know the person you will employ.

Direct payments – Money given as an alternative to social care services to be spent on meeting the same needs in a more flexible way.

Disabled Facilities Grant – A grant made by the local housing department to pay for adaptations to a house to make it more accessible.

Disability Living Allowance – The main state benefit for disabled children.

Domiciliary care – Services provided within the home.

Eligibility criteria – These describe the situations in which children and families are most likely to get help. They are a way of deciding how to spend social services' limited budget.

Eligible needs/assessed needs – Those needs that social services have agreed you can have help with and are in your care plan.

Employers' liability insurance – Insurance that protects you from having to pay out if your employee sued you because they injured themselves in their work.

Personal assistant – Someone employed to provide support to a disabled adult or child, as opposed to a carer who is unpaid.

Public liability insurance – Insurance that protects you from having to pay out if you were sued because your employee injured someone else or damaged their property.

Referral – When a health professional or social worker passes on details about you and your child to another professional or service and asks them to make contact with you.

Respite/short break – Short break or respite carers are individuals or families who look after disabled children on a regular basis for short periods of time. This care can also be provided in residential units. Direct payments mean that families can buy in extra help to give them a ‘break’ but this wouldn’t necessarily mean the child leaving the family home.

Support schemes – Sometimes called ‘independent living schemes’, these provide information, advocacy, peer support and back-up to direct payments users. Most provide a payroll service. In some local authorities, the support function is carried out in-house, but the best support schemes are generally those that are managed by people who use direct payments.

Useful contacts and information

National Centre for Independent Living

NCIL can provide information on direct payments and employing someone and put you in touch with your nearest support scheme.

250 Kennington Lane
London
SE11 5RD

Tel: 020 7587 1663
Fax: 020 7582 2469
Text: 020 7587 1177

Email: ncil@ncil.org.uk
Website: www.ncil.org.uk
www.ncil.org.uk/employers_kit

Contact a Family

Support and advice to parents with disabled children and children with rare health conditions.

209-211 City Road
London
EC1V 1JN

Tel: 020 7608 8700
Fax: 020 7608 8701
Minicom 020 7608 8702

Helpline 0808 808 3555
(10am-4pm, Mon-Fri)

Website: www.cafamily.org.uk
Email: info@cafamily.org.uk

Carers UK

20/25 Glasshouse Yard
London
EC1A 4JT

Tel: 0808 808 7777
Fax: 020 7490 8824

Website: www.carersuk.org
Email: info@carersuk.org

Disability Alliance

Advice on benefits and direct payments.

Universal House
88-94 Wentworth Street
London
E1 7SA

Tel & Minicom: 020 7247 8763
Mon-Wed 2-4pm

Website:
www.disabilityalliance.org
Email:
office.da@dial.pipex.com

Direct payments guidance

Can be downloaded from:

www.dh.gov.uk
(search for direct payments)

A Parent's Guide to Direct Payments

A Department of Health/ Council for Disabled Children publication, a good introduction to employing someone with your direct payment.

You can order a copy from:

Department of Health
Publications
PO Box 777
London
SE1 6XH

Tel: 08701 555 455
Email: doh@prolog.uk.com

Parent and carer factsheets

Written by parents themselves, with practical advice and tips

<http://www.audit-commission.gov.uk/disabledchildren/parentfactsheet.asp>

Transition Information Network

c/o Bronia Kita
Scope
6 Market Road
London
N7 9PW

Tel: 020 7619 7244
Email: bronia.kita@scope.org.uk

Inland Revenue New Employer's Helpline

Tel: 0845 60 70 143

Website:
www.inlandrevenue.gov.uk/newemployers/index.shtml

Scope

Scope has a network of fieldworkers across the country who have local knowledge and can provide independent information and support.

Scope
PO Box 833
Milton Keynes
MK12 5NY

Telephone: 0808 800 3333
Website: www.scope.org.uk
Email: cphelpline@scope.org.uk

Notes

Toolbox

Notes