

From Child to Adult

Disability, transition
and family finance



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Written by Working Families



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. Their entitlement may depend on whether they are still in education, job seeking or claiming benefits. Parents' and carers' benefits and tax credits will depend not only on the student or employment status of the young person but also on what benefits the young person is claiming.

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 person as a dependant.

Section 1 of this booklet provides 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 (section 3). At the end of the booklet is a list of organisations, publications and website which can help you – including Working Families.

Working Families' website, www.workingfamilies.org.uk, includes information relevant to families combining paid work and caring for children and adults. Working Families has a free helpline for disadvantaged families and parents and carers of disabled children: **0300 012 0312**.

'Waving *not* drowning', Working Families' network and advice service for parents and carers of disabled children who are trying to

combine work and caring, produces a free quarterly newsletter and a monthly e-bulletin. To add your name to the distribution lists, email advice@workingfamilies.org.uk.



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 a British citizen or not normally resident in the UK. You will also need to take further advice if the young disabled person in the family has children of their own.



1 Parents and carers

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, any educational course they are enrolled in, 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.

Carer's Assessment

If you are looking after a disabled child, 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 is assessing the needs of your son or daughter.

The Carer's 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.



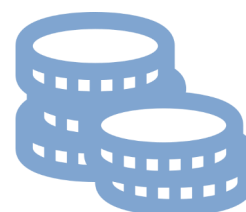
Direct payments

If social services agree that your child qualifies for services, they may offer you 'direct payments' to pay for some of the services yourself. Direct payments can be applied for by a disabled person aged 16 or over, or it can be applied for by a carer aged 16 years old or over. 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 usually have to set up a separate bank account for your direct payments.

Direct payments can also be paid to disabled people aged 16 and over (see page 13).



Finance

Carer's Allowance

Carer's Allowance (CA) is a benefit for people who provide full-time care to a person who is in receipt of disability benefits. If you are thinking of changing the hours you work or you are about to move in or out of paid work, you may need to calculate the effect on your entitlement to Carer's Allowance.

You can claim CA if

- you look after someone who gets middle or higher rate DLA, or PIP daily living component, and
- you look after them 35 or more hours a week, and
- you earn no more than £120 a week, and
- you are not in full-time education.

The £120 a week threshold is after you have taken off tax, National Insurance, half of employee 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 set out above. However, you should seek advice, as your claim for CA could reduce their benefits if they no longer live with you.

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

Child Benefit

If your child leaves school when they are over 16, you lose the Child Benefit paid for them at the next terminal date (the last day in February, May, August or November – whichever of these dates comes up first after your child leaves school). Alternatively, Child Benefit can continue until a young person is 19 if they are still in non-advanced (below degree level), full-time education (or even until they are 20 if they started, were accepted or enrolled on a course before they were 19). You might be entitled to an extension of up to 20 weeks after they leave education if your child is 16 or 17, not in work, education or training and is registered with the careers service or a similar specified organisation.

You can find more information on this at www.gov.uk.



Bear in mind that you may not be able claim Child Benefit for your young person if they claim benefits for themselves. Conversely, your young person cannot claim benefits for themselves if you claim Child Benefit for them. You may need advice or a better-off

1 Parents and carers *continued*

calculation (see page 21) to work out which option gives your family more money, as well as taking other factors into account. Consider using an online benefits calculator, such as the one found on the website

www.entitledto.co.uk.

Since January 2013, in families where at least one partner or parent has income of more than £50,000 (even if they are not the parent of the child you're claiming for), you must pay back some or all of the Child Benefit you claim via a tax charge. If the person claiming Child Benefit is not paying National Insurance (NI), because for example, they don't work or have low earnings, it can still be worth claiming Child Benefit for a child under 12 to receive NI credits. Have a look on the HMRC website for more information (www.hmrc.gov.uk).

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 or PIP – see page 14).

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

childcare costs is £122.50 for one child or £210 a week for two or more. To get the childcare element, both members of a couple must be working 16 hours a week, or one works at least 16 hours and the other is disabled or a full-time carer receiving Carer's Allowance (CA). If you are a lone parent, you must work 16 hours a week.

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, 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 young person to claim their own benefits or for you to claim for them as your child (see page 21). If they are in full-time education, they can be counted as a child for Tax Credit purposes until they are 20 (as long as they started, enrolled or were accepted onto the course before they were 19) unless they are working or claiming their own benefits. They have to follow a non-advanced course (below degree level). You can use www.gov.uk/tax-credits-calculator to calculate your entitlement if your circumstances change as your child grows older, or use the benefits calculator on the website www.entitledto.co.uk which will give you an overview of all your tax credits and benefits.

If you are overpaid tax credits, you should get advice. Overpayments can happen for many reasons. In some cases you can challenge the decision to make you repay an overpayment. An advice agency such as Citizens Advice may be able to help you.



Example – Child Tax Credit (CTC) and Working Tax Credit (WTC):

Kirsty is a lone parent of three children, the eldest of whom receives the 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 for her disabled daughter. She gets WTC (including the childcare element) and CTC.

Kirsty's disabled daughter turns 16, goes to college and claims her own benefits (Universal Credit and PIP) and Kirsty can no longer claim for childcare costs for her disabled daughter.

Kirsty gets no WTC (as it is now all tapered away by her earnings). She continues to get CTC for her two younger children.



Universal Credit

Universal Credit (UC) is a single, monthly-paid benefit which replaces the following benefits from the 'old' (legacy) system:

- Income Support
- Income-related Employment and Support Allowance (ESA)
- Income-based Jobseeker's Allowance (JSA)
- Working Tax Credit (WTC)
- Child Tax Credit (CTC)
- Housing Benefit (HB)

As of January 2019, it is no longer possible to make a new claim for any of the benefits listed above unless you have three or more children. Most claimants seeking to make a new claim will have to claim UC instead.



Between July 2019 and March 2022, people on the 'old' benefits will be moved over to UC. Once a person has claimed UC it is not possible to go back to the legacy benefits mentioned above.

UC includes amounts for children, additional amounts for disabled children (including those over 16 in full-time education if you continue to claim for them), and amounts to help with childcare costs, as well as a housing element. The amounts for children will be higher depending on whether your child/young person receives DLA/PIP and if so, at what rate.

For a disabled adult claiming UC they can ask to be assessed to see if they have limited capability for work and limited capability for

work-related activity. The test is the same as the test for ESA (see page 18). The outcome of the capability assessment will determine whether they have to meet work-seeking requirements. If they are found to have both limited capability for work and limited capability for work-related activity, then this will increase their UC award. People receiving UC can still claim PIP.

Universal Credit and childcare

Universal Credit (UC) has a childcare element. This covers up to 85% of childcare costs, up to a maximum monthly amount of £646 if you have one child or £1,108 if you have two or more children. To be eligible you must work but there is no hours test to qualify so you can get the childcare element even if you work less than 16 hours. If you have a partner they must also work unless your partner is a carer who is eligible for Carer's Allowance or your partner is unable to provide childcare because they have limited capability for work.

Free school lunches

Entitlement to free school lunches depends on receiving the benefits below. If your young person is claiming any of these benefits in their own right, 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 (JSA) and income-related Employment and Support Allowance (ESA) – and in England and Wales, the Guarantee

- Credit component of Pension Credit;
- Child Tax Credit (CTC) and not being entitled to Working Tax Credit (WTC);
- Working Tax Credits (WTC) with a household income under £16,190 (£16,105 in Scotland);
- Working Tax Credit (WTC) 'run-on', which is the payment a person may receive for a further four weeks after they stop qualifying for WTC;
- Universal Credit (with a household income of less than £7,400 a year after tax and not including any benefits you get);
- In Scotland only, getting maximum Child Tax Credit (CTC) and maximum Working Tax Credit (WTC) and with your income being under £6,420.

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.

Help with your rent and council tax

You can get help with your rent through Housing Benefit or through the housing element which is paid as part of UC. As of January

2019, it is no longer possible to make a new claim for Housing Benefit unless you have more than three children. Most people making a new claim will have to claim UC instead.

Under UC, most claimants will get their housing element paid to them and it will be the claimant's responsibility to pay their landlord. If this affects your young person



and they would struggle to manage paying their rent, ask the Department for Work and Pensions (DWP) if an exception can be made so that the housing element of UC is paid direct to their landlord by the DWP.

In addition, your local authority will also have a scheme to help people with council tax costs called Council Tax Reduction or Council Tax Support. It is worth checking these with your local authority.

Furthermore, 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 Reduction, 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, it is still worth checking to see whether you can get any additional help. Council Tax Reduction works differently in different local authorities, so you should ask your council what applies to you.

When your child reaches 16, what they decide to do can affect these benefits. Housing Benefit, UC and most Council Tax Reduction schemes are 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. Therefore, you should contact DWP and your local authority if this is the case to prevent any overpayment

of 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/UC and Council Tax Reduction.

If your income changes, this will also affect Housing Benefit, UC and Council Tax Reduction. 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 do a better-off calculation (see page 21) so you can see what difference it would make financially. You can use an online benefits calculator such as www.entitledto.co.uk.



Help with health costs

You can get information on help with health costs (prescriptions, sight tests, NHS dental treatment) on the www.gov.uk 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 any of the following:

- Income Support;
- Universal Credit (UC), provided your earnings are below the threshold (see below);
- Income-based Jobseeker's Allowance (JSA);
- Income-related Employment and Support Allowance (ESA); and/or

1 Parents and carers *continued*

- In some cases, the Guarantee Credit component of Pension Credit.

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

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

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

To qualify through Universal Credit (UC) you must either:

- a. receive Universal Credit and have had no earnings, or had net earnings of £435 or less, in your last Universal Credit assessment period; or
- b. receive Universal Credit, which includes an element for a child, or you (or your partner) had limited capability for work (LCW) or limited capability for work and work-related activity (LCWRA), and you either had no earnings or net earnings of £935 or less, in your last Universal Credit assessment period.

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 the website www.gov.uk.

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 websites www.gov.uk and www.nhs.uk.

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 are particularly relevant to their age group such as driving lessons, laptops and equipment for college. Families on certain benefits can apply – the benefits include Universal Credit (UC), tax credits, income-related Employment and Support Allowance (ESA), income-based Jobseeker's Allowance (JSA), Income Support, Pension Credit and Housing Benefit. For more information visit www.familyfund.org.uk.

Banking and registering as an appointee

Once a young person receives benefits in their own right, they will need their own bank account. 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. To become an appointee, you will need to contact the relevant benefit department. They



will then arrange an interview with your young person as a claimant and you as the prospective appointee to determine that an appointee is needed and check you are a suitable person. If you become an appointee, you will have permission to act for your child in everything to do with the claim. 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.

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 can be 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.justice.gov.uk/about/opg.



Parents and carers in the workplace

Parental and emergency leave

Once you have worked for your employer for a year, you are entitled to take 18 weeks unpaid parental leave for each child. This leave must be taken before your child turns 18. 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. For a

disabled child (a child receiving DLA or PIP), this time can be taken one day or more at a time (it doesn't have to be in weeks). For a child who does not have a disability, the leave must be booked in blocks of one week. 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. Your employer cannot refuse your request for parental leave, however they can postpone it by up to six months if they meet certain conditions.

If you need extra time off once your young person is 18, you can of course request time off using your normal paid holiday entitlement or 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, which is called emergency leave or time off for dependants. An emergency includes not only the sickness of a relative, but also includes the unexpected 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

1 Parents and carers *continued*

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 or approach your manager.

The right to request flexible working

You can always make an informal flexible working request to your manager but if you have been in your job at least 26 weeks and you are an employee, you have a legal formal right to request flexible working. 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. If you have been in your job for less than 26 weeks, you can make an informal request for flexible working; however, your employer will not have a legal duty to consider it. You can find more information about the right to request from Working Families' website, www.workingfamilies.org.uk, and Acas, www.acas.org.uk.

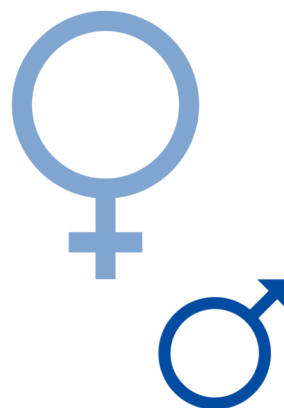


Sex discrimination

Because women tend to have more childcare responsibilities than men, insisting that employees 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. However, employers are allowed to justify the refusal of a flexible working request (even if it is discriminatory) if it is genuinely necessary for the business.

Men cannot claim indirect sex discrimination when they've been turned down for flexible working. However, a man can claim direct sex discrimination in certain circumstances, for example, if he is refused flexible working in a situation where women doing similar jobs are allowed to work part-time.

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.



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 do not normally live 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. 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 19). They will not affect you or your parents' entitlement to other benefits.

Local authorities are beginning to change over to 'personal budgets'. Personal budgets are a more flexible way of accessing services including council services.



Finance

Disability Living Allowance (DLA) or Personal Independence Payment (PIP) – young person

As a child, your parents may have been claiming Disability Living Allowance (DLA) for you. Once you turn 16, if you have been on DLA, you will soon be invited to claim Personal Independence Payment (PIP). DLA is ending for people who are 16 and over. If you are making a completely new claim at 16 and you were not on DLA before, you will have to claim PIP. It is worth considering a claim for PIP even if you didn't get DLA, as it has different eligibility criteria.

If you are on DLA when you are 16 and you are invited to claim PIP, your DLA should be extended so that there is time for the PIP assessment to happen. However, if you don't claim PIP when you are invited to do so, your

DLA will stop – the letter should give you a time limit by which you have to make your PIP claim.

DLA and PIP give you extra income to help with the costs of disabled living and also act as 'passport benefits'. Qualifying for DLA or PIP can automatically entitle you to some other benefits and concessions.

You will usually need to open a bank account so that your DLA/PIP can be paid direct to you – see page 19. If you can't manage to receive payments yourself, payment can be made to someone else on your behalf, called an 'appointee' – see page 10. This could be your parent or someone else who will take responsibility for the claim.

DLA and PIP are complex benefits and it can be difficult to make a successful claim by yourself. It is a good idea to seek advice about how to claim from an expert. Your parents may well already have experience of claiming and know a suitable adviser. Otherwise, find out if your local council has a benefits advice service, contact your local Citizens Advice or a disability organisation. It can be tricky making clear the extent of the help and support you need. You may be so accustomed to your own way of doing things that you do not realise what you need to explain to someone who doesn't know you.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is in two parts: care and mobility components.

You qualify for the care component if your disability is severe enough for you to need help caring for yourself or need someone to supervise you, for your own or someone else's safety.

There are three rates which depend on how often you need care:

- Lower rate – needing help with personal care for a significant portion of the day (at least an hour in total most days)
- Middle rate – needing frequent help or constant supervision during the day or needing supervision at night
- Higher rate – needing help or supervision throughout both night and day, or are terminally ill

Remember, you do not have to actually receive the care to qualify.

There are two rates of the mobility component:

- Lower rate – needing guidance when in unfamiliar surroundings
- Higher rate – either unable or virtually unable to walk, or some blind or partially sighted people, or severely mentally impaired people with severe behavioural problems who also qualify for the highest care component rate

activities such as washing, going to the toilet, dressing, eating and communicating. You can also get points if you have difficulty with activities such as engaging with people and budgeting.

The mobility component looks at how you manage with planning and following journeys and moving around. If you get the enhanced mobility component, you can use it to buy or lease a Motability vehicle.

Always keep copies of your completed claim form and any letters or emails you send and keep notes on telephone conversations. If your claim is turned down, seek advice straight away about challenging the decision. There are very strict time limits: you have one month to request a mandatory reconsideration. If you are unhappy with the outcome of the mandatory reconsideration, you may request an appeal within one month of the new decision. You should seek advice when challenging a PIP decision.

If you are invited to claim PIP, your DLA won't end until a decision is made. But if you don't claim PIP within the time limit you are given, your DLA will end anyway.

Personal Independence Payment (PIP)

Personal Independence Payment has two components, mobility and daily living, which both have two rates. PIP is a points-based benefit. Eligibility is usually assessed by looking at the answers provided on the claim form, medical evidence and a medical assessment. You get points depending on how difficult you find it to do everyday activities and to move around. You need eight points for the standard rate, and 12 points for the enhanced rate. The daily living component looks at how you cope with

Carer's Allowance (CA)

If you get middle or higher rate DLA care component, or PIP daily living component, someone who helps you with personal care can claim Carer's Allowance. This doesn't have to be a relative or someone who lives with you. The person must:

- help you for 35 or more hours a week and
- earn no more than £120 a week (after tax and other deductions) and
- not be in full-time education.

2 Young people *continued*

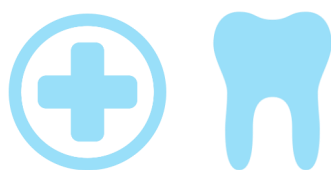
If you are claiming other benefits such as Income Support, income-based Jobseeker's Allowance (JSA), income-related Employment and Support Allowance (ESA) or Housing Benefit, you should get advice before someone claims Carer's Allowance for helping you, as it could reduce the amount you receive.

VAT exemption

As a disabled person you may not have to pay Value Added Tax (VAT) on some goods and services designed to be of practical help because of your disability, such as an adjustable bed or low vision aids, if you are buying them solely for your personal use. There is information about who qualifies for VAT exemption and on what goods and services at www.hmrc.gov.uk. They also provide a sample form which you can use to declare your entitlement.



Help with health costs



You can get information on help with health costs (prescriptions, sight tests, NHS dental treatment) on the www.gov.uk and www.nhs.uk websites.



Prescriptions are free for all people in Scotland, Wales and Northern Ireland.

You will also get help with health costs whilst you are under 16, or under 19 and in full-time education. If you leave education after age 16, you might still qualify if you claim benefits

or tax credits for people on low incomes. It's also possible to get free prescriptions because of certain conditions. You can get more information about these from www.gov.uk and www.nhs.uk.



If help with health costs is important to you, this is another thing to consider when you are deciding who in your family should claim for you. 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 www.gov.uk and www.nhs.uk websites.



Financial support for young people who continue with education

If you continue in education after school leaving age you may be able to get some financial support called an Education Maintenance Allowance, but only in Wales, Scotland or Northern Ireland.

Education Maintenance Allowance (EMA) has been abolished in England. If you need financial help to continue in education, you should ask your school or college about their discretionary funds.

In Wales and Scotland, you can get EMA of £30 a week depending on your family income. Look on www.gov.uk where it will direct you to the relevant sites.



In Northern Ireland, you can get EMA of £30 a week depending on your family income, but there are other types of EMA if you are on certain training schemes which do not depend on family income. Look on www.gov.uk for more information.



If you are getting EMA, you must attend school or college each week and meet the goals agreed with the course provider.

You usually have to set up a bank account to get EMA, so that it can be paid directly to you. But it can be paid to your parents if you can't manage the payments yourself. EMA does not affect the benefits you or your parents get.

Other financial support may be available for some students. You should speak to student services at your school, college or training provider to see whether there is any financial support to help you continue your studies.



You can get more information about financial support in education from www.gov.uk, or from your school or college.

Financial support for young people who go into higher education

Higher education (sometimes called advanced education) includes university degrees, Higher National Diplomas and foundation degrees. Being a student in higher education means that it is not possible for a parent or carer to receive additional amounts of Child Benefit, tax credits or Universal Credit in respect of the young person who is studying.

If you go on to higher education, you can get maintenance loans and tuition fee loans to cover living expenses and the cost of your course. Many universities offer means-tested bursaries and scholarships to students from low income backgrounds or those who are disadvantaged for other reasons such as disability.

Usually undertaking advanced education means that you will not be entitled to income related benefits such as ESA, JSA, UC or HB. However, if you are in receipt of PIP or DLA and you have limited capability for work (see page 18) then you may be entitled to ESA or UC and HB. Beware that student loans and grants count as income for many income-related benefits and so being eligible for grants and loans may reduce your benefit award.

You will continue to receive PIP or DLA if you choose to attend university. The amount you receive will remain the same and will not be affected by student loans or grants.

Disabled Students Allowance

If you are a disabled student in higher education, you can apply for Disabled Students Allowance (DSA) to help pay for extra support because of your disability, such as computer equipment, non-medical assistance and travel. The assessment, how much you can get and other details are at www.gov.uk/disabled-students-allowances-dsas. Disability Rights UK, www.disabilityrightsuk.org, publishes a factsheet and once you've been accepted on a course you can seek advice from your college's Disability Officer. DSA is not means-tested and will not affect other benefits you or your parents are receiving.



Universal Credit

Universal Credit (UC) is a benefit for people who are looking for work or cannot work because of an illness or some other reason including being a carer or single parent with

young children. It can include payments towards your rent, childcare costs and additional amounts if you have children. Usually to receive UC you must meet certain conditions such as attending interviews and looking for work. However, you may be exempt from these conditions due to illness, disability, childcare responsibility or caring responsibility. If you cannot work because of an illness or disability, see the next section on the work capability assessment (WCA) for more information. If you have made a claim before January 2019 or you have three children or more then you might be excluded from claiming UC and you will have to claim under the old benefits system instead.

The work capability assessment (WCA)

If you cannot work because of illness or disability, you will need to go through a work capability assessment in order to be exempt from work-seeking requirements. The work capability assessment used to be something that was only used to decide if someone was eligible for Employment Support Allowance (ESA), but now it is also used in Universal Credit (UC) claims to decide whether you will have to meet work-seeking requirements as a condition of receiving your benefit.

When you first apply for ESA or UC you are put on the basic rate for your age. The work capability assessment consists of a questionnaire and (in most cases) a medical assessment. 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 you have limited capability for work and, if so, whether you have limited capability for work-related

activity. A score of less than 15 in the 'limited capability for work test' means you have been deemed able to work. If you have made a claim for ESA this means that your claim will be refused; if you have claimed UC you will remain on UC but will have to meet the work-seeking requirements in order to continue receiving payments. If you want to challenge the refusal, you have one month from the date of the decision letter to submit a mandatory reconsideration and if the mandatory reconsideration is not successful you then have one further month to request an appeal in the tribunal.

A score of 15 or more means that you have limited capability for work and this means you will be awarded ESA or UC with exemptions from certain work-seeking requirements. The assessment will also look at whether you have 'limited capability for work-related activity'. This is a separate test about severe limitations in specific daily activities. It is not points-based – all that matters is whether you can or cannot do the activities in the test. If you cannot do one or more of the activities, then you are found to have limited capability for work-related activity (LCWRA). Having LCWRA will mean that you will receive an additional payment as part of your ESA or UC. In addition, it means that you do not have to attend work-focused interviews or other work-related activity. If you are found to have limited capability for work but not limited capability for work-related activity you will not have to apply for jobs, accept jobs and attend compulsory training; however, you will have to attend work-focused interviews and do other work-preparation activities.

If you are thinking about whether to claim ESA/UC you should consider how much you will get, whether you can still get it whilst in education, and how it will affect your family finances (see page 21).

Banking

If you are to receive benefits, you will need your own bank account. Banks vary in what they offer but have information about their services and charges on their websites and in their branches. You can work out which suits you best and whether you want to bank on-line.

In order to open an account you need to provide proof of your identity. An official letter, such as one about your disability living allowance (DLA), can be used to prove your address. If you haven't got the sort of documents the bank demands to prove your identity, it is worth trying another bank. They have different rules. You can find out more about banking at www.fca.org.uk/consumers/opening-bank-account.



If you can't manage to run a bank account, even with support, someone else can be your 'appointee' and deal with your money matters on your behalf. See page 10.

Young people in the workplace

Access to Work

Access to Work (ATW) can help pay for support you need at work because of your disability. It can help with such things as specially adapted equipment, travel and sometimes someone to help you. ATW can help you if you're employed, self-employed, doing a work trial or with some apprenticeships. If you start work and you think you might need help from ATW, it is essential that you contact them straight away.

After you've been there six weeks they are only prepared to pay a proportion of the costs. You can contact ATW through your local ATW centre or through your Disability Employment Adviser (DEA) at Jobcentre Plus.

Help with travel and leisure

Cinema card

A Cinema Card entitles you to a free ticket for someone, over 16, accompanying you to participating cinemas. You can apply for a card if you are in receipt of DLA, PIP or are registered blind. It costs £5.50 and lasts a year. For further information and an application form visit www.ceacard.co.uk.



Bus pass

You are entitled to a bus pass for free off-peak travel on local bus services nationwide if you

- are blind or partially sighted
- are profoundly or severely deaf
- are without speech
- have a disability, or have suffered an injury, which has a substantial and long-term effect on your ability to walk
- do not have arms or have long-term loss of the use of both arms
- have a learning disability
- would, if you applied for a licence to drive a motor vehicle under Part III of

2 Young people *continued*

the Road Traffic Act 1988, have your application refused under section 92 of the Act (physical fitness) on grounds other than persistent misuse of drugs or alcohol

Bus passes are provided by your local authority and some make more generous provision in their own area, such as free 24-hour travel, underground travel and concessions for accompanying carers. You need to enquire locally. There will be information on your local authority's website.

You will also need to enquire locally about other travel facilities your council may provide such as taxicards, dial-a-ride services and community transport. Visit www.disabledpersons-railcard.co.uk to find out about disabled persons' rail cards.



Leisure passes

Local authorities have a variety of different concessions available to local disabled people who want to use leisure and library facilities. Enquire locally to see what your local authority provides. Individual leisure providers such as sports venues or theatres often have their own schemes for reduced prices for disabled people, people on benefits, students, etc. It is worth enquiring.



Motability

If you get the high rate mobility (HRM) component of DLA or the enhanced rate mobility component of PIP, you can use it to buy or lease a car through Motability. If you can't drive, you can nominate up to two other people, for example your parents or personal assistants, who can drive it. There are restrictions on your choice of car if you are under 25, for insurance reasons. Visit www.motability.co.uk for more details. People on HRM can get a provisional licence and learn to drive at age 16.



If you are unsure about whether you could learn to drive or want to know about adaptations, you can have an assessment.

Blue Badge

Blue Badges are a Europe-wide scheme. They can be used by disabled drivers and passengers and entitle you to some toll, congestion charge and parking concessions. The extent of the concessions can vary locally. Some people, such as those who are registered blind, get the higher rate mobility component of DLA or have been awarded eight points or more in the PIP 'moving around' activity, are automatically eligible for a Blue Badge. Others, such as those who are unable to walk or have substantial difficulty in walking or drive regularly and have a severe disability in both arms and have considerable difficulty in operating parking meters, can qualify after an assessment. Apply to your local authority (www.nidirect.gov.uk in Northern Ireland) for a Blue Badge. They can charge a fee.



3 Better-off calculation

As a young person moves towards adulthood, the family finances inevitably change. If the young person is disabled, the situation can be complex because of the range of benefits and tax credits which may be involved. Parents and carers may also want to change their work patterns as caring responsibilities change.

The family probably needs to do a 'better-off' calculation whenever a young disabled person moves on a stage, to further or higher education, job seeking or claiming their own benefits as well as when they reach a milestone birthday of 16, 17, 18 or 19.



It is important to remember that benefits and allowances paid to the young person belong to them, and not to their families, so the decision isn't just about how much money is paid out overall.

You might need to get advice about how much you would get in different situations. You can use a free benefits calculator, such as www.entitledto.co.uk, or you could seek advice from



your local Citizens Advice or disability information service to see which option is best.

To give you a general overview of which course of action would make your family better off, we have created a table for you to complete, on the next page. Fill in the two left-hand columns, thinking about what your family would get if the young person remains a dependant. Then fill in the two right-hand columns, thinking about what each of you would get if the young person was regarded as an independent adult.

Bear in mind that payments made to young people belong to them and not to the family.

Total up the columns to see which course of action makes your family better off. Remember to make each payment cover the **same** time period (for example weekly or monthly), so that you are adding up the right amounts.



3 Better-off calculation *continued*

Benefit/ allowance	If disabled young person is still dependent on their parent(s)		If disabled young person is regarded as independent	
	Parent(s)	Young person	Parent(s)	Young person
Child Benefit				
Carer's Allowance				
Housing Benefit				
Council Tax Reduction				
Jobseeker's Allowance				
Employment and Support Allowance				
Tax credits				
Income Support				
Universal Credit				
DLA/PIP				
Free school lunches (amount you would spend if you had to pay)				
EMA or DSA				
Other benefits/ allowances				
Total:				
Family total:				



Useful organisations, publications and websites



Working Families' website, www.workingfamilies.org.uk, includes information relevant to families combining paid work and caring for children and adults. Working Families has a free helpline for disadvantaged families and parents and carers of disabled children: **0300 012 0312**.



'Waving *not* drowning', Working Families' network and advice service for parents and carers of disabled children who are trying to combine work and caring, produces a free quarterly newsletter and a monthly e-bulletin. To add your name to the distribution lists, email advice@workingfamilies.org.uk.



Other useful organisations/websites

Advisory Conciliation and Arbitration Service (Acas) www.acas.org.uk

Carers UK www.carersuk.org

Cinema Card www.ceacard.co.uk

Citizens Advice (previously Citizens Advice Bureau) www.citizensadvice.org.uk

Disability Rights UK www.disabilityrightsuk.org

Disabled Person's Rail Card www.disabledpersons-railcard.co.uk

Family Fund www.familyfund.org.uk

GOV.uk www.gov.uk

Money Advice Service www.moneyadviceservice.org.uk

Motability www.motability.co.uk

Office of the Public Guardian www.justice.gov.uk/about/opg

Scope www.scope.org.uk

Transport for All www.transportforall.org.uk





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