

from child to adult



a guide to **disability,**
transition and **family finance**

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and family finance



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how to use this publication

As young disabled people turn 16, 17, 18 or 19 they become entitled to benefits and support in their own right. What they're entitled to may, or may not, depend on whether they're still in education, are job seeking or claiming benefits as the young adult they now are. Parents' and carers' benefits and tax credits can depend not only on the student or employment status of their disabled sons or daughters and their other children but also on what their disabled offspring are claiming.

In some instances all that parents, carers and disabled young people need to know is what to claim when. Sometimes there are choices to be made. Depending on the family circumstances, sometimes it will be more advantageous for a young person to claim their own benefits. Sometimes the family will be better off if parents or carers continue to claim for the young people as their dependants.

Section 1 of this booklet is information about parents' and carers' entitlements.

Section 2 is about young disabled people's entitlements. You may need to read both sections and do the arithmetic to work out what is best for your family.

Look at Section 3 for help with your 'better-off' calculation.

At the end of the booklet is a list of websites, organisations and publications which can help you, including Working Families.

Working Families' website, www.workingfamilies.org.uk, carries information relevant to families combining paid work and caring for children and adults.

Working Families has two helplines; 0800 013 0313 for low income families and a dedicated helpline for carers and parents of disabled children, 020 7017 0072.

Waving *not* drowning, Working Families' project for carers and parents of disabled children who are trying to combine work and caring, produces a free newsletter two or three times a year and a monthly e-bulletin.

To add your name to the distribution lists, contact Janet Mearns at janet.mearns@workingfamilies.org.uk, 020 7017 0072, or 1-3 Berry Street, London EC1V 0AA.

Benefits and tax credits are complex. The following is a general guide. You may wish to take specialist advice about your own situation, particularly if you are not British or not normally resident in the UK. You will also need to take further advice if the young disabled person in the family is a parent themselves.

section 1

parents

As the parent of a disabled young person you may be receiving benefits and tax credits to help you pay for their needs. Exactly when you cease to claim benefits and tax credits as a parent depends on both your child's age, on any course they are following and on whether they are regarded as independent, as well as your other family circumstances. You may continue to claim some benefits and tax credits but they may have to be recalculated when your family circumstances change.

If you are from abroad or if your son or daughter is a parent themselves, you need to seek further advice.

carer's assessment

If you are looking after a disabled child or adult, you are entitled to a 'Carer's Assessment' from Social Services. Depending on local policy, this may or may not be done at the same time by the person who assesses your son or daughter.

The assessment is a chance to discuss what help you can get. When doing a Carer's Assessment the social worker is obliged to take into account your wishes to do paid work or to study.

You can refer yourself to Social Services for a Carer's Assessment. Social Services can be contacted through your council offices or via their website. You can be assessed as a carer even if the disabled person you care for does not wish to be assessed.

You can get more information about Carer's Assessments from Carers UK, www.carersuk.org.

finance

Disability Living Allowance

Once your child reaches 16 they will have to claim Disability Living Allowance (DLA) for themselves, albeit probably with your help and support at least the first time. They usually have to have a bank account so that DLA can be paid to them directly. They can choose to have an account which allows them to collect their benefit at a Post Office if they prefer.

If your child is not able to act for themselves then payment can be made to you as their appointee. This means that you apply in writing to act for your child in everything to do with the claim, and you must notify changes in their circumstances which could affect their benefits. It may be very useful to become an appointee as it means that benefit staff will discuss your child's case with you. See our information on banking for more about being an appointee.

The DLA claim form is lengthy and it can be difficult to make a successful claim without help. The claim pack is different to the one you use when your child is under 16. It is a good idea to get some advice if you can before completing the form, for example, from a Citizens Advice Bureau. Remember that DLA can be paid for problems with getting around (the mobility component) and/or for personal care needs (the care component). It is the needs that matter and not how much care is actually provided.

The government has decided that DLA will be abolished in the future and replaced with a benefit called a Personal Independence Payment. This will not happen until 2013 at the earliest. The Personal Independence Payment will have a component for mobility and a component for 'daily living activities'. Both components will have two rates.

Carer's Allowance

If you are thinking of changing the hours you work or about moving in or out of paid work you may need to work out its effect on your entitlement to Carer's Allowance (CA).

You can claim CA if

- **You look after someone who gets middle or higher rate DLA (care) and**
- **You look after them 35 or more hours a week and**
- **You earn less than £100 a week (2010/11 rate).**

The £100 a week threshold is after you have taken off tax, National Insurance, half of certain pension contributions and care costs for your children and the disabled person you care for (up to half your wages). If you only work some weeks you can average the costs over the year.

Only one person can claim CA for looking after each disabled person. As your son or daughter becomes an adult they may want someone other than you to claim CA for caring for them, see page 15.

You can still get CA for your son or daughter if they claim benefits in their own right, or if they live somewhere else, as long as you meet the conditions.

If you care for two or more disabled people you still only get one payment of CA.

Child Benefit

If your child leaves school at 16, you lose the Child Benefit paid for your child from 31 August after your child's 16th birthday. It can be extended until they are 20 if they are still in education. You might be entitled to an extension of up to 20 weeks after they leave education if your child is 16 or 17, job seeking and is registered with Connexions, the local careers service in Scotland or Wales or the Department for Employment and Learning or an Education and Library Board in Northern Ireland. You can find more detail at www.direct.gov.uk.

If a young person is claiming benefit themselves (see page 18) there may be an overlap. You can't both claim. You may need advice or a better-off calculation to work out which option gives your family more money, as well as taking other factors into account.

From 2013, the government has announced that in families where at least one parent is paying higher rate tax, Child Benefit will be clawed back through the PAYE system. If the other parent is not paying National Insurance (NI) it would still be worth claiming Child Benefit for a child under 12 to receive NI credits, assuming the rules stay the same.

Child Tax Credit and Working Tax Credit

Child Tax Credit (CTC) and Working Tax Credit (WTC) are complicated. They are calculated together and the maximum amount you can get is based on your family circumstances. This maximum is greater if you have disabled children (who get DLA). You can also be entitled to more if you are disabled yourself (see page 18).

You can include 70% of your childcare costs (from April 2011), up to £175 a week for one child or £300 a week for two or more children, in the maximum award, for your disabled child(ren) up to the September after their 16th birthday, for your non-disabled children up to the September after their 15th birthday. This means that the maximum you can get for your childcare costs is £122.50 for one child or £210 a week for two or more.

This maximum tax credit is tapered away in line with your earnings. The more you earn the less you get. If you are part of a couple, either a man and a woman or a same sex couple, you are assessed jointly. Either of you may make the claim.

If your son or daughter becomes eligible for benefits in their own right it is advisable to do a 'better-off' calculation to establish whether it is more advantageous for the family for the young person to claim their own benefits or for you to claim for them as your children. If they are in full-time education, they can be counted as children for Tax Credit purposes until they are 20 unless they are working or claiming their own benefits. They have to follow a non-advanced course (below degree level). You can use the Tax Credits calculator on the HMRC website (www.hmrc.gov.uk) to calculate your entitlement if your circumstances change as your child grows older.

Example:

Kirsty is a lone parent of three children, the eldest of whom receives higher rate care component of DLA.

Kirsty works full-time and earns £20,000 a year (£384.62 a week). She pays an average of £100 a week (£5,200 a year) for childcare. She gets £62.37 a week WTC and £232.82 CTC.

Kirsty's disabled daughter turns 16, goes to college and claims her own benefits (Employment and Support Allowance and DLA) and Kirsty no longer has to pay for childcare.

Kirsty gets no WTC (as it is now all tapered away by her earnings). She gets £91.04 a week in CTC.

If you are overpaid tax credits, you should get advice. Overpayments can happen for many reasons. An advice agency such as the Citizens Advice Bureau may be able to help you.

Childcare Element of Working Tax Credit

If you are paying for registered childcare for any of your children, 70% of the cost (up to £175 a week for one child or £300 a week for two or more) can be included in the calculation of Working Tax Credit. This is worth up to £122.50 a week for one child or £210 for two or more. Your entitlement to the Childcare Element for a disabled child ceases the September after their 16th birthday (15th for non-disabled child).

Financial Support for Young People Who Continue with Education

If your young person continues in education after school leaving age they may be able to get some financial support.

The Education Maintenance Allowance (EMA) has been abolished in England. Some young people who are at school or college in the school year 2010/11 may still get EMA, but no one can make a new application for it now. EMA is £10, £20 or £30 a week, depending on your household income. If your young person is too late to apply for EMA, you should ask the school, college or training provider whether they can get any financial support.

In Wales, a young person can get EMA of £10, £20 or £30 a week depending on your family income.

In Scotland, a young person cannot apply for an EMA for 2010/11 after 31 March 2011. There is one level of EMA and it is for families on less than £20,351 (or £22,403 if there are two or more dependent children).

In Northern Ireland, a young person can get EMA of £10, £20 or £30 a week depending on your family income.

If the young person is getting EMA, they have to attend each week and meet the goals agreed with the course provider.

Your young person's income from part-time work or DLA is not taken into account. If you or your partner get DLA it is not taken into account.

EMA will not affect any benefits you get.

Your young person usually has to set up a bank account to get EMA, so that it can be paid directly to them. But it can be paid to you if your child can't manage the payments themselves.

Although EMA is going, there may be other financial support available for your young person. If your family is struggling with the costs of your young person being in education, you should ask student services at the college, school or training provider whether there is any financial help available.

You can get more information about EMA and other financial support in education from www.direct.gov.uk, or from your young person's school or college.

Free School Lunches

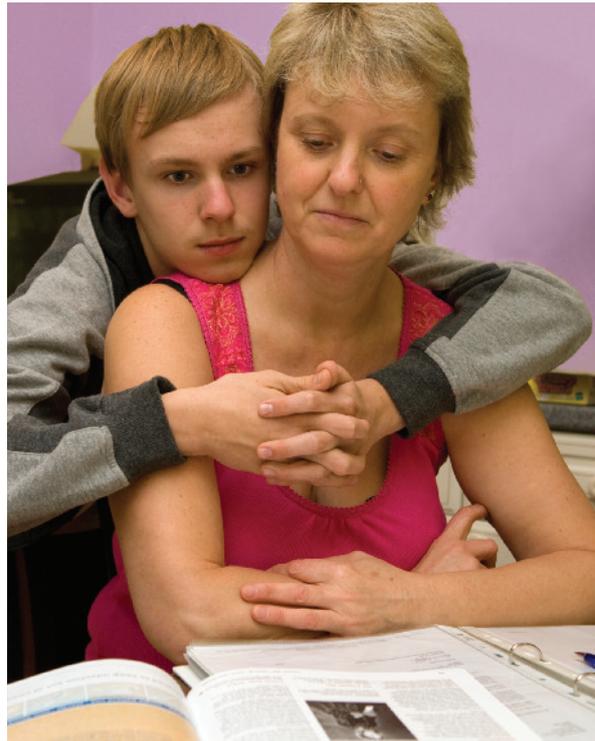
If your children are getting free school lunches your entitlement will have to be re-calculated when any of your children leaves school or if you take up or increase your paid work, otherwise your children will continue to get

their free school lunches until they leave school. If any of them is claiming any of the benefits below, they will be able to claim free school lunches for themselves irrespective of your income.

Qualifying benefits for free school lunches:

- **Income support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance**
- **Maximum child tax credit and working under 16 hours a week (no WTC)**
- **In Scotland only, getting maximum child tax credit AND WTC**

You claim by completing a form from the education department of your local authority, and sending it to the school with evidence of your benefit entitlement.



Benefits if a Young Person is Looking for Work – Jobseeker's Allowance

If your child is over 18, looking for a job and does not have enough money to live on, they may be able to get Jobseeker's Allowance (JSA).

If your young person's disability means that they cannot work or would have difficulty working, they may be able to claim Employment and Support Allowance (ESA) instead (see page 20). However, the medical to get ESA is quite strict and so the young person may be disabled but still found to have 'capability for work'. You should get advice if you are not sure or if your young person is turned down for ESA and you feel that this is not right, as they might be able to appeal.

There are two types of Jobseeker's Allowance, contribution-based and income-based. Contribution-based JSA is paid where someone has been working and meets the contribution conditions. Young people are usually not entitled to contribution-based JSA because they have not been working for long enough.

Income-based JSA is for people who are not working (or working less than 16 hours a week), on a low income and have savings of under £16,000. If your young person is aged 16 or 17 and is living at home, it is very difficult to claim JSA. They can usually only get it on the grounds of 'severe hardship' and this can be difficult to show. Important factors will include their disability and whether your family is on an income-based benefit. They will also have to register for work and training with the relevant careers service (for example Connexions if you are in England).

To get JSA a young person also has to show that they are actively seeking and are available for work. They may be allowed to restrict their availability for work (for example, say that they are only looking for part-time work or certain types of job) because of their physical or mental condition. They will usually have to provide medical evidence before they are allowed to restrict their availability.

A young person can claim Jobseeker's Allowance from Jobcentre Plus. You can get more information on the Direct Gov website www.direct.gov.uk, or you can ring Jobcentre Plus on 0800 055 66 88.

Employment and Support Allowance

If your child's disability means that they are unable to work or it is difficult for them to find a job, they may be able to get Employment and Support Allowance (ESA) when they reach 16. If your young person is thinking of applying, check your circumstances first. You might have a choice about who claims what if your young person is staying on in education (see page 6).

ESA is for someone who has 'limited capability for work'. It does not necessarily mean that your child cannot work at all. In some cases the Department for Work and Pensions (DWP) might decide that your young person's capability for work is not limited and refuse their claim for ESA – you should get advice if this happens.

There are two types of ESA, contribution-based and income-related.

If a young person is aged 16 to 19 then they do not need to have paid National Insurance (NI) contributions to qualify for 'contribution-based' ESA. This can also apply to people who are 20-24 who started a course of education or training at least three months before their 20th birthday. However, a young person cannot get ESA under these rules if they are under 19 and in full-time education, although some hours of education can be ignored if they are only provided because of your child's disability.

Income-related ESA has additional rules about having a low income and level of savings. A young person cannot get income-related ESA if they are in education unless they get DLA. If a young person is on DLA then they can study full-time and still get income-related ESA.

When a young person first applies for ESA they are put on the basic rate for their age. They usually have to undergo a 'Work Capability Assessment', consisting of a questionnaire and, probably, a medical. Some people are automatically treated as having limited capability for work, but this only applies in a few circumstances. The assessment is a points based scheme and determines whether your young person is entitled to ESA and, if so, whether they will be put in the 'support' group or the 'work related activity' group. A score of less than 15 in the 'limited capability for work test' means the young person has been deemed able to work and their claim for ESA will be refused. You should get advice if this happens. You might be able to appeal, or your young person may have to consider claiming Jobseeker's Allowance (JSA) (see page 18).

A score of 15 or more means that the young person has limited capability for work, and they can get ESA. The assessment will also look at whether they have 'limited capability for work-related activity'. This is a separate test about severe limitations in activities and it is not points based – all that matters is whether the young person can or cannot do the activities in the test. If they cannot do one or more of the activities, then they are put in the support group and they get a support component (extra money per week). Otherwise they are put in the work related activity group and payment of benefit will depend on their attending work focused interviews and other work-related activity. They will get a work-related activity component which is worth less than the support component. If your young person is in the support group, they will not be expected to do anything related to preparing for work or looking for work, but they can if they want to.

If your child is thinking about whether or not to claim ESA you should consider how much they will get, whether they can still get it in education, and how it will affect your family finances (see page 24).

Help with Your Rent and Council Tax

If you are on a low income, you may be able to get help with your rent and council tax through benefits. Housing Benefit can help you with your rent, and Council Tax Benefit can help you with the council tax.

If you are the only adult in your home, you should also be able to get a 25% discount off your council tax bill. Some adults are not counted, for example full-time students, some people with severe mental disabilities, and carers, so you may count as the only adult even if other people live with you. You should check with your council if you are not sure. This is not Council Tax Benefit, it just means that you have less council tax to pay, regardless of how much money you have coming in. If you get the 25% discount and you are on a low income, you may still be able to get some Council Tax Benefit as well.

When your child reaches 16, what they decide to do can affect these benefits. Housing Benefit and Council Tax Benefit are both worked out by looking at who is your dependant for benefit purposes. If your young person does not count as a dependant (for example, because they are claiming benefit themselves), then this will affect how much benefit you get. If you are not claiming benefits for your young person when they are 18, then a 'non-dependant deduction' might be made which will reduce your benefit. If you are claiming benefits for your child, then they count as your dependant and they will be included in your claim for Housing Benefit and Council Tax Benefit.

If your income changes, this will also affect Housing Benefit and Council Tax Benefit. The benefits take into account your earnings and your income from tax credits. It is not the hours you work which matter, but the money you make per week.

This can make it difficult to decide what to do and whether you should carry on claiming for your young person or whether they should claim themselves. It is a good idea to get some advice and a 'better-off calculation' so you can see what difference it would make financially.

Help with Health Costs

You can get information on help with health costs (prescriptions, sight tests, NHS dental treatment) on the Direct Gov website.

Prescriptions are free in Wales, and NHS dental check ups and sight tests are free in Scotland.

You will also be able to get free prescriptions, NHS dental treatment and free sight tests if you get:

- **Income Support**
- **Income-based Jobseeker's Allowance**
- **Income-related Employment and Support Allowance or**
- **Guarantee credit of Pension Credit,**

You also get this help if you claim tax credits, your income for your tax credit award is no more than £15,276 and you get one of the following:

- **Child Tax Credit and you are not eligible for Working Tax Credit because you don't work enough hours**
- **Child Tax Credit and Working Tax Credit**
- **Working Tax Credit with a disability or severe disability element.**

If you qualify through tax credits you should be sent an exemption certificate.

Your son or daughter will get help with health costs if they are under 16, or under 19 and in full-time education. If they leave education after age 16, they might still qualify because of the benefits they receive. It's also possible to get free prescriptions because of certain conditions. You can get more information about these from Direct Gov.

If help with health costs is important to you, this is another thing to consider when you are deciding what to do as your young person gets older. Even if you don't qualify for full help, you may be able to get some help because you are on a low income, through the NHS low income scheme. There is information about how to apply for this on the Direct Gov website.

Family Fund

The Family Fund gives discretionary grants to families with severely disabled children under 18, so if you're likely to qualify get your application in before your child turns 18. They have their own definition of 'severely disabled'. The grants are for things not supplied by statutory authorities and they encourage requests from young people that have particular meaning to their age group such as driving lessons, laptops and equipment for college. Families on certain benefits can apply – the benefits include Tax Credits, Employment and Support Allowance or Incapacity Benefit, income-based Jobseeker's Allowance, Income Support, Pension Credit and Housing Benefit. For more information visit www.familyfund.org.uk.

Banking

Once a young person receives benefits in their own right they will need their own bank account (see page 23). If your young person would not be able to manage this, even with support, you can apply to the Department for Work and Pensions (DWP) to become an appointee. You don't need to do this if a court has already appointed a person (you or another adult) to look after your young person's affairs.

For more information contact your local DWP office and see the British Bankers' Association website, www.bba.org.uk. If your son or daughter has money other than their benefits, you might need to apply to the Office of the Public Guardian to become their deputy so that you can handle their finances under supervision from the Office of the Public Guardian. The fees for this are paid out of the disabled person's money. If the disabled person is on a low income and/or is in receipt of certain means tested benefits they can be exempted from the fees. See www.publicguardian.gov.uk.



parents and carers in the workplace

Parental and Emergency Leave

When your disabled child turns 18 you lose your right to Parental Leave.

Once you have worked for your employer for a year you are entitled to take 18 weeks' unpaid parental leave for each disabled (gets DLA) child, to take before your child turns 18, and 13 weeks altogether for each non-disabled child, to take before your child turns five. Check your contract or with human resources, your employer may make more generous provision. If your contract doesn't specify, you can usually only take four weeks per child during any one year unless your contract gives you longer, but you can always ask your employer to be more flexible. You are also supposed to give 21 days' notice, but again, you should ask your employer because they may be able to be more flexible.

If you need extra time because of your caring commitments you can of course request some unpaid leave, but as a carer of an adult you do not have a right to it. You are still entitled to a short time off if an emergency arises. An emergency includes not only the sickness of a relative, but also the breakdown of normal care arrangements.

You can get more information about Parental and Emergency Leave from Working Families, www.workingfamilies.org.uk and ACAS, www.acas.org.uk.

flexible working

Changing Your Work Pattern

When your son or daughter leaves school or college you may need to change the way you work to fit in with the new routine. If you need to change your hours, perhaps to part-time or to fit with the longer holidays college students get, or perhaps you want to do some of your work from home, you have some legal rights. Your employment contract may give you better rights than the legal minimum detailed below. If you want to make a change first consult your contract or, if yours is a large employer, contact the human resources department.

Right to Request Flexible Working

If you have been in your job at least 26 weeks you have the right to request flexible working if you are the parent of a child under 17, the parent of a disabled child under 18 (who gets DLA) or if you care for an adult of 18 or over who needs care. You need to apply in writing and you and your employer must follow a set procedure. Your employer must consider the request seriously and can only turn you down on specified grounds.

You can find out more details about the right to request from Working Families' website or helpline (0800 013 0313) or from ACAS.

Sex or Marital Discrimination

Because women tend to have more childcare responsibilities than men, insisting that women work long or inflexible hours can be indirect sex discrimination. The same principles should apply where women employees need flexible work to care for adults. Employers are allowed to refuse flexible working if they have genuine business reasons.

Men cannot claim indirect sex discrimination when they've been turned down for flexible working. However, a married man or a man in a civil partnership might be able to claim indirect marital discrimination, if, without justification, he was not permitted to work flexibly, and suffered harm as a result. Also, men, whether married or not, can claim direct sex discrimination in certain circumstances, for example, if women are allowed to work part-time in similar jobs but a man is not.

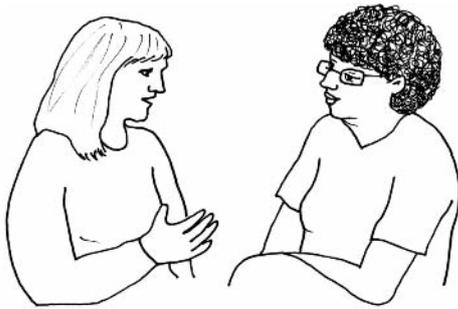
If your new regime means that you are in a position to work increased hours you cannot use the 'Right to Request Flexible Working' procedure detailed above, but you can just ask your employer if the increased hours you want are available. It could still be discrimination if you were turned down because of your caring responsibilities without good business reasons.

If your request to change the way you work has been turned down and you want to take matters further you can get advice from Working Families, your union or ACAS.



section 2

young people



Money matters are complicated.
Getting care can be difficult.
You may want to get advice.

What follows is general information. You may need to take more detailed advice about your own situation, especially if you are not normally resident in the UK, are not British or are a parent yourself.

care and support

If you are 16 or over and your disability means that you need care and/or support to be independent, you can ask your social services for an assessment. If social services agree that you qualify for services they may offer you 'direct payments' to pay for the services yourself or they may offer you the choice of direct payments or using their services. You have the right to choose direct payments instead of the council's services unless you are unable to manage the scheme.

If you get direct payments to employ a personal assistant (PA), you will also get the extra you need to pay Employer's National Insurance contributions. Many local authorities also provide support with the responsibilities of being an employer.



You will have to set up a separate bank account for your direct payments, see page 23, and they will not affect you or your parents' entitlement to other benefits.

Local authorities beginning to change over to 'Personalised Budgets'. 'Personalised Budgets' are a more flexible way of accessing services including council services.