

# contact

*For families  
with disabled children*

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Bookmark – to publicise our helpful guide and other services – free to give to parents.

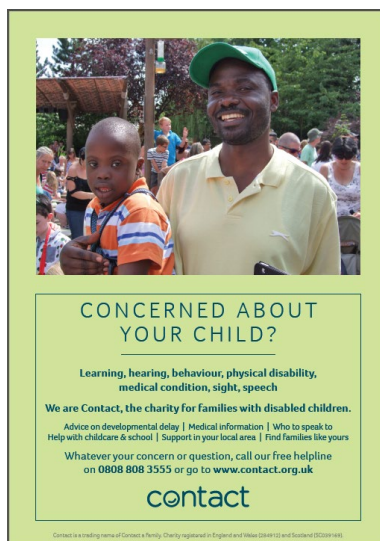


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Learning, hearing, behaviour, physical disability, medical condition, sight, speech

**We are Contact, the charity for families with disabled children.**  
Advice on developmental delay | Medical information | Who to speak to  
Help with childcare & school | Support in your local area | Find families like yours

Whatever your concern or question, call our free helpline on 0808 808 3555 or go to [www.contact.org.uk](http://www.contact.org.uk)

**contact**

Contact is a trading name of Contact a Family. Charity registered in England and Wales (2084912) and Scotland (SC039148)

# Money and finance

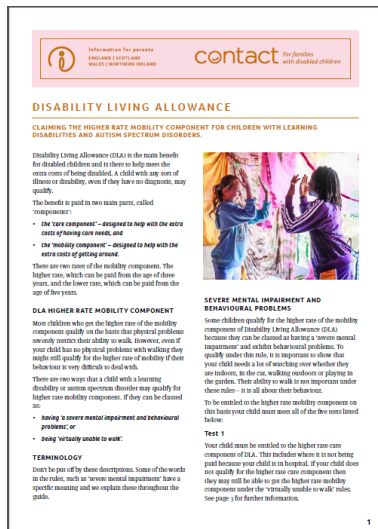
[Money Matters checklist– England/Wales](#)

[Money matters checklist –Scotland](#)

Benefits and other financial support [online]

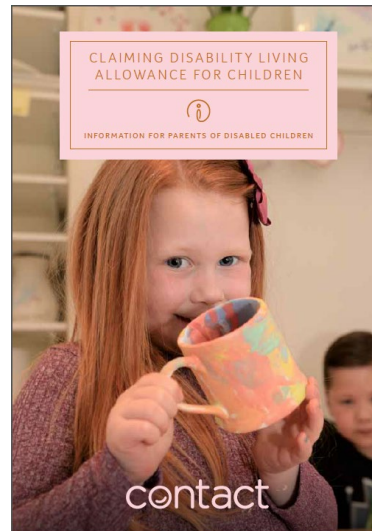


[Disability Living Allowance for children with learning disabilities - high rate mobility component](#) [online]



[Claiming Disability Living Allowance for children](#)

How to fill in the form [online]

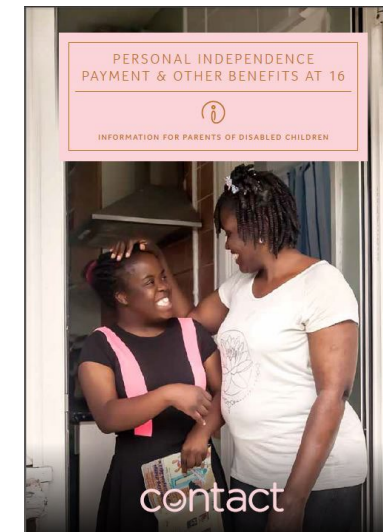


[Claiming Child Disability Payment – Scotland](#) [online]

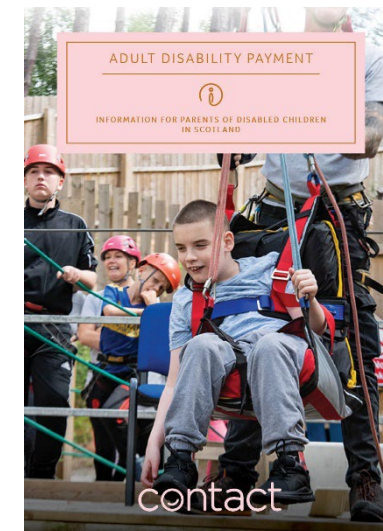


[Personal Independence Payment and other benefits at](#)

[16](#) [online]



[Adult Disability Payment – Scotland](#) [online]





## Disability Living Allowance when your child is in hospital [online]

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### DISABILITY LIVING ALLOWANCE WHEN YOUR CHILD IS IN HOSPITAL


The government has scrapped the rules which previously stopped payment of Disability Living Allowance (DLA) or Personal Independence Payment (PIP) when a child was in hospital.

**WHAT ARE THE DLA HOSPITAL RULES FOR CARERS?**

In the past, once a child had been a hospital inpatient for 84 days (or 28 days of aged 16 or above) their DLA payments were suspended.

In addition, where a child first made a claim for DLA when they were in hospital, they used to have to wait until they were discharged home before those payments could start. Similar rules applied to PIP.

These rules have been scrapped for children under 18 years of age.



**WHY HAVE THE RULES BEEN SCRAPPED?**

In July 2018 the Supreme Court found that the DLA hospital rules breached the human rights of a severely disabled child called Cameron Mathison.

Following the Mathison decision, the government introduced an interim policy of not suspending DLA or PIP payments when a child was in hospital.

This interim policy has now become law, as a result of changes to regulations introduced on the 24 June 2019 in England, Wales and Scotland, and from the 6 July 2019 in Northern Ireland.

**WHAT ARE THE NEW RULES?**

So long as you see your daughter or son aged under 18 when they become an inpatient, payments of DLA or PIP continue as normal while they are in hospital. It does not matter how long they stay in hospital for.

You do not have to prove how much care you continue to provide to your child while in hospital, nor what extra costs you will incur – all children aged under 18 are exempt from the rules restricting DLA/PIP payments in hospital.

If your child first claims DLA or PIP when they are in hospital, payments can start regardless of the age that they are at on the date that their time as a hospital inpatient starts, their DLA or PIP payments will be suspended once they have spent 84 days in hospital.

**YOUNG PEOPLE AGED 16 OR ABOVE**

The hospital rules remain for young people and adults aged 16 or over. This means that if your child is aged at or over on the date that their time as a hospital inpatient starts, their DLA or PIP payments will be suspended once they have spent 84 days in hospital.

If someone is aged 16 or above and first claims PIP when they are a hospital inpatient and they do not already have a claim for DLA, they will need to wait until they are discharged home before their PIP payments can start.

Young people who are 16 or above in hospital are not affected by the DLA/PIP hospital rules. This is because you can expect to live as you would when you are in hospital if you are aged 16 or over.

## Factsheet – Universal Credit – the essentials [online]

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### UNIVERSAL CREDIT – THE ESSENTIALS

Universal Credit is a new benefit for people aged between 16 and 64. It can be paid to people who are out of work and to those who are in employment. It is replacing most of the existing means-tested benefits for people of working age with a single monthly payment. It is administered by the Department for Work and Pensions (DWP) and most people are expected to claim online.

**UNIVERSAL CREDIT – THE ESSENTIALS**

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**WHICH BENEFITS ARE BEING REPLACED BY UNIVERSAL CREDIT?**

Universal Credit is gradually replacing:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Child Tax Credit
- Working Tax Credit
- Housing Benefit (except for those in some types of supported accommodation)

There are known as the 'legacy benefits'. Other benefits such as Carer's Allowance, Child Benefit, Disability Living Allowance (DLA), Personal Independence Payment (PIP), and Council Tax Reduction will remain and can be paid alongside Universal Credit.

**WHO CAN CLAIM UNIVERSAL CREDIT?**

You cannot claim Universal Credit if you have three or more dependent children. Apart from this, most people of working age can claim. You can claim regardless of whether you are out of work or in employment. You can claim if you are a job seeker, a carer, or someone who is unable to work. You must meet certain rules based on your residence and presence in the UK.

**WHEN WILL I BE EXPECTED TO CLAIM UNIVERSAL CREDIT?**

When Universal Credit was first introduced, you couldn't claim if you were looking after a disabled child, or if you were a disabled adult. However, clear a slowly changing and career and disabled adults can be asked to claim Universal Credit if they live in a care home or the Universal Credit 'full service' has been introduced, to full service you will be expected to claim Universal Credit.

**WHAT AGE MUST I BE TO MAKE A CLAIM?**

Usually claimants have to be aged at least 16 but special rules allow some 16 or 17 year olds to claim, including young disabled and young carers. Most people in full-time education cannot claim Universal Credit unless they have a dependent child. However, disabled students can claim if they get DLA or PIP and are also assessed as unable to work.

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## Factsheet: Carer's Allowance [online]

Explains the rules of the main benefit for carers

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### CARER'S ALLOWANCE

Carer's Allowance is the main benefit for carers. You might be able to claim if your child receives Disability Living Allowance (DLA) care component at the middle or highest rate or the daily living component of Personal Independence Payment (PIP). For more information about DLA and PIP see our factsheet [Disability Living Allowance for children and Personal Independence Payment \(PIP\)](#).

**HOW ARE MY EARNINGS ASSESSED FOR CARER'S ALLOWANCE?**

Only your own earnings are counted. If you have a partner who works their earnings are ignored. In calculating your earnings, the Department for Work and Pensions (DWP) can make certain deductions from your gross wages. This includes not only any tax and national insurance you pay but also deductions for:

- any other pension over that you have. This includes any children's care costs that you have while you are working whether the child is disabled or not or any other children under 16. If the person you care for is aged 16 or over and you have to pay someone to look after them while you work then those care costs can also be deducted.
- There is a cap on the maximum amount that can be deducted in this way – this is half of your net earnings. There is no requirement that you pay a registered childcare provider. These costs can still be deducted so long as you pay someone other than a close relative.
- 50 per cent of any pension contribution that you make under a work or personal pension scheme, and
- an amount for any expenses you have that are 'wholly, exclusively and necessarily incurred' in carrying out your work for which you are not reimbursed.

If your employer, for example if you have to buy equipment or specialist clothes or have to pay for travel between work places (if over between work and home that not count).

If your earnings vary they should be averaged out, although the period over which they are averaged is at the discretion of the DWP. If you are self-employed your average earnings will normally be based on your most recent tax accounts, unless there has been a change in the pattern of your business.

**HOW DO I QUALIFY FOR CARER'S ALLOWANCE?**

You can claim if you are aged 16 years or over and:

- you look after someone who gets DLA care component at the middle or highest rate or the daily living component of PIP or benefit for other people with disabilities called Attendance Allowance
- you look after that person for at least 3.5 hours a week
- you are not earning more than £123 a week. See below for more details about how your earnings are calculated.
- you are not in full-time education. Generally you're treated as in full-time education if your course is described as full-time by the educational establishment, although there are exceptions (for example you've been granted an exemption from parts of your course or the course is not a traditional university-type course requiring private study). Even if your course isn't described as full-time, you'll still be treated as being in full-time education if it involves 21 hours or more supervised study per week
- you meet certain rules linked to your immigration status and the length of your presence in the UK.


You can only get one award of Carer's Allowance, even if you are looking after more than one disabled person. If you claim the care of your child with another person and you each provide at least 3.5 hours a week care, only one of you can get Carer's Allowance for that child.

## Help with Council Tax bills [online]

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### Help with council tax bills

For families with disabled children



**Introduction**

This guide is about the different schemes that exist for reducing your council tax bill. It is written for families who have a disabled child and the examples given apply mainly to those families, although other individuals may also qualify for help.

The three main schemes for reducing your council tax bill are outlined. It is possible to qualify for help from more than one of these schemes at the same time and it makes no difference whether you are a tenant or a homeowner.

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Help with council tax bills

## Factsheet – Universal Credit – claiming for a young person [online]

**contact** For families with disabled children

### UNIVERSAL CREDIT – CLAIMING FOR A YOUNG DISABLED PERSON

Universal Credit is a new benefit for people aged between 16 and 64 and certain qualifying age. It is replacing most of the existing means-tested benefits for people of working age with a single monthly payment. This factsheet explains when you might be able to claim Universal Credit as a young adult and the impact this might have on any benefits that you get for them as a dependent child.

Over your child's name of they will normally be expected to claim Personal Independence Payment instead of Disability Living Allowance. However, claim that will also have the option of claiming Universal Credit in their own right as a young disabled adult.

Universal Credit is a means-tested benefit for people of working age. You normally have to be aged at least 16 to claim Universal Credit, but special rules allow 16 and 17 year olds to claim it either:

- they are submitting medical certificates from their GP or
- have established that they have a limited capability for work.

If your son or daughter chooses to claim Universal Credit this can affect the benefits that you receive. They will stop being treated as a dependent child of yours and this means that Child Benefit, Child Tax Credit or other payments that you receive for them as part of your family will stop.


Your child's age of 16 and being in full-time education or starting to work as part of your family or help them claim Universal Credit in their own right. If you will need to weigh up both options in likely to know your family better off.

**WHICH BENEFITS ARE BEING REPLACED BY UNIVERSAL CREDIT?**

Universal Credit has replaced new claims for the following benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Child Tax Credit
- Working Tax Credit
- Housing Benefit

These are known as the legacy benefits.



## Factsheet – Benefits if your child is in residential accommodation [online]

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### BENEFITS IF YOUR CHILD IS IN RESIDENTIAL ACCOMMODATION

This factsheet looks at what happens to benefit payments where a disabled child is in residential accommodation. If your child has overnight stays away from home in a residential care or a residential educational setting, some of the benefits you receive are likely to be affected.

This factsheet will explain what happens to your benefits if your disabled child is away from home in any of the following settings:

- residential school or college
- residential care home
- respite or short break placement in a residential setting

**HOW WILL IT AFFECT MY BENEFITS?**

There are different rules for each benefit. Some may stop altogether, some may be reduced, while others may continue to be paid as usual. It is important that you tell the relevant benefits and Tax Credit offices when your child goes into residential care even if they only go in for a few nights each month.

**WHO SHOULD I TELL?**

You need to tell each office separately as they do not always pass on information. No one will do this on your behalf, so you will need to do this on your own arrangements.

**Disability Living Allowance (DLA) or Personal Independence Payment (PIP)**

If you get either of these benefits for your child, contact:

DLA helpline: 0800 121 4400  
PIP helpline: 0800 121 4433

**Carer's Allowance**

If you get Carer's Allowance, contact:

Carer's Allowance helpline: 0800 371 3097

**Child Tax Credit**

If you get Child Tax Credit contact:

Tax Credits Office: 0800 371 3097

**Child Benefit**

If you get Child Benefit contact:

Child Benefits Office: 0300 100 3100


**Income Support, Universal Credit or another benefit**

Tell the relevant benefit office.

**Housing Benefit or Council Tax reduction**

Tell your local council.

The rules for each benefit are explained overleaf.



# Education and childcare

## Home to school transport – England [online]

Information for parents  
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### HOME TO SCHOOL TRANSPORT – ENGLAND

Most children make their own way to school either accompanied by their parents, or independently if they are older. For some disabled children this may not be possible, either because their school is too far away, or because they are not able to walk or use public transport in the same way as other children. Local authorities must make free travel arrangements for these children.

**THIS FACTSHEET WILL TELL YOU**

- which children are eligible for free school transport
- what sort of transport can be provided
- how to apply for school transport
- how to challenge a school transport decision
- where to find out more.

This factsheet covers children of compulsory school age (5 to 16) in England only. References to children with Education, Health and Care plans (EHCP plans) also cover those who still have Statements under the old system.

**LOCAL AUTHORITY DUTIES IN BRIEF**

Local authorities must make travel arrangements they consider necessary to enable eligible children to attend school. These arrangements must be provided free of charge under section 508B of the Education Act 1996.

Local authorities also have the discretion under section 508C of the Education Act 1996 to provide transport for a wider group of children. This could be free or charged for.

**WHO IS ELIGIBLE?**

Some criteria apply to all children, and pupils with special educational needs or disabilities (SEND) may be eligible under these. Others apply only to children with a disability, special need, or mobility difficulty.

## Extra help in education for 19-25 year olds [online]

Information for parents  
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### EXTRA HELP IN EDUCATION FOR 19-25-YEAR-OLDS

This factsheet is for parents/carers of young people with special educational needs aged between 19-25 in England. It describes the education options available for your son or daughter, and their right to extra help.

**WHAT ARE SPECIAL EDUCATIONAL NEEDS?**

The law says:  
"A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her"  
*Children and Families Act 2014 section 20.1*

A child with special educational needs (SEN) may need more help, or a different kind of help, from that usually given to children of the same age.

A request can be made at any time before a young person's 25th birthday. See our factbooks *Education, Health and Care needs assessments* and *Education, Health and Care plans* for further information about the process.

**IMPORTANT CHANGES UNDER THE CHILDREN AND FAMILIES ACT**

- Further education colleges have the same duties as schools to use their best endeavours to provide extra support to learners with a special educational need or disability (SEND)
- young people with special educational needs can have an EHCP after they reach 25 if they need educational support that a main-stream education setting could normally provide
- young people can express a preference for a main-stream or specialist college to be named on an EHCP plan (including a wide range of independent providers)
- young people have a right to be consulted and to make their own decisions about the EHCP process if they have the mental capacity to do this.

**EDUCATION BEYOND 19 – WHAT DOES IT LOOK LIKE?**

Many young people with SEN will move on from their school or college at around age 16. Some may continue to a specialist or mainstream education setting, while others may continue their education outside a formal institution.

Education has a broad meaning for young people with SEN in this age group. It does not have to include studying for formal qualifications. Work experience or training to develop skills independently can be part of an educational programme. A recent court case

In 2014, the Children and Families Act came into force. The law extended the special educational needs system to young people up to the age of 25. It also brought in Education, Health and Care plans (EHCP plans) to replace statements.

**WHAT IS AN EHCP PLAN?**

An EHCP plan is a legal document which enables a child or young person to extra help so they can access education. Some young people will need an EHCP plan to finish their education or training. This is likely to be the case if they need more help with their education than a mainstream college can normally provide, and if they were previously supported through a Statement of Special Educational Needs in school or a Learning Difficulty Assessment in college.

Your son or daughter may not have had this support, or they may be wanting to education after a long break. If they may need an EHCP Plan to finish their education or training, you or your son or daughter can ask the local authority to carry out an EHCP needs assessment.

## Challenging school transport decisions – England [online]

Information for parents  
ENGLAND
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### CHALLENGING SCHOOL TRANSPORT POLICIES – ENGLAND

The provision of home to school transport is governed by law, statutory guidance and local authorities' own policies. Local policies must offer at least the minimum legal entitlement. However, research in part of Contact's school transport campaign has shown that a number of policies do not comply with the law. We are also aware of parent groups who have successfully challenged potentially unlawful policies when they have been put out for consultation.

**WHAT THIS FACTSHEET WILL TELL YOU**

This factsheet will be useful to parent groups and individual parents who want to challenge a local school transport policy. It will help you understand:

- local authorities' duties with regard to transport policies
- the need for a fair consultation
- common issues on which a policy could be challenged

For more details on transport eligibility see our factsheet on *Home to school transport*.

**CHILDREN OF STATUTORY SCHOOL AGE (5-16)**

The local authority must publish its school transport policy under the Education (School Arrangements) (England) Regulations. This must form part of the consultation prospectus published annually for school admission in the following year. The complete prospectus must be published by 15 September in the year before admission.

Statutory guidance from the Department for Education – *Home to school travel and transport guidance* – states that the information should:

- be clear and easy to understand
- give full information on travel and transport arrangements

- explain both statutory transport provision and that provided on a discretionary basis
- set out the appeal process.

The law does not say how or when the local authority should consult on transport policies for the age group. However, *Home to school travel and transport guidance* recommends that local authorities consult widely on any changes to their school transport policy with all interested parties for at least 28 days during term time.

**YOUNG PEOPLE OF SIXTH FORM AGE (16-18)**

Under section 508B of the Education Act 1996, the local authority must publish a transport policy statement for 16-18-year-olds. This must be published by 31 May to take effect the next academic year (from September). Local authorities must have regard to statutory guidance (*Home to school travel and transport guidance*) when they draw up their local policy for this age group. There are legal requirements detailing who must be involved in the consultation including young people and their carers.

**YOUNG ADULTS (18-24 YEAR-OLDS WITH AN EHCP PLAN)**


Under section 508C of the Education Act 1996, the local authority must publish a transport policy statement for 'relevant young adults' who are entitled to transport under the school transport duty. Relevant young adults are defined as those under 25 with an EHCP plan (the guidance however still uses the old terminology) 'subject to learning difficulty assessment'. The policy must be published by 31 May to take effect the next academic year. There are legal requirements for who must be involved in the consultation, including relevant young adults and their carers.

## A guide to dealing with bullying [online]

Information for parents  
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### DEALING WITH BULLYING

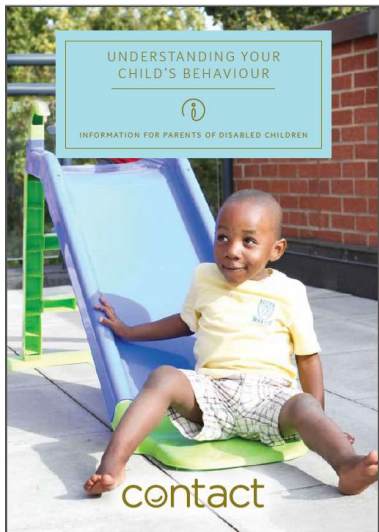
INFORMATION FOR PARENTS OF DISABLED CHILDREN



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## Behaviour

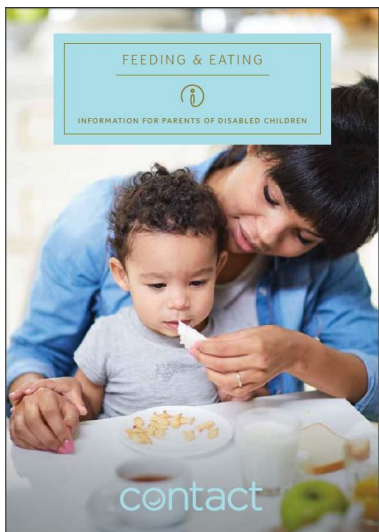
[Understanding your child's behaviour](#) [in print and online]



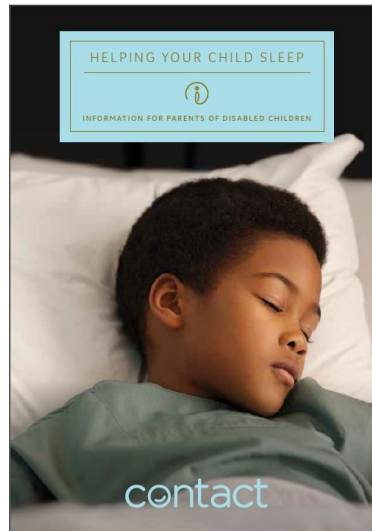
[Potty/Toilet training](#) [in print and online]



[Feeding and eating](#) [in print and online]



[Helping your child's sleep](#) [online]



# Social care services

## [Services and support from your local authority](#) – England [in print and online]

**SERVICES & SUPPORT FROM YOUR LOCAL AUTHORITY**

INFORMATION FOR PARENTS OF DISABLED CHILDREN

**contact** for families with disabled children

## [Carers' assessments – help for parent carers](#) - England how parents can access their own support [online]

**CARERS ASSESSMENTS – HELP FOR PARENT CARERS**

All parent carers have a right to ask for an assessment of their needs at any time. 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.

**WHAT THE LAW SAYS**

- It appears to be the intention that the parent carer may have needs for support or help
- include a request from the parent carer to assess the parent carer's needs for support

These assessments are called parent carers' needs assessments. The Act also says that:

- A parent carer's needs assessment must include an assessment of whether it is appropriate for the parent carer to provide, or continue to provide, care for the disabled child, in the light of the parent carer's needs for support, other needs and wishes.
- The aim of the assessment is to assess the parent carer's needs for support, other needs and wishes.
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## [Short breaks – help for you and your child to take a break](#) – England [online]

**SHORT BREAKS – HELP FOR YOU & YOUR CHILD TO TAKE A BREAK**

Many families with disabled children and/or health conditions benefit from regular breaks from their caring responsibilities. Taking a break from caring for your child is not an admission of failure or a way of saying you don't care. It is a chance to recharge batteries, spend time with others or pursue a particular interest. A break may also allow your child a change of scene, try different experiences, have fun and make friends. This may contribute to your child's personal and social development and reduce social isolation. It can also be helpful to get your child used to spending time in different settings and with other people as they grow up. In the event you need to leave them with someone in the future.

**WHAT ARE SHORT BREAKS?**

Local authorities have legal duties to provide breaks for carers and disabled children, called 'short breaks' and make it clear how families with disabled children can access them. Short breaks come in a variety of forms. Each one can last from just a few hours to a few days, and occasionally longer, depending on the type of provision and the needs of your child and family. Short breaks can include:

- Day care at home**: This includes sitting or care schemes, which provide someone to sit with or 'babysit' your child while you do another activity. They can also be useful in preparing children and parents for eventual placements in a care home.
- Family link schemes**: Where your child may with another family on a regular basis or occasionally.
- Support for disabled children/young people**: To access activities in universal settings, for example with the support of a befriending, reading or specialist service, volunteer or mentor.
- Day care away from home**: This includes nurseries, playgroups, after school and weekend clubs, young clubs, summer holiday play schemes, sports activities, for example inclusive cycling or martial arts, music, art and drama activities.
- Overnight short breaks**: Taken in your own home, or an overnight sitting or nursing service if your child needs it in the night in a hospital or home service for children with complex disabilities and palliative care needs.
- Residential breaks**: Where your child stays in a residential home, special unit in hospital or hospice – especially they offer both indoor and outdoor activities as well as being used to provide nursing care and support to needed.

## [Personal budgets in England](#) overview of personal budgets [online]

**PERSONAL BUDGETS**

A personal budget sets out the amount of money that is available to spend on support for your child, to meet their assessed needs. This money may come from your local social care services, local education authorities, or in some cases from your NHS clinical commissioning group (CCG), if you receive funding from the NHS this is known as a personal health budget.

Having a personal budget should mean that it is much easier for you to manage and control over how your child's needs are met. You should:

- know how much money is available to pay the support your child needs to meet their assessed needs
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**WHAT ARE THE ADVANTAGES OF HAVING A PERSONAL BUDGET?**

- know how much money is available to pay the support your child needs to meet their assessed needs
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## [Introduction to the Care Act 2014](#) – England [online]

**INTRODUCTION TO THE CARE ACT 2014 – ENGLAND**

The Care Act was passed in March 2014. The Act is accompanied by new regulations and statutory guidance, which replaced the system for providing support and services for disabled adults aged 18 or over and their carers. The Act also includes new rights for families with a child who may need support to prepare for the transition to adult services, and also young carers who are approaching adulthood, state cases for you. This may result in getting services or direct payments to meet your own assessed needs.

The aim of the Care Act 2014 is to get a full picture of the person and what needs and goals they may have. The local authority will then consider whether any of the needs identified are eligible for support.

The Act also includes new rights for families with a child who may need support to prepare for the transition to adult services, and also young carers who are approaching adulthood, state cases for you. This may result in getting services or direct payments to meet your own assessed needs.

**DUTIES ON LOCAL AUTHORITIES**

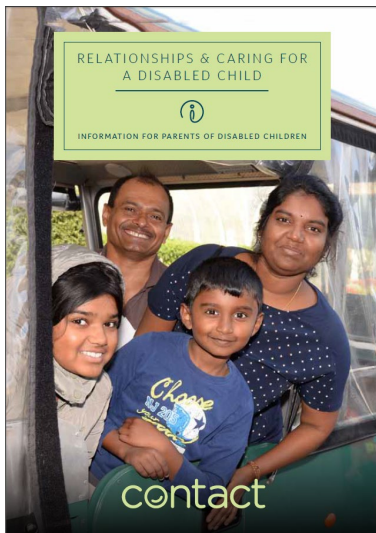
Local authorities have legal duties when they make any decisions in a care assessment. These duties also apply when they plan for a young person's transition to adult services, and for a disabled adult's care and support needs. Under the Act the local authority must promote the wellbeing of disabled adults and their carers.

- domestic, family and personal relationships
- ability of being accommodated
- contribution to society
- provide or arrange services that will contribute towards preventing, delaying or reducing a person's need for care and support
- take and coordinate services with the local Clinical Commissioning Group (CCG) and NHS
- establish and maintain an information and advice service relevant to care and support for adults and carers
- participation in work, education, training or recreation
- social and economic wellbeing

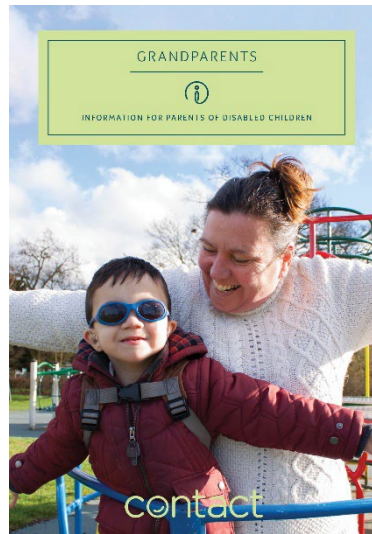


# Family Life

[Relationships and caring for a disabled child](#) [online]



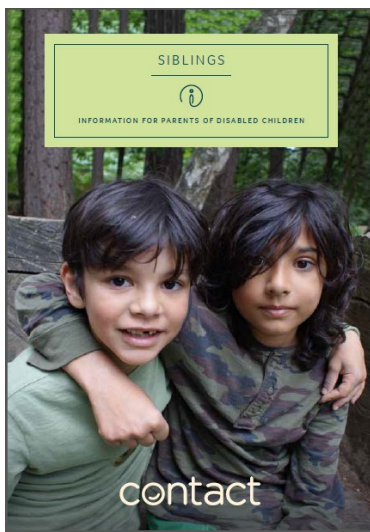
[Grandparents](#) – [online]



[Growing up, sex and relationships - for parents of young disabled people](#) [online]



[Siblings: information and resources](#) [online]



[Growing up, sex and relationships - for young disabled people](#) [online]





# Health

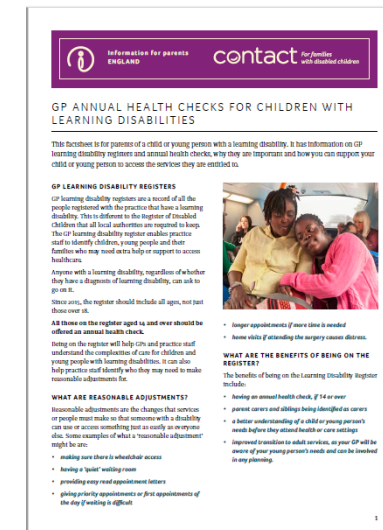
[Concerned about your child](#) Professionals who can help [in print and online]



[Living with a rare condition](#) – for parents of children who have a rare condition [in print and online]



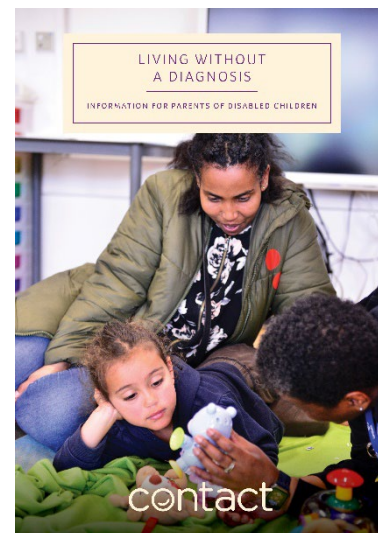
[GP annual health checks for children with learning difficulties](#) – how to access health support [online]



[Developmental Delay](#) - help for concerned parents, with developmental milestones [in print and online]



[Living without a diagnosis](#) – if your child doesn't have a diagnosis or if you are waiting for one [in print and online]



[Guide to eye care](#) for children with learning disability, autism or both



[Guide to hearing care](#) for children with learning disability, autism or both



## Reports and research

We publish a number of research, reports and campaign briefings, see [www.contact.org.uk/research](http://www.contact.org.uk/research)

## Parent Carer Participation

To find information and resources for parent carer forums, see <http://www.contact.org.uk/pcp/resources>

## For parent support groups

To find resources for local and national support groups, see <http://www.contact.org.uk/lgn>

[Guide to dental care](#) for children with learning disability, autism or both



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