Introduction

This booklet is a general guide to tax credits for families with disabled children. It includes information on who qualifies and how the tax credits system works in practice. We’ve also included ‘ready reckoner’ tables to give you an idea of how much you should get.

Tax credits are nothing to do with income tax. They are regular payments made by the government to families on low to moderate incomes. You can claim tax credits even if you don’t pay tax. If you would like a full breakdown of your likely entitlement or any other information on tax credits, please call our free helpline. We employ welfare rights specialists who can provide detailed advice on any aspect of a tax credit claim.

Figures used in this guide

The figures used in this guide are based on benefit rates announced by the government for the year April 2009-2010. However, there is a possibility that the government may make additional increases to benefit and tax credit rates during 2009. Contact our helpline for up to date information about whether any of the figures used in this publication have changed.

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What are tax credits?

There are two tax credits offering financial support to families. Working Tax Credit can be claimed by anyone who works for at least 16 hours a week and is responsible for a child. Certain other workers who don’t have children can also apply. Child Tax Credit can be claimed by families with children, whether they work or not.

Tax credits are administered by Her Majesty’s Revenue and Customs (the Revenue) and depending on your circumstances you could qualify for either or both. An estimated nine out of ten families are eligible for tax credits.

If you are self-employed, then please refer to our guide ‘A tax credits guide for self-employed parents’, available free from our helpline.

Who is included in my claim?

If you have a partner you must make a joint claim. This includes people living with a same sex partner.

You can claim for a child who normally lives with you until the September after their 16th birthday. You can also claim until they are 19 if they are in full-time, non-advanced education, or certain types of unwaged work-based training. This can be extended up to the young person’s 20th birthday, so long as they’re completing a course of education or training they started, or were accepted onto before they turned 19.

If a young person starts to claim certain benefits in their own right (such as Income Support, income-based

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you get tax credits, you only get the adult amounts of IS/ibJSA with a separate Child Tax Credit payment for children. Most parents will continue to get IS/ibJSA at a reduced rate, but some families may find that they no longer get IS/ibJSA when amounts for their children are removed.

The government expects most parents on IS/ibJSA to be better off or see no change in their weekly income as a result of moving onto Child Tax Credit. However, a very small number could be worse off. For more information contact our helpline or see our guide 'Child Tax Credit and Income Support'.

Can I claim Working Tax Credit?

To claim Working Tax Credit you must be:

• aged 16 years or over, and
• living in the UK and not subject to immigration control (with some exceptions), and
• working for at least 16 hours per week and be responsible for one or more children.

Note: Some other workers without children can claim Working Tax Credit (for example, disabled workers). If you don’t care for a child, you should seek advice from a local citizens advice bureau (CAB) or welfare rights service.

To assess whether you work for at least 16 hours a week, the Revenue count the hours you normally work, ignoring unpaid meal breaks. So if you work overtime most weeks, the extra hours will be included.

There are special rules to allow some people to qualify who were working but have temporarily stopped, including term-time only school workers, women on Statutory Maternity Pay or Maternity Allowance, people on Statutory Adoption or Paternity Pay, and some people who are off work sick (contact our helpline for more details).

If you stop working or reduce your hours to below 16 hours, you can continue to receive Working Tax Credit for four weeks. However, you must tell the Revenue about this change in circumstances within one month.

Extra help from Working Tax Credit towards childcare costs

If you spend money on childcare when you work, your claim for Working Tax Credit may include help with ‘eligible childcare costs’. For childcare costs to be taken into account, you must either be:

• a lone parent who works at least 16 hours per week, or
• a couple who both work 16 hours or more a week, or
• a couple where one member works 16 hours or more a week and the other receives certain disability or incapacity benefits (or they are in hospital or prison).

What type of childcare costs can be taken into account?

Only registered or approved childcare can be taken into account. This includes registered childminders, nurseries and

Care in the child’s own home can also be counted if it is provided by someone who is registered or approved.

Childcare provided by a relative in the child’s home is not counted, even if the relative is an approved childcarer.

If a child is on Disability Living Allowance (DLA) or registered blind, childcare costs can be included until the September after their 16th birthday. Otherwise childcare costs can only be included until the September after their 15th birthday.

The maximum amount of childcare that can be taken into account is £175 per week for one child, and £300 per week for two or more children. But only 80 per cent of childcare costs can be met. This means the most that can actually be paid towards childcare costs is £140 a week for one child (80 per cent of £175) and £240 a week for two or more children (80 per cent of £300). These are the maximum amounts payable and the actual amount you will get depends on your income and family circumstances.

Contact a Family produce a guide ‘Finding and paying for childcare’, available free from the helpline. It gives more detailed information on eligible childcare costs.

There are proposals to trial an increase in the maximum amount of childcare costs met by tax credits for working families.

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Can I claim Child Tax Credit?

To claim Child Tax Credit, you must be:

• aged 16 years or over, and
• living in the UK, not be subject to immigration control and have the right to reside in the UK, and
• responsible for one or more dependent children.

Child Tax Credit can be claimed whether you are in work or not and is paid in addition to Child Benefit. It can be paid by itself or alongside Working Tax Credit.

The amount of Child Tax Credit that you receive may be higher if you have a child on Disability Living Allowance (DLA). This is because an extra amount known as the ‘disability element’ is added to your tax credit calculation for each child who gets Disability Living Allowance (DLA) or is registered blind. If your child gets the high rate of the DLA care component, a further ‘severe disability element’ is also added.

How are tax credits paid?

Working Tax Credit is paid to the parent who is working, except for any childcare costs. Child Tax Credit and any Working Tax Credit towards childcare costs are paid to the child’s main carer. Payments are usually made into a bank account. You can choose weekly or four-weekly payments.

Calculating income

Your entitlement to tax credits also depends on your annual taxable income. Although tax credits are income-based you should not assume that you have too much money to qualify.

You are guaranteed some Child Tax Credit so long as your income is less than £58,000 (£66,000 if you have a baby aged under one). In some circumstances, you may get tax credits even if your income is above these figures, for example, if you have more than one child on DLA and have substantial eligible childcare costs. If you are a part of a couple then your partner’s income is counted. A dependent child’s income is never counted.

A tax credit award is usually assessed on the income from the previous tax year. However, if your current year’s income is likely to be less than the previous year’s, an estimate of your current income can be used instead. If your current year’s income is likely to exceed your previous year’s income by more than £25,000, then the current year’s estimated income minus £25,000 is used.

Even if you think your income will be too high to get tax credits, it’s worth making a claim. This will protect your right to backdated tax credits if you have an unexpected drop in income.

What income counts?

Annual income before tax is counted. As a general rule income that is taxable is taken into account. This includes:

• gross earnings
• taxable profits from self-employment
• some social security benefits including Carer’s Allowance (see below for those not counted)
• income from property
• income from capital
• pensions (state, private and occupational)
• other income subject to income tax.

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What income is ignored?
Some income is completely ignored for tax credit purposes. This includes:

- maintenance payments
- most forms of student income
- adoption and fostering payments (but not any reward element)
- Disability Living Allowance
- Attendance Allowance
- Child Benefit
- Guardian’s Allowance
- Income Support
- Income-based Jobseeker’s Allowance
- Income-related Employment and Support Allowance
- Bereavement Payment
- Maternity Allowance
- the first £100 per week of any Statutory Maternity, Statutory Paternity or Statutory Adoption Pay
- Severe Disablement Allowance
- Short-term low rate Incapacity Benefit
- Transitional long-term Incapacity Benefit (that is, in payment since before 13th April 1995)
- Industrial Injuries Benefit.

This list is not exhaustive and some other forms of income are also ignored. Contact our helpline for details.

What if I have a lot of capital or savings?
There is no capital limit preventing a claim for tax credits. Instead any taxable income you get from your capital is counted, for example, interest on your savings (unless they are in a tax free savings account like an ISA).

How much tax credit will I get?
The Revenue uses your family’s circumstances to work out a ‘maximum tax credits entitlement’. If you get Income Support, income-based Jobseeker’s Allowance, income-related Employment and Support Allowance or Pension Credit, you are automatically entitled to maximum Child Tax Credit.

If not, you need to compare your annual taxable income to a set threshold. This is £16,040 if you are only eligible for Child Tax Credit and £6,420 if you are also eligible for Working Tax Credit (where you or your partner work 16 hours a week or more).

If your income is at or below the threshold, you’ll get the maximum tax credits for your circumstances. If your income is higher than the relevant threshold, the award will be reduced. For every £1 of income you have above the threshold, your maximum tax credits entitlement is reduced by 39p.

However, you are guaranteed at least £545 per year as long as your annual taxable income is less than £50,000. This payment is known as the family element of Child Tax Credit. If your income exceeds £50,000 a year, the family element is gradually reduced.

Using the tables
The following pages include some ready reckoner tables to help you estimate the amount of tax credits you might get. Although tax credits are usually calculated as an annual award, the tables show the weekly equivalents. All amounts are rounded down to the nearest pound. Remember your award is normally based on your previous year’s income.

If neither you nor your partner work for at least 16 hours a week, use Table 1. There are separate columns depending on the number of children you have and how many of them are disabled. A child is classed as disabled if they are registered blind or they are in receipt of Disability Living Allowance at any rate. Use the appropriate column to get an idea of how much tax credit a family in your circumstances might get (remember weekly amounts are used).

If you or your partner do work for at least 16 hours a week, the table you should turn to depends on the number of children you have and how many of them are disabled. A child is classed as disabled if they are registered blind or getting Disability Living Allowance.

- If you have one child and they’re disabled, use Table 3.
- If you have two children and both of them are disabled, use Table 4.
- If you have three children and one of them is disabled, use Table 5.
- If you have three children and two of them are disabled, use Table 6.

What about if you pay for childcare?
The amount of tax credits you receive may be higher if you are paying for eligible childcare. Tables 2-6 have extra columns showing the tax credit award parents might get when they’re paying the maximum amounts towards eligible childcare. See ‘Extra help from Working Tax Credit towards childcare costs’ for when childcare is counted. You can’t get help with childcare costs if you are only eligible for Child Tax Credit.

If you get Income Support, income-based Jobseeker’s Allowance, income-related Employment and Support Allowance or Pension Credit, you are automatically entitled to maximum Child Tax Credit.
### Table 1: Eligible for Child Tax Credit only*

<table>
<thead>
<tr>
<th>Annual taxable income</th>
<th>Family with one child who is disabled (£) weekly</th>
<th>Family with two children, one is disabled (£) weekly</th>
<th>Family with two children, both are disabled (£) weekly</th>
<th>Family with three children, one is disabled (£) weekly</th>
<th>Family with three children, two are disabled (£) weekly</th>
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</thead>
<tbody>
<tr>
<td>£16,040 and under</td>
<td>104</td>
<td>147</td>
<td>199</td>
<td>190</td>
<td>242</td>
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<td>£20,000</td>
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<td>19</td>
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<td>62</td>
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### Table 2: Working family with one child, that child being disabled**

<table>
<thead>
<tr>
<th>Annual taxable income</th>
<th>No eligible childcare costs (£) weekly</th>
<th>Includes maximum childcare costs (£) weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>£6,420 or under</td>
<td>176</td>
<td>316</td>
</tr>
<tr>
<td>£10,000</td>
<td>164</td>
<td>304</td>
</tr>
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</tr>
<tr>
<td>£55,000</td>
<td>4</td>
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### Table 3: Working family with two children, one is disabled**

<table>
<thead>
<tr>
<th>Annual taxable income</th>
<th>No eligible childcare costs (£) weekly</th>
<th>Includes maximum childcare for one child (£) weekly</th>
<th>Includes maximum childcare for two or more children (£) weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>£6,420 or under</td>
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<td>360</td>
<td>460</td>
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<tr>
<td>£10,000</td>
<td>207</td>
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<td>170</td>
<td>310</td>
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<td>132</td>
<td>272</td>
<td>372</td>
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<td>95</td>
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<td>57</td>
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<td>297</td>
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<td>20</td>
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<td>10</td>
<td>123</td>
<td>223</td>
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<td>10</td>
<td>85</td>
<td>185</td>
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<tr>
<td>£50,000</td>
<td>10</td>
<td>47</td>
<td>147</td>
</tr>
<tr>
<td>£55,000</td>
<td>4</td>
<td>10</td>
<td>110</td>
</tr>
</tbody>
</table>

### Table 4: Working family with two children, both are disabled**

<table>
<thead>
<tr>
<th>Annual taxable income</th>
<th>No eligible childcare costs (£) weekly</th>
<th>Includes maximum childcare for one child (£) weekly</th>
<th>Includes maximum childcare for two or more children (£) weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>£6,420 or under</td>
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<td>511</td>
</tr>
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<td>£10,000</td>
<td>259</td>
<td>399</td>
<td>499</td>
</tr>
<tr>
<td>£15,000</td>
<td>221</td>
<td>361</td>
<td>461</td>
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<td>£20,000</td>
<td>184</td>
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<td>424</td>
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<td>£25,000</td>
<td>146</td>
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<td>386</td>
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<td>£30,000</td>
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<tr>
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<td>71</td>
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<td>199</td>
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<tr>
<td>£55,000</td>
<td>4</td>
<td>61</td>
<td>161</td>
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</table>
How do I claim tax credits?

Child Tax Credit and Working Tax Credit are administered by Her Majesty’s Revenue and Customs (the Revenue) and both are claimed on application form TC600. This is available from your local Revenue office or from the Tax Credits Helpline on Tel: 0845 300 3900 (Textphone: 0845 300 3909)

You will need to provide details of your taxable income for the previous tax year. This information can be obtained from your P60, your payslips from work or from an annual statement of taxable benefit from the Department for Work and Pensions.

**Backdating tax credits**

Claims can be backdated up to three months. The claim form does not have a section inviting you to ask for backdating. If you want this, you should either attach a written backdating request to your claim pack or telephone the Tax Credits Office about it.

**Getting a decision on your claim**

Once the Revenue has processed your claim, they should send you an award notice. This will outline not only the amount of tax credits you are being paid but also the family circumstances your award was based on (for example, your annual taxable income, the number of dependent children you have and the number of children classed as disabled).

Higher payments may be made to families with a disabled worker, with a baby under one, with a family member on the high rate of DLA care component, or with someone aged 50 or over returning to work after a period on certain benefits.

Table notes

*Table 1 note:* If you have a baby aged under one, you may qualify for higher payments. If you have a child in receipt of the high rate of DLA care component, you may qualify for higher payments.

**Tables 2,3,4,5 and 6 notes:** These tables assume that families with incomes of £10,000 and above are working for 30 hours a week or more.

Higher payments may be made to families with a disabled worker, with a baby under one, with a family member on the high rate of DLA care component, or with someone aged 50 or over returning to work after a period on certain benefits.

### Table 5: Working family with three children, one is disabled**

<table>
<thead>
<tr>
<th>Annual taxable income (£) weekly</th>
<th>No eligible childcare costs (£) weekly</th>
<th>Includes maximum childcare for one child (£) weekly</th>
<th>Includes maximum childcare for two or more children (£) weekly</th>
</tr>
</thead>
<tbody>
<tr>
<td>£6,420 or under</td>
<td>262</td>
<td>402</td>
<td>502</td>
</tr>
<tr>
<td>£10,000</td>
<td>250</td>
<td>390</td>
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<tr>
<td>£55,000</td>
<td>4</td>
<td>53</td>
<td>153</td>
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</table>

### Table 6: Working family with three children, two are disabled**

<table>
<thead>
<tr>
<th>Annual taxable income (£) weekly</th>
<th>No eligible childcare costs (£) weekly</th>
<th>Includes maximum childcare for one child (£) weekly</th>
<th>Includes maximum childcare for two or more children (£) weekly</th>
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</thead>
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<tr>
<td>£6,420 or under</td>
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<td>454</td>
<td>554</td>
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<tr>
<td>£10,000</td>
<td>302</td>
<td>442</td>
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</tr>
<tr>
<td>£55,000</td>
<td>4</td>
<td>104</td>
<td>204</td>
</tr>
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</table>
At the end of the tax year

Once awarded, a tax credit award normally lasts until the end of the tax year. The Revenue then carry out an annual review. They issue you with a review pack outlining the personal details used to calculate your existing award which you must check for accuracy. You will be asked to confirm or to amend this information and also to confirm your annual taxable income for the year just ended.

Families who only get the basic family element of Child Tax Credit may not have to complete a declaration form. If your personal details are the same and your income is within certain bands (outlined in the review pack), an award of the family element should continue automatically. Your renewal pack should make clear if this applies to you. However, if there have been any relevant changes in your circumstances, you must notify the Tax Credit Office. All other families must complete the declaration form.

When the Revenue get confirmation of your details, they will use it to calculate your tax credit award for the new tax year. They will use the details to check whether you got the right amount of tax credits in the previous year.

If you have been underpaid tax credits, you should get a lump sum for any arrears. If you have been overpaid tax credits, the Revenue may try to recover the overpayment, usually by reducing your award for the new tax year (see ‘What happens if I have been overpaid tax credits’ on page 16).

It can take several months for the Revenue to receive confirmation of your details and to process your new award. Meanwhile, in the first few months of the tax year, they make ‘provisional payments’ based on your last reported income and circumstances.

Changes of circumstances during the tax year

Although a tax credits award will normally run until the end of the tax year, it can be adjusted during the year if there is a relevant change of circumstances. Certain changes must be reported to the Revenue within one month or you will face a £300 penalty. These are:

• a change in the number of adults claiming (for example, going from a couple to a lone parent or vice versa)
• a reduction in average childcare costs by £10 or more for at least four weeks in a row
• if you go abroad for more than eight weeks (12 weeks if you go abroad due to an illness or bereavement)
• if you stop working for at least 16 hours a week
• if your working hours drop from 30 hours a week or more to below 30 hours
• you stop being responsible for a dependent child or young person
• a young person in your family stops qualifying for tax credits. This might happen because a young person leaves full-time non-advanced education or because they start claiming Employment and Support Allowance, Incapacity Benefit or Income Support in their own right
• if a dependent child or young person dies.

Other changes of circumstance don’t have to be reported until the end of the year. But it may be in your interests to report some changes sooner. There is a three month backdating rule which means you may lose money if you delay telling the Revenue about a change that would increase your tax credit award. The earlier section ‘What is taken into account in calculating my tax credit award?’ on page 6 gives a brief overview of the kinds of circumstances that affect your award.

Starting to get Disability Living Allowance (DLA) for the first time or getting an increase in DLA

There are some exceptions to the three month backdating limit. If your child is awarded DLA or has an existing DLA award increased to the high rate for personal care, this can lead to extra Child Tax Credit payments.

So long as you notify the Tax Credits office within three months of getting the DLA decision, any extra tax credits will be backdated in line with the DLA award. You should take similar steps if you or your partner have health problems and get DLA in your own right.

If a change in circumstances reduces your tax credit award, the reduction is always backdated in full. To avoid overpayments or underpayments, you should tell the Tax Credits Office about any relevant changes in circumstances as they happen.

Changes in income

If you have a change in income, you can choose to tell the Revenue straight away or leave it until the end of the tax year. If your annual income increases, it will have no affect on your current year’s award, unless it goes up by more than £25,000. However, the increased income will be counted for tax credits in the following tax year. Because of this, it is a good idea to tell the Revenue as soon as your income increases.

If you choose to wait until the end of the year before telling them, you run the risk of being overpaid ‘provisional payments’ when you are waiting for the renewal of your claim (see ‘At the end of the tax year’). This is because your provisional payments for the early part of the new tax year will be based on an artificially low income.

Freephone helpline: 0808 808 3555
Web: www.cafamily.org.uk
Ultimately, if you wish to avoid overpayments or underpayments of tax credits, it is in your interests to report significant increases or drops in income as they happen.

What happens if I have been overpaid tax credits?

If you have been overpaid tax credits, the Revenue will normally try to recover the overpayment by reducing your tax credit payments. However, they should not recover any overpayment that is the result of an ‘official error’, so long as you have met all of your responsibilities as a claimant. Your responsibilities include providing them with accurate information, notifying them of changes of circumstances, checking your award notice for errors, checking that the payments you actually receive match the payments shown on your award notice and contacting the Revenue if you do not understand your award notice.

If an overpayment was caused by an official error and you met all of your responsibilities, none of it should be recovered. If it was caused by official error but you also failed to meet any of your responsibilities, the Revenue may still agree to write off part of the overpayment.

The Revenue also has the discretion not to recover an overpayment if you can show that this will cause you hardship.

Seek advice if you are told by the Revenue that you’ve been overpaid or are likely to be overpaid. If you dispute that an overpayment has occurred or dispute the amount of the overpayment, you can lodge an appeal.

But if you accept you’ve been overpaid, you have no right of appeal against a Revenue decision to recover the money. Instead you can dispute their decision to recover it, using form TC623, found at the end of leaflet WTC/AP available from the Revenue.

How can I get a tax credit decision changed?

The Revenue can revise a decision if there is a change of circumstances, if they have made a mistake or if they think your award is wrong. If you disagree with their decision, you can appeal. The time limit for appealing is 30 days from the date of the decision. An appeal must be in writing and must say why you are appealing. Appeals can be made on form TC623, found at the end of leaflet WTC/AP available from the Revenue.

Unless you’re reporting a change of circumstances, it’s usually better to ask for an appeal rather than a revision. This is because the appeal deadline of 30 days is not extended if you ask for a revision and it’s turned down. Late appeals are sometimes possible up to one year and 30 days after a decision. However, a late appeal is only granted in limited circumstances, so you should always try and make sure you meet the normal appeal deadline.

Tax credits and other help for families on low incomes

For detailed advice on how a tax credit claim will affect any of the benefits you currently get, please call our free helpline.

Income Support (IS) and income-based Jobseeker’s Allowance (ibJSA)
Child Tax Credit replaces payments for children made with IS or ibJSA. See ‘Tax credits and families on Income Support’ for more details.

Housing Benefit and Council Tax Benefit
Ongoing payments of tax credits are counted as income when calculating rent and Council Tax rebates (unless you’re over 60, in which case Child Tax Credit payments are ignored). However, payments for arrears of tax credits are often disregarded. Contact the helpline for further advice.

Health Benefits
You can get full help with health costs if your annual taxable income is less than a fixed threshold (£15,276 in England — at the time of writing the figure is £15,050 elsewhere in the UK, but this is may be increased) and you get:

• Working Tax Credit and Child Tax Credit.
• Working Tax Credit with a disability element, or
• Child Tax Credit and you are not eligible for Working Tax Credit.

Vouchers for free milk, fruit and vegetables
If you are pregnant or have a child under four, get Child Tax Credit (but not Working Tax Credit) and have an annual taxable income of less than £16,040, you should qualify for vouchers towards milk, fresh fruit and fresh vegetables. You may also be able to get free vitamin
supplements. This help is provided by the Healthy Start Scheme and more information is available from the Healthy Start Helpline on Tel: 0845 607 6823 Web: http://www.healthystart.nhs.uk

**Free school meals**
If you are entitled to Child Tax Credit (but not eligible for Working Tax Credit), and your annual taxable income is less than £16,040 you will be able to get free school meals.

**Sure Start Maternity Grant and Funeral Grants**
You may be able to claim if you get:

- Working Tax Credit with the disability or severe disability element, and/or
- Child Tax Credit at a rate greater than the basic ‘family element’.

**Contacts for further information and advice**
If you would like further advice regarding tax credits or other social security benefits, please call the Contact a Family helpline
Tel: 0808 808 3555 (Mon-Fri, 10am-4pm; Mon, 5.30-7.30pm)
e-mail: helpline@cafamily.org.uk

Contact a Family employ welfare rights specialists who are able to give detailed advice about any aspect of claiming tax credits.

**Other organisations**

**CarersLine**
Tel: 0808 808 7777 (Wed & Thurs 10am-12pm & 2-4pm)
Provide advice over the telephone.

If you would prefer to speak to someone face to face then you should try contacting your local citizen’s advice bureau or a welfare rights project.

**Her Majesty’s Revenue and Customs Tax Credit Helpline**
Tel: 0845 300 3900
Textphone: 0845 300 3909 (Mon-Sun, 8am-8pm)

Written by Derek Sinclair
This information applies to tax credits claims and rules for the tax year April 2009/April 2010.

Contact a Family thanks Her Majesty’s Revenue and Customs for their financial assistance in producing this guide.

Contact a Family is on Facebook, MySpace, Bebo and YouTube. We also have an office in Second Life.

Join us at:

**MySpace**
www.myspace.com/contactafamily

**Bebo**
www.bebo.com/contactafamily

**Facebook**
www.facebook.com
and search for ‘Contact a Family’

**Twitter**
http://twitter.com/contactafamily

**YouTube**
www.youtube.com/user/cafamily

**Second Life**
You can find our Contact a Family virtual advice office in Second Life on Aloft Island 19.40.22 (PG) or visit http://tiny.cc/P9A5l to teleport there directly

Freephone helpline: 0808 808 3555
Web: www.cafamily.org.uk

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Getting in contact with us

Free helpline for parents and families 0808 808 3555
Textphone 0808 808 3556
Open Mon–Fri, 10am–4pm; Mon, 5.30–7.30pm
Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

• Benefits, tax credits and other financial help (UK)
• Disabled children’s services (England and Wales)
• Fathers (UK)
• Understanding your child’s behaviour (UK)
• Siblings (UK)
• Special educational needs (England)

Incorporating The Lady Hoare Trust
Getting in contact with us

Telephone Contact a Family: 0808 808 3555
Open Monday – Friday 10am – 4pm and Monday 5.30pm – 7.30pm

This call is free

We are happy to give information to family, friends or anyone who knows the family well.

Online: www.cafamily.org.uk www.makingcontact.org

This leaflet is available from Contact a Family, translated in various languages.

Telephone interpreter service

You can telephone Contact a Family and access qualified interpreters in over 100 languages who can assist in providing information.

To use this service:
- telephone Contact a Family on 0808 808 3555
- give them your telephone number
- tell them which language you need
- if you can, let them know in English what type of help you are looking for
- within a few minutes someone will ring you back with an interpreter to assist your call.

How Contact a Family might help – English version

Contact a Family working with The Royal College of Paediatricians and Child Health
Does your child have difficulties with any of these?

- **Hearing**
  Is your child deaf or do they have difficulties with hearing?

- **Sight**
  Is your child blind or not able to see very well?

- **Speech**
  Does your child have difficulty communicating with others?

- **Physical disability**
  Do they have difficulties using certain parts of their body e.g. walking, handling objects, going to the toilet?

- **Learning**
  Do they have difficulty in understanding simple instructions?

- **Behaviour**
  Does their behaviour cause problems to themselves or others?

- **Medical condition**
  Do they have a long term medical condition which affects their daily life?

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**If you would like help you can get in touch with Contact a Family**

Contact a Family is an organisation which provides information and support to families needing extra help because of their child’s disability or medical condition. Contact a Family is not part of the government and if you prefer you can call us without giving your name.

You can telephone Contact a Family for advice and information on many topics including:

- **Education**
  We can help you find out if you can get extra help to support your child at school.

- **Medical information**
  We can usually provide information about your child’s condition and help you make contact with support groups who can also help.

- **Behaviour**
  If your child’s behaviour is causing you concern we can provide information to help you understand and control their behaviour.

- **Equipment in your home**
  We can tell you how to get help with equipment and get work done to your house to make it easier to look after your child.

- **Transport**
  We can help you find out what is available to help you and your child get around.

- **Short Breaks or help caring for your child**
  We can put you in touch with local services who might be able to provide someone to look after your child for a few hours or perhaps overnight so you can have a rest.

- **Holidays and leisure**
  We can give you information about local places where you can take your child to have fun and enjoy yourselves. We can also tell you how to get help finding and paying for holidays.

- **Want to study or go to work**
  We can provide information to help you find suitable child care if you want to get a job or training to help you find work. We can also tell you about your employment rights if you decide to go back to work.

- **Finance**
  We can tell you about financial help that you may be entitled to.

---

**Debt**
If you are struggling to pay your bills we can put you in touch with organisations who can help.

**Contact with other families**
We can help you make contact with other parents whose child has the same condition or make contact with other parents living close to you who face similar problems.

Freephone helpline: 0808 808 3555
Web: www.cafamily.org.uk
Concerned about your child? – English version

These people may be able to help

Parents & Paediatricians together

Order code: C5

Speech
Feeding
Coordination
Teeth
Toilet training
Learning
Behaviour
Sleep
Concerned about your child?

It can be very difficult to decide whether your child is just slow in developing and will catch up or whether you need to ask for help.

For some children getting help early can make a real difference and there are lots of different people who can help.

Local **children’s centres** can also provide advice and help your child’s development through play and learning experiences. In Scotland these are called family centres or early years centres.

You are given a Personal Child Health Record when your child is born. It can help you decide whether your child is slow in their development. Try to keep it up to date and take it with you when you go to see your doctor or health visitor.

Any word that appears in **bold** is described more fully at the end of this document.

Where the word could not be translated from English the trans-literal (phonetic) spelling is given in brackets.

If **speech and communication** can be very difficult to decide whether your child is just slow in developing and will catch up or whether you need to ask for help.

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Any word that appears in **bold** is described more fully at the end of this document.

Where the word could not be translated from English the trans-literal (phonetic) spelling is given in brackets.

If your child is being seen at a hospital or clinic you can always ask the nurse or doctor for their advice.

If your child is under five a doctor or **health visitor** might suggest:

- a **pre-school home visiting/service** which helps children with early communication and pre school learning skills,
- a **nursery or play school/group** who have people trained to help your child develop social skills.

**Speech and communication**

If compared to other children of their age your child is slow to understand simple words, uses few words, or has difficulty in making certain sounds.

A doctor or health visitor might refer you to:

- an **audiologist** who works with children who have hearing difficulties and can advise on aids to improve hearing,
- a **speech and language therapist** who can work with you and your child to develop communication skills. If a child cannot talk they can help them find other ways to communicate.
Feeding and eating

If your child has difficulty swallowing, eating, drinking or is reluctant to eat.

Your health visitor can give advice on feeding including breast feeding, bottle feeding and weaning on to solid food.

A doctor or health visitor might refer you to:
• a speech and language therapist who can provide help where there are physical problems with swallowing,
• a dietician who can provide advice on food, diet and nutrition,
• a clinical psychologist who can offer support and advice on how to encourage your child to eat.

Movement and coordination

If compared to other children of their age your child has difficulty sitting up, walking, handling objects, or using certain parts of their body.

A doctor or health visitor might refer you to:
• a physiotherapist who can advise you and help with exercises to improve your child’s mobility and coordination,
• an occupational therapist to assess your child’s coordination and mobility, provide advice and recommend aids/equipment to help with everyday activities.

As your child grows or their condition changes they might need further help. Do not hesitate to go back and ask for further help.

Teeth

If your child has difficulty cleaning their teeth or finds visiting the dentist difficult.

A doctor or health visitor or local dentist might suggest you take your child to see:
• a community dentist who has been trained to work with children and has special equipment for working with children with disabilities.

Toilet training or incontinence

If your child is slow in developing control of their bladder or bowel.

Your health visitor can give advice on toilet training. They might refer you to:
• a continence advisor to give you advice and practical help if your child is incontinent,
• a paediatrician to check for medical reasons why your child might be finding this difficult,
• a clinical psychologist to give advice on how to encourage your child to use the toilet.

If your child requires nappies over the age of 3 the NHS can sometimes help by providing nappies and incontinence equipment. Your health visitor or GP can tell you more about this service.
If your child has problems remembering information, learning early educational skills, or responding to requests.

A doctor or **health visitor** might refer you to:
- a **nursery** or **play school/group** for children under 5 who have people trained to help your child learn new skills,
- a **pre-school home visiting/service** to help your child with early communication and learning skills, long before they start school.

**Difficulties learning or poor attention skills**

- a **Special Educational Needs Coordinator (SENCO)** is a teacher responsible for coordinating any extra support a child needs in England and Wales. In Scotland the home visiting teacher, the child’s class teacher or another member of school staff takes on this role,
- an **educational psychologist** might observe your child and advise on which teaching or behaviour programmes will be of most benefit.

If your child’s behaviour seriously impacts on family life and his or her ability to learn.

Challenging behaviour can be the result of certain medical conditions. Difficult behaviour can sometimes be resolved using simple strategies. Parents should not feel embarrassed asking for help.

A doctor, **health visitor** or your child’s school might refer you to:
- a **social worker** to support you, help you access **parenting skills class** or find strategies to manage your child’s behaviour,
- an **educational psychologist** or clinical psychologist for help with managing the problem,
- a **paediatrician** or **psychiatrist** for assessment and advice on how best to manage your child’s behaviour.

If your child takes a long time going to sleep or wakes frequently during the night.

A child that does not sleep creates exhausted parents yet solutions can sometimes be found:
- a **health visitor** can suggest strategies to promote a good sleep pattern,
- your doctor might refer you to a **paediatrician** or **psychiatrist** who can assess your child’s needs and suggest various treatments or behaviour plans to help your child’s sleep.

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- a **paediatrician** or **psychiatrist** for assessment and advice on how best to manage your child’s behaviour.
Concerned about your child?

Some health visitors have specialist roles such as involvement with children with disabilities. A nursery or play school/group provides opportunities for pre-school children, usually aged 3-5 to take part in educational and fun activities. Some places have staff specifically trained to work with children with additional needs to stimulate and help their development.

A paediatrician is a doctor who specialises in looking after babies, children and young people. A paediatrician can coordinate and liaise with other agencies involved in the management, care and education of the child and family. Parenting skills classes are sometimes run locally to help parents improve their relationship with their children and find strategies to deal with common problems faced by parents.

An audiologist carries out hearing tests and can help a child obtain hearing aids should they need them. A clinical psychologist can offer advice on eating, toileting and behavioural difficulties. Parents may also find it helpful to talk to them about how their child’s difficulties affect the whole family.

A community dentist can provide advice on diet and planning for healthy teeth as well as dental services to children who find mainstream dental services difficult. A dietician can advise on food, diet and nutrition where a child is reluctant to eat, needs to be on a special diet or has difficulties in chewing and/or swallowing.

An educational psychologist can assess a child’s development and provide support and advice on learning and behaviour to the child’s parents and teachers.

A family doctor (GP) will be the first person to ask for medical help and advice. They can ask for your child to be seen by another specialist.

A health visitor is a nurse who has undertaken extra training to work with families in the community. They can give practical advice on day to day matters such as feeding, sleep, teething, development and behaviour. Some health visitors have specialist roles such as involvement with children with disabilities.

A nursery or play school/group provides opportunities for pre-school children, usually aged 3-5 to take part in educational and fun activities. Some places have staff specifically trained to work with children with additional needs to stimulate and help their development.

An occupational therapist pays particular attention to hand-eye coordination, perception and manipulative skills. They can advise and provide suitable aids to help with everyday activities such as feeding, dressing, toileting, bathing and play in younger children and writing skills in older children.

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Parenting skills classes are sometimes run locally to help parents improve their relationship with their children and find strategies to deal with common problems faced by parents.

A physiotherapist helps in the management and development of movement skills. There are a number of ways in which children can be helped. These may include exercises to strengthen weak muscles and games to improve coordination and motor skills.

A dietician can advise on food, diet and nutrition where a child is reluctant to eat, needs to be on a special diet or has difficulties in chewing and/or swallowing.

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Concerned about your child?

A speech and language therapist helps children learn to communicate, either through speech or other methods. They can also help if there are problems with eating, drinking and swallowing.

In some areas local children’s centres give advice and support on education, health and childcare to children under five and their families. In Scotland these are called family centres or early years centres. By 2010 there should be one in every community.

Further information and advice

If you have a disabled child, Contact a Family can help you access further information and advice, including:

- organisations who provide advice on dealing with communication, continence or behaviour problems
- support groups for specific medical conditions
- advice on your rights and entitlements.

A pre-school home visiting service is sometimes available for children with delayed development. In England this is called Portage. A teacher or portage home visitor works alongside parents in the home offering practical help and ideas to assist with the development of play, communication, relationships and learning for young children.

A social worker supports children and families by advising them on practical and financial issues, telling them about local services and sometimes helping to arrange the support they need.

A psychiatrist is a doctor who specialises in problems that affect the ways a person thinks, feels or behaves. A child and adolescent psychiatrist specialises in working with children and young people. The psychiatrist might want to meet the whole family before deciding what help is appropriate. They can prescribe medication and might suggest a child be seen by a clinical psychologist.

A speech and language therapist helps children learn to communicate, either through speech or other methods. They can also help if there are problems with eating, drinking and swallowing.

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A social worker supports children and families by advising them on practical and financial issues, telling them about local services and sometimes helping to arrange the support they need.

A special educational needs coordinator (SENCO) is responsible for coordinating support for children with special educational needs in England and Wales. This can begin at an early age well before the child starts school and continues while they attend school. In Scotland the pre-school home visiting teacher takes on this role before they start school. Once they attend school either the child’s class teacher or a member of the Additional Support Learning staff is responsible.
Helping your child’s sleep
Information for parents of disabled children

Order code: C2
Parents & Paediatricians together
Contact a Family working with The Royal College of Paediatricians and Child Health

Getting in contact with us
Telephone Contact a Family: 0808 808 3555
Open Monday – Friday 10am – 4pm and Monday 5.30pm – 7.30pm
This call is free

We are happy to give information to family, friends or anyone who knows the family well.

Online: www.cafamily.org.uk www.makingcontact.org

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Telephone interpreter service
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- give them your telephone number
- tell them which language you need
- if you can, let them know in English what type of help you are looking for
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Helping your child’s sleep

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Introduction

Sleep problems affect the whole family
A child who does not sleep well can affect the whole family. Parents can be left exhausted, unable to think clearly and struggling to cope with their daily activities. The child can be left feeling either tired or overactive, both signs of lack of sleep. Brothers and sisters are also affected, feeling tired at school and sometimes resentful towards the sibling disturbing their sleep. If this continues over a long period of time it can have an adverse effect on the health and well being of all members of the family.

Many children are sleeping through the night by the age of one, though it is quite normal for sleep to be occasionally disturbed because of illness or other changes in routine. Disabled children and those with certain medical conditions are more likely to have persistent problems with sleeping.

There are some standard approaches which help all children, including disabled children, but these might take longer to work depending on the nature of the child’s medical condition or disability.

Why disabled children can have sleep problems
If a child is having trouble sleeping it is important to seek medical advice, to make sure there is not a medical cause. Disabled children are more likely to have sleep disorders such as sleep apnoea, which disturbs their nights sleep. If a sleep disorder is suspected, the child might need to spend a night in hospital so tests can be carried out while they sleep.

A child with a physical disability might find it difficult to get comfortable at night, or experience discomfort caused by muscle spasm, incontinence or breathing difficulties. Where a child cannot move independently and needs to be turned in the night it is much harder for the child to learn that night-time is for sleeping. Professionals may be able to help; for example, a physiotherapist might be able to give advice about a good position for the child to sleep in or a doctor might be able to prescribe medication to relieve any discomfort. A child’s prescribed medicine can sometimes affect their sleep pattern e.g. medication for epilepsy can cause sleeplessness.
Neurological conditions which affect the brain, such as cerebral palsy, can also cause sleep problems if the brain’s normal sleep-wake cycle is disturbed. If this is the case a doctor might be able to prescribe medication to assist but having regular bedtime routines will also help. It is advisable not to use medicines purchased over the counter without first talking to a doctor.

Children with learning disabilities or difficulty in communicating might find it difficult to understand why and when they need to sleep. Many children with autism seem to be affected with a disturbed sleep pattern. They might have difficulty in going to sleep or wake frequently for no obvious reason or because they want reassurance.

What can cause a child to wake
Some common causes of sleep disturbance include:

- Too much sugary food during the day or a diet which is high in additives.
- Becoming too hot or cold, a cooler bedroom often improves peoples sleep.
- Being hungry or thirsty.
- Having a nappy that needs changing.
- Experiencing bad dreams.
- Attention seeking behaviour.

What might help
Make the bedroom a relaxing place
It helps to make the child’s bedroom a safe, calm and pleasant place for the child to be in. If you can, decorate in pale shades as these are less stimulating than bright colours. Avoid too much furniture and lots of stimulating toys and games but do include a few favourite pictures, posters and cuddly toys. Reduce noise coming into the room as much as possible by placing the child’s bed as far away from sources of noise as possible.

If the bedroom is too light try using black out linings on curtains to make the room darker. If the child finds the bedroom too dark try using a small night light. Some children feel more comfortable with a blanket whilst others prefer a duvet. Certain children respond to calming background music to help them relax. Toy shops often sell lullaby lamps that provide a soft light shapes with music. Electric aromatherapy night lamps have also been found helpful in setting a relaxing environment for some children.

There is scientific evidence that lavender and bergamot essential oils can help with sleep problems. Work out which of all of these suits your child best.

Make sure the child thinks of the bedroom as a comfortable and relaxing place. Try not to send a child to the bedroom during the day as a punishment. Try to find other ways to encourage good behaviour. Contact a Family has a fact sheet in English called ‘Understanding Your Child’s Behaviour’ which might provide ideas.

Keeping a sleep diary
A sleep diary can be useful to help parents find out what triggers poor sleep behaviour and what seems to help. A sleep diary might contain:

- The time the child went to sleep and period of times awake during the night.
- The number and length of naps during the day to see if cutting down naps and keeping child awake for longer periods during the day helps.
- The process of preparing the child for bed to identify whether changes to bedtime routine work well.
- Medication and time given as giving medication at different times of the day might help.

The diary can also be useful:

- To show to professionals to help them understand the severity of their child’s sleep behaviour.
- To provide evidence when applying for benefits e.g. Disability Living Allowance.
- As a visual incentive so the child can be rewarded if they stay in bed and try to sleep.

Having a regular bedtime routine
It always helps to having regular routines around going to bed so the child becomes familiar with the routine and can predict what happens next. Pick a good time to start a new bedtime routine. e.g not just before going on holiday when the child will be sleeping in unfamiliar surroundings. If other members of the family occasionally prepare the child for bed try to make sure everyone follows the same routine. It helps to:

- Keep a regular bedtime for the child and wake them at the same time each morning.
- Limit day time naps.
- Make sure the child is not hungry at bedtime.
- Avoid drinks with high sugar content and foods full of additives during the day.
- Avoid TV, computer screens or play stations for at least one hour before bedtime, as the light from the screen can disrupt the child’s normal sleep rhythm.
The routine needs to fit in with everyday family life and be one the child finds pleasurable. Typically the routine might consist of four or five calming activities such as:

- Relaxation time when the child receives as much undivided attention as possible. Avoid stimulating activity such as rough play or frightening fairy tales.
- Biscuit / milky drink.
- Bath time.
- Story, song or music tape.
- Settle in bed – tucked in with special toy – goodnight kiss or phrase e.g. “Goodnight, sleep tight, see you in the morning”. The child understands from this it is time to settle down and go to sleep.

Different things help different children and it helps to work out what is best for each child. If the child has difficulty communicating and/or understanding then pictures, photos, symbols or certain objects e.g. a dolls pillow may be used to help them understand what comes next. Favourite toys can also be used to act out the bedtime routine to help the child become familiar with it.

Once in bed...
It is normal for all children to wake a few times in the night. It is best not to stay with the child in the bedroom until they are sleep. This way the child gets used to falling asleep on their own, does not expect to see you should they awake and instead learns to settle themselves.

If your child comes into your bedroom during the night allowing them into your bed might help in the short term but sets a long term habit that is difficult to break.

Breaking bad habits

Crying to avoid bedtime
Sometimes children cry to get their parent’s attention, because they don’t want to go to sleep. It can be difficult for parents to know whether the crying is because the child is distressed or simply wanting attention, especially if the child cannot talk. Some parents find it very difficult to leave their child to cry, but if they go to them the moment the crying starts, the child soon learns that this is a way of avoiding bedtime and it becomes a regular occurrence.

Sleep experts advocate two methods of tackling this type of behaviour, both of which are known to work and are described below.

Technique 1 – Leaving the child to cry
This technique should only be tried after discussion with a health visitor or other health professional, especially where the child has a medical condition or other significant additional need. Parents often find leaving their child to cry stressful and might prefer the next technique, though it can take longer to work.

Parents leave the child to cry until the child eventually learns crying does not work. The first few nights this is tried the child is likely to cry for some considerable length of time. This is the fastest way of resolving this type of behaviour but before trying this approach, parents need to give it some careful thought and planning.

1. To begin with the crying may go on hours, but this will ease as days go by. Parents may want to start this approach at a time when disturbing other family members is not too much of a concern, for example during school holidays. Parents may also need to take practical steps such as warning neighbours.

2. Parents can find this approach very stressful and need to be sure they can carry it through. If parents ignore the crying for say 30 minutes, but then find it impossible to bear any longer, they effectively teach the child that persistent crying pays.

3. If the child has behavioural problems, parents need to know the child will be safe. They might need to prepare the bedroom and remove anything the child may hurt themselves on and use a stairgate to prevent the child from getting into other areas of the house. Some parents whose children have very challenging behaviour have had to resort to screwing furniture down.

Technique 2 – Controlled Crying
If the child starts to cry, go in after 2-5 minutes (less if the crying upsets them) and gently but firmly resettel them with as little touching as possible and repeat your ‘goodnight phrase’. Leave again. If the crying persists, go back at regular intervals of 2-5 minutes and go through the same resetteling routine. Parents may have to go in many times to begin with but this will lessen each time until the child eventually falls asleep on their own.
If the child comes out of the bedroom take them immediately back to bed without giving eye contact or talking and gently but firmly resettle them. Repeat their ‘goodnight phrase’ and leave again. If they come out again, just repeat this.

If the child wants you in the room
If your child is used to having you in the bedroom when they go to sleep, and is very distressed when you leave them, it helps to gradually get them accustomed to you not being in the room. To begin with sit alongside them and avoid getting into bed with them or cuddling them to sleep. Try to avoid eye contact and any conversation. If you find this hard then reading a book or magazine to yourself might help.

Every few days gradually increase the distance between you and your child (e.g. sit by the bed, sit a bit further away, stand in the door, stand outside the door etc.) until the child no longer needs you to be there for them to fall asleep.

Remember to be patient and firm

Whichever of these techniques you use, it is common for a child to start to improve and then for their behaviour to get worse. It is important to be firm and stick to the routine and their behaviour will start to improve again. Otherwise the child continues to have bad habits which results in constant attention-seeking and postponement of bed times.

Changing bedtime habits might take a while, and the child’s behaviour might get worse before it gets better, but if you persevere, it can have great benefits for everyone.

If a particular behaviour is ‘rewarded’ in some way it is more likely to happen again. A reward can be anything that a child finds pleasant, such as praise, a drink, a hug or attention. Star charts are one way of rewarding good behaviour which children often like. Make a chart showing all the days of the week, place it in the home where everyone can see it and show it to people who visit. Each day your child is given a goal and if they achieve it they are given a star. At first start with simple goals, (e.g. going to the bedroom when asked) and gradually set more demanding ones (e.g. staying in bed once parents have left the room, staying in bedroom all night etc). Once the child has got a set number of stars they are rewarded with an activity they enjoy e.g. a trip to the cinema or park.

Reward your child’s good behaviour

If your child needs care and attention during the night because of sleep problems, you might qualify for Disability Living Allowance (DLA) or a higher rate if you’re getting this already. Contact our Helpline for further information.

Getting help

This information sheet has listed a few ideas that might help, but there are other sources of help and support available.

• Health visitors and community nurses can often provide advice on encouraging children to sleep.
• Your GP or paediatrician might also be able to help, or refer you to a psychologist, psychiatrist or sleep specialist.
• If you live in Scotland the charity Sleep Scotland provides both information and a sleep counselling service for families of children with additional needs who have severe sleep problems – see contact details below.
• National support groups often provide information on sleeping for families of children with certain conditions. A few are listed below and Contact a Family can provide details of others.
• Many families find it helps to talk to others who have had, or are facing similar problems. Contact a Family can provide details of local parent support groups.
• If your sleep is being continuously disturbed you can ask for a Carer’s Assessment from Social Services. They may be able to provide short breaks or respite, where someone else looks after your child for a few nights so you can get an uninterrupted nights sleep Contact a Family have a factsheet called ‘A Guide to Assessments and Services’ which gives more details of this.

This factsheet is available from Contact a Family, translated in various languages.
Useful contacts

Contact a Family
Freephone helpline 0808 808 3555
open Monday – Friday 10am-4pm,
Monday evening 5.30pm to 7.30 pm
Offers an interpreting service in over
120 different languages
Email: helpline@cafamily.org.uk
Web: http://www.camily.org.uk
Address: 209-211 City Road,
London, EC1V 1JN

Sleep Scotland provides a service
in Scotland to help families of children
with special needs or with severe
sleep problems.
Tel: 0845 603 1212
Mon-Fri 9:30am – 5.30pm
Email: enquiries@sleepscotland.org
Web: http://www.sleepscotland.org
Address: 8 Hope Park Square,
Edinburgh, EH8 9NW, Scotland

The National Autistic Society provide
information, advice and support for
people affected by Autistic Spectrum
Disorders (ASD). Their information fact
sheet ‘Helping your child with autism
to sleep better’ can be downloaded
from their website.
Tel: 0845 070 4004
Monday-Friday 10.00am – 4.00pm
Offers an interpreting service in over
120 different languages to callers using
landline telephones in the UK
Web: http://www.nas.org.uk
393 City Road, London, EC1V 1NG

Scope provide information and advice
to people affected by cerebral palsy.
Their information fact sheet ‘Sleep
problems in children’ can be
downloaded from their website.
Freephone: 0808 800 33 33
9am – 7pm weekdays and 10am – 2pm
on Saturday
Email: response@scope.org.uk
Web: http://www.scope.org.uk
Address: Scope Response,
PO Box 833, Milton Keynes, MK12 5NY
(Please include SAE for a reply)

Further reading

‘The Good Sleep Guide for you and
your baby’
Angela Henderson
Published by ABC Health Guides 1997
Muir of Logie Farmhouse, Forres, Moray,
IV36 2QG Tel: 07020 922 750

‘Sleep Better! – A Guide to Improving
Sleep for Children with Special Needs’
V. Mark Durand
Paul H. Brookes Publishing Co. 1998

‘Solving Children’s Sleep Problems:
A Step by Step Guide for Parents’
Lyn Quine
Beckett Karlson (Huntingdon) 1997

‘Solve Your Child’s Problems; The
Complete Practical Guide for Parents’
Dr Richard Ferber
Dorling Kindersley, London 1986
Getting in contact with us

Telephone Contact a Family: 0808 808 3555
Open Monday – Friday 10am – 4pm and Monday 5.30pm – 7.30pm
This call is free

We are happy to give information to family, friends or anyone who knows the family well.

Online:
http://www.cafamily.org.uk
http://www.makingcontact.org

This leaflet is available from Contact a Family, translated in various languages.

Telephone interpreter service

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To use this service:
- telephone Contact a Family on 0808 808 3555
- give them your telephone number
- tell them which language you need
- if you can, let them know in English what type of help you are looking for
- within a few minutes someone will ring you back with an interpreter to assist your call.

Feeding and eating
Information for parents of disabled children

© Contact a Family, January 2007
Feeding and eating

It is the natural instinct of a mother to feed her child from birth to infancy and onwards. If a child refuses food or has difficulty with eating, it can leave parents feeling very anxious, helpless and frustrated. A disabled child can have difficulty feeding for several reasons. The child may:

- find it difficult to chew, swallow or digest certain food.
- have limited mobility, making it more difficult to feed themselves on their own.
- have a learning disability, making it more difficult for them to learn, or understand appropriate behaviour when eating and at mealtimes.
- be reluctant to eat, or only eat a few types of food. This type of behaviour can be associated with certain medical conditions.
- be prevented from feeding/sucking as babies, because of medical problems and then find it harder to develop these skills later on.

If your child is having problems eating it is important you seek help from a health professional who can check for possible medical causes as well as provide advice on how to deal with the problem.

Perseverance and patience can often be needed so mealtimes do not become a battle ground, leaving both child and parent frustrated with each other. Parents often find it helpful to talk to others who have faced similar problems. Contact a Family can help you find groups who provide support around a child’s specific medical condition and may also be able to direct you to parents living in your area.

This fact sheet lists some of the physical problems that can cause difficulties with feeding, provides a few tips and ideas around managing meal times, and gives details of other organisations that may be able to help.

Physical problems that affect eating/feeding

**Difficulty sucking** – Many new babies experience initial problems and this does not imply they have a long term medical condition. Problems with sucking can occur with certain conditions such as cleft palate and cerebral palsy. This problem will be apparent very early on and staff on the maternity ward, the midwife or a health visitor should all be able to offer suggestions.

**Weaning** – This is the process when a young child moves on from drinking to eating solid food. Some children find it harder to chew solid foods so moving from milk to semi-solids to solids is harder for them. However some babies who find sucking difficult find eating semi-solid food easier so may thrive better when weaned. A health visitor can advise on this.

**Bite reflex** – This occurs during feeding when the child immediately ‘locks’ the mouth onto anything that is introduced into it. The child is not doing this deliberately. A speech and language therapist can advise on techniques that may help and a plastic spoon will lessen the chance of injury to the mouth or damage to the teeth.

**Choking** – Regular choking can cause considerable anxiety for both the child and the carer. A doctor, health visitor, physiotherapist or speech and language therapist should be able to advise how to prevent choking and what actions to take if it does occur.

**Constipation** – This is when a child is unable open his/her bowels. It can be caused by an underlying medical problem, not eating enough of certain types of food, not drinking enough liquids or the consequence of reduced mobility. A health visitor, a paediatrician or the child’s GP should be able to help.

**Dental care** – Difficulties in feeding can be because of the way teeth close together or as a result of pain caused by a dental problem. It can be more difficult to keep a disabled child’s teeth clean. Frequent check ups at the dentist is recommended and it may be necessary to go to a community dentist who has experience of dealing with disabled children.

**Reflux** – is when food that has been swallowed comes back up into the oesophagus tube that goes into the stomach. This can cause discomfort both during and after eating and may cause vomiting. It should always be investigated by a doctor who can advise on treatment options.

**Vomiting** – frequent vomiting may be distressing for all concerned. Where the child is physically disabled this may be improved by changing the child’s position and avoiding lying down too soon after eating. If it persists seek advice from your health visitor or GP.
Eating independently

It can take longer for a disabled child to learn to feed themselves, however, as they get older most children prefer to be able to do this and find depending on others frustrating. It may take time and effort to help a disabled child to develop these skills but it will help them in other areas such as language development, mobility and hand-eye co-ordination.

Equipment and utensils

Most babies can be fed with the ordinary spoons designed for young children and readily available in high street stores. As children mature and begin to attempt to feed themselves there are a number of utensils that may help. Special plates, bowls, cups, adapted cutlery and non-slip mats that help to keep the dish in place are all available as are specialist bibs to help keep food off clothing. An occupational therapist can advise what would be most appropriate.

Diet – A nourishing and well balanced diet is important for staying healthy. Health visitors and dieticians can advise on suitable diets. If there is a problem in chewing and swallowing then a speech and language therapist can advise on suitable food textures and consistency. This should help increase the range of food the child will take.

Tube feeding

Sometimes it is necessary for babies and children who are not able to suck or swallow adequately to get proper nutrition to be fed by tube.

A Naso-gastric tube (NG tube) is inserted into the stomach and is passed up the nose into the tube leading to the stomach.

A gastrostomy tube is placed through a small incision in the abdomen directly into the stomach. This involves surgery.

Both have been shown to be helpful in assisting some people. Tube feeding may be a short term procedure but occasionally needs to be permanent. Sometimes a combination of tube and conventional feeding is recommended. Details of PiNNNT, a support group who offer advice to parents of children being tube fed is provided at the end.

Hints/tips around mealtimes

Eating together as a family

Sitting down as a family to eat a meal together helps children learn appropriate eating behaviour. It is particular helpful to children who have problems learning or listening as they find out about appropriate behaviour by watching others.

Parents can find it difficult to organise regular family meals, especially if other members of the family are coming and going at various times. Always make sure at least one person sits with the child while they eat and try to organise family meals whenever possible.

Decide a place for the child to sit at meal times

Regular routine at meal times helps the child understand what is being asked of them. Try to choose a table and chair in proportion to the child’s size. Some parents choose to sit their child in front of the television or video, so they can be distracted whilst eating. This may be a difficult habit to break and cause problems if eating out. It may be better to use a more mobile distraction, which can be more easily moved to the main table. e.g. a favourite toy or book.

Get the child into the right position

If your child is physically disabled they may need supporting so they are sitting in the right position. It is very difficult to eat or drink with the head tilted back. Seek advice from a physiotherapist/occupational therapist.

Warn your child when the meal is nearly ready

If a child is engrossed in an activity they might have temper tantrums if suddenly told to stop what they are doing and come to eat. Warn the child the meal will soon be ready by talking to them, giving signs such as laying the table or showing them pictures of food.

Reluctant eaters

When introducing new food intersperse it with food you know they like. Don’t force them to eat food they dislike. If the child has sat at the table for a short time and eaten a little food, then praise and reward them. If they find it difficult to sit for long periods you might try timing your child sitting down by using a large egg timer, and allow your child to move once time is up. This will give them a visual link for ‘sitting down time’. Over time you can gradually build up the sitting down period. Again don’t rush things and don’t expect instant change.
Feeding and eating

Possible causes of problems
Try to identify what might be causing problems. Here are some possible ones:

- Not in the right position to eat comfortably, not able to see what they are eating or feeling insecure sitting in a big chair.
- Not liking certain foods. Children can sometimes dislike certain textures, tastes or smells. Keep a note of foods accepted or rejected to see if there is a pattern. This may simply be a ‘food fad’ which can affect all children.
- Not liking the feel of cutlery in their mouth. Metal utensils and forks are more likely to be troublesome.
- Some children, like to see the food presented on the plates in a certain order and don’t like their food being mashed together.
- Being overwhelmed with the amount of food on the plate. It can be better to only offer a little food at first, and add more if wanted.
- Some babies prefer to feed themselves with finger food rather than being spoon fed.
- Having to sit close to one particular person.
- Lots of noise or distractions from other members of the family.

Unsocial behaviour
If your child really plays up at the table and even resorts to spitting food on the floor, try not to give them a reaction as this will only reinforce their behaviour and may encourage them to do it again. This is not an easy thing to do. Never try to force food as this will create even more of a problem.

Remember
Try not to let your child sense if you are feeling stressed about his/her eating habits as this may create further anxiety and make the problem worse.

Is your child eating enough?
It may sometimes feel that your child has hardly eaten anything all day, so it is sometimes worth writing down what they have eaten. It might surprise you that it is quite a lot even if this is chocolate, sweets and crisps! Take this with you when you go to discuss their diet with a health professional.

Getting specialist help
There are times when parents need specialist help and support. Don’t struggle alone but talk to your child’s doctor, health visitor or nurse. Try to get a referral for help from an appropriate professional. The dietician, community nurse, speech and language therapist and occupational therapist all have particular skills which can help you and your child.

This factsheet is available from Contact a Family, translated in various languages.

Useful contacts
Contact a Family provides support to families of disabled children, whatever their condition. They offer a telephone interpreting service in over 120 different language and written information in various languages can be downloaded from their web site.
Tel: 0808 808 3555 Monday – Friday 10.00am-4pm, Mon 5.30-7.30pm
email: helpline@cafamily.org.uk
web: http://www.cafamily.org.uk

National Autistic Society provides advice and information services for parents of children with an autistic spectrum disorder (ASD). They offer a telephone interpreting service in over 120 different languages and written information in various languages can be downloaded from their web site.
Tel: 0845 070 4004
Monday – Friday, 10.00am-4pm
Autism Helpline,
The National Autistic Society,
393 City Road, London, EC1V 1NG
Email: nas@nas.org.uk
Web: http://www.nas.org.uk

PINNT (Patients on Intravenous and Naso-gastric Nutrition Therapy) Offers advice to parents of children on tube, naso-gastric or intravenous feeding.
Tel: 01202 481625
PO Box 3126
Christchurch
Dorset BH23 2XS
Email: pinnt@dial.pipex.com
Web: http://www.pinnt.com

Scope produce factsheets and a CD-ROM about feeding children with cerebral palsy from birth to six years.
Price £15.00
Tel: 0808 800 3333 Monday – Friday 9am – 9pm, Weekends 2pm to 6pm
Cerebral Palsy Helpline
PO Box 833
Milton Keynes
MK12 5NY
Fax: 01908 321051
Email: response@scope.org.uk
Web: http://www.scope.org.uk

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- tell them which language you need
- if you can, let them know in English what type of help you are looking for
- within a few minutes someone will ring you back with an interpreter to assist your call.

Potty/toilet training
Information for parents of disabled children

Order code: C3
Parents & Paediatricians together
Contact a Family working with The Royal College of Paediatricians and Child Health
When should you start toilet training your child?

Look for signs that your child is ready to use the potty. These might include awareness of:
• Passing urine or having a bowel movement.
• Showing discomfort when a nappy is wet or soiled.
• Waking from a daytime sleep with a dry nappy.
• Showing an interest in a potty or the toilet.

What if your child does not show these signs?

If your child’s condition means that s/he is not showing any of these signs you should discuss it with one of the people looking after your child. This could be the health visitor, community nurse, occupational therapist, paediatrician or, if they are in a nursery or school setting, the teacher, teacher assistant or school nurse. You will need support from the people who deal with your child on a day to day basis and it is important that parents and professionals work together on different ways of addressing the problem.

Before starting

• Choose a time when you can spend a lot of time with your child, when your child seems happy and there are no major distractions or stressful events like starting nursery, moving house, moving from a cot to a bed.
• Make sure the time you choose fits in with you as well – perhaps at a time when there is someone else to help you if this is possible.
• It may take some time for the child to learn, so make sure that the toilet training programme can be carried out in the other places your child visits such as the playgroup, nursery, or school.
• If the child has difficulty in sitting, an occupational therapist should be able to help with equipment and check whether the toilet needs to be adapted so it is more comfortable for the child.

Once you start

• Be patient—don’t expect instant results.
• Keep to the planned routine as much as you can.
• Do not show any signs of concern — it will make the child feel anxious.
• If your child is reluctant to sit still, you could sing some songs or read a book with them just for a few minutes to get your child used to sitting on the potty. Never leave your child on the potty for more than five minutes.
• If the child is older and too big for a potty and still not showing interest in using the toilet then make sure they visit the toilet area regularly. You may need to put a favourite book, picture or toy next to the toilet or play a favourite piece of music to encourage the child to come into the room.
• Praise your child first for showing an interest in the potty or toilet, then for using the potty – every small step should be rewarded with praise.
• Make sure your child sees you washing your hands after wiping them so it becomes part of the process of using the toilet.
• Let your child get used to the routine of washing his/her hands after being on the potty or toilet.

All children learn to use the toilet at a different stage in their life. Most children start to show an interest in moving on to a potty or toilet at about two years old.

Children with a physical problem or learning disability might not be ready to start until they are older. It can also sometimes take a longer time for them to learn to use the potty or toilet.

It is important to speak to a doctor to check for physical problems if a child is having difficulty in learning to use the toilet.

Some children, particularly those with profound and multiple impairments may never be able to use the toilet on their own, but they still need to have a toileting programme which will make sure they are treated with respect. Ask your health visitor or community nurse for advice.

All children are different and the way they learn to use the toilet may be linked with the specific condition they have. It is a good idea to get in touch with the relevant support groups to get advice from people who have more experience.
**Bowel movement**

- Sit the child on the toilet or potty when you think s/he is likely to have a bowel movement and encourage the child to push down gently. To encourage this, try making the child laugh or to blow into a toy or whistle – the child sitting upright will also help to encourage a bowel movement.
- If nothing happens, say nothing and try again a bit later.
- If it is acceptable to your family, take your child into the toilet when you or family members go, to show the child what is expected. It may take much longer than with other children, so be patient.

**Children who find it hard to communicate**

- Make sure your child can communicate to you when s/he needs to use the toilet.
- Some children who are able to speak will be able to use words, others may not be able to ask to use the toilet and may need to use another system such as a signing system like makaton or the pictorial PECS system. Other children may be able to use a photograph or object such as a roll of toilet paper to show that they need to go to the toilet.
- Make sure the child knows where the toilet or potty is, and can get in and out of that room easily.
- Make it fun – find a special toy which your child only uses when in the toilet – this will help him/her to associate going to the toilet with fun and not stress.
- If your child needs to be cleaned, make sure that people working with him/her know this should be done in a private bathroom area in an age appropriate way. (It is not acceptable for a physically able young person to be ‘changed’ whilst lying down.)

**If your child takes a long time to learn to use the toilet**

- Try to get clothes that are easy to wear, change, and wash.
- Items such as large size nappies, waterproof mattress covers, and covers for duvets and pillows may be available from the continence service, when your child is 3 – ask your health visitor. If not, you can get them from larger chemists.
- The Family Fund gives grants to families on low income for washing machines, tumble driers or towards cost of bedding and clothing.
- For children who are older, it is often the parents or carers who live with them who understand their needs and will devise their own strategies. Do not despair. Try and speak with other parents for support, advice and tips.

**Smearing**

Some children with learning disabilities smear their faeces after going to the toilet. There can be various reasons for this. It could be the child has simply not understood the process of wiping with paper properly. Others enjoy the feel of the texture of the faeces and providing them with an alternative activity such as play dough can resolve the situation. Some will use it as a way of getting attention, or because they have learnt they are rewarded for such behaviour by being given a nice warm bath. Children can also behave in this way because they are extremely upset and agitated.

If your child smears:
- Try to stay calm.
- Avoid giving them lots of attention as a result of their behaviour.
- Reinforce good behaviour by give them lots of praise when they carry out other activities well.
- Try to see if there is a pattern to their behaviour, as it might help you understand why they are doing it.
- Seek advice from a professional such as a nurse, occupational therapist or psychologist on dealing with this.

This factsheet is available from Contact a Family, translated in various languages.
Useful contacts

This is a leaflet offering general advice for families but you may find it more helpful to get in touch with specific support groups around your child’s condition. Some are listed below and if you need help in finding one for your child’s condition call the Contact a Family helpline.

Contact a Family Help Line
Tel: 0808 808 3555
Mon-Fri 10am – 4pm,
Mon eve 17.30-19.30
Offers an interpreting service in over 120 different languages to callers using landline telephones in the UK
Email: helpline@cafamily.org.uk
Web: www.cafamily.org.uk

Contact a Family, 209-211 City Road,
London EC1V 1JN

Education and Resources for Improving Childhood Continence (ERIC) have a helpline for parents, and offer products and publications to buy from their web:
Tel: 0845 370 8008
Mon-Fri 10am – 4pm
Web: www.eric.org.uk

ERIC 34 Old School House, Britannia Rd,
Kingswood, Bristol BS15 8DB
(please include stamped addressed envelope)

Family Fund
Unit 4, Alpha Court, Monks Cross Drive,
Huntington, York YO32 9WN
Tel 0845 130 45 42
Email: applications@familyfund.org.uk
Web: www.familyfund.org.uk

National Autistic Society provides information advice and support for people with autistic spectrum disorders and their families, including a fact sheet on toilet training.
Tel: 0845 070 4004
Mon-Fri 10am – 4pm
Offers an interpreting service in over 120 different languages to callers using landline telephones in the UK
Web: www.nas.org.uk

The National Autistic Society,
393 City Road, London EC1V 1NG

Scope supports families of children with cerebral palsy and can provide written information on toilet training.
Tel: 0808 800 33 33
Mon-Fri 9am – 7pm,
Saturday 10am – 2pm
Email: response@scope.org.uk
Web: www.scope.org.uk

Scope Response, PO Box 833,
Milton Keynes, MK12 5NY
(Please include stamped addressed envelope)