

Personal Independence Payment and other benefits at 16

Information for parents of disabled children in England, Scotland and Wales



The information in this guide is accurate as of October 2017. This guide applies to England, Scotland and Wales. In Northern Ireland some changes to the benefit system have been delayed. Personal Independence Payment was introduced in Northern Ireland in June this year but there may be differences in how it is administered. Universal credit is being introduced in Northern Ireland in October.

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Introduction

This guide looks at the benefits it may be possible for a young disabled person to claim once they turn 16 years of age.

Part 1 looks at Personal Independence Payment (PIP).

This is the benefit that is replacing Disability Living Allowance (DLA) for people aged 16-64. You can still receive payments of Child Benefit and any other benefits you get for your child alongside PIP.

Part 2 is in three sections and looks at other benefits your child may be able to claim in their own right once they are 16 or over. If they claim some of these other benefits, any Child Benefit and any other payments you receive for them as a dependant will stop.

Section 1 looks at what happens if your child stays on in certain types of education or training. In this situation you are likely to have a choice of either continuing to claim benefits for your child as a dependant, or helping them claim benefit in their own right as a disabled adult.

Section 2 gives a brief outline of the benefits your child may be able to claim when they leave non-advanced education or training and move into advanced education, training or work, or none of the above.

Section 3 looks in more detail at the benefits that can be claimed by a young person aged 16. What they may claim depends on whether or not they are in education, training or paid employment, and what other income they have.



Part 1

Personal Independence Payment (PIP)

What is Personal Independence Payment?

Personal Independence Payment (PIP) is a benefit that replaces the current Disability Living Allowance (DLA) for people aged 16 to 64.

Although PIP looks similar to DLA in some respects, it uses entirely new rules to decide whether you qualify for the benefit, and at what rate.

Most people will also be asked to attend a face-to-face meeting with a health professional when they are being assessed for PIP.

DLA will remain as a benefit for children aged under 16.

PIP has two parts – called components. There is a daily living component and a mobility component. Depending on their needs, your son or daughter may qualify for one of these components, or for both at the same time.

PIP is not means-tested so it makes no difference what savings or income your son or daughter has. It can also be paid regardless of whether they are working, and it does not depend on National Insurance contributions.



Who can claim PIP?

The main thing that will determine whether your child qualifies for PIP is how their condition affects their ability to carry out certain key activities necessary for independent living. See page 18 for more details of the activities that are considered.

Anyone who is applying for PIP must also:

- be aged between 16 and 64, and
- meet the required period condition (see box below), and
- not be subject to immigration control, and
- meet certain tests linked to their residence and presence in the UK.

What is the required period condition?

If your child isn't already on DLA and makes a claim for PIP, you normally must show that they met the relevant disability tests for the previous three months, and also expect to continue to meet them for at least a further nine months. This does not mean that you will necessarily have to wait three months before your payments start – as you may be able to show that they met the disability tests in the three months before they claimed.

If your child is moving from DLA to PIP, you won't have to show that they met the tests in the previous three months. But their needs must still be expected to last for at least nine months. You may also be exempt from meeting the three month test if reclaiming PIP within two years of a previous award ending. This will apply so long as they are claiming the same component of PIP, and they have the same condition (or a condition that has developed from the original condition) as before.

These tests do not apply to either component if a claim is made on the grounds of a terminal illness, see page 28.

Generally speaking, you can only claim PIP if you have spent at least 104 weeks in the UK over the last three years. But some people are exempt from this 'past presence' test, for example some EEA nationals, some UK nationals who have lived in another EEA country and refugees and their family members. Seek further advice from our freephone helpline.

When will my child be asked to claim PIP?

Disabled young people aged 16 or over who do not already get DLA will need to claim PIP. They do not have the option of claiming DLA instead.

Young people turning 16 who get DLA

Young people turning 16 who receive DLA will be reassessed under PIP – even if their DLA award was not due to run out at 16. This also includes young people with an indefinite award of DLA. The only exceptions to this are:

- if a young person is claiming DLA under the special rules for the terminally ill
- if a young person is a hospital in-patient on the date they would normally be asked to claim PIP. In this case their DLA payments will be extended temporarily until they have been discharged from hospital. This is a new rule and only applies from the 29th June 2016 onwards.

Before your child turns 16, the Department for Work and Pensions (DWP) will contact you as their parent to let you know how to claim PIP, and to find out if your child needs an appointee (a person responsible for making claims on their behalf, usually a parent – see page 35). They should write to you:

- when your child is aged 15 years and 7 months
- three months later – they will send you a reminder
- shortly after your child turns 16, the DWP will then send a letter to your child (or to you if you have been made their appointee) inviting them to make a claim for PIP.

If your child's current DLA award is due to run out on their 16th birthday, their DLA payments can continue temporarily until a decision has been made on their PIP claim. However, if they fail to claim PIP when invited to do so, their DLA payments will stop.

Special rules for terminally ill children

Terminally ill children who turn 16 can continue to get DLA rather than PIP. A DLA award under the special rules for the terminally ill will continue until the end of the existing award, or until your child is selected to claim PIP as part of the process of moving all remaining adult DLA claimants onto PIP.

Moving from DLA to PIP

Just because your child gets DLA, it doesn't mean that they will automatically qualify for PIP. They will have to make a claim for PIP once invited to do so by the DWP. You need to do this within 28 days, by phoning the PIP claim line.

If they don't claim when the DWP asks them to, their DLA payments will stop. If you think that they will have difficulties making a claim within this deadline, they (or you) can ask the DWP for an extension, which they may agree to.

If your child doesn't make a claim within the 28 day period (or within any extended period that the DWP have agreed to) their DLA payments will be suspended. The DWP must write to them (or you) to tell them this is happening.

If your child's payments are suspended they will be given a further 28 days to claim PIP. If they claim PIP, their DLA award will be restored until a decision on their PIP claim is made.

If they still don't claim before the second 28 day deadline, their DLA award will end. They (or you) will not be able to appeal that decision. They will be able to make a claim for PIP instead.



Young people and adults aged 16-64 who are getting DLA

As well as young people turning 16, an adult on DLA is also re-assessed under the PIP rules if:

- they have a change of circumstances that might affect the rate of DLA they are entitled to, or
- their current DLA award is ending – rather than being sent a renewal claim pack for DLA they will be invited to claim PIP, or
- they volunteer to claim PIP rather than DLA.

Volunteering to claim PIP early

Young people and adults on DLA aged 16–64 have the option of volunteering to claim PIP straight away if they want. But it is really important that you seek advice before you do this for your child, as more people are expected to lose out than gain under PIP. Once your child chooses to make a claim for PIP they won't be allowed to change their mind and continue to receive DLA.

Young people and adults with long-term or indefinite awards of DLA

If your adult son or daughter's DLA award is not due to run out for some time, or if they have an indefinite DLA award, they will be asked to claim PIP at some point between now and March 2018. The government started this process by reassessing claimants living in certain postcode areas, but it may start randomly selecting people with long-term or indefinite awards. Once your son or daughter is selected the DWP will notify them of what they need to do to claim PIP.

By March 2018 the DWP plan to have invited all current DLA claimants aged 16–64 to claim PIP. Call our freephone helpline for updates on the timetable.

How do I claim PIP?

To claim PIP your son or daughter will need to complete two forms:

- a Personal Independence Payment claim form (PIP1 form)
 - normally completed over the telephone
- *How your Disability Affects You* questionnaire (PIP2 form).

To start a PIP claim, they must telephone the PIP new claims number on:

 **0800 917 2222 (textphone 0800 917 7777)**

If you are your child's appointee (see page 35) you must make this call rather than them. If English is not your first language, ask the Department for Work and Pensions (DWP) staff member answering your call to use the DWP telephone interpreting service.

Completing the PIP1 claim form

First, your son or daughter needs to complete a Personal Independence Payment claim form (PIP1 form). This is usually done over the phone with a DWP worker, and should take no more than 20 minutes. However, if they have difficulties using the phone, a paper form can be sent by post. Or you can ask someone from the DWP to make a home visit to help complete the form. Online claims may be possible at a later date.

The PIP1 form asks basic questions such as your child's name, contact details, nationality, bank account details and for details of the main health professional supporting them.

This form is also used to check that your child meets the main basic qualifying conditions. For example, that they are at least 16 and meet certain tests linked to their immigration status and presence in the UK.

Completing the PIP2 questionnaire

Once the DWP has received the signed PIP1 form and established that your son or daughter meets the basic qualifying conditions, you will then be sent a questionnaire called *How Your Disability Affects You* (PIP2). If they are told they do not meet the basic rules, seek advice from our helpline.

The PIP2 questionnaire gathers information about a young person's ability to do a range of different activities. This is their (or you as their appointee) opportunity to give a detailed explanation of how their condition affects them, so they should give as much detail as possible.


You can also attach additional evidence, such as information from health staff or other professionals supporting your son or daughter, or from friends or relatives who help with everyday activities.

Your son or daughter, or you as their appointee, must complete and return the questionnaire within a month. The date for return will be stated in the covering letter. If the questionnaire is not returned by that date, the claim for PIP will normally be turned down. Any existing DLA payments will also stop.

So, where possible, always try to return the questionnaire by the stated date to avoid delays and missed payments.

The DWP can make exceptions with late returns of PIP2 but only if it accepts that there was a good reason for not completing and returning the PIP2 questionnaire in time.

DWP guidance does state that if it knows a claimant has a mental or cognitive disability and does not return the questionnaire, it will refer the person directly to a healthcare professional rather than closing down the claim automatically.

For more information on completing the PIP questionnaire see Disability Rights UK's guide ***Personal Independence Payment – a guide to making a claim*** available free from  www.disabilityrightsuk.org

Asking for more time to complete the questionnaire

If more time is needed to complete the form, your son or daughter, or you as their appointee, should telephone the DWP and ask for an extension (a later return date). However, you must do this before the original one month deadline is up.

The DWP is only likely to grant a long extension, or more than one extension, if it agrees that the young person, or you as their appointee, have good reasons for not completing the form sooner.

The Personal Independence Payment ‘consultation’

As well as having to complete the necessary claim forms, PIP1 and PIP2 (see page 12), most young people applying for Personal Independence Payment (PIP) will be asked to attend a face-to-face assessment by a healthcare professional. This is known as a ‘consultation’.

Most consultations take place in a medical centre, but they can be carried out at home. Your son or daughter’s usual GP will not carry out the consultation. Instead, a healthcare professional under contract to the Department for Work and Pensions (DWP) will carry it out. The healthcare professional will work for one of two companies, Atos or Capita, depending on where in the UK you live. Capita offers most claimants the option of a home consultation, while Atos only offers this if it agrees it is necessary (correct at time of writing).

The healthcare professional assessing the young person will:

- look at their ability to carry out a range of activities, and
- look at their PIP2 questionnaire, and
- look at any other medical evidence that has been gathered.

You must be given at least seven days notice of a face-to-face consultation (unless less notice has been agreed). The young person can bring someone to the consultation for support.

In some cases, Atos or Capita may decide that there is no need for a face-to-face consultation. Reasons for this include the evidence they have already received or the distress a face-to-face consultation might cause.

Instead, they will make an assessment based on the questionnaire and any other evidence your son or daughter or the appointee has provided. Or they may carry out the consultation by phone. Those claiming under the special rules for the terminally ill won't have to take part in a consultation.

What happens at the consultation?

At the consultation, the healthcare professional will ask the young person about their condition, their day-to-day life and how they manage at home and out of doors. The healthcare professional may also carry out a brief physical examination.

After the consultation, the healthcare professional will complete a report and send it to the DWP.

Failure to take part in the consultation

If your child is asked to take part in a consultation (at a medical centre, at home or by phone), you should try to make sure they do so. If they don't take part and the DWP thinks they didn't have a good reason not to, they will be refused PIP.

When deciding whether someone has a good reason for not taking part, the DWP must take into account their disability and state of health. They will contact the young person to ask why they did not take part. If the DWP decides they did not have good reason for not taking part, you can ask them to reconsider (see page 30) and then appeal.



What tests are used to decide if someone gets PIP?

PIP is made up of two parts, called components: a daily living component and a mobility component. People applying for PIP are awarded points according to how well they can carry out 10 daily living activities and two mobility activities:

10 daily living activities

- preparing food
- taking nutrition (eating and drinking)
- managing therapy or monitoring a health condition
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally (speaking)
- reading and understanding signs, symbols and words
- engaging with other people face-to-face (mixing with people)
- making budgeting decisions (making decisions about money).

Two mobility activities

- planning and following a journey
- moving around.

PIP activities and points system

The tables that follow outline the scoring system that is used to decide whether a young person qualifies for PIP, and at what rate. In making sense of the tests set out in the tables it is important to understand how certain words are interpreted by the DWP.

DEFINITIONS

- assistance:** means physical intervention by another person and does not include any help provided through speech
- supervision:** means the continuous presence of another person for the purpose of ensuring your safety
- prompting:** means reminding, encouraging or explaining by another person
- unaided:** means without supervision, prompting, assistance or the use of an aid or appliance
- aid or appliance:** means any device which improves, provides or replaces impaired physical or mental function

DAILY LIVING COMPONENT

Activity 1. Preparing food

Points

can prepare and cook a simple meal unaided	0
needs to use an aid or appliance to be able to either prepare or cook a simple meal	2
cannot cook a simple meal using a conventional cooker but is able to do so using a microwave	2
needs prompting to be able to either prepare or cook a simple meal	2
needs supervision or assistance to either prepare or cook a simple meal	4
cannot prepare and cook food	8

prepare: in the context of food means make food ready for cooking or eating

cook: heat food at or above waist height

simple meal: cooked one course meal for one using fresh ingredients

This activity aims to assess a claimants physical or mental capacity to cook a simple main meal and not whether they actually cook for themselves or not. Factors such as special dietary requirements or cultural/religious differences are not taken into account.

Activity 2. Taking nutrition

Points

can take nutrition unaided	0
needs (i) to use an aid or appliance to be able to take nutrition or (ii) supervision to be able to take nutrition or (iii) assistance to be able to cut up food	2
needs a therapeutic source to be able to take nutrition	2
needs prompting to be able to take nutrition	4
needs assistance to be able to manage a therapeutic source to take nutrition	6
cannot convey food and drink to their mouth and needs another person to do so	10

take nutrition: cut food into pieces, convey food and drink to one's mouth and chew and swallow food and drink, or take nutrition by using a therapeutic source

therapeutic source: parenteral or enteral tube feeding, using a rate-limiting device such as a delivery system or feed pump

DAILY LIVING COMPONENT (cont)

Activity 3. Managing therapy or monitoring a health condition

Points

either (i) does not receive medication or therapy, or need to monitor a health condition, or (ii) can manage medication or therapy, or monitor a health condition unaided

0

(i) therapy: to be undertaken at home, prescribed or recommended by (a) registered (i) doctor; (ii) nurse; or (iii) pharmacist; or (b) health professional regulated by the Health Professions Council; but does not include taking or applying, or otherwise receiving or administering, medication (whether orally, topically or by any other means), or any action which, in the claimant's case, falls within the definition of 'monitor a health condition'.

(ii) manage medication or therapy: take medication or undertake therapy where a failure to do so is likely to result in deterioration in health.

needs either (i) to use an aid or appliance to be able to manage medication or (ii) supervision, prompting or assistance to manage medication or monitor a health condition

1

(i) medication: medication to be taken at home which is prescribed or recommended by a registered doctor, nurse or pharmacist

(ii) monitor health: detect significant changes in a health condition which are likely to lead to a deterioration in health and take action advised by a registered doctor, registered nurse or health professional who is registered by the Health and Care Professions Council, without which health is likely to deteriorate

needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week

2

needs supervision, prompting or assistance to manage therapy that takes more than 3.5 but no more than 7 hours a week

4

needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 but no more than 14 hours a week

6

needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week

8

Note: any action which falls under the definition of monitoring a health condition cannot be treated as therapy – no matter how much time is spent in monitoring the disabled person's condition.

Note: It is the time taken to supervise, prompt or assist someone to manage therapy that is measured, not how long the therapy itself takes.

DAILY LIVING COMPONENT (cont)

Activity 4. Washing and bathing

Points

can wash and bathe unaided	0
needs to use an aid or appliance to be able to wash or bathe	2
needs supervision or prompting to be able to wash or bathe	2
needs assistance to be able to wash either their hair or body below the waist	2
needs assistance to be able to get in or out of a bath or shower	3
needs assistance to be able to wash their body between the shoulders and waist	4
cannot wash and bathe at all and needs another person to wash their entire body	8

bathe: includes getting into or out of an unadapted bath or shower. If you have an adapted bath you will need to explain what problems you would have in using an unadapted one

Activity 5. Managing toilet needs or incontinence

Points

can manage toilet needs or incontinence unaided	0
needs to use an aid or appliance to be able to manage toilet needs or incontinence	2
needs supervision or prompting to be able to manage toilet needs	2
needs assistance to be able to manage toilet needs	4
needs assistance to be able to manage incontinence of either bladder or bowel	6
needs assistance to be able to manage incontinence of both bladder and bowel	8

toilet needs: getting on and off an unadapted toilet, evacuating bladder and bowel. Note: help in dressing or undressing is not taken into account

manage incontinence: manage involuntary evacuation of the bowel or bladder, including use of a collecting device or self catheterisation, and clean oneself afterwards.

Note: incontinence pads fall within the definition of an aid or appliance

DAILY LIVING COMPONENT (cont)

Activity 6. Dressing and undressing

Points

can dress and undress unaided	0
needs to use an aid or appliance to dress or undress	2
needs either (i) prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed or (ii) prompting or assistance to be able to select appropriate clothing	2
needs assistance to be able to dress or undress their lower body	2
needs assistance to be able to dress or undress their upper body	4
cannot dress or undress at all	8

dress and undress: includes putting on and taking off socks and shoes

Activity 7. Communicating verbally

Points

can express and understand verbal information unaided	0
needs to use an aid or appliance to be able to speak or hear	2
needs communication support to be able to express or understand complex verbal information	4
needs communication support to be able to express or understand basic verbal information	8
cannot express or understand verbal information at all even with communication support	12

communication support: support from a person trained or experienced in communicating with people with specific communication needs, including interpreting verbal information into a non-verbal form and vice versa. It is not limited to interpreters and can include friends or family.

complex verbal information: information in native language conveyed verbally in either more than one sentence or one complicated sentence

basic verbal information: information in native language conveyed verbally in a simple sentence

Activity 8. Reading and understanding signs, symbols and words	Points
can read and understand basic and complex written information either unaided or using spectacles or contact lenses	0
needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information	2
needs prompting to be able to read or understand complex written information	2
needs prompting to be able to read or understand basic written information	4
cannot read or understand sign, symbols or words at all	8

read: includes reading signs, symbols and words but does not include reading Braille

complex written information: more than one sentence of written or printed standard size text in native language

basic written information: signs, symbols and dates written or printed in standard size text in native language

Activity 9. Engaging with other people face-to-face	Points
can engage with other people unaided	0
needs prompting to be able to engage with other people	2
needs social support to be able to engage with other people	4
cannot engage with other people due to such engagement causing either (i) overwhelming psychological distress to the claimant or (ii) the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person	8

engage socially: interact with others in a contextually and socially appropriate manner, understand body language and establish relationships

social support: support from a person trained or experienced in assisting people to engage in social situations. Can be provided by friends or family

psychological distress: distress related to an enduring mental health condition or an intellectual or cognitive impairment

Note: This activity assesses the ability to mix with people in small groups or in one-to-one situations rather than with others in a crowd

Activity 10. Making budgeting decisions	Points
can manage complex budgeting decisions unaided	0
needs prompting or assistance to be able to make complex budgeting decisions	2
needs prompting or assistance to be able to make simple budgeting decisions	4
cannot make any budgeting decisions at all	6

simple budgeting decision: decisions involving calculating the costs of goods, and calculating change required after a purchase

Complex budgeting decisions: decisions involving calculating household and personal budgets, managing and paying bills, and planning future purchases

MOBILITY COMPONENT

Activity 11. Planning and following journeys	Points
can plan and follow the route of a journey unaided	0
needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant	4
for reasons other than psychological distress cannot plan the route of a journey	8
For reasons other than psychological distress cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid	10
cannot undertake any journey because it would cause overwhelming psychological distress to the claimant	10
For reasons other than psychological distress cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid	12

psychological distress: distress related to an enduring mental health condition or an intellectual or cognitive impairment

assistance dog: dog trained to guide or assist a person with a sensory impairment

orientation aid: specialist aid designed to assist disabled people to follow a route safely

Activity 12. Moving around	Points
can stand and then move more than 200 metres either aided or unaided	0
can stand and then move more than 50 metres but no more than 200 metres either aided or unaided	4
can stand and then move unaided more than 20 metres but no more than 50	8
can stand and then move using an aid or appliance, more than 20 metres but no more than 50 metres	10
can stand and then move more than 1 metre but no more than 20 metres either aided or unaided	12
cannot either aided or unaided (i) stand or (ii) move more than 1 metre	12

stand: stand upright with at least one biological foot on the ground

aided: with supervision, prompting, or assistance, or with the use of an aid or appliance

How the points system works

The DWP must take into account your child's ability not just to carry out an activity, but to carry it out 'reliably'. This means being able to carry out an activity:

- **safely** – in a manner that is not likely to cause harm to themselves or others, not being able to carry out a task safely means that it is likely that harm will occur, rather than it simply being possible that harm will occur. A risk can be said to be likely if there is a real possibility of something happening which cannot be sensibly ignored. You do not have to prove that the risk is more likely than not. Whether someone needs supervision to carry out an activity safely depends not just on the frequency of the episodes of risk but also the severity of the possible consequences.
- **repeatedly** – as many times as reasonably required
- **in a reasonable time period** – no more than twice as long as someone without any health problems
- **to an acceptable standard** – of a standard that is 'good enough' and which most people would normally achieve. The effects of any pain and breathlessness experienced will be relevant in deciding whether an activity is carried out to an acceptable standard.

So if someone is able to wash and bathe themselves independently they would not normally score any points for that activity. However, if that person was at risk of falling when washing and bathing themselves, or couldn't wash themselves to an acceptable standard, or would take hours to do so they may still score points.

If your child uses an aid or appliance, or could be reasonably expected to, this will be taken into account when assessing their ability to carry out an activity.

Every activity in the tables has a set of descriptions. For example, the first daily living activity above is called 'preparing food', and there are six descriptions in that activity:

- the first description is 'can prepare and cook a simple meal unaided'
- the second is 'needs to use an aid or appliance to be able to either prepare or cook a simple meal', and so on.

Each of these descriptions has a number of points a person can score. The number of points varies depending on how limited a person's abilities are.

If more than one description in an activity applies to your son or daughter, they are awarded the one that gives them the most points.

For example:

in the activity 'making budgeting decisions', the descriptions are:

- can manage complex budgeting decisions unaided – 0 points
- needs prompting or assistance to be able to make complex budgeting decisions – 2 points
- needs prompting or assistance to be able to make simple budgeting decisions – 4 points
- cannot make any budgeting decisions at all – 8 points.

In this example, if a young person needs assistance to make complex budgeting decisions (worth 2 points) and also needs assistance to make simple budgeting decisions (4 points) they will be awarded the highest score that applies – 4 points.

The scores they have been awarded in each of the 10 daily living activities are then added together to decide whether the person qualifies for the daily living component and at what rate – standard or enhanced.

Their score in each of the two mobility activities is added together to decide whether they qualify for the mobility component and at what rate.

A young person will only be awarded points for an activity if their ability to carry it out is affected for at least half of the days over a 12 month period.

Variable conditions

You don't need to show that an activity description applies to your son or daughter for the whole of the day. So long as it applies at some point during a day, it should be treated as applying to them.

If their condition varies on different days, then:

- if only one description applies on more than 50 per cent of the days, that is the description the DWP will use to award points
- if two descriptions apply on more than 50 per cent of days, the description with the higher number of points applies.

Where no single description applies on more than 50 per cent of days, you will still score points if two or more of the different descriptions (not counting the one that scores zero points) added together apply on over 50 per cent of days.

If this applies, their score will be based on the description that applies for the greatest number of days.

So in the activity of preparing food, someone may need prompting to cook a simple meal on 33 per cent of days (2 points) but also need assistance to prepare a meal on an additional 25 per cent of days (4 points). Because the two descriptions added together apply on 58 per cent of days they will score points for this activity, and 2 points will be awarded since that description applies for the greater number of days. If 2 descriptions applied for an equal number of days, for example each applied on 33 per cent of days, then the higher score is awarded.

How much is PIP?

Daily living component

The Department for Work and Pensions (DWP) adds together the young person's score from the 10 daily living activities to decide whether they get the daily living component. It also uses this score to decide whether they should get paid the daily living component at the standard or enhanced rate.

Daily living component

0–7 points – no award

8–11 points, standard rate – £55.65

12 or more, enhanced rate – £83.10

Mobility component

The DWP adds together the scores from the two mobility activities to decide if they get the mobility component. This score also decides whether they should get the mobility component at the standard or enhanced rate.

Mobility component

0–7 points – no award

8–11 points, standard rate – £22

12 or more points, enhanced rate – £58

Terminally ill applicants

If your son or daughter is terminally ill and not expected to live for more than six months, they will automatically qualify for the enhanced rate of the daily living component. They won't have to take part in a consultation.

If this applies to your child, ask their doctor for a DS1500 certificate and send this to the DWP after you have phoned to make a claim. Terminally ill claimants will be asked questions about their mobility during the initial telephone claim, however they are not expected to complete the PIP2 questionnaire.



Getting a decision on a PIP claim

A case manager at the DWP will decide whether a young person is entitled to PIP, and at what rate. They take into account all of the information in the claim form, the Atos or Capita health professional's report, and any other information you or the young person have provided.

The DWP will send you a decision letter outlining the reasons for the decision. It will explain the number of points your son or daughter was awarded for each daily living and mobility activity.

If they are awarded PIP, the letter should also set out how long the award is for. If they are refused PIP or awarded a lower rate than was paid under DLA, you may also get a telephone call from the case manager explaining the reasons for the decision.

Once a decision is made on a PIP claim, DLA continues to be paid for the first 28 days after the young person's next DLA pay day. After that the PIP decision comes into force.

How long will PIP be awarded for?

Most awards will be made for a fixed period. It has been suggested that this might be for up to two years if a condition is likely to change.

If it's unlikely your son or daughter's condition will change, awards can be made for longer. In a small number of cases, awards are made for an indefinite period. But even an indefinite award can be reassessed at any point if the DWP decide to check that a young person still meets the qualifying conditions.

What if I disagree with the decision?

If you disagree with the decision on your son or daughter's PIP claim, they (or you if you are their appointee) can ask the DWP to look at it again. This is known as a 'mandatory reconsideration'.

You must do this within one month of the date of the decision, although a late request may be accepted in certain circumstances. Another DWP decision maker will then have a fresh look at the case and give you a new decision in writing.

If you are still unhappy with the new decision you can appeal directly to Her Majesty's Courts and Tribunals Service. But you can't appeal until after you have a decision on your request for a mandatory reconsideration. Advice Now produce a free guide ***How to win a PIP appeal*** available from their website at www.advicenow.org.uk.

PIP and stays in hospital or residential accommodation

PIP can be affected by overnight stays away from home. There are different rules depending on whether your child is in hospital or residential accommodation.

If a young person is in hospital and is aged 18 or over, payment of both the daily living and mobility components of PIP are suspended after 28 days.

If a young person is aged 16 or 17 when their period as a hospital in-patient started then they are not affected by these rules and their PIP payments should continue without interruption.

If a young person is in residential accommodation that is paid for out of public funds, including a residential school, the daily living component stops being paid after 28 days. This applies to all PIP claimants including those aged 16 or 17. The mobility component is not affected.

When working out when payments of a young person's PIP will stop, it is important to know that different stays in hospital or care separated by fewer than 28 days at home are added together to count the number of days they have been away. For further information on these 'linking rules' contact our freephone helpline.

PIP and its effect on other benefits

PIP is never treated as income in calculating other benefits. In fact getting PIP can actually lead to an increase in other benefits, or help you qualify for other entitlements.

The following is a brief checklist of benefits and entitlements which may become available following an award or increase of PIP. Call our freephone helpline for more detailed advice.

Carer's Allowance


If a young person gets the daily living component of PIP at either rate (standard or enhanced) you may be able to get Carer's Allowance. You must be providing at least 35 hours of care each week. To get Carer's Allowance, you must not be a full-time student and not be earning more than a set figure, currently £116 (after certain deductions and costs) each week.

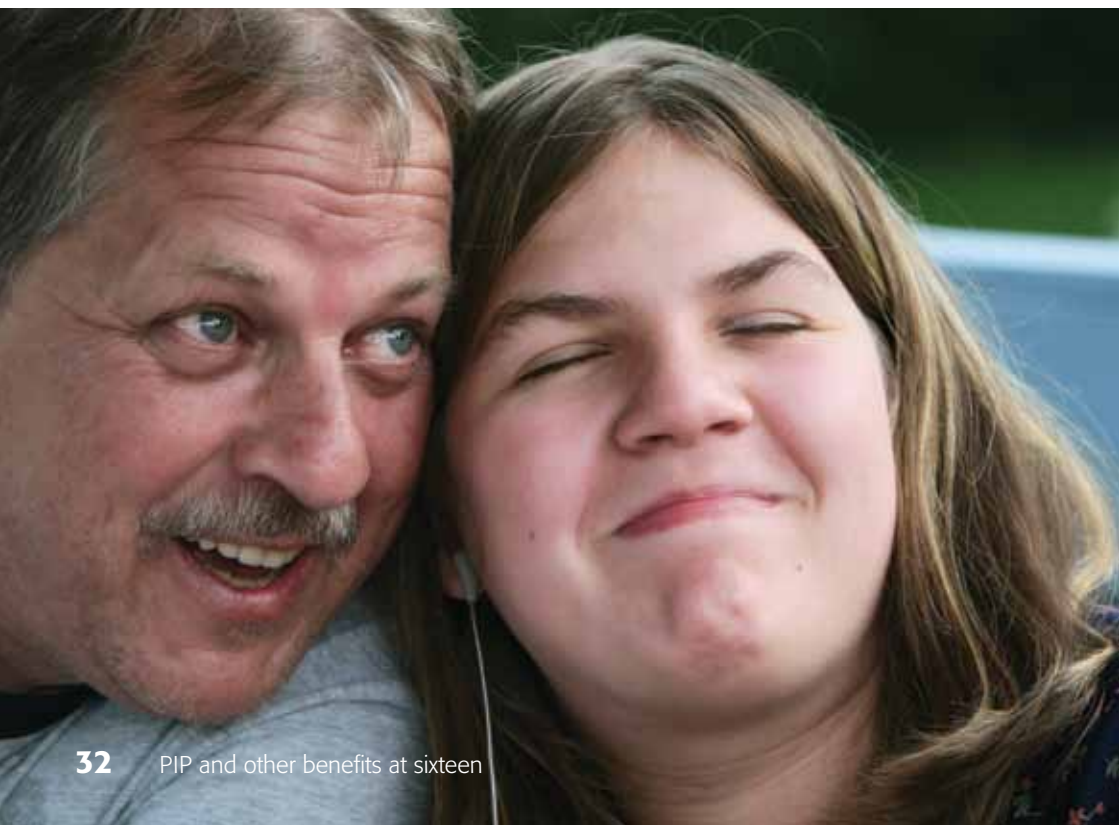
Child Tax Credit

If a young person for whom you receive tax credits gets PIP, your Child Tax Credit payments will increase. This is because you will qualify for an extra disability element. You will also get a further severely disabled child element if they have been awarded the daily living component at the enhanced rate.

The disability and severe disability elements can be backdated in line with the PIP award, but only if you tell the tax credit office within one month of the date on the decision letter awarding PIP.

Universal Credit

Universal Credit is a new benefit that is replacing tax credits and other means-tested benefits for people of working age. If you are getting Universal Credit and a young person who is included in your claim receives PIP, you will qualify for extra Universal Credit payments. At the time of writing, Universal Credit only applies to families with disabled children in those areas where the Universal Credit full service applies. See information on pages 37 and 65 for more information or read our free factsheet **Universal Credit – the essentials** available to download at  www.contact.org.uk or call our freephone helpline for a copy.



Income Support

For families still getting payments for their children in their Income Support, an award of PIP can lead to extra money being added to your Income Support. This is known as the disabled child premium. If a young person is awarded the daily living component at the enhanced rate, the enhanced disability premium is also added. You will need to let the office dealing with the Income Support claim know about the PIP award.

Employment and Support Allowance

If a young person gets Employment and Support Allowance, an award of the enhanced daily living component of PIP may lead to an increase in their Employment and Support Allowance. Let the office dealing with Employment and Support Allowance know about a new award of PIP or any change to the existing award.

Help with rent and council tax

If you get Housing Benefit, an award of PIP for a dependant child or young person may lead to extra Housing Benefit if you are not already getting your rent met in full. Depending on the council tax reduction scheme, a PIP award for a dependant young person may also lead to more help towards your council tax bill.

If a young person is 18 or over and receives the daily living component of PIP at any rate (only the enhanced rate in Scotland) you might qualify to be 'discounted' as a carer for council tax. Depending on who else lives in your home this could lead to more help with your council tax. See our guide on *Help with council tax bills* for more details.

Exemption from 'benefit cap'

If a young person for whom you claim benefits as part of your family gets PIP, you will be exempt from the household benefit cap which limits the amount of benefit that an out-of-work family can receive.

Blue Badge for disabled parking

A young person will be automatically entitled to a Blue Badge for disabled parking in England if they score eight points or more in the PIP activity of 'moving around' (see tables on page 24). In Scotland and Wales PIP claimants will be eligible for a Blue Badge if they either get eight points for 'moving around' or 12 points for 'planning and following a journey'. Other individuals can also access a Blue Badge. See 📞 www.disabilityrightsuk.org for more details, or call our freephone helpline.

Help with road tax

If a young person is awarded the mobility component of PIP at the enhanced rate, you may be exempt from paying road tax. If they qualify for the mobility component at the standard rate you may be eligible for a 50 per cent reduction instead.

Help with getting a car

If you're interested in getting a car and your son or daughter is awarded the mobility component of PIP at the enhanced rate, you can hire or buy a car through the Motability Scheme. To be eligible, their award of the enhanced rate mobility component must have at least 12 months left to run.

If you're unable to drive and need help to pay for lessons, or help to get a deposit for a car through the scheme, then you may qualify for grant assistance. Contact Motability on 📞 0300 456 4566 or visit 📞 www.motability.co.uk

Help with bus travel

All local authorities operate schemes that allow disabled people of any age to apply for a bus pass or voucher for free bus travel. In some areas, a named carer accompanying the disabled person is also entitled to free travel. Schemes operate differently from one local authority to another so contact your local council to check out what's available in your area.

Other concessions

It is also worth checking to see if there are any special schemes, concessions or facilities available to families with disabled children in your area. Call our freephone helpline for local contacts.

When a young person is unable to manage their benefit claims

A child turning 16 is usually expected to take on responsibility for any benefits they claim in their own right. But if they're unable to manage their affairs, you can become their 'appointee' for benefit claims.

What is an appointee?

Becoming an appointee means you are responsible for making any claims, giving any information required, and telling the Department for Work and Pensions (DWP) about any changes that may affect your child's entitlement to benefits. The benefits will be paid to you on their behalf.

Becoming an appointee for benefit purposes does not mean you have any wider rights to deal with their affairs.

How do I become an 'appointee'?

The DWP should write to you about this in the six months before your child turns 16. Usually they do this at the same time as giving you information about making a claim for PIP. If this doesn't happen contact the DWP to ask that an appointee be considered. The DWP should then arrange a home visit. This is usually a straightforward process and should not delay any claims that you are making.

You can't become an appointee simply because it is more convenient for you or your child. The DWP can only agree to you becoming their appointee if they believe that your child lacks the capacity to manage their affairs. Usually this will be due to mental incapacity but in exceptional circumstances it can be because of a physical disability.

If you have already been appointed by the courts to look after their affairs, you won't have to do anything else.



Part 2

Other benefits once your child turns 16

The information about benefits other than Personal Independence Payment in Part 2 of this guide only applies to a young person if they live in an area where the Universal Credit full service has not been introduced.

If you live in an area where the Universal Credit full service has been introduced, your son or daughter will not be able to make a new claim for income-related Employment and Support Allowance, income-based Jobseeker's Allowance, Income Support, Housing Benefit or tax credits. They will need to claim Universal Credit instead.

Call our freephone helpline for more information.

At the time of writing the Universal Credit full service has only been rolled out to a small number of Jobcentre areas. However, the government intends to gradually expand the number of areas covered by the Universal Credit full service until it covers the whole country by September 2018.

To find out if the Universal Credit full service applies in your area either check your postcode at:

📍 <http://universalcreditinfo.net>
or ask your local Jobcentre Plus office.

For more information about Universal Credit read our free factsheet ***Universal Credit – the essentials*** available to download at 📍 www.contact.org.uk or call our freephone helpline for a copy.

Section 1 Claiming benefits for a young person who remains in non-advanced education or approved training

This section makes clear when you have the option of continuing to get Child Benefit, tax credits and other payments for a 16–19 year old as part of your family. It also explains what might cause these payments to stop – including a young person claiming certain benefits in their own right.

If your son or daughter stays on in non-advanced education or approved training, you will have a choice. You can either continue to claim benefits for them as part of your family, or help them to claim benefits as a young disabled adult.

We also set out some of the issues you will need to consider in choosing whether to carry on claiming for your child as part of your family or helping them to claim as a young disabled adult.

Claiming benefits for your child as part of your family

Children and young people under the age of 16 cannot claim benefits and tax credits in their own right. You as a parent must claim for them as a ‘dependant’ member of your family. When we talk about ‘benefits and tax credits’ in this section, we do not mean Personal Independence Payment (PIP). We mean the payments listed below:

- Child Benefit
- Child Tax Credit
- additional amounts for a child or young person paid with Income Support or income-based Jobseeker’s Allowance – this only applies to claimants who have not yet claimed Child Tax Credit
- additional amounts included in the assessment of any Housing Benefit and Council Tax support you claim
- additional amounts for a child or young person paid as part of a Universal Credit award.

As a general rule, you can get these benefits and tax credits for a young person until the September after their 16th birthday. After that, whether you will be able to continue getting payments depends on their circumstances.

Note: Child Tax Credit, Income Support, income-based Jobseeker's Allowance, Housing Benefit, and Council Tax Support are all means-tested. Whether you qualify for these will also depend on your financial circumstances. Universal Credit will replace most of these benefits. See page 37 for details of the timetable for its introduction.

Claiming for a young person after 16 who remains in non-advanced education

From the September following a young person's 16th birthday, it is only possible to carry on getting payments for them as a dependant if:

- they attend a course of full-time, non-advanced education, or
- an approved training course or,
- in England only, 'appropriate full-time education'.

Payments can then usually continue until their 19th birthday, unless they stop attending the course or training before that date (see box on page 41 for more details).

Payments can be extended to their 20th birthday (September after their 19th birthday for Universal Credit) if they're completing a course they started, or were enrolled on, or offered a place on, before they turned 19.

If a young person cannot enrol or be accepted on a course or training before reaching 19 call our freephone helpline for advice.

When is a course treated as full-time?

To count as full-time, a young person's course must be for more than 12 hours a week during term time. This includes classes, tuition and any supervised study. It doesn't include meal breaks or unsupervised study.

The education has to be at a recognised educational establishment or 'elsewhere'. This means that home education may count in some cases.

What is non-advanced education?

A course is non-advanced education when it is below the level of an HND (HNC in Scotland). This includes:

- 'A' levels and below
- Advanced Highers (Scotland) and below
- NVQ/SVQ Level 3 and below
- Ordinary National Diplomas or BTEC Diplomas.

Other courses may also be classed as non-advanced. If you are uncertain about the level of your son or daughter's course, seek further advice.

What is 'appropriate full-time education' in England?

This is education that is suitable for the young person, depending on their age and ability, and taking into account any special educational needs. The course must also be non-advanced (see above). For example, a study programme of at least 540 hours in any 12 month period, or a programme of activity designed to help the young person participate in education or training would count.

What is an approved training course?

Young people who are attending certain types of approved training are treated as if they were in non-advanced education. This applies to work-based training programmes that don't pay a wage.

The types of courses classed as 'approved training' depend on which part of the UK you live. Some examples of the approved training courses are:

- **England** – Appropriate education or training. See above for more details
- **Scotland** – Employability Fund activity
- **Wales** – Traineeships or Foundation Apprenticeships



Call our freephone helpline on 0808 808 3555 if you are not sure whether your child is in approved training.

Do the payments I get for my child stop as soon as they leave their course?

Generally speaking, you can continue to receive payments such as Child Benefit and Child Tax Credit for a short period after your child leaves education or training.

September after 16th birthday

If your child leaves education or training you can usually carry on getting payments for them until at least 31 August after their 16th birthday.

Terminal date

Child Benefit payments for your child don't usually stop on the day they stop going to their course. They usually continue to a 'terminal date' that falls after the course ends. Call our freephone helpline for details of the terminal date for your child's course.

Child Tax Credit payments will stop as soon as your child leaves education (if the September following their 16th birthday has passed) unless they register with Connexions or the Careers Service.

Extension period

If a young person is 16 or 17 years old and is not in education, training or work you may be able to carry on getting payments for them for 20 weeks from the day they leave their course.

This only applies if they register with a qualifying body (for example, a local Careers Service).

If a young person turns 18 during this extension period, these benefits will stop on their 18th birthday.

You can also carry on getting payments for a young person if they've finished one course and are enrolled on another course they are waiting to start (for example, over the summer holidays). The new course must also be full-time and non-advanced.

Temporarily unable to attend the course

If a young person has to have a break from their education or training, this can be ignored if it is seen as reasonable to do so and they intend to resume education or training. This can usually be for up to six months, but it can be indefinitely if the interruption is due to physical or mental illness or disability. This means you may still be able to claim benefits and tax credits for them during this time. In deciding whether it is reasonable to ignore a temporary interruption, the Child Benefit and Tax Credit offices have to consider all of the relevant circumstances.



Keeping the Child Benefit office informed

The Child Benefit office will write to you during the school year that your son or daughter turns 16 to ask if they will be staying on in full-time education or approved training, and when you expect them to leave.

If you say they are leaving full-time education or training, or if you don't return the form, your Child Benefit will stop.

Keeping the Tax Credits office informed

The Tax Credits office automatically assumes any young person aged 16 will leave education in the summer after they turn 16. They automatically stop any payments for them from the September after their 16th birthday.

For tax credits to continue, you must contact the Tax Credits office during the summer to tell them the young person will continue in non-advanced education or approved training. Similarly if you have a 17, 18 or 19 year old who will be staying on in education after the summer holidays, make sure that you let the Tax Credits office know.

Keeping Income Support, Housing Benefit and Council Tax offices informed

Payments for a young person as part of Income Support, Housing Benefit or Council Tax Support should continue as usual.

But if Child Benefit stops, then any Income Support, Housing Benefit or Council Tax support allowances for them will also stop. It is your responsibility to report any changes that may affect your entitlement to these benefits.

What happens if a young person starts work while in education or training?

If your son or daughter works, this will not affect your benefits as long as they are still attending a course. Your payments will also not be affected if:

- they are working during a gap between courses (as long as they are enrolled on another course), or
- the August following their 16th birthday has yet to pass.

However, if they are working more than 24 hours a week, you will not get benefit during any period after they have left the course but are waiting for the terminal date or end of their extension period. See box on page 41 for more information.

When your child lives elsewhere

If your child lives away from home, for example at a residential school, this may have an effect on your own benefits. Contact our freephone helpline for more advice.

When a young person claims benefits in their own right

Many young disabled people in education or training have the option of claiming benefits in their own right. But if they do so, you may lose any benefits you claim for them as part of your family, and end up worse off. So you may have to make a choice between continuing to claim benefits for them as a dependant or helping them to claim benefits as a young adult.

Impact on a parent's benefits if a young person claims benefits

A young person will stop being treated as a dependant of yours if they claim any of the following benefits:

- Employment and Support Allowance (see page 55)
- Income Support (see page 63)
- income-based Jobseeker's Allowance (see page 63)
- Universal Credit (see page 65)

Also, if a young person starts claiming Tax Credits in their own right, you can no longer get payments for them.

When a young person claims any of the above, you will no longer get Child Benefit, tax credits or any other payments for them as part of your family. This is the case even if they remain in full-time non-advanced education or approved training. If they are 18 or over, further reductions known as 'non-dependant deductions' may be applied to your Housing Benefit, Council Tax reduction and help with mortgage interest, which means you will have to pay more towards your rent and council tax.

NOTE If your son or daughter starts to get Personal Independence Payment (PIP) or Disability Living Allowance (DLA) paid to them directly, it will not stop you continuing to get benefit and tax credit payments for them as your dependant.

Tell the relevant benefit office

If your son or daughter does opt to claim these benefits in their own right, you must make sure you tell the relevant benefit and tax credit offices. If you don't, you run the risk of being overpaid, and you will have to pay it back.

Will we be better off if my son or daughter claims benefits in their own right?

This will depend on your family circumstances. You need to compare how much they will get if they claim in their own right, with what you will lose from your benefits and tax credits.

If you receive child support payments for a disabled young person, call our freephone helpline for advice about whether a claim for benefits in their own right will affect the amount of maintenance you get.

If you have a high income

If your family income is high and you don't qualify for any Child Tax Credit — or you only receive a small amount of Child Tax Credit — there is a good chance your household will be better off if your child claims benefits in their own right.

If you have a lower income

Families with a lower income — who therefore get higher tax credit payments — run the risk that they will be worse off if a young person claims benefits in their own right. The higher your tax credit payments, the less chance you will gain if your son or daughter claims in their own right.

In some circumstances, you could not only lose Child Benefit and tax credit payments, but also see a reduction in help with Housing Benefit and Council Tax. Also, some young people on Employment and Support Allowance in England lose their right to free prescriptions.

Employment Support Allowance and charges for adult services

If your son or daughter is getting funding for residential or community care services through the local authority's adult team, (generally, from the age of 18) they can be charged for those services.

It is only the young person's income that can be taken into account when applying a charge, so when they are classed as your dependant and have no income in their own right the local authority will not be able to charge for services.

But if they claim Employment and Support Allowance, for example, this counts as income, along with some of the care part of Disability Living Allowance (DLA) (or the daily living component of PIP), so it is possible that a charge could be made.

If a young person is in residential care they would stand to lose a large part of their Employment and Support Allowance.

The possibility of charging is an issue that needs to be taken into account when you decide whether to continue claiming for a young person, or for them to claim their own benefits.



Call our freephone helpline for further information.

Warning!

Families on low incomes who get the maximum rate of Child Tax Credit or who get Income Support or income-based Jobseeker's Allowance run the risk of being significantly worse off if a young person claims a benefit like Employment and Support Allowance. But other families can lose out too.

If your son or daughter decides to claim in their own right you may lose your exemption from the 'benefit cap'. See page 68.



Education Maintenance Allowance and the 16–19 bursary fund

Education Maintenance Allowance is a weekly payment for young people in Scotland and Wales, who stay on in full-time, non-advanced education after the age of 16.

The amount of Education Maintenance Allowance paid will depend on your family income and where in the UK you live. If your parental income is above a certain threshold, no Education Maintenance Allowance is paid. Application forms are available from the school or college.

Education Maintenance Allowance in England was replaced by the 16–19 bursary fund. A young person who gets either DLA or PIP, and who also gets Employment and Support Allowance may get a 'vulnerable bursary' of £1,200 a year, so long as they are on an eligible course. This may be paid in kind, rather than in cash. The bursary may be reduced if the course is part-time or lasts less than 30 weeks. Whether a course is eligible depends on how it is funded, so you will need to contact the course provider to confirm whether a bursary can be paid.

Normally the earliest that a young person can receive a bursary is from the start of the new academic year that follows their 16th birthday.

Other groups of students such as those on Income Support are also eligible for a vulnerable student's bursary.

Most students who are eligible for a vulnerable student's bursary will receive one. However, guidance issued by the Education Funding Agency suggests that where an eligible student's costs are already being met, the educational establishment could decide to award a reduced bursary or no bursary at all.

If a student is on an eligible course but cannot get a vulnerable student's bursary (for example, they do not get Employment and Support Allowance) they can apply for a discretionary bursary instead – although whether they receive payments, the amount given and how long for will be at the discretion of the school or college.

Payment of an Education Maintenance Allowance or a 16–19 bursary doesn't affect any of the benefits or tax credits that you receive. Neither will it affect any payments your child gets if they claim benefits in their own right. However, if your son or daughter claims Employment and Support Allowance in order to access the vulnerable student's 16–19 bursary, the fact that they start to receive Employment and Support Allowance means that you will no longer be able to receive benefits such as tax credits and Child Benefit for them as a dependant child.

Training Allowances

In some parts of the UK, young people on approved training can still get a training allowance. It may be possible to continue claiming Child Benefit and Child Tax Credit for your son or daughter in these circumstances. For more information about Education Maintenance Allowance, the 16–19 bursary and training allowances, please call the Contact freephone helpline.

Get advice

Ultimately, each family's circumstances are different, so it is important to get your individual situation checked, preferably before your child turns 16.

Contact employ expert parent advisers who can offer you free detailed advice about whether your household would be better or worse off if a young person makes claims for benefits, such as Employment and Support Allowance or income-based Jobseeker's Allowance. To access this free help, call our freephone helpline.

Who will be paid the benefits for my child?

If you claim Child Benefit or Child Tax Credit for your child as a dependant, they are always paid directly to either you or your partner.

From the age of 16, Disability Living Allowance (DLA) or Personal Independence Payment (PIP) will usually be paid directly to a young person. Also, if they claim Employment and Support Allowance or any other benefit, these will usually be paid to them rather than to you.

The only exception is if they lack the mental capacity to manage their own affairs. If this is the case, you may be able to receive and manage benefits for them as their appointee (see page 35).

If a young person gets a bursary or other funding to attend their course, will this affect the payments I get?

Student funding will not affect any tax credits you get. Also, it will not affect any Child Benefit or Housing Benefit. But if you get Income Support (and have not claimed Child Tax Credit yet), then the amount of Income Support you get for that young person could be reduced.

Student funding apart from Education Maintenance Allowance and the 16–19 bursary can impact on means-tested benefits claimed by your son or daughter in their own right. Call our freephone helpline for further advice.



SECTION 2 When a young person leaves non-advanced education or approved training

The choice between continuing to claim benefits for your son or daughter, or them claiming in their own right, only arises if they stay in full-time, non-advanced education or approved training.

Once they've left non-advanced education or training, you cannot normally continue to claim benefits for them as a dependant. The financial support available to them will depend on what they do next.

This section gives a brief summary of the most common types of support available.

NOTE The information in this section does not apply to a young person if they live in an area where the full Universal Credit service has been introduced. See page 65 for more details.

Advanced education

If a young person leaves school to move into advanced education, such as a university course, any benefits and tax credits you claim for them as your dependant will stop.

As a student, your son or daughter may be eligible for financial support in the form of tuition fee loans, loans for living expenses, supplementary grants and bursaries.

The exact type of student support available will depend on the young person's specific circumstances, including where in the UK they study. For advice on the types of financial support available to disabled students, see 'Getting further advice' on page 69.

Benefits for students in advanced education

Some students in advanced education may be able to claim benefits such as Employment and Support Allowance.

Some disabled students who either get DLA or PIP, or who study part-time can claim income-related Employment and Support Allowance (see page 56). But since Employment and Support Allowance is means-tested, the amount paid will depend on what other student income they have from grants, loans and other sources.

Full-time students in advanced education who get DLA or PIP are exempt from the limited capability for work test (see page 60) when claiming income-related Employment and Support Allowance (but not contributory Employment and Support Allowance – see page 55). However, they may still have to undergo the other parts of the work capability assessment (see page 60). More information on Employment and Support Allowance is on page 55.

If a disabled student works in paid employment for 16 hours or more a week, they may be able to get Working Tax Credit.

If your son or daughter is studying or living away from home, they may also be able to claim Housing Benefit and Council Tax Support. Call our freephone helpline for further advice.

Training

Some young disabled people move from school onto a training course. There are a variety of different government training courses for young people and the financial support available to the trainee will depend on the type of course.

If the training course the young person attends is not an 'approved' training course (see page 40), you will no longer be able to claim benefits or tax credits for them. The financial support available will depend on whether they have the status of a trainee or an employee.

Classed as a trainee

If classed as a trainee, the young person should get a training allowance which, if low enough, may be topped up with Income Support. In limited circumstances a trainee may be able to claim ESA – call our free helpline for more details.

Classed as an employee

If classed as an employee, the young person should get wages:

- if they work more than 16 hours a week, they may also be able to claim Working Tax Credit
- if they work less than 16 hours and have low earnings, call our freephone helpline for further advice.

The rules governing payment of benefit while on a training course are complex, so always seek further advice from our helpline. For advice about training in your area, speak to your local Connexions or Careers Service adviser.

Young people not in work, education or training

If a young person leaves education but is unable to access work or training because of their disabilities, they should be able to claim Employment and Support Allowance as a young adult. See page 55.

When a young person moves into work

If a young person leaves school or college to start working, you will no longer get benefits or tax credits for them as your dependant. Depending on their circumstances, they may be able to claim benefits or tax credits on top of their earnings.

Working 16 hours or more a week

If a young person works 16 hours a week or more, they should consider making a claim for Working Tax Credit as a disabled worker.

Working less than 16 hours a week

In limited circumstances, it may also be possible for someone to keep their Employment and Support Allowance while working. See the information on permitted work, on page 62.



SECTION 3 Benefits that may be claimed by a young person from 16 years of age

This section gives more information about the benefits that a young disabled person who is aged 16 or above may be able to claim in their own right.

In particular it provides detailed information about claiming Employment and Support Allowance for a young disabled person. However, it also provides general information about other benefits and financial assistance that a young person may be able to claim.

The information in this section does not apply to a young person if they live in an area where the Universal Credit full service has been introduced. See page 65 for more details.

Employment and Support Allowance

Employment and Support Allowance is a benefit paid to people who are assessed as having a limited capability for work because of illness or disability. ESA replaced Incapacity Benefit and Income Support for ill or disabled people.

ESA has two types of payment — contributory ESA and income-related ESA.

Contributory ESA

In order to claim contributory ESA you normally need to have worked and paid National Insurance contributions. For this reason most young people are only able to claim income-related ESA.

However, some young people who claimed ESA before May 2012 may still be getting a special type of contributory ESA known as ESA in Youth. ESA in Youth was abolished in May 2012 for new claimants (February 2016 for Northern Ireland). See the box on page 59 if your child receives ESA in Youth.

Income-related ESA

This is a means-tested benefit but it is based on a young person's income and capital, not yours as their parent. It can be paid as a top-up to other income, such as a student loan, or contributory ESA, or it can be paid in full as a young person's only income. A young person may qualify for this benefit if they have limited capability for work and they:

- are aged at least 16
- have no income, or income below a certain amount
- have no more than £16,000 capital — this means things like savings, investments and property
- are not in full-time education (unless they get Disability Living Allowance (DLA) or Personal Independence Payment (PIP), see below)
- are not subject to immigration control (there are some exceptions to this so it is best to seek specialist advice)
- are habitually resident in the UK.

Income-related ESA and full-time education

A young person in full-time education cannot get income-related ESA unless they are getting either DLA or PIP.

Whether a course is full-time depends on the type of course and where your son or daughter is studying. Call our freephone helpline for more details.

Part-time students are eligible to claim whether they get DLA/PIP or not.

Income-related ESA and capital

A young person with capital of £16,000 or more will not qualify for income-related ESA. Capital means things like savings, investments and property.

Certain 'discretionary' trust funds are ignored, but any payments made from the trust to your son or daughter can be taken into account as income or capital.

If a young person has capital between £6,000 and £16,000, they will be treated as having a regular weekly income from their capital, and their payments will be reduced accordingly.

Income-related ESA and other income

Whether someone gets income-related ESA, and the amount they get, depends on their individual circumstances and on their existing income.

Some types of income are ignored, for example:

- Disability Living Allowance (DLA)
- Personal Independence Payment (PIP)
- the Education Maintenance Allowance (or 16–19 bursary payment in England)
- earnings from 'permitted work'.

But many other types of income are taken into account, including things such as student grants or loans and any earnings above the 'permitted work' levels (see page 62).



To find out if your child is likely to qualify for income-related ESA or any other benefits, please call our freephone helpline.



How much is income-related ESA?

During the first 13 weeks of an ESA claim (known as the assessment phase) it is paid at a reduced basic rate. This is normally £57.90 per week. If a young person gets DLA care at the highest rate (or PIP daily living component at the enhanced rate) an extra £15.90 should be added to their payments in the assessment phase, increasing these from £57.90 to £73.80 per week.

Once a young person has undergone a medical assessment and it has been accepted that they have a limited capability for work (see page 60 for more information) the payments they get should increase. This should happen from week 14. Usually it will take significantly more than 14 weeks for your son or daughter to be assessed. However, any increased payments will be backdated to week 14.

First, the basic rate increases from £57.90 to £73.10 per week. However, a further additional amount is maybe added. This will depend on whether your son or daughter is placed in the support or work-related activity group.

If they are in:

- the support group, they should get an extra amount of £52.45 per week – that is, £125.55 in total
- the work-related activity group, they will normally only receive £73.10 per week. However, this will be £89.00 if they qualify for the enhanced rate of PIP daily living component or the highest rate of DLA care component. Payments are higher for those who claimed ESA before 6 April 2017.
- Some young people might be entitled to additional payments, for example, if they live in their own accommodation or if they themselves help to care for someone else.

Please note that all the amounts given above can be lower if the young person has certain types of income or capital above certain levels.

Existing claimants on ESA in Youth

Prior to May 2012 it was possible to claim contributory ESA under special 'youth rules'. This allowed some young people to be paid contributory ESA despite never having worked or paid National Insurance. ESA in Youth is not means-tested so it is not affected by any income or savings that a young person may have. ESA in Youth can be topped up with income-related ESA if the young person has little or no income or capital.

Call our freephone helpline for further advice if your child gets ESA in Youth or you are told that their ESA in Youth will be stopping. Some young people whose ESA in Youth has stopped may be able to get contributory ESA if they are re-assessed as being in the 'support group' for ESA.

Making a claim for ESA

Most claims are now made by telephone to a contact centre (see page 69). Details of the claim are taken over the phone and a written statement or claim form is sent out to be checked, signed and returned.

Both contributory and income-related ESA are claimed on the same form (ESA1). Your son or daughter should make the claim unless you are their appointee (see page 65), but you can make the phone call on their behalf. They may have to be there to give their permission for you to speak on their behalf.

If a telephone claim is not suitable for you, it is possible to get a claim form sent to you.

Backdating of ESA

ESA can be backdated for three months, providing your son or daughter satisfies the conditions, and you provide backdated fit notes covering the correct amount of time.

Providing medical evidence

In order to make a claim for ESA, you will need to provide medical evidence that your son or daughter has a limited capability for work. Usually this evidence will take the form of a statement of fitness for work – otherwise known as a ‘fit note’ – from your GP.

Fit notes and backdated claims

If a claim is made after a young person turns 16, then it is possible for payments to be backdated for up to three months, or to the young person’s 16th birthday, whichever date is the more recent. For this to happen, you will need to provide a backdated fit note.

What is meant by ‘limited capability for work’?

To qualify for ESA, the Department for Work and Pensions (DWP) has to accept that the person claiming has a ‘limited capability for work’.

Most people claiming ESA will have to undergo an assessment known as the ‘work capability assessment’. There are two parts to this assessment.

The first part is to decide whether the person claiming has ‘limited capability for work’. This involves completing a questionnaire (form ESA50) and in most cases also attending an examination by a health professional. This means some young disabled people may need to attend two appointments with a health professional, one in relation to claiming ESA and the other in relation to PIP.

The assessment is based on a points system, and if not enough points are scored, ESA will not be awarded. It is important to get advice before completing the ESA50 form. The points system in ESA is different from that used to assess PIP. You can call our freephone helpline for advice.

The second part of the assessment is to decide which of two groups the person should be in:

- the ‘support group’, for more severely disabled people, or
- the ‘work-related activity group’ for people assessed as having some prospect of moving into work with support and training.



Some people are exempt from the usual assessment and will automatically be treated as having a limited capability for work. This includes people who are:

- classed as terminally ill, or
- within the next six months receiving, or likely to be receiving, certain types of chemotherapy, or
- the carrier of an infectious disease, or
- pregnant and work would mean a serious risk to their own or their baby's health, or
- receiving haemodialysis for renal failure for at least two days per week.

Most people will still have to be assessed in order to decide which group they should be in — the 'support group' or the 'work-related activity' group.

Support group

When someone is assessed as being in the support group, it means they will not be required to attend any work-focused interviews or undertake any work-related activity. They will also receive a higher level of ESA.

Work-related activity group

When someone is assessed as being in this group they will be expected to attend work-focused interviews (unless they are under 18) and other work-related activities.

Failure to attend any of these assessments without a good reason can result in a sanction being applied and a reduction in benefit.

Claiming ESA and doing 'permitted work'

If you claim ESA on the basis that you have limited capability for work, you would normally expect benefit to stop if you actually started working. However, in certain circumstances it may be possible for a young person to do some paid work and keep their ESA. This is known as 'permitted work'.

There are three types of 'permitted work':

- a young person claiming ESA can earn up to £20 a week without losing any of their benefit
- a young person can do 'supported permitted work' regardless of the hours worked. The work must be arranged by a public or local authority or by a voluntary organisation. They can earn up to £120 a week (after certain deductions) and will be able to keep their ESA
- a young person can work in any type of employment for a temporary period as long as it is for less than 16 hours a week and earnings are no more than £120 a week (after certain deductions).

Note: It is best to let the DWP know if your son or daughter is starting a job. Different permitted work rules will apply if they are claiming Income Support – get advice from our freephone helpline.

Other benefits

Income-based Jobseeker's Allowance

Income-based Jobseeker's Allowance is a benefit for people who are looking for work. It is a means-tested benefit and claimants have to prove they are actively looking for work. There are also particular rules which make it difficult for most 16–17 year olds to claim income-based Jobseeker's Allowance. For these reasons most young disabled people claim Employment and Support Allowance rather than income-based Jobseeker's Allowance.

Usually, single job seekers who are aged 18 or above are expected to claim Universal Credit rather than income-based Jobseeker's Allowance. This may apply even if they live in an area where the full Universal Credit service has not been introduced for other groups. Call our freephone helpline for further advice if your child is thinking of claiming income-based Jobseeker's Allowance.

For people who have paid National Insurance in the past, contribution-based Jobseeker's Allowance may be another option. Call our freephone helpline for more information about Jobseeker's Allowance.

Income Support

Income Support is a means-tested benefit for groups of people who are unable to look for work because of their specific circumstances, for example carers and some lone parents. It can also be claimed by some trainees to top up a training allowance or low earnings.

DLA or PIP and work

DLA or PIP can be paid to someone in employment and should not be affected by work. However, the fact that someone is able to carry out certain tasks relating to a job may call into question the extent of their care or mobility difficulties, and could lead to a review of their current award. If this happens, seek advice from our freephone helpline.

Working Tax Credit

Working Tax Credit is a benefit that can be claimed by a young disabled person if they are in paid work for at least 16 hours a week. The young person has to be at least 16 years old and they must have a physical or mental disability that puts them at a disadvantage when getting a job.

Also, the young person must either currently be getting DLA or PIP or have been in receipt of certain disability or incapacity payments within the last six months. Some people who were submitting medical certificates to the Department for Work and Pensions before they started working may also qualify.

The amount of Working Tax Credit paid will depend on your son or daughter's circumstances, including their taxable income. To claim Working Tax Credit call the Tax Credits Office on 0345 300 3900.

Carer's Allowance

You can carry on claiming Carer's Allowance for your son or daughter as long as they either get DLA care component at the middle or highest rate, or the daily living component of PIP at any rate and you satisfy the other rules of entitlement. If they have started to claim benefits in their own right, this should not affect your entitlement to Carer's Allowance.

If your son or daughter is a carer for someone else, they may be able to claim Carer's Allowance. They will need to be at least 16 years of age and caring for someone who gets DLA at the middle or higher rates for care or the daily living component of PIP. The care they provide is not defined in the rules but it must be for at least 35 hours a week.

Also, there are rules that prevent people who are on a full-time course from claiming Carer's Allowance. Call our freephone helpline for more information.

'Underlying entitlement' to Carer's Allowance

Sometimes a payment of Carer's Allowance cannot be made because another benefit, like contributory Employment and Support Allowance or Incapacity Benefit, is in payment. However, it is still important to make the claim as this will establish an 'underlying entitlement' to Carer's Allowance.

An underlying entitlement to Carer's Allowance can lead to an increase in the amount of any means-tested benefits the person claims, like Income Support.


Warning!

An award of Carer's Allowance can sometimes lead to a 'cared for' adult's benefits being reduced. Before making a claim for Carer's Allowance, it is important to get advice from our freephone helpline.

Universal Credit

Universal Credit is a new benefit that is gradually replacing most means-tested benefits for people of working age. See page 37. If your son or daughter lives in an area where the Universal Credit full service applies, and they try to make a new claim for a means-tested benefit such as income-related Employment and Support Allowance, they will be asked to claim Universal Credit instead.

Entitlement to Universal Credit for a young disabled person is assessed in much the same way as income-related Employment and Support Allowance. For example, if your disabled child claims Universal Credit on the basis they have a limited capability for work, they will need to provide a statement of fitness for work and undergo a work capability assessment to determine whether their payments should increase from week 14 of their claim. However, the amount received by a young person on Universal Credit could be different to what is paid under Employment and Support Allowance. Young people in full time education currently face particular problems in claiming Universal Credit and will need detailed advice from an independent benefits adviser.

Contact our freephone helpline for advice if you live in an area where the Universal Credit full service applies. For more information about Universal Credit, read our free factsheet **Universal Credit – the essentials** available to download at  www.contact.org.uk or call our freephone helpline for a copy.

Other financial help

As a parent, you may already qualify for some or all of the following forms of help while you claim for your child as part of your family. If they start claiming benefits for themselves, they might instead qualify for this help in their own right.

Free school meals

A young person aged 16, 17 or 18 qualifies for free school meals if they get income-related Employment and Support Allowance, Income Support, income-based Jobseeker's Allowance or Universal Credit in their own right.

If you still claim benefits for them as a dependant, then entitlement will depend on the benefits and tax credits you receive.

School clothing grant

Each local authority has its own rules so it is best to check with them or a local advice agency.

Health benefits

A young person can get free prescriptions, free NHS dental treatment, free NHS sight tests and help with fares to hospital. To qualify, they have to be:

- in full-time education and aged under 19, or
- getting income-related Employment and Support Allowance, Income Support or income-based Jobseeker's Allowance, or
- getting Child Tax Credit or Working Tax Credit which includes a disability element, and with gross annual income of no more than £15,276, or
- an asylum seeker getting support from the National Asylum Support Service or the local authority, or
- getting Universal Credit, and they had no earnings, or their net earnings in the most recent assessment period were no more than £435 per month (£935 if their award includes an element for having a limited capability for work or limited capability for work-related activity, or it includes an element for a child).

If none of these apply, it is still possible to get help on the grounds of low income. If you still claim benefits for your son or daughter as a dependant, the help you get will depend on your income and the benefits or tax credits you receive.

Prescription charges are free in Scotland and Wales and for people in England with certain medical conditions. Call our freephone helpline for more information.



Warning!

In April 2013, the government introduced a household 'benefit cap', which restricts the total amount of benefit payments that an out-of-work family can receive. At the time of writing the cap is £442 per week (£296 for single carers without a dependant child) in London and to £385 per week (£258 for single carers without a dependant child) elsewhere.

This cap does not apply to certain families, including those who work enough hours to be eligible for Working Tax Credit (16 or 24 per week depending on your circumstances).

It also does not apply where the claimant, their partner or any dependant child gets DLA, PIP, or certain other benefits.

If your disabled son or daughter is the only person you claim for who gets DLA or PIP and they start to claim benefits in their own right, they will no longer be treated as your dependant. This could mean that you lose your exemption from the cap.

However, you are also exempt from the benefit cap if you are entitled to Carer's Allowance or the Carer's addition in Universal Credit. If you are affected by the benefit cap call our freephone helpline for further advice.

Getting further advice

It is very important to get full and detailed advice about your benefit and tax credit entitlement, as well as that of your son or daughter. Contact employs experienced benefits advisers who can calculate your benefit and tax credit entitlements over the phone.

We can also try and help you identify a local adviser if you need help completing forms or if you need someone to phone the DWP or tax credit offices about your claim. You can contact us on freephone



0808 808 3555

✉ **helpline@contact.org.uk**

You may wish to contact the office paying your benefits or tax credits directly:

Child Benefit Office

Tel: 0300 200 3100

Textphone: 0300 200 3103

Tax Credit Helpline

Tel: 0345 300 3900

Textphone: 0345 300 3909

Disability Living Allowance Helpline

Tel: 03457 123 456

Textphone: 03457 224 433

Personal Independence Payment Unit:

Claims line: 0800 917 2222

Textphone: 0800 917 7777

Enquiry Line: 0345 850 3322

Textphone: 0345 601 6677

Employment and Support Allowance

Jobcentre Plus

Tel: 0800 055 66 88

Textphone: 0800 023 48 88

To discuss a claim for ESA.

For advice about grants, bursaries, loans and other financial support, contact:

Disability Alliance freephone helpline

0800 328 5050

www.disabilityrightsuk.org/funding-further-education-disabled-students

You can also contact your college or university's Student Support Service for further advice.

Other useful booklets from Contact

We have guides for parents on a range of topics, including:

- *Money Matters - a checklist when your child has additional needs*
- *Claiming Disability Living Allowance for children*
- *Carer's Allowance*
- *Siblings*
- *Fathers*
- *Grandparents*
- *Living with a rare condition*
- *Holidays, play and leisure*
- *Understanding your child's behaviour*
- *Getting social care services for your child with additional needs*
- *Aids, equipment and adaptations.*

A full list of Contact publications is at the link below.

All our publications are free to parents who call our helpline, and are free to download.

 www.contact.org.uk/publicationslist  **0808 808 3555**

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 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@contact.org.uk (Access to over 200 languages)

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