Getting social care services when your child has additional needs

Information for families

England

Incorporating The Lady Hoare Trust

Freephone helpline 0808 808 3555
www.cafamily.org.uk
Introduction

Local authorities have a legal responsibility to help families with disabled children. Many children have additional needs and disabilities, and some are more severely affected than others. Some disabled children and their parents will need practical support both inside the home and outside it.

This guide explains your right to get the support you need from your local authority through departments like social services, sometimes known as ‘children with disabilities teams’ or ‘children’s services’.

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What is social care?

Social care is a term that generally describes all forms of personal care and other practical assistance for children, young people and adults who need extra support.

Duties of social services

Social services departments of local authorities are legally responsible for arranging support for disabled children and their carers. You have a right to have your child and family’s needs assessed by social services. The legal duties of social services to disabled children and their families include:

- providing a social worker service
- maintaining a register of disabled children
- providing information about services which may be available
- assessing the needs of disabled children and their carers
- providing a range of services to meet these needs.

Social services departments have a general duty under Section 17 (10) of the Children Act 1989 to safeguard and promote the interests of ‘children in need’. The law recognises disabled children as being in need.
Up to 18 years of age, your child’s needs are assessed under the Children Act 1989. The Care Act 2014 applies to disabled adults aged 18 or over and their carers. It also includes new rights for families with a child who may need support to prepare for the transition to adult services before they reach the age of 18, and for young carers. Additionally, the Act places a legal responsibility on local authorities to cooperate, and to ensure that all the correct people work together to get the transition right. Assessments under the Care Act also apply to people who are not receiving children’s services but who are likely to have care and support needs as an adult, for example young people with degenerative conditions or mental health issues. For more information call our freephone helpline.

Children in need are defined as children who are under 18 years of age and:

- are ‘unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without the provision of services by a local authority’, or
- whose ‘health or development is likely to be significantly impaired or further impaired without the provision of such services by a local authority’, or
- are ‘disabled’.

Section 17 (11) of the Children’s Act 1989 states that a child is disabled if they:

- are blind
- deaf, or
- non-verbal, or
- suffer from a ‘mental disorder of any kind’, or
- are ‘substantially and permanently handicapped by illness, injury or congenital deformity, or such other disability as may be prescribed’.

This part of the legislation can be found at www.legislation.gov.uk/ukpga/1989/41/section/17.

A child in need is entitled to an assessment from the social services department. The assessment is the start of the process to decide if services are needed. It is an opportunity for you to tell a professional about your child and family’s needs. An assessment is important because it can lead to a number of services being provided, like practical help in the home and short breaks.
**What is an assessment?**

An assessment is the process social services use to gather information about your child and family, so they can make a decision about what help you may need. The process for carrying out an assessment is contained within the guidance *Working Together to Safeguard Children*, introduced in April 2013. This replaced *The Framework for the Assessment of Children in Need and their Families* (2000).

This guidance tells local authorities what they must do to meet their legal responsibilities to families with disabled children. It’s up to each local authority to decide how much detail is needed in each assessment, but the maximum timeframe for any assessment is 45 working days from the date they get a referral.

**Urgent assessments**

If you need help urgently, you can ask for services to be put in place straight away without waiting for the outcome of an assessment.

Local arrangements for assessments must be published. The social worker must make clear to children and families how the assessment will be carried out and when they can expect a decision on the next steps.

A local authority social worker should make a decision about the type of response needed within one working day of a referral being received. They must also acknowledge receipt of the referral to the person asking for the assessment. Remember, if services are needed urgently they should be provided before the assessment is finished.

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As mentioned earlier the maximum timeframe for the assessment to finish should be no longer than 45 working days from the point of referral. If an assessment isn’t completed in 45 working days then the social worker should record the reasons for exceeding the time limit.

The full guidance is on the Department for Education website at www.education.gov.uk/aboutdfe/statutory/g00213160/working-together-to-safeguard-children

**How do I ask for an assessment?**

Many social services departments have ‘children with disabilities’ teams. You should find the number in the telephone directory under the name of your local authority (LA), social services or children’s services, or call our freephone helpline for information. From September 2014, all local authorities will have to publish a ‘local offer’ which will tell you about support available for disabled children and young people and how to access it. You should also find information on your local authority’s website.

If you’re unclear what LA you come under visit www.gov.uk/apply-needs-assessment-social-services. Your local Family Information Service can also advise, visit http://findyourfis.daycaretrust.org.uk/kb5/findyourfis/home.page. Or call our freephone helpline for information.

You can ask for an assessment yourself. Our freephone helpline has a template letter you can use to help you.

Always put your request in writing and keep a copy of your letter or email. The request doesn’t need to be detailed but should include:

- your name and address
- details of who is in your household, including any other children
- a brief description of your child’s disability
- what kind of extra help your child needs
- whether you need help urgently.

Or you can ask your GP, health visitor, community nurse, paediatrician or voluntary organisation to contact social services to ask for an assessment on your behalf.

**Getting information about the assessment**

Beforehand, you should be told how the assessment will be carried out and be

**Combining assessments**

The Children Act 1989 says that various assessments can be combined, for example an assessment under the Chronically Sick and Disabled Persons Act 1970 or the Education Act 1996 (replaced by the Children and Families Act from September 2014). This means, for example, that if your child’s special educational needs (SEN) are being assessed, then social services should assess your child’s needs under the Children Act at the same time.
given information about what services are available, not just those which are provided by social services departments (for example, a local playscheme).

What is a ‘needs-led’ assessment?

It is very important to remember that the starting point of an assessment is your child’s needs, regardless of whether services exist to meet them. The Working Together to Safeguard Children guidance emphasises the importance of the assessment being child and family centred. The approach should also be holistic, addressing the child’s needs within their family and wider community. So as well as your child’s disability and health needs, social services should also consider other aspects of your child’s life, for example, education and religious or cultural needs.

Preparing for an assessment

It can be useful to make a list of questions before you meet, and you are entitled to have a friend or advocate there with you. The social worker may also want to speak to your child’s health visitor, doctor or school to help them get a full picture of their needs.

What to expect at an assessment

A social worker will usually come to your home to talk to you. They should ask you for information about your child, for example, sleeping patterns, eating habits, how your child communicates, what activities they enjoy and whether you have any other children to look after. Don’t be worried about asking for clear information about the focus of the assessment. It is an opportunity to have a conversation about how to meet your child’s needs. But do remember that the assessment should be based on your’s and your child’s needs, and not based on services already available.

What if an assessment has been carried out in the past?

When services are already being provided the assessment should be reviewed regularly. But if your circumstances have changed, you can ask for a re-assessment or review in the same way you ask for an assessment (see page 6).

What if I’m refused an assessment?

If your child is disabled (and in need of services) you can’t legally be refused an assessment. You don’t need to have a diagnosis for your child to get an assessment or help from social services. It can sometimes take time before a diagnosis can be made for a number of reasons, but if your child needs the type of help or support described on page 4 an assessment of their needs should still be made. Consider making a complaint if this doesn’t happen – see page 19, ‘Challenging decisions’ for more information.

Advice on challenging a refusal to assess your child’s needs can be found at www.cafamily.org.uk/refusal-letter

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Tips for attending meetings with social services

- Be prepared. For example, you might want to have visited a school or a residential home if you’re planning to talk about your child going there.

- Keep copies of everything like letters you’ve written about your child to the authorities, as well as those they send you. Keep everything in a file, making sure you read everything you think might be relevant before the meeting to refresh your memory.

- Make notes. It’s easy to forget something so having a few notes handy at meetings with professionals will help to make sure you cover all the points you want to make. Listen to what the professional workers have to say too and make notes of what is said.

- Take someone with you. If you have a partner, make sure you both attend any meetings with professionals. If that’s not possible, or you are a single parent, take a friend or someone from a local support network.

- Don’t be frightened to ask if you don’t understand what’s being said; ask questions until you do.

- Keep calm. Don’t lose your temper if things are going wrong. Try and give reasoned, counter arguments.

- Follow up. Compare notes and draw up a summary of the main points made at the meeting, what was agreed, and what still needs to be agreed.
Your needs as a carer

The Children and Families Act 2014 came into force on 1 September 2014, giving strengthened rights to assessments for parents carers, young people and young carers. Parents should use this Act to ask for an assessment. The Carers (Recognition and Services) Act 1995 and Carers (Equal Opportunities) Act remain in force for other family members caring for a disabled child, who may be able access assessments if they are providing substantial and regular care.

You can ask for a carer’s assessment in the same way as asking for an assessment for your child – see page 6. The carer’s assessment focuses on you as a parent and your needs. Social services should discuss issues like the help you need and whether there is anyone else who helps, or if you are your child’s only carer.

The carer’s assessment should also consider your wellbeing, including health and safety issues, and important commitments like relationships and employment.

Adult carers of disabled people aged 18 or over should request an assessment of their needs under the Care Act 2014. Note also new rights for carers of young people approaching their 18th birthday referred to on page 4.

Why get a carer’s assessment?

An assessment of your child should also consider your needs as a carer and your capacity to continue with caring. The aim of a carer’s assessment is to give you a chance to tell social services about the things that could make looking after your child easier for you. This may result in getting services or direct payments to meet your own assessed needs. The Carers (Equal Opportunities) Act 2004 requires local authorities to tell all carers about their rights to an assessment. The Act also makes sure that work, education and leisure opportunities are considered when you’re being assessed.

Our factsheet Carers assessments – help for parent carers has further advice and is available free to parents who call our helpline or to download. It lists examples of some of the services which may be offered following the assessment. See: www.cafamily.org.uk/carers-assessement-factsheet

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Your local carers organisation may also be able to help. To find your local carers centre visit www.carers.org/carers-services/find-your-local-service.

What services can be provided?

After the assessment

After social services have carried out an assessment, they need to reach a decision about whether you and your family are in need of services, and which services are needed.

They may decide there is no need for services, which could result in your case being closed with no further action taken. If you disagree with this decision you can challenge it using the local authority’s complaints procedure. See page 13 ‘When you don’t meet the eligibility criteria’, and page 19 ‘Challenging decisions’. Or they may decide that there is a need for services and these should be provided. The local authority will then produce a plan of services, called a ‘care plan’.

The care plan

In many local authority (LA) areas a panel decides the package of services that may be offered. A care plan should be agreed between social services and you and your family, to meet any identified needs. The plan should give details of:

- what services will be provided
- for how long the services are needed
- what the local authority plans to achieve by providing the services
- what each person and agency is expected to do
- the date of the next review.

Importantly, the care plan should be reviewed regularly to make sure any services remain appropriate.

It is important to seek advice if your
needs change or your LA has told you a service is no longer available. If you’re unhappy with the outcome of any aspect of an assessment see page 19, ‘Challenging decisions’.

**What services can I expect for my child and family?**

Services for disabled children are available under Section 2 of the Chronically Sick and Disabled Persons Act 1970 and under the Children Act 1989.

The Chronically Sick and Disabled Persons Act sets out what kind of help should be provided. Under this Act, the duty to provide services is to the individual disabled child and does not extend to other members of the family. These services are:

- practical assistance in the home, like help with the personal care of your child, for example help with getting in and out of bed
- equipment for a recreational need, like a TV, radio or computer
- leisure facilities (this could mean outings or a placement at a day centre), or
- education facilities (this could mean home-based education or funding for the personal care requirements of students so they can study)
- travel and other assistance, like travel to and from a day centre
- home adaptations and disabled facilities, for example fitting handrails or hoists
- holidays
- meals
- telephone equipment.

The Children Act 1989 sets out a range of support services which should be available. This includes the right to permanent or temporary residential accommodation, if your child needs it. It forms the legal basis for residential short breaks. If your child needs this service, then it should be provided. If there are no suitable facilities locally, your local authority can look outside its own area.

There are other services listed in the Children Act 1989. Here are some examples:

- occupational, social, cultural or recreational activities
- home help
- assistance to enable your child and family to have a holiday
- advice, guidance or counselling
- travel assistance.

Under the Children Act 1989 local authorities have a general duty to make

“We were told time and time again: unless you were in crisis there was no support for us. Looking back, I think we were in crisis, but you don’t like admitting it.”

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a range of services available to help children in the area. Importantly, the Act allows social services to provide help which will benefit other family members, like siblings and other carers.

**Short Breaks**

The Breaks for Carers of Disabled Children Regulations 2011 requires local authorities in England to set out a range of services which will help parents of disabled children have time away from their caring responsibilities. The range of services must include:

- day time care in the homes of disabled children or elsewhere
- overnight care in the homes of disabled children or elsewhere
- educational or leisure activities for disabled children outside their homes or elsewhere
- services available to assist carers in the evenings, at weekends and during the school holidays.

Local authorities must have prepared a statement for carers which sets out the range of services above, eligibility criteria, and how these services are designed to meet the needs of carers in their area. Also, the statement must be published and made available on their website, reviewed, and consider the views of local people.

Some short break schemes may be described as ‘universal’, which means they are available to all children and you don’t need an assessment to access them.


**When should services be provided?**

Services available under both the Children’s Act and the Chronically Sick and Disabled Persons Act should be provided when there is an assessed need, and services are necessary to meet those needs. But in practice, most local authorities use ‘eligibility criteria’ to help them make this decision.

**Eligibility criteria**

There are many disabled children in an area who need help but social services have limited financial resources. Using ‘eligibility criteria’ for deciding who has a ‘need’ for services is a way they can prioritise, to make sure the people most in need get help.

The criteria are different from one local authority to another and this means if you move to a different local authority area you may no longer qualify for the same help.

For example, one of the services listed under the Chronically Sick and Disabled Person’s Act is ‘holidays’. This doesn’t mean every disabled child must be given a holiday each time they ask. There will be local eligibility criteria. It might say for instance, that holidays will normally only be given if a child has not had a holiday for five years and there is a risk of family breakdown if it’s not given.
When an assessment shows you meet the criteria

Once your child’s assessed needs match the local eligibility criteria, the local authority has a duty to provide or arrange services to meet those needs.

In this example, if your child had not had a holiday for five years and you could show that your family was under such stress that family breakdown was possible, there would be an obligation to fund the holiday regardless of the local authority’s financial difficulties.

However, the local authority can take its resources into account to decide how it will actually meet the needs. It might limit the type of holiday it provides, or it might arrange for another organisation to do so. It could even apply for a charitable grant to fund the holiday.

If the service is not actually assessed as a need (perhaps seen as only useful), or if it is assessed as a need but does not fit the local criteria, the local authority has no actual obligation to provide or arrange the service. They should still try their best to meet the need, for example by contacting a local charity or voluntary agency for help.

If the decision is that services aren’t needed, or that you don’t fit the eligibility criteria, you should be given clear reasons. This is to help in case you want to challenge the decision using the complaints procedures (see page 19).

Beware!
It is quite common to hear statements

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like, ‘Our local authority no longer provides short breaks’ or, ‘We don’t do carers assessments in this local authority.’ These statements are unlawful and you should have good grounds for a complaint (see page 19).

In fact, the local authority should not put a blanket ban on any service and should always consider the needs of the individual child and family. Other families have challenged these statements in court and the courts have decided that a local authority can’t ‘unlawfully fetter its discretion’. This means they must always be prepared to consider requests which don’t fit into their eligibility criteria.

Using the holiday example from earlier, it would be illegal for a local authority to say, ‘we never give holidays to children unless they have not had one for five years’. They can say, ‘we don’t usually give holidays’ but they must always listen to any reasons you have about why you should be treated as an exception.

**Cutting back on services**

Decisions on closing down certain services and facilities have been successfully challenged in the courts because of an authority’s failure to carry out a proper consultation. Other successful challenges refer to duties under human rights and disability discrimination legislation. For further information see *Using the Law to Fight the Cuts to Disabled Children’s Services* from Every Disabled Child Matters at www.edcm.org.uk/media/8260/using_the_law_to_fight_cuts.pdf.
Charging for services

Will I have to pay for any services provided?
Local authorities do have the power to charge for services they provide under the Children Act 1989 and the Chronically Sick and Disabled Persons Act.

Each local authority will have its own charging policy and it is usually your income and savings as a parent that are taken into account. Your child’s Disability Living Allowance shouldn’t be taken into account, and you should not be asked to pay more than you can afford.

When a child reaches 16 years of age, they are assessed in their own right. This means it should be their ability to pay which is taken into account and not yours.

When should I not be charged?
If you get Working Tax Credit, or Child Tax Credit (paid at a rate above the family element) or Income Support or income-related Employment and Support Allowance, you should not be charged for Children Act services. You should also not be charged for advice, information and counselling services, regardless of your financial situation.

Do I have to pay for services provided to me as a carer?
Services for carers of disabled children are normally provided under the Children Act and the same charging rules above apply.

What if I can’t afford to pay the assessed charges?
If you feel you are being charged wrongly, or at a level which is more than you can reasonably be expected to pay given your circumstances, you can ask for the charges to be reduced or waived completely. If you’re still unhappy with the amount you’ve been asked to pay you can make a formal complaint (see page 19 ‘Challenging decisions’).

If you have any further questions about charging, call our freephone helpline.

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Early Help Assessments

Often referred to as a Common Assessment Framework (CAF), this is another way that children and families can be assessed and receive services. But it is important to note that this process does not replace the detailed assessments under the Children Act described above. The duty to assess under the Children Act remains.

The CAF can be used if you, or someone who works with your child, would like them to receive extra help and benefit from co-ordinated support from more than one agency (for example education, health and housing). It will help to identify your child’s additional needs, and other workers required to support your family.

If you and your child agree, a worker will ask you both some questions to find out what help and support you might need. This information is recorded on a simple form. Once you’re satisfied with the information on the form you’ll be given a copy of it. Based on the information you both provide, everyone who can help your child should work together to provide the support they need.

A ‘lead professional’ will be appointed who should keep you informed, listen to your views and support you. They will also co-ordinate all the services supporting your child. You should be allowed a say in who should be the lead professional.

Further information on how the CAF operates in your area should be available from your local authority and is usually on their website.
Personal budgets and direct payments

Personal/individual budgets

Families and carers can have more control of how they arrange and buy services to meet their child’s needs. This is also sometimes referred to as ‘self directed support’.

Increasingly, local authorities are offering families the option of personal or individual budgets alongside direct payments (see page 18). You can have a mixed budget which includes direct payments and services from the local authority or an independent provider. The budget can be used for support that could come from several places, for example health as well as social services.

Unlike direct payments, the budget is not an amount paid into the account of the user of services. Instead it should be thought of as a figure or amount of money which the local authority considers sufficient to meet all of your child’s eligible needs.

From September 2014 families can get a personal budget as part of an Education, Health and Care plan (see page 18). But the duty to assess a child’s needs in relation to social care services will not change. This type of assessment will still need to be asked for separately, by contacting your children’s social work team (see page 6).
challenged in the courts and criticised for their lack of transparency and failure to address specific individual need. If you’re offered a budget you should ask the local authority to break it down to show how it meets your child’s assessed needs.

Families also have the right to decline the ‘indicative amount’ and the personal budget. Instead families can insist that their care package is provided by the local authority or via direct payments. The legal duty to carry out assessments and provide services for eligible, assessed needs still remains.

The charity KIDS have worked with other charities to produce guidance and resources which support families to use and manage personal budgets. For more information visit www.kids.org.uk/learning-and-resources. Or you can call our freephone helpline for information.

**What are direct payments?**

Local authorities can give payments, instead of providing services themselves, to allow disabled people and carers to buy in the services they’ve been assessed as needing. Any payments you receive must only be used to pay for these services.

Like personal budgets, the aim is to promote the independence of parents and disabled children who would like to manage their own social care needs. If your child is under 16 years of age, direct payments will usually be made to you as their parent. When a child turns 16 they can receive payments in their own right, to allow them to buy in the services they’ve been assessed as needing.

A request for direct payments should only be refused in very limited circumstances.

**How much are direct payments?**

The amount you receive should be enough to allow you to meet all the costs involved in arranging the services that social services have agreed to help with. This should include any tax and national insurance you might have to pay if you employ someone, as well as the cost of a disclosure and barring service check (previously criminal records check).
Social services will usually deduct an amount from the payments, equivalent to what you would have been charged if they’d arranged the services. Or they may make the payments in full and ask you to reimburse them any assessed charge.

**Further information about direct payments**

Contact a Family has a guide *Getting direct payments for your disabled child*. Call our freephone helpline for a copy or visit the resources section of our website to download it at www.cafamily.org.uk.

**Challenging decisions**

Under The Children Act 1989 ‘Representations Procedure (England) Regulations 2006’ parents and carers can complain about:

- service quality or appropriateness
- delays in decisions being made or services being put in place
- how services are delivered (or not delivered) including the way complaints are dealt with
- the amount of help given, how frequently a service is provided, any changes made to services or how much you are asked to pay
- the attitude or behaviour of staff
- how eligibility and assessment criteria are applied
- a local authority policy which impacts on you or your child
- any aspect of the assessment, reviews or care management.

**Who deals with a complaint?**

Each local authority has a ‘designated officer’ who receives all complaints, called the complaints manager. They don’t have to handle all stages of the complaint but are responsible for administering the scheme to make sure complaints are dealt with swiftly and effectively.

**How quickly can I expect a complaint to be dealt with?**

Time scales are summarised below but you can ask the authority to respond sooner.

**Stage 1 – Local resolution**

You should bring your concerns to the attention of the person providing the services locally. The local authority should consider mediation at this stage, and all other stages.

They should make a first attempt to resolve matters within 10 working days. This can be extended by another 10 days, for example if an advocate needs to be appointed.

If the matter isn’t resolved, or if there is agreement for an investigation to take place, then the complaint should go to Stage 2.

If you wish the complaint to go to this stage you can request this orally or in writing.
Stage 2 – Investigation
The local authority should arrange an investigation that produces a report and a decision within 25 working days (or sometimes, in extreme circumstances, this can be extended to 65 working days). If the matter is still not resolved then you can ask for a panel to consider your complaint. The investigation will be undertaken by a nominated complaints officer.

Stage 3 – Review Panel
The person making the complaint can ask for the matter to go to a Review Panel within 20 working days of receiving a Stage 2 decision. This is a meeting of three independent people who will consider the complaint and make recommendations. The process of holding a Review Panel must follow certain time limits. See box above.

Unhappy with the outcome of a Review Panel?
If, after a Review Panel has considered your complaint, the matter is still not resolved then you can take your complaint to the Local Government Ombudsman (LGO). You may be able to approach the LGO earlier – for more information see the next page.

You can find further information about complaints in government guidance,
Local Government Ombudsman

If you’re not happy with the panel’s decision then there are various other options, like taking the issue up with your local authority (LA) or MP or complaining to the respective Local Government Ombudsman (LGO).

The Ombudsman can investigate complaints against principal councils (not town, parish or community councils) and certain other bodies. By law they must look for ‘maladministration’ by a local authority. Maladministration is a term which describes the actions of a government body which can be seen as causing an injustice. Examples include:

- delays
- incorrect action or failure to take any action
- failure to follow procedures or the law
- failure to provide information
- inadequate record-keeping
- failure to investigate
- failure to reply
- misleading or inaccurate statements
- inadequate liaison
- inadequate consultation, and
- broken promises.

The Ombudsman will decide whether the LA has done something wrong which has directly affected you and caused you an injustice. They won’t investigate a complaint against the local authority simply because you disagree with it. There are two LGOs in England that deal with complaints from different parts of the country. For details visit www.lgo.org.uk/contactus or call 0300 061 0614.

Complaints against your local authority

Each year the Local Government Ombudsman sends an annual review to all LAs about complaints made about them to the ombudsman.
This is a useful way of assessing the local authority’s performance in dealing with complaints. The review includes statistics but also lists a few cases which have been investigated and reported. To see your LA’s review letter visit www.lgo.org.uk/CouncilsPerformance/

**Taking legal action**

**Judicial Review**

If your complaint is very urgent and you can’t wait for the complaints procedure to resolve the matter, you can apply to the courts for a Judicial Review. Judicial Review is a procedure where the High Court looks at the way a decision was reached to see if it was legally correct.

You can also apply for Judicial Review if you have exhausted the complaints procedure and are still unhappy with the outcome. To do this you will need legal assistance.

If you have a low income you may qualify for legal aid. Also, some solicitors offer a free first interview.

Further information about help with legal costs can be found on GOV.UK, at www.gov.uk/legal-aid.

For help with finding a specialist legal adviser visit http://solicitors.lawsociety.org.uk.

Or call our freephone helpline for advice.

**Other ways to complain**

Ofsted is the Office for Standards in Education, Children’s Services and Skills. They inspect and regulate services that care for children and young people, including children’s homes. They also inspect services that provide education and skills for learners of all ages. Ofsted have some powers to investigate concerns about services they inspect or regulate. For more information visit www.ofsted.gov.uk/contact-us/how-complain or call 0300 123 4666.

Healthwatch England is the consumer body for users of health and care services. They have the power to raise concerns and influence the policy of health and care providers. You can contact your local Healthwatch which may be able to offer advice and support with your complaint. For more information visit www.healthwatch.co.uk/complaint.

The Care Quality Commission regulates and inspects children’s homes that provide healthcare performed by a qualified healthcare professional. It also regulates and inspects home care agencies that provide services for children. For more information visit www.cqc.org.uk/content/share-your-experience.

Both Ofsted and the Care Quality Commission value hearing about any concerns about the care provided by services they inspect. If you’re concerned about the care your child is getting, do share it with them, as other parents may have reported concerns too. It helps them build up a picture of what is going on in a local area and may trigger an investigation if parents are reporting bad practice.
Frequently Asked Questions

“" My social worker said I should put my disabled child on a register of children with disabilities. What does this mean? ""

Social services have an obligation to keep a register of children with disabilities. This isn’t the same as the child protection register and doesn’t suggest in any way that your child is at risk. You don’t have to agree to your child’s name being added to the register and it doesn’t affect your entitlement to services.

A register allows social services departments to try and plan services for disabled children more effectively in their area. It is sometimes used as a way of getting relevant information to families so you might get a newsletter as a result.

“" Can I use direct payments to employ my sister-in-law who lives with me to look after my son? ""

The 2003 Direct Payments Regulations make it that clear that a direct payment should not be used to employ a spouse, partner or close relative living in the same household as the disabled person.

However, employing a close relative may be possible if this is the only effective way to meet a child or young person’s needs. For example, if a child has complex communication needs or specific cultural needs then it may be acceptable to employ a family member who could meet those needs.
My daughter is disabled and I'm wondering if I can get a Blue Badge?

The Blue Badge Scheme is a UK arrangement of on-street parking concessions for disabled people. The badge can also be used in many European countries.

If your child has severe walking difficulties, is registered blind, has severe upper limb disabilities or receives the higher rate mobility component of Disability Living Allowance, you may be eligible. If you are the parent of a child who is less than three years old, you may apply for a Blue Badge for your child if they have a specific medical condition which means that they either:

- must always be accompanied by bulky medical equipment which cannot be carried around without great difficulty, or
- need to be kept near a vehicle at all times, so that they can, if necessary, be treated in the vehicle, or quickly driven to a place where they can be treated, such as a hospital.

For more information contact your local authority or visit www.gov.uk/apply-blue-badge.

Department of Transport guidance can be found at www.dft.gov.uk/publications/blue-badge-scheme-local-authority-guideance.

My son has ADHD and is also autistic. Social services won’t assess my child, saying they can only help children with physical disabilities and they don’t have any suitable services.

Under the Children Act 1989 a local authority has a duty to assess any child in need. See the definition of ‘children in need’ on page 4 of this guide. The definition includes a reference to someone who ‘suffers from mental disorder of any kind’. Whilst this phrase is outdated it can include a wide range of conditions, including Asperger syndrome/high-functioning autism, attention deficit hyperactivity disorder (ADHD) and attention deficit disorder (ADD) as well as impairments such as learning disability, mental illness and personality disorder. In light of this definition it would appear that social services have acted incorrectly by refusing your request for an assessment and failing in their general duty to provide a range of services for all disabled children. But you should note that they’re also allowed to set eligibility criteria for
specific services which could mean that your child won’t qualify for a service because they don’t meet the criteria. If this is the case and you’re unhappy about their decision, you can make a complaint using the local authority complaints procedure. See page 19.

More advice written by community care lawyers on challenging a ‘refusal to assess’ decision can be found from Every Disabled Child Matters at www.edcm.org.uk/media/141030/refusal-to-assess-letter.pdf.

“Can my social worker advise me on which benefits my family are entitled to?”

Social workers do have a duty to provide advice and guidance. They should explain to you what benefits are available and make sure you’re getting the benefits you’re entitled to.

However, most social workers are not benefits experts and they may rely on the local authority’s welfare rights service or similar advice agency to help you. They may also direct you to a voluntary organisation like the Family Fund for further help. Advice about your entitlements can be found in a range of guides from Contact a Family, available from our freephone helpline. Helpline advisers can answer benefit enquiries and refer you to our welfare rights team for specialist advice if you need it. More information, including advice about changes to benefits can be found on our website at www.cafamily.org.uk/know-your-rights/benefits-and-tax-credits.

“Due to the cuts, I’m worried that I will lose help the local authority provide with getting my daughter ready for school in the mornings. I’m disabled too and couldn’t manage without this.”

Your local authority must continue to provide the service as long as you continue to meet the criteria you were assessed against. Also, the authority can’t take its resources into account if you would be left at severe physical risk if the help wasn’t provided.

However, the local authority can take its resources into account when setting criteria for services. This means they may choose to introduce new stricter criteria which could make it harder for you to access the same level of help. Even if they introduce new criteria they can only reduce or withdraw a service after carrying out a re-assessment of your needs, and you don’t meet the new criteria. You may still be able to challenge a decision to withdraw or reduce a service in this way by using the complaints procedure or taking legal action. Call our freephone helpline for further advice. See Using the Law to Fight the Cuts to Disabled Children’s Services from Every Disabled Child Matters at www.edcm.org.uk/media/8260/using the law to fight cuts.pdf.

Freephone helpline 0808 808 3555
www.cafamily.org.uk
“Do I have a right to see my child’s records?”

Under the Data Protection Act 1998 professionals and agencies have a duty not to disclose information about disabled children and their families without the consent of the ‘subject’. This applies to children as well as adults provided that, if they are under 16 years of age, ‘they have the ability to understand the choices and their consequences’.

Even though there’s a duty not to disclose without the child or young person’s consent, the public body concerned (for example, the health service or local authority) still have the discretion to allow access to the information. In most cases parents should have no difficulty seeing their child’s records.

Guidance also says that advocates should be given access to relevant information about the person they’re representing. Our freephone helpline can give you more advice about access to personal records.

“I contacted social services for help with getting a short break and accessing local activities and play schemes but I was told that this is what my child’s Disability Living Allowance should be used for. Is this correct?”

Disability Living Allowance is not intended to replace funding from the local authority where there is an assessed eligible need. You should still ask for an assessment. An assessment of your child’s needs will hopefully identify the need for short breaks and lead to services being provided. This may include the offer of direct payments which can be used to employ someone to enable your son to attend an activity which he enjoys. If you’re told otherwise, ask for this in writing and then challenge their decision. See page 19 for advice about challenging decisions. Our guide, Holidays, Play and Leisure, has more information about your child’s rights to access play and leisure opportunities. Call the helpline for a copy or visit our website where you can download it at www.cafamily.org.uk
I’m finding it very difficult to cope and need help at home, but I’m scared that if I contact social services they’ll take my children away.

Unfortunately, there are many parents who feel that needing help will lead to social services taking their child away. Some even feel that a request for help is a sign of weakness or bad parenting. For this reason we understand that some families will not seek help.

It’s important to understand that while social services have specific duties around child protection issues and protecting vulnerable children from harm, they also have duties and responsibilities to support families. This means where possible keeping the family together.

Social services should respond to your situation by carrying out an assessment to identify your needs. If you like, you can also ask for a separate assessment as a carer. Either way, this should lead to a recognition of your needs and the practical support you’re looking for to help ease the situation at home.

Some parents get regular breaks which allow them to spend time either with their other children or alone, so they can recharge their batteries. Spending time away from your disabled child may also help foster a sense of independence. This may be particularly helpful with transition to adulthood, as they grow up.

If you’re still concerned about approaching social services, you may find it helpful to contact a voluntary organisation for support and advice. They may be able to support you in your request for help or tell you about other services which aren’t linked to social services. Contact our freephone helpline for further information.

Freephone helpline 0808 808 3555
www.cafamily.org.uk
My husband and I are asylum seekers and care for our severely disabled daughter. We can’t claim any benefits and we’re not allowed to work. Instead we receive asylum support from the UK Border Agency (UKBA). We’re finding it very difficult to lift our daughter in and out of the bath and onto the toilet. She also needs a wheelchair - without one we can’t take her anywhere. Are we entitled to any extra help?

The UKBA are responsible for maintaining you, your husband and your child. They are responsible for providing for a child’s ‘essential living needs’. This means the needs of ‘an ordinary child or adult with no special peculiarities or disabilities’.

Although section 122 (5) Immigration and Asylum Act 1999 states that local authorities cannot provide ‘assistance’ under section 17 of the Children Act 1989 to a child whose parents are receiving UKBA asylum support, this doesn’t prevent them from providing support to a child who is disabled. Any needs that go beyond ‘essential living needs’, such as the needs arising from a child’s disability, should be provided for by the local authority.

Under the Children Act 1989 the local authority can provide further support and services for your daughter’s needs as a disabled child. If UKBA asylum support is inadequate you can approach your social services department for help.

It is important to seek further clarification about your rights to make sure you don’t jeopardise your status and current support. You may find, for example, that getting practical help from another source to meet another need could affect the asylum support you get from UKBA. Call our freephone helpline for further information on specialist sources of advice.
"I am a student from overseas, living with my wife and disabled child. Because of our immigration status we’ve been told we have ‘no recourse to public funds’. What does this mean?"

Most people coming to stay in the UK under the immigration rules are expected to be able to house and support themselves financially, without having to rely on public funds or state support. This is what is meant by ‘no recourse to public funds’.

In reality this means you’re not usually allowed to claim benefits like Income Support, Housing and Council Tax benefits, Disability Living Allowance and tax credits. Also, you’re not usually allowed to apply for local authority housing.

For the purposes of immigration rules ‘public funds’ does not include NHS treatment, state education or help from social services, for example under the Children Act 1989. If you’re not clear about your rights it’s very important to seek specialist advice. If you don’t, it could affect your status and right to remain in the UK.

The Contact a Family freephone helpline can provide limited advice and assistance on immigration matters, including advice on rights to entitlements. But we can’t help with more complex issues like challenging a failed application for asylum or advising on deportation.

If we can’t give the help you’re looking for, we should be able to suggest where to get help in your area.

Call our freephone helpline for information about specialist immigration advice services on 0808 808 3555 or email helpline@cafamily.org.uk.

Parent Advisers can arrange for an interpreter if English is your second language.
Changes to the law

The law on how children and young people with special educational needs (SEN) in England changed in September 2014 under the Children and Families Act 2014. It introduced a number of changes such as an education, health and social care (EHC) plan, which replaces statements of special educational need. Like the statement, the EHC plan is a legal document specifying a child or young person’s special educational needs, the special educational provision they will get, and the nursery, school or further education college they will attend. However, the process of transferring to an EHC plan will happen gradually and it is expected that this will happen by April 2018.

We have a range of factsheets about getting support for your child in education. Parents can call our freephone helpline to ask for free copies, or you can download them at www.cafamily.org.uk/the-sen-process

Please note the duty to assess a child’s needs in relation to social care services will not change. This type of assessment will still need to be triggered separately by contacting your children’s social work team.

Since September 2014, local authorities in England have been required to publish a ‘local offer’. A local offer is intended to provide information about provision it expects to be available to children with special educational needs and disabilities in their area including leisure activities and childcare. Local offers should be available on your local authority website.

The local offer should also include details of how parents and young people can request an assessment, and include information about how to get a short break.

For advice on this or any aspect of caring for a disabled child call the Contact a Family helpline on 0808 808 3555.
Social networking

Contact a Family is on Facebook and Twitter. Join us at:

Facebook
www.facebook.com/contactafamily

Twitter
www.twitter.com/contactafamily

Podcasts
To listen to and download our podcasts click the iTunes link on the bottom of our website homepage:
www.cafamily.org.uk

Videos
You can watch videos on our YouTube channel at:
www.youtube.com/cafamily
Getting in contact with us

Free helpline for parents and families
0808 808 3555
Open Mon–Fri, 9.30am–5pm
Access to over 170 languages
www.cafamily.org.uk
www.makingcontact.org

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children including:

- A guide to claiming Disability Living Allowance for children (UK)
- Fathers (UK)
- Understanding your child’s behaviour (UK)
- Holidays, play and leisure (UK)
- Grandparents (UK)
- Siblings (UK)
- Special educational needs
- Preparing for adult life and transition
- Getting direct payments for your disabled child.

All our guides can be downloaded from our website www.cafamily.org.uk
Parent carers can call our freephone helpline and ask for a copy of any of our guides.