

SERVICES & SUPPORT FROM YOUR LOCAL AUTHORITY



INFORMATION FOR PARENTS OF DISABLED CHILDREN – ENGLAND



contact

This guide covers England

CONTENTS

WHAT IS SOCIAL CARE?	5
DUTIES OF SOCIAL SERVICES	6
WHAT SERVICES CAN I EXPECT FOR MY CHILD AND FAMILY?	10
HOW DO I ACCESS SERVICES?	13
EARLY HELP ASSESSMENTS	18
YOUR NEEDS AS A CARER	19
AFTER THE ASSESSMENT	22
WILL I HAVE TO PAY FOR SERVICES?	27
PERSONAL BUDGETS AND DIRECT PAYMENTS	28
MOVING INTO ADULT SERVICES	32
COMPLAINTS ABOUT DECISIONS	39
FREQUENTLY ASKED QUESTIONS	47



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', 'children's' or 'social care services'.

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. This can include support provided via your local health service. Health bodies and local authorities are expected to work together to meet the health needs of disabled children. However, the focus of this guide is to provide advice about the rights of families to support from their local authority.



For more information about health services visit:
www.contact.org.uk/health

DUTIES OF SOCIAL SERVICES

Social services departments of local authorities are legally responsible for arranging support for disabled children, their siblings, and their carers.

WHAT DOES THE LAW SAY?

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:

- ***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,' and to promote their upbringing by their families. The law recognises disabled children as being in need.

'Children in need' are children 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 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`.***

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. See page 13.

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. The Act places a clear duty on the local authority to 'promote the wellbeing of disabled adults and their carers'.

The Care Act also includes new rights for families with a child who may need support to prepare for the transition to adult services, and young carers. The Act makes clear that services arranged before a child's 18th birthday to meet their assessed needs can continue after their 18th birthday until adult services are in place. See page 32 .

IF YOUR CHILD IS BEING ASSESSED FOR AN EDUCATION, HEALTH AND CARE PLAN

Some children who need extra help in education may be assessed for an Education, Health and Care plan (EHC plan).

The local authority will gather information about your child's social care needs as part of the assessment for an EHC plan – the EHC needs assessment. If your family is not already getting support from children's services, you can ask them to do a separate assessment for your child's social care needs. The assessment should also consider the needs of parents and other family members.

Social care, help and support should be given to the child and family as soon as a need is identified and not wait until the completion of an EHC plan needs assessment.



For more information about extra help for your child at school or college, assessments for EHC plans, and what to do if you're unhappy see www.contact.org.uk/education or call our freephone helpline to speak to one of our education advisers on **0808 808 3555**.

“Where a local authority is under a duty to undertake an ‘EHC assessment’, this will include a specific duty to assess their social care support needs.”



WHAT SERVICES CAN I EXPECT FOR MY CHILD AND FAMILY?

Services for disabled children under 18 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, such as help with the personal care of your child, for example help with getting in and out of bed***
- ***recreational equipment such as a TV, radio or computer***
- ***leisure facilities (this could mean outings or a day centre placement)***
- ***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, such as handrails or hoists***
- ***holidays***
- ***meals***
- ***telephone equipment.***

The Children Act 1989 lists a range of help, 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. Here are examples of other services listed in the Children Act:

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

SHORT BREAKS

The Breaks for Carers of Disabled Children Regulations 2011 requires local authorities to set out a range of services that will help parents of disabled children have time away from their caring responsibilities. This is known as the Short Breaks Statement. 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.**

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



More information on short breaks is in our factsheet **Short breaks – how you and your family can benefit** available free from our helpline or to download. You should also find information about short breaks and other services for families for disabled children in the ‘local offer’ on your council’s webpage.



HOW DO I ACCESS SERVICES?

Services may be provided following an assessment of your child's needs under Section 17 of the Children Act. 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 statutory guidance, *Working Together to Safeguard Children*. This guidance tells local authorities what their legal responsibilities are to families with disabled children. The guidance requires local authorities to set out their process for assessments. This process should be published and easily available, including on the local authority's website. The guidance also requires local authorities to complete the full assessment within 45 days from the date of the request. Local authorities must follow this statutory guidance.

HOW DO I ASK FOR AN ASSESSMENT?

Although you can ask for an assessment verbally, it is best to ask for a 'Section 17 Children in Needs assessment' in writing. You can do this yourself, or a professional who is helping you can do it for you.

Many social services departments have 'children with disabilities' teams who are responsible for carrying out assessments. You should find the number on your local authority's website under social services or children's services, or call our free helpline for information.

If you're not sure which local authority you come under type your postcode into the search bar at www.gov.uk/find-local-council.



Our helpline team has produced a template letter you can use to ask for an assessment. Download it from our website at www.contact.org.uk/needs-assessments or call **0808 808 3555**.

TOP TIPS

- Check your local authority website's 'local offer' for information on needs assessments and help from social services
- Ask to see the eligibility criteria set by your Local Authority Children's Services Department
- Ask your family about the type of help you and your child might need and why it would make a difference to you and your child.
- Write a letter to Children's Service requesting an assessment of your child's needs.
- Give information about the nature of your child's disability
- Set out the support you need and how this will help with your child's development.
- Explain how you think the local authority's eligibility criteria for services applies to your child
- Why do you think their needs warrant the help you're looking for
- Date the letter and make a copy to keep before you send it to send to the Children with Disabilities team.

If you're in contact with a professional who knows your child, ask if they can write a letter supporting your request for help, or if they can make the referral themselves.

GETTING INFORMATION ABOUT THE ASSESSMENT

The local authority should provide information about the process and timescales. You should also be told how the assessment will be carried out, and be given information about what services are available – not just those which are provided by social services departments (for example, a local play scheme).

WHAT IS A ‘CHILD IN 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 consider the needs of the whole family and those of the 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.

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. In order to get a full picture a health professional such as your child’s GP or health visitor and your child’s school may also be asked for information.

KEY REQUIREMENTS

Local authority 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. This includes arrangements if you need help urgently. Further information may also be available on your council's local offer website page.

Time scales

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.

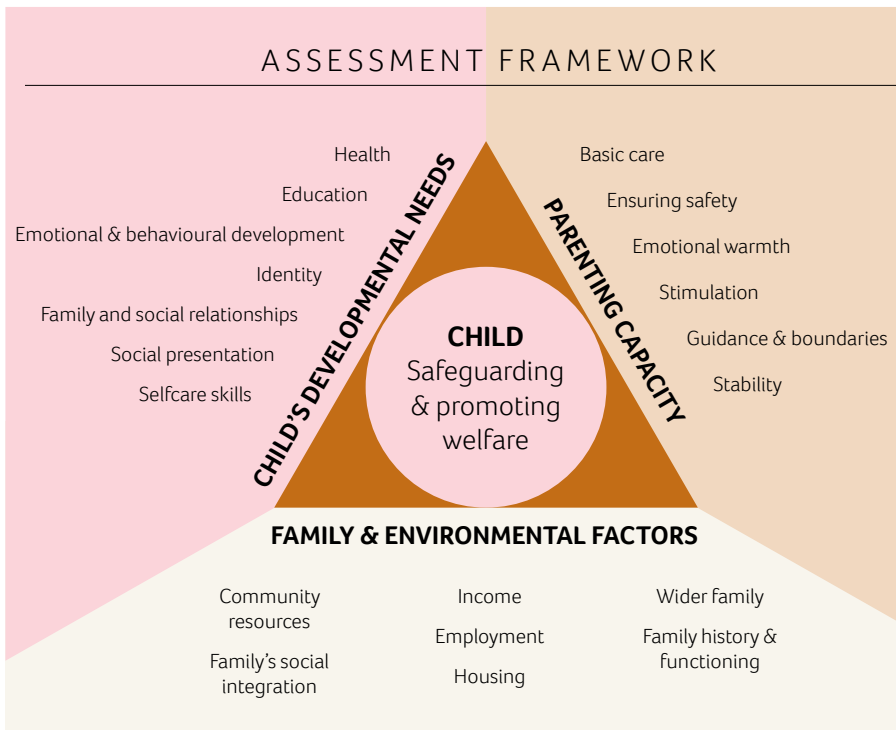
The maximum time frame for the assessment to finish should be no longer than 45 working days from the point of referral.

If an assessment isn't completed within 45 working days then the social worker should record the reasons for exceeding the time limit.

An outline of the process and time scales is on pages 33–34 of the *Working Together to Safeguard Children* guidance. Search for the title at www.gov.uk

Don't be worried about asking for clear information about the focus of the assessment. The person carrying out the assessment should work in an open way. This means listening to your views as well as sharing any relevant information with you. It is an opportunity to have a conversation about how to meet your child's needs.

Remember that the assessment should be based on you and your child's needs, and not based on services already available. The local authority must follow the detailed assessment framework included in the statutory guidance *Working Together to Safeguard Children*. It is a holistic approach that aims to understand a child's needs within the wider family and their environment, as shown in the image below.



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 13).

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 9, an assessment of their needs should still be made. Consider making a complaint if this doesn't happen – see page 39 'Complaints about decisions' for more information.

EARLY HELP ASSESSMENTS

Sometimes 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 earlier. 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.



YOUR NEEDS AS A CARER

Any assessment of your disabled child should take into account the needs of the rest of the family members, including parents and siblings, and consider their needs as a carer and capacity to continue with caring. Please see the Assessment Framework diagram on page 17. However, 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. Examples of services that can be provided include help with driving lessons, housework and gardening.

A carer's assessment focuses on you as a parent and your needs. Social services should discuss issues such as 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 which include the following elements:

- ***personal dignity and respect***
- ***physical and mental health and emotional well-being***
- ***protection from abuse and neglect***
- ***participation in work, education, training or recreation***
- ***social and economic well-being***
- ***domestic, family, and personal relationships***
- ***suitability of living accommodation***
- ***the individual's contribution to society.***

All carers have a right to ask for an assessment of their needs at any time, for example if your needs have changed (you may wish to take up education, training or employment) in the same way as asking for an assessment for your child. The aim of a carer's assessment is to give you a chance to tell social services about what could make looking after your child easier for you.

HOW DO I ASK FOR AN ASSESSMENT

Parents of disabled children (called parent carers in the legislation), young people and young carers have rights to an assessment of their needs under the Children and Families Act 2014.

An assessment for a sibling, known as a young carer, is triggered where there is an ‘appearance of need’. That means it is not necessary for the young person to request this, so any assessment of you or your disabled child should take into account any brothers and sisters.

The Carers (Recognition and Services) – Act 1995 and Carers (Equal Opportunities) Act applies to other family members who are providing ‘substantial and regular’ care to a disabled child. For example a grandparent, aunt or uncle who provide care, but who do not have parental responsibility for the child. Substantial and regular care is usually defined as 35 hours or more care per week.

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.***



We have template letters you can use to ask for a carer’s assessment, plus more detailed information in our factsheet, ***Carers’ assessments – help for parent carers***. Download it from www.contact.org.uk/carers-assessment-factsheet or call our helpline for a free copy on **0808 808 3555**.

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

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 24 'When you don't meet the eligibility criteria', and page 39, 'Complaints about 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 39, 'Complaints about decisions'.

WHEN SHOULD SERVICES BE PROVIDED?

Services available under both the Children 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 may differ 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.

WHEN YOU DON'T MEET THE ELIGIBILITY CRITERIA

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 your child doesn't fit the eligibility criteria, you should be given clear reasons. You can challenge the decision using the complaints procedures (see page 39).

BEWARE!

It is quite common to hear statements 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 39).

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 that 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

When commissioning or changing services for disabled children and families, the local authority must consult with local parents via their local parent carer forum. This is a group of parents and carers of disabled children who work with local authorities, education settings, health providers and others to make sure the services they plan and deliver meet the needs of disabled children and families.

If you are told a service is being cut or changed, get in touch. You can also sign up to your local forum just to receive news for families with disabled children. To find your local parent carer forum go to the 'Who we are' section of the National Network of Parent Carer Forum's website at: **www.nnpcf.org.uk**



For further information, download *Challenging cuts to short breaks services* free from www.contact.org.uk/short-break-cuts-guide or call our helpline for a free copy on **0808 808 3555**.

Decisions on closing down certain services and facilities have also 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.



WILL I HAVE TO PAY FOR SERVICES?

Local authorities 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. 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 their ability to pay is taken into account and not yours.

WHEN SHOULD I NOT BE CHARGED?

If you get Universal Credit, 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 that is more than you can reasonably be expected to pay, 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 39).

PERSONAL BUDGETS AND DIRECT PAYMENTS

Local authorities might offer families the option of a personal or individual budget. This is also sometimes referred to as self-directed support.

A personal budget is an allocated amount of money that the local authority considers sufficient to meet all of your child's eligible needs.

To decide how much will be allocated some authorities use a computerised system generally referred to as a resource allocation scheme (RAS).

Because of this method, the outcome of the RAS may lead to a shortfall in necessary services and support. Such systems have been challenged in the courts and criticised for their lack of transparency and failure to address specific individual need. If offered a personal or individual budget, you should ask the council to break down the budget to show it meets your child's assessed needs.

Families also have the right to decline the 'indicative amount' and the personal budget and 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.

Once the amount of the personal budget has been agreed, you can decide how to make best use of it. You can ask someone else (like a friend, local organisation or your local authority) to manage the budget on your child's behalf, or you might choose to organise your child's care yourself, taking your child's personal budget in the form of direct payments.



WHAT ARE DIRECT PAYMENTS?

Local authorities can give payments, instead of providing services themselves, to allow disabled people and carers to buy in and arrange 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 called 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.



For further information download our free guide:

Personal Budgets in England

www.contact.org.uk/personal-budgets-factsheet

or call our helpline for a copy on **0808 808 3555**.



MOVING INTO ADULT SERVICES

Disabled people over 18 years old have their needs met by adult care and support. This means that a disabled child receiving support from children's services will be transitioned to adult care and support when they turn 18.

In England the rights to services and support for disabled adults and their carers are covered under the Care Act. The Act was introduced in April 2015. Provisions under the Act should ensure that there is no gap in services when a young person makes this transition. There is no duty or power for a local authority to meet the child's needs under the Care Act before they reach the age of 18. Therefore, the general rights of parents and disabled children under 18 will remain the same. Parents still have the right to request an assessment of their child's needs, and the local authority is still under a duty to arrange support and practical assistance in meeting those recognised needs, subject to criteria.

If a child is likely to have needs when they turn 18, the local authority must carry out a 'child's needs assessment' before then, to determine what these will be. The local authority will carry out the assessment if it considers it a 'significant benefit' to the child to do so.

These assessments will give you an idea of the help that you and your child can expect when they move into adult care and support. After the assessment, the local authority should draw up a care and support plan; this may include a personal budget or direct payments to meet some of their needs. See page 28.

Section 59 of the Care Act also requires to local authority to provide advice and information about what can be done now in order to meet or reduce the need. They should also consider measures which can delay or prevent the development of more extensive needs.

WHEN CAN YOU ASK FOR AN ASSESSMENT?

There is no specific age or time before the child's 18th birthday at which the assessment must take place.

Instead, the statutory guidance suggests that these assessments take place when it is easier to understand what the needs of the child and carer will be beyond the age of 18.

For children with Education, Health and Care plans, it is likely that they will take place during the transition process, from Year 9 onwards.

The local authority must also carry out a 'child's carer's assessment' where there is 'likely need' for support when their child turns 18, and when it is of 'significant benefit.'



We have a template letter you can use to ask for a assessment in transition. Download it at www.contact.org.uk/transition-letter or contact our free helpline for a copy on **0808 808 3555**.

If the local authority refuses to carry out this assessment then you should ask them to provide their reasons in writing, and also ask when they think it would be appropriate to do so.

A child's carer's assessment will look at the carer's ability and willingness to continue caring for their child when they turn 18, the outcomes they hope to achieve (such as paid work or study) and the support they might need to do so.

The local authority should draw up a care and support plan for the carer; this may include a personal budget or direct payments to meet some of their needs (see page 28). Care and Support Statutory Guidance provides stronger legal rights to parent carers during the transition period.

THE NEEDS OF YOUNG CARERS TURNING 18

Young carers who provide support to their disabled sibling, and who are under the age of 18 can access support under the Children and Families Act 2014.

Young carers who are approaching the age of 18 are eligible for help in their own right under the Care Act. This is regardless of the age of their sibling.

When a young carer approaches their 18th birthday, they can ask for an assessment of their needs to find out what support can be put in place to help them achieve their aspirations, for example to go to college or work.

WHEN A CHILD TURNS 18

The Care Act is intended to prevent a gap in services when a child turns 18. For this reason, the Act makes clear that any children's services a child is receiving before their 18th birthday will continue after their 18th birthday, until adult care and support takes over.

The same is true of a carer receiving support from children's services when their child is under 18. The local authority must not allow a gap in care and support when young people and carers move from children's to adult services.

If a carer is not currently receiving services when they receive a child's carer's assessment, the local authority can choose – but is not legally required – to meet a carer's needs before the child reaches the age of 18.

THE RIGHTS OF DISABLED ADULTS AND THEIR CARERS

If a disabled adult has been assessed as having needs for care and support from the local authority, they will receive a care and support plan, and advice about decisions on how to meet their needs. They might have some of their needs met via direct payments (see page 28).

Under the Care Act, charging reforms were scheduled for introduction in April 2016. These have now been postponed to April 2020. In the meantime, the local authority may charge for services depending on the disabled adult's finances. People will only be asked to pay what they can afford, and this will be decided by a financial assessment carried out by the local authority.

The Care Act provides much greater rights for carers of adults aged 18 and over. For the first time, the needs of a disabled adult's carer will be treated in the same way as the needs of the disabled adult themselves. Carers can ask for an assessment if they 'appear' to have needs for support. This is a low threshold and will entitle most carers to an assessment.

The assessment will take into account the carer's wellbeing, any outcomes they'd like to achieve, whether they are willing and able to care for the disabled adult, and whether they would like to access work, education or training.

IF YOUR CHILD CAN'T MANAGE THEIR AFFAIRS

Some people have a disability or type of illness that affects their ability to understand and make decisions for themselves. They may need help with managing their affairs and making personal welfare decisions. This may affect decisions that need to be made about their education, health, social care, money or where they live.


Most day-to-day decisions about daily living won't be controversial, as parents and carers are expected to act in their child's best interest. But some professionals may disagree and question the actions of the parent or carer. If you are concerned about this, seek further advice about your options in ensuring your views are being listened to.

In difficult cases, under the Mental Capacity Act, steps can be taken to ensure that a parent or carer has the authority to make key welfare decisions on behalf of the disabled person age 16 or over.

This involves applying to the Court of Protection to become a deputy, which incurs costs and legal fees. However, the Mental Capacity Act 2005 Code of Practice states that 'deputies' for personal welfare decisions will only be required in the most difficult cases where:


- ***important and necessary actions cannot be carried out without the court's authority, or***
- ***there is no other way of settling the matter in the best interests of the person who lacks capacity to make particular welfare decisions.***

If a personal welfare decision is not controversial and no-one opposes it, it may be possible to make the decision on behalf of the person who lacks the mental capacity to make it her/himself without referring to the Court of Protection.

 For further advice you can contact the Office of the Public Guardian. The Office supports and promotes decision making for those who lack capacity: **0300 456 0300**. You can also find out more in the *Special educational needs and disability code of practice* on page 20: 'Participating in decision making', and in Annex 1: 'Mental Capacity'. Search for it at: **www.gov.uk**

BEST INTEREST DECISIONS

Under the Mental Capacity Act a health professional must ensure that any decisions affecting the welfare of a person lacking mental capacity is made in their best interests. This can include decisions affecting where the individual lives, what care services and support is provided and health treatment. As part of this process there is an expectation that their primary carers would be consulted. Also, where the patient is a child (including a 16 or 17 year old who lacks capacity) a parent's consent to treatment must be obtained.

 Visit **www.contact.org.uk/moving-into-adult-services** for more information, where you can download our factsheet *Preparing for Adulthood*, or call **0808 808 3555** for a copy to be sent to you.



COMPLAINTS ABOUT 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.***

Similar rights exist in respect of complaints about adult social care services.

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 ARE COMPLAINTS DEALT WITH?

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

ACTION	TIME FRAME
You request a Review Panel	Up to 20 working days after receipt of the Stage 2 decision
Complaints manager acknowledges request	Within two working days
Complaints manager appoints a Chair and confirms attendees and content of the panel papers	Within 10 working days of your request for Review Panel
Local authority agrees the other panellists and date for Review Panel	Within 30 working days of your request for Review Panel
Local authority circulates panel papers	Within 10 working days of the date for the Review Panel
Review Panel produces its written report (including any recommendations)	Within five working days of the Review Panel meeting
Relevant director issues their response	Within 15 working days of receiving the Review Panel's report

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 on page 40.

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 page 43.



You can find further information about complaints in government guidance *Children's social care: getting the best from complaints* by searching for the title at www.gov.uk

TIPS ON MAKING A COMPLAINT

- **CONTACT THE ORGANISATION:** and ask them for information about their complaints procedure.
- **NOTE NAMES AND POSITIONS:** of everyone involved in your complaint.
- **DEPENDING ON THEIR PROCEDURE:** you can complain by speaking to someone or complain in writing.
- **DO IT WHILE THINGS ARE FRESH IN YOUR MIND:** and ask when you can expect to hear back.
- **GET HELP:** from a local organisation like a Citizen's Advice Bureau, a carers' centre or an advocacy service. Contact our helpline on 0808 808 3555 for details of other groups who may be able to help.
- **KEEP CALM AND FOCUSED:** this may result in your complaint being sorted out sooner.
- **MAKE IT CLEAR:** with information about what happened and who was involved
- **SAY WHAT YOU WOULD LIKE TO PUT THINGS RIGHT:** such as an apology or changing the way things are done to prevent the same mistake happening again.
- **INCLUDE YOUR CONTACT DETAILS:** and information on how you would like to be contacted.
- **INCLUDE A REFERENCE NUMBER:** if you have been given one.
- **KEEP COPIES OF EVERYTHING:** for future reference.

LOCAL GOVERNMENT AND SOCIAL CARE OMBUDSMAN

If you're not happy with the panel's decision then there are various other options, like taking the issue up with your MP, or complaining to the Local Government and Social Care Ombudsman.

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 that describes the actions of a government body that 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 caused you an injustice. They won't investigate a complaint against the local authority simply because you disagree with it.



To contact the Local Government and Social Care Ombudsman visit www.lgo.org.uk/contact-us or call **0300 061 0614**.

COMPLAINTS AGAINST YOUR LOCAL AUTHORITY

Each year the Local Government Ombudsman sends an annual review to all local authorities (LAs) about complaints made about them to the ombudsman. This is a useful way of assessing the LA's performance in dealing with complaints. The review includes statistics but also lists a few cases that have been investigated and reported.



To see your LA's review letter visit

www.lgo.org.uk/information-centre/councils-performance

TAKING LEGAL ACTION

You can also seek legal advice about taking action in order to put things right. However, there you may have to pay a charge for legal advice about challenging decisions about services. If you are on a low income, you may qualify for legal aid and some solicitors may offer a free first interview.

If your complaint is very urgent and you can't wait for the complaints procedure to resolve the matter, seek legal advice. Judicial Review is a type of legal proceeding where a judge reviews the lawfulness of a decision or action by a public body such as a local authority. However, an application for Judicial Review cannot be brought simply because you don't agree with the decision that has been made. Judicial reviews are a challenge to the way in which a decision has been made, rather than the rights and wrongs of the conclusion reached.



Further information about help with legal costs can be found at

www.gov.uk/legal-aid For advice about seeking legal help visit

www.contact.org.uk/legal-advice or call our freephone helpline

0808 808 3555.

OTHER WAYS TO COMPLAIN

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, 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.

OFSTED

Ofsted is the Office for Standards in Education, Children's Services and Skills. It inspects and regulates services that care for children and young people, including children's homes. It also inspects services that provide education and skills for learners of all ages. Ofsted has some powers to investigate concerns about services it inspects or regulates.

www.ofsted.gov.uk/contact-us/how-complain

0300 123 4666

The Care Quality Commission

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.

www.cqc.org.uk/content/share-your-experience

Healthwatch England

Healthwatch England is the consumer body for users of health and care services. It has 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.

www.healthwatch.co.uk/complaint

First Tier Tribunal for Special Educational Needs and Disability

The SEND tribunal has extended powers in relation to social care as part of a two year national trial which started in April 2018. When parents or young people appeal about a refusal to issue an Educational Health and Care (EHC) plan, or about the educational parts of the EHC plan, the tribunal can make non-binding recommendations about the social care parts of the EHC plan at the same time. For example, the tribunal can recommend that a social care assessment is carried out if this has not been done. More information about the National Trial can be found at the website below. Search for 'SEND tribunal' at:

www.gov.uk



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 to 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.

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 that he enjoys. If you're told otherwise, ask for this in writing and then challenge their decision. See page 39 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.contact.org.uk

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 6 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 39.




More advice written by community care lawyers on challenging a 'refusal to assess' decision can be found at www.contact.org.uk/refusal-letter

Can social services help with my housing situation? I live in a 2 bedroom flat on the 3rd floor with 3 children. My son has challenging behaviour and is unable share a bedroom with his younger sibling and there is nowhere safe to play.

You can contact social services to request a ‘child in need’ assessment. As well as your son’s needs the assessment should also consider your housing situation. Statutory guidance (*Working Together to Safeguard Children*) requires the local authority to consider factors such as health and safety and the environment, which includes housing needs. Other important factors include your child’s emotional and developmental needs, along with wider family and social relationships. See page 13 for further information about the assessments process.

The assessment may lead to recognition of your family’s housing needs and their impact on your child and family. In addition you may have further rights under housing law and your local authorities housing allocation policy.

 You may need to seek specialist independent advice from a local advice agency such as Citizen’s Advice or a local law centre. To find local housing advice see <http://england.shelter.org.uk> Or call our free helpline for further information **0808 808 3555**.

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.

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, many parents 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.



Call our freephone helpline for further information on **0808 808 3555**
or email **helpline@contact.org.uk**

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. In addition, 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 or visit our website to see how you can make a complaint www.contact.org.uk/services-complaints


GET IN CONTACT


Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.


 0808 808 3555

 info@contact.org.uk

 www.contact.org.uk

 twitter.com/contactfamilies

 facebook.com/contactfamilies

 youtube.com/contactfamilies

Contact Head Office
209–211 City Road
London EC1V 1JN



We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

Contact is a trading name of Contact a Family. Charity registered in England and Wales (284912) and Scotland (SC039169). Company limited by guarantee registered in England and Wales (1633333). VAT registration GB 749 3846 82.

© Contact, January 2019

Order code i19

