

## CHAPTER 5

### Money matters



Most of us are used to claiming benefits to help meet some of the additional costs of caring for our disabled children. As well as Disability Living Allowance, many of us claim additional passported benefits like Carers Allowance and disabled child tax credits. We get used to having this money around; it becomes part of the family budget. Often it pays everyday household bills, especially if parents can't work or work part-time.

Most people agree the benefits system in the UK is too complex. As this handbook goes to print the landscape of disability and welfare benefits seems even more complicated: many changes are in the pipeline, but few have been rolled out locally. So, in

this chapter we will do our best to explain what a young person might claim now and how to do this most effectively, as well as how to tackle claiming the new benefits that are on their way.

The government plans to introduce a radical new approach to welfare benefits called Universal Credits (UC). So far, this has only been launched in a few places in other parts of the country. But as UC is rolled out, many familiar benefits, tax credits and allowances will disappear to be replaced by one monthly payment. Migrating all existing benefit claimants to UC will take at least three years; over this time the current and the new system will be run side by side. Some families will continue to claim an array of benefits while others who report a change of circumstances will be moved to Universal Credit. We don't know when this will begin to happen locally.

Alongside changes to other benefits, Personal Independence Payment (PIP), the new benefit for eligible working age people, replaces Disability Living Allowance (DLA). But the timescale for rolling this out has also stalled. Although there are no new DLA claims for adults, just for now, the picture is different for young people aged 16 who have been getting DLA as children. PIP is likely to be introduced for young people in the near future, but as this edition goes to print (February 2014), families of children who are rising 16 are being sent a 'hybrid' adult DLA claim pack.

As your child reaches 16, and when circumstances change – for example your child leaves education or begins to claim their own benefits – there can be a knock-on effect on your income as a parent. We outline some of the things you'll need to consider, but we recommend you seek advice to ensure you and your child make the right financial decisions.

In this chapter we will look at benefits you and your child might be getting now, what changes as your child reaches 16 and as

PIP is introduced, and what we think will change again as households are moved to the new system of Universal Credits.

We also look at other sources of help like Motability, Direct Payments and grants. We will signpost you to other sources of information and advice. If you need information on funding for students, you'll find it in Chapter 3, 'Further and higher education'.

### What benefits are you getting now?

- **Child Benefit:** presently this is paid to families with responsibility for a child under 16, as long as no parent is a higher rate tax payer. It can be extended up until the age of 19 if a child stays in full-time education or on a government-recognised training scheme
- **Disability Living Allowance (DLA):** many parents are used to claiming DLA for a child who has a disability, illness or special need that has a significant effect on daily living. Parents claim it on their child's behalf
- **'Passported' benefits:** these are benefits you can get if your child receives DLA. They include Carer's Allowance, extra Tax Credits to top up earned income, and extra Tax Credits or premiums on your own benefits (like Income Support, Job Seekers Allowance, Local Housing Allowance and Council Tax reductions)

### WHAT CHANGES AT 16?

When a young person reaches 16, they have the right to manage their own money or ask someone else to do it for them. At 16, young people can claim benefits for themselves. Claiming benefits in their own right can be the key to getting other sorts of help. They may be able to get benefits like DLA or PIP (once it is introduced) and Employment and Support Allowance (ESA), as well as other sources of financial help.

What you and your child decide to claim may affect your own entitlement to benefits, so you may want to get expert advice. The **Money Advice and Community Support Service (MACSS)** can give advice about entitlements to benefits and support you to make claims. Call them on 01273 664000, or visit [www.maccs.org.uk](http://www.maccs.org.uk). Or you could get one of the 'under 18' advisers at **Brighton Jobcentre Plus** to do a 'better off calculation' for you to help you understand how the benefits your child claims might affect yours. Call them on 01273 647400.

In some circumstances, it may make financial sense for a young person to claim benefits in their own right when they reach 16. More often though - especially if your household claims income-related benefits - the picture isn't as clear.

There is an expectation that parents are responsible for their child's 'keep' up to the age of 20. So as long as your child stays in full-time education at school or college or unpaid work-based training, under the current system, you can continue to claim Child Benefit and Child Tax Credits (CTC) for them. Universal Credit will include allowances for children and young people and extra money if they are disabled.

### When should a young person claim benefits as an adult?

If your child can manage their own money, it makes sense for them to claim DLA (or PIP) for themselves at 16: even if they do, they can still be considered a child for the purposes of other benefits like Child Benefit and Child Tax Credits.

Presently, at 16, some severely disabled young people are entitled to claim ESA, but the rules about who can claim are hard to meet. And as soon as a young person makes a claim for ESA, their parent must stop claiming child-related benefits like Child Benefit and - more importantly for parents on low incomes - (disabled child) Tax Credits and premiums.

If your household isn't entitled to Child Tax Credits (CTC), it makes sense for a young person who meets the strict eligibility criteria, to claim Employment and Support Allowance (ESA) at 16, because ESA's worth a lot more than the Child Benefit that will be lost. One exception is if they're at a residential school or college - because although they may be entitled to ESA, most of the income may not be payable because the council (local authority) is paying for their care and lodgings (just like the care component of their DLA). See page 114 for more details on the rules for claiming ESA.

If you're getting Child Tax Credits, these continue to be paid up to the age of 20 as long as a young person remains in full-time non-advanced education, as we said above. So it makes sense to keep claiming these.

If your household is getting the full entitlement to CTC, it probably isn't worth a young person claiming ESA at 16. But if your household is only getting some CTC, you may want to get advice. Once again, Money Advice and Community Support Service (MACSS), your local Jobcentre Plus and Brighton and Hove Citizen's Advice Bureau can help you do a 'better off calculation'. This should help you work out which option will leave you better off. Find their details at the back of this book.

Benefits like ESA are 'means tested' - so other income and savings are taken into account when deciding how much a young person needs to live on. If your child is a beneficiary of a discretionary trust, it shouldn't be taken into account when calculating their entitlement to benefits - as long as they aren't getting a regular income and purchases made by the trustees on your child's behalf are irregular. Parents' savings and income don't affect a young person's claim to ESA.

For more information on how the benefits you are already claiming can be affected when your child claims benefits, see page 117.

### **What if your child can't manage their own money?**

A young person can claim benefits in their own right, even if they need someone else to act on their behalf. Awards for DLA are usually reviewed in the five months before a child reaches 16. PIP can be claimed once a young person is 16. Claiming DLA or PIP at 16 is often the first time young people have to think about their ability to manage significant amounts of money.

In reality most disabled young people don't feel ready to take on this responsibility and ask their parents to look after their money for them, pay their bills and give them an allowance. This means parents take on the role of 'appointee'.

An appointee acts on a young person's behalf in all benefits matters, not just DLA. This includes telling the DWP (Department of Work and Pensions) about any changes in their circumstances, banking benefit money for them and using it in their best interests.

Before an appointee is agreed, the DWP will arrange to visit both a disabled young person and the person (often the parent) making the application to act on their behalf. The DWP has to agree that a young person is not able to act on their own behalf.

If you haven't had a letter from the DWP to ask whether you will be your child's appointee, call a few months before your child turns 16.

**PARENT TIPS**

- ☺ Talk to your child about the pros and cons of managing their own money and how much of it they want to practise budgeting with. Agree how it will be used - how much will be pocket money, how much they will contribute towards the help you give them and what they will save
- ☺ When you arrange the DWP visit, make the representative aware of your child's communication, learning, or mental health problems and whether they're careless about money or vulnerable to financial abuse

*'I reminded Alex about last month when he'd raided his savings and spent £80 in an hour on the pier buying rides and fish and chips for 'friends'. And how angry he had been that he couldn't get the trainers he'd been saving for. We all agreed it's best that I manage his DLA for another few years.'*

**What should your child pay towards their care?**

Once your child starts claiming benefits, it's a good idea to agree how much they will contribute to the household bills and how much they'll pay towards the care you give them, and other stuff like running them around in the car. This way any changes in either of your financial circumstances shouldn't leave you out of pocket and the young person will get a better idea of how much it costs to live and how far their money goes. MACSS (see page 88) can help you and your child work out what a reasonable contribution might be and offer advice about budgeting.

*'Half our household income comes from money because of James' special needs. He's already decided he's leaving home when he leaves college so if I don't start planning for my future, I might end up destitute!'*

Start thinking how you would manage without your child's contribution. Sooner or later most young people leave home to live more independently.

**DISABILITY LIVING ALLOWANCE (DLA)**

Disability Living Allowance (DLA) is a benefit for children under 16 and, it is still available for some young people aged 16 until PIP is rolled out locally. A young person can claim DLA if they need help looking after themselves, or they need watching over to stay safe, or if they find it difficult to walk about or get around because of a disability or chronic illness.

DLA isn't taxed and income from DLA is 'disregarded'. This means it's not taken into account if you or your child, claim other benefits. DLA is a 'passport' to other sorts of financial help too. If you claim other benefits because you are on a low income, it's always worth saying your child gets DLA: there can be extra benefits or Tax Credits for parents. Similarly, if a young person claims benefits as an adult, getting DLA can entitle them to extra allowances, disability premiums and credits.

If your child is 14 or 15 years old and you haven't thought of claiming DLA for them before, you might want to think about it now. It's best to get the claim pack from the DWP as they will date stamp the form. As long as you get the completed form back within six weeks, a successful claim will start from the date you requested the pack.

A child DLA claim pack is very different from the 'rising 16' adult claim pack. Our companion handbook Through the Maze has advice about filling this in, or you can download our fact sheet 'Tips for claiming DLA for a child' from our website. You can download a DLA claim pack by visiting the DWP website at [www.dwp.gov.uk](http://www.dwp.gov.uk) or call 08457 123456 or text on 0845 722 4433 for a paper copy.

In the future all young people will have to claim PIP. If your child is 16 or over and they have never claimed DLA, expect to fill in a PIP claim form for them: more about this on page 101.

If your child is already getting DLA, you may be sent a 'hybrid' adult DLA claim pack about five months before they reach 16.

## Making a successful DLA claim

To make a successful claim for DLA you need to show a disabled young person 'requires' substantially more 'attention' in connection with their 'bodily functions' than is usually required by an adult; or 'continual supervision to avoid substantial danger' or someone 'to be awake for a prolonged period or at frequent intervals' at night to 'watch over you'.

### What does all the jargon mean?

- **'requires'** does not mean medically require, it means reasonably require. For example, a young person with a speech and language disorder may have a reasonable requirement for attention from another person to make themselves understood and make sense of what others are saying
- **'attention'** is help from another person to do the personal things a young person cannot do for themselves
- **'bodily functions'** are anything to do with how the body works and what it does
- **'continual supervision'** means a young person needs someone around to minimise the risk of them coming to harm, or putting others in danger
- a **'prolonged period'** is at least 20 minutes
- **'frequent intervals'** means at least three times a night
- **'watch over you'** means someone is awake and alert and getting up to check on a young person

### What counts as 'bodily functions'?

There's a very long list of what counts as bodily functions: breathing; hearing; seeing; talking; listening; signing; reading; eating; drinking; walking; sitting; maintaining good posture; sleeping; turning; changing bedclothes in the night; eliminating waste products; getting in and out of bed, the bath or chair; washing; shampooing hair; cleaning teeth; brushing hair; dressing and undressing; help with medication or therapies; managing feelings and behaviour; thinking; problem solving; making choices; being prompted, reminded or encouraged

### What counts as 'attention'?

All sorts of things count as attention (or help). These can include:

- The resourcefulness, time and energy you put into helping your teenager learn what other young people seem to pick up effortlessly - including problem solving when unexpected things happen
- Practical and hands on help, or prompting and encouragement with everyday activities like dressing, washing, and toileting, cooking or even getting along with other people
- The thinking you do to anticipate and manage potential difficulties
- The ways you adapt your communication: some disabled young people need help to make themselves understood, make sense of what's going on around them, or to manage difficult feelings like anger or anxiety
- Nursing or therapeutic help: monitoring a young person's medical condition, giving medication, helping a young person use special equipment or carry out a therapy programme
- Help to get out and about and to keep safe

Don't underestimate the help your child needs. Some young people need much more help than others. Even if your child needs extra help with just some of the things we have mentioned, we think it's worth making a claim for DLA.

If your claim is successful, DLA is payable in two parts – 'care' and 'mobility' components.

### The care component of DLA

A young person can claim this if they need help with 'personal care' or looking after themselves. This includes things like keeping safe and communication. A young person can claim as long as they have needed the extra help for at least three months and will continue to need the help for at least another six months. There are three rates at which the care component can be paid.

**The low rate:** if a young person needs some help for a significant portion of the day and/or they cannot prepare a cooked main meal for themselves.

**The middle rate:** if a young person needs frequent help or constant watching over to stay safe or keep others safe during the day. Or some help or watching over at night.

**The high rate:** if a young person needs help day and night.

### The mobility component of DLA

A young person can claim this if they need extra help with getting around. There are two rates for this:

**The lower rate:** if a young person needs someone around to keep them safe, or someone to help them find their way around.

**The higher rate:** if a young person's ability to get around is severely restricted because they:

- Cannot walk at all, or are virtually unable to walk
- Have no legs or feet, or walking would be dangerous for their health
- Have the most severe visual impairment or are deaf and blind
- Have severe learning disabilities affecting both cognitive and social functioning and/or disruptive behaviour that is unpredictable and regularly requires physical intervention to prevent injury. They also need to be getting the high rate of the DLA care component

To get the high rate for mobility, young people are likely to have a severe physical or sensory impairment; a life threatening neurological, cardiac or respiratory disorder; or the most severe autism or learning disability and challenging behaviour.

If a young person is awarded the higher rate for mobility:

- The vehicle used by the disabled young person may be exempt from Road Tax
- A young person will be entitled to a Blue Badge. This should make it easier to park close to the places they need to go
- The young person or their appointee may be able to buy or lease a car or purchase an electric wheelchair through the Motability scheme (see page 208 for more information).

### Special Rules

If a young person is diagnosed with a life limiting illness and unlikely to live more than six months, they can claim DLA under Special Rules.

Though claiming benefits is likely to be the last thing on your mind if you've just been told your child has such a poor prognosis, it is a good idea to try to claim it on their behalf as

soon as you feel able; DLA can't be backdated to before the day you actually claim it - even in such distressing circumstances.

Claiming DLA under Special Rules means that you don't have to wait three months and you only need to fill in the first few pages of the claim pack. If DLA is awarded on these grounds, a young person will automatically be awarded the high rate care component.

Ask your child's consultant for a DS1500 report and send it with your claim. If you'd rather not read what they write, ask for the DS1500 to be handed to you in a sealed envelope, or give the parts of the claim you have completed to your child's doctor or specialist nurse: they will be happy to send it for you. The DWP aims to make decisions about these claims within eight days.

### **What's different about the adult DLA claim form?**

Many parents will be used to claiming DLA for their child: similar rules apply for over 16s and the benefit rates are the same. But there is a difference in the eligibility requirement. Your teenager's need for care or supervision must 'be greater than another adult's' as a result of their illness or disability. This is simpler than the rule that applies to child claims; that their illness or disability has to be 'greater than another child of the same age who does not have that illness or disability'. Nevertheless, it's still worth making comparisons on the claim form between your teenager, their peers and younger siblings if this seems relevant.

As you tackle each page of the form, you need to think: 'what's the impairment or disability?', 'what's the problem arising from this?', 'what's the help my child needs?' and 'what would happen if they didn't get this help?' Do your best to touch on all these aspects as you fill in each page.

If you're used to making childhood claims for DLA, the adult claim pack will look unfamiliar. There are tick boxes and text boxes where you can explain the help your child needs. You are invited to say more and we would strongly encourage you to do so. The text boxes are small and many of us have found that we've had to add additional sheets of paper to explain the help our child needs in sufficient detail. Experience shows the claim is less likely to be successful if you don't use the text boxes.

The importance of play and learning disappears on the adult claim pack. Issues around communication are condensed into one page and include problems your child may have using a telephone, reading and writing, managing forms and letters, as well as making themselves understood, understanding other people and their social skills. There is no mental health page, so it's important to weave any difficulties your teenager has managing their feelings into the other pages.

Perhaps the most different thing of all on the adult form is 'the cooking test'.

#### **The cooking test**

To fail the cooking test, you need to demonstrate that a young person can't prepare a cooked main meal for themselves without help because of their disability. This help can be:

- Reading instructions and labels, guidance to follow a recipe
- Identifying, weighing and measuring ingredients
- Putting basic food safety and hygiene into practice
- Using sharp knives, hot pans, cookers and other equipment safely
- Recognising when food is properly cooked or safe to eat
- Timing it so that everything's ready together

**TIPS FOR A MAKING A SUCCESSFUL DLA CLAIM**

- ☺ Never assume that because your child has always been awarded DLA as a child, this time will be a 'shoe-in'. Put as much time and effort into this application as each previous claim.
- ☺ Concentrate on what a young person can't do; you need to 'tell it how it is'. Young people are often the ones who know how their illness or disability affects them, so think about how you can involve them in making the claim.
- ☺ Look up the most recent advices and reports you have about your teenager and read through them. They can often help you understand the underlying reasons why your child might appear clumsy or not to listen
- ☺ If possible, send supplementary evidence to support what you're saying. Copies of things like diaries, medical reports, speech and language assessments and Statements of special educational need (SEN) are often useful. These may help persuade a decision maker who will never get to meet your child
- ☺ Make photocopies of everything you send: the claim pack and any extra evidence - you will need to refer to them if you want a decision looked at again, or when the claim is reviewed
- ☺ Keep copies of everything in a safe place. The next time your child's DLA is reviewed, or they are invited to apply for PIP, they may have left school or college - and evidence of their level of need and abilities will be harder to come by.
- ☺ Think about returning your claim by Special Delivery. It protects you from the claim getting lost in the post, or the DWP saying they haven't received it. You get a receipt for Special Delivery items and the DWP has to sign to say they've received it.

*'I said I didn't realise how rubbish I was at so many things. The lady said it's OK there was lots of things she's still learning to do too. I told her about the ice skating, the lady said she can't do that for toffee, that made me laugh, 'cos skating's easy.'*

**PARENT TIP**

- ☺ Focusing on what your child can't do is miserable. So once the application's complete, make time to talk about what your child is good at as well

If you don't agree with any part of the DWP's decision (a non-award, the rate of either the care or mobility component, or the length of the award), you need to act quickly. There are short timescales for challenging decisions, so get advice as soon as possible

**Getting help with claiming DLA**

DLA application forms are long and detailed and it's worth getting help to fill them in. Ask a friend to help. Other parents who have teenagers with similar problems can be a great source of information about what to say and what not to say.

Amaze can also help with DLA claims. We produce a factsheet, 'Tips for Claiming Disability Living Allowance', that should also get you off to a good start or if you are really stuck we can give you more direct one to one support with making a claim. Call the helpline on 01273 772289. Other disability-specific organisations like the Fed can also offer useful advice about claiming DLA for young people or adults with specific chronic illnesses, disabilities or impairments.

## PERSONAL INDEPENDENCE PAYMENT (PIP)

Personal Independence Payment or PIP is a new benefit for working age people who face extra challenges carrying out everyday activities or getting out and about. PIP replaces DLA. PIP is not taxed or counted as income for means tested benefits. It's not based on National Insurance contributions and can be paid both in and out of work. A fast track application process works if you are claiming under Special Rules, in much the same way as it does under DLA (see page 96).

Like DLA, PIP is a passport to disability premiums and extra child Tax Credits in the current benefits system. In future, if a young person is included in their parent's Universal Credit claim, a disabled child amount will be payable in the household's UC award. Any household that includes someone getting PIP will be exempt from the benefit cap.

If a young person is entitled to the daily living component of PIP, then someone else may be able to claim Carer's Allowance for looking after them.

Getting the higher rate of the mobility component will entitle a young person to access the Motability scheme and a Blue Badge.

### What's different about PIP?

**PIP is paid in two parts:** a mobility component based on a young person's ability to get around, and a daily living component based on their ability to 'look after themselves'.

**Each component of PIP will be paid at one of two rates known as the standard and enhanced rate:** the DLA care component currently has three. Realistically, this means that if you are already getting the lower rate of the care component, you are more likely to be at risk of being turned down for PIP. The

weekly payment rates for PIP are the same as the rates payable for DLA.

**DLA rules allow for some people with certain conditions to automatically qualify for DLA components at specific rates. Under PIP no-one, (other than people who are terminally ill) will have any automatic entitlement.** Nearly all awards will be time limited, with very few indefinite awards. We also think most awards are likely to be shorter and reviewed more frequently than awards for DLA.

**PIP includes a broader range of practical skills than were included under DLA.** For example handling money, understanding how much change to expect and budgeting are new key tasks

**PIP shines a torch on social skills:** asking about the person's ability to mix and get on with others. It's easier to know where to include how a young person struggles to 'read' other people's intentions or understand how what they say and do can have an impact on how others feel towards them.

**There is no page asking about night time needs** and we really welcome this. Under DLA rules, no matter how dependant you are on other people to do things for you throughout the day, if you sleep through the night, you would only ever be entitled to the middle rate of the care component. And if you have a severe learning disability and challenging behaviour, under DLA you can only ever be awarded the higher rate of the mobility component, if you are also up at night! We have always thought these rules bizarre!

**PIP uses an entirely new set of criteria, a points-based system, to decide whether someone qualifies for the benefit,** and if they do at what rate they will be paid. For most young people

the new assessment process will also involve a face to face meeting with a health professional. More about this later.

### **When will a young person need to claim PIP?**

If your child is 16 or over and they have never claimed DLA, they will need to claim PIP. If your child is over 16, and you report a change in 'circumstances', which might affect the rate of their DLA award, they will be reassessed under PIP.

If your child is rising 16 or they are over 16 and their existing DLA award is coming to an end, but you have not been sent a DLA renewal form, you'll get a letter to tell you when and how to apply for PIP.

You cannot apply for PIP until you are 16, so there will be special arrangements allowing current DLA awards to run on after your child's birthday, until a decision is made on their PIP claim. We understand these claims will be looked at by a specialist team of decision makers.

You can choose to make an application for PIP even if your child has an indefinite award of DLA. This would make sense where a young person is likely to be awarded a higher rate under PIP than their current DLA award. For example if they have high support needs throughout the day but not at night.

From October 2015, PIP will be rolled out to everyone else. There will be no automatic migration between DLA and PIP. Everyone still getting DLA, will over time, be contacted and invited to claim PIP. Young people with indefinite or lifetime awards of DLA will be the last to be reassessed under PIP.

As appointee, you need to act promptly as soon as the Department for Work and Pensions (DWP) writes to you or your child about PIP. If neither of you reply to the invitation to

apply for PIP, their DLA award will be suspended four weeks later. If a claim is made within four weeks after the suspension, the DLA award will be restored until a decision is made on the PIP claim. If you do nothing during the four weeks suspension, your child's DLA claim will end permanently eight weeks after they wrote to you. There will only be limited appeal rights against this decision.

### **How to start a claim**

PIP claims begin over the phone. Ring the Department of Work and Pensions (DWP) on 0800 917 2222. You can call on behalf of a young person but they should be with you when you do this.

It's worth getting organised before you ring. You will be asked for basic details like your child's name, address, date of birth and main area of difficulty. You will also need to give your child's National Insurance number, their doctor's or health worker's names and have information to hand about time your child has spent abroad, in a residential school, care home or hospital. The DWP will also ask for bank or building society details.

As long as a young person has had the additional needs for at least three months, expects to have the same needs for at least the next nine months and meets the residency test, they will be sent a 'How your condition affects you' form. The claim pack is personalised. It comes with notes to help you fill it in.

### **Making a strong claim for PIP**

PIP will use an entirely new set of criteria, a points-based system, to decide whether someone qualifies for the benefit, and if they do at what rate they will be paid. To make a successful claim for PIP, a young person needs to score 8 points to qualify for the standard rate of component: 12 points or more qualifies them for the enhanced rate.

This new type of assessment will focus on a young person's ability to carry out everyday activities. There are ten daily living activities and two mobility activities and a set of descriptors for each: what a young person scores against each activity should reflect the difficulty they experience in the following areas:

- Preparing food and drink
- Taking nutrition
- Managing therapy or monitoring a health condition
- Bathing and grooming
- Managing toilet needs or incontinence
- Dressing and undressing
- Communicating
- Engaging socially
- Making financial decisions
- Planning and following a journey
- Moving around

The number of points a young person scores in the last two categories will determine if they get the mobility component, and at which rate. Scores in the other categories will determine whether they get the daily living component.

Each activity has a list of descriptors that carry different scores. Some activities attract more points: speaking, eating, and planning a journey carry more weight than activities like budgeting, planning a meal and washing.

You can only be awarded points for one descriptor in each activity, so it's worth giving as clear a picture as you can. To get any points for an activity, you need to satisfy at least one of the descriptors for at least 50 per cent of days.

The new assessment prompts you to explain the challenges a young person faces doing a task safely, to an acceptable standard, as often as they need to, as well as the individual way

they tackle a task when they don't have someone to help and have to 'get by'. It's important to focus on these prompts.

### TIPS FOR CLAIMING PIP

- ☺ Do your best to 'tell it how it is'. Young people are often the ones who know how their illness or disability affects them, and most will be invited to a face to face assessment, so think about how you can involve them in making the claim.
- ☺ Gather evidence: advices, assessments, reports, from health, education or social care practitioners. If your child has a Statement of SEN, an Education Health and Care Plan (EHCP) or a Moving On Plan, make sure you have a copy. Include as much supporting information as you can with the claim.
- ☺ Act quickly and stick to DWP deadlines, otherwise you risk losing your child's DLA and a gap in payments.
- ☺ Always keep a copy of the claim, so far as we are aware you aren't sent back any paperwork before a face to face interview.

PIP application forms are long and detailed and it's worth getting help to fill them in. All the tips about making a strong claim for DLA apply to claiming PIP, so check pages 93 to 100. Disability Rights UK has a very helpful guide to making a PIP claim. It includes the scoring system for the twelve activities. You can download it at [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

### Unpicking the jargon: what counts as help?

- You will be assessed as able to carry out an activity '**unaided**' (and that means score no points for it) if you can carry it out '**without the use of an aid or appliance; or supervision, prompting or assistance.**' These terms carry very specific meanings within PIP regulations.

- **'Assistance'** means physical 'hands on' help: it does not include spoken encouragement or explanation
- **'Supervision'** means the 'continuous presence of another person for the purpose of ensuring (the disabled person's) safety'
- **'Prompting'** is 'reminding, encouraging or explaining to another person': it doesn't explicitly require the presence of another person, but must be essential for the activity to be carried out'. So for example the other person might be at the other end of the phone.
- **'Aid or appliance'** is any device which improves, provides or replaces a disabled person's impaired physical or mental function; and includes a prosthesis. Examples might be adapted cutlery, modified kitchen utensils, a standing frame, communication apps, grab rails etc and count even if the claimant doesn't use the aid but could be 'reasonably expected' to use one but does not for reasons of cost, availability or cultural reasons.
- **'Unaided'** also relies on a disabled person being able to carry out the activity 'in a way that is safe and reliable and does not take too long and can be repeated as needed. If they cannot do so, another descriptor must be chosen and ultimately the individual may be considered to be unable to complete the activity at all'.

Don't leave it up to an assessor to have to guess! It's always worth giving a very detailed account to explain what happens in reality.

For example, to get the higher rate of the mobility component, and score 12 points on grounds of physical impairment alone, you will need to provide evidence that a young person who 'can stand and then move 1 metre, cannot move more than 20 metres, either aided or unaided'. This seems a really tough test, especially as the distance under DLA to get the higher rate of the mobility component was 50 metres.

The next descriptor, that a young person may be able to walk more than 20 metres but no more than 50 metres, only scores 10 points. This is not enough to get the higher rate under PIP, or access the Motability scheme or a Blue Badge. Remember though, this descriptor can only be applied if a young person can do this safely, to an acceptable standard, repeatedly and in a reasonable time. If you can explain how a young person cannot meet one or more of these additional requirements, we think you can reasonably argue the descriptor that best fits is the one that attracts 12 points.

*'Zoe has cerebral palsy. She can walk 40 metres with a walking frame, but to do this she needs to draw on all her resources. The physical and thinking effort of getting her body to do what she wants is exhausting. Just this short distance takes her at least five minutes. The first 20 metres takes her 2 minutes but the next 20 metres takes at least 3 minutes. Then she needs to stop and rest. She needs to be able to sit down and take a break for at least five minutes. On a bad day she would need a longer rest. This means on a good day it will take Zoe 15 minutes to walk 80 metres. Even on a good day, Zoe would not be able to repeat this more than two more times, on another day she may only be able to repeat this once. On a bad day Zoe may not be able to repeat this at all. Any amount of walking has an impact later in the day. If Zoe has been out in the morning, she will need to sleep most of the afternoon to recover.'*

This means that at best, using her walking frame, Zoe may be able to walk 160 metres, but it would take her 35 minutes. Then she would not be able to walk any further for several hours. So on a good day, it would take Zoe at least 155 minutes to walk 161 metres. We think you can argue that Zoe cannot maintain this level of activity 'repeatedly' or 'in a reasonable time'. She certainly cannot do it even once without her walking frame.

If a young person has good and bad days, it's really helps to explain this too. Describing exactly what they can do two days out of seven and what they can manage on the other five, helps the assessor work out which descriptor (and so how many points) best reflects a young person's abilities. Points will be awarded for the descriptor that best fits 50% of the time.

Experience of DLA tells us that claims are less likely to be successful if you don't use the opportunity to give examples, PIP is the same. Many of us have found that we've had to add additional sheets of paper to explain the help our child needs in sufficient detail. The clearer the picture you can give, the less likely it is that a young person will be called for a face to face assessment.

If you feel stuck with a PIP claim pack, download the Disability Rights UK Guide to claiming PIP at [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org) - it is comprehensive and has useful examples. Or call the Amaze helpline and we may be able to offer you and your child individual support.

### Face to face assessments

It is very unlikely that severely disabled young people will be asked to attend a face to face assessment. Nevertheless, be sure to send as much supporting evidence, and give as detailed an account of how they cope with daily activities, their communication or access needs as you can, to avoid unnecessary interviews.

Many other young people will be required to attend a face to face assessment. For most claimants and especially disabled young people, the idea of going for a face to face interview is likely to feel overwhelming. There is a lot you can do to make this a fair and a positive experience.

A young person should always have someone to support them and may need help to think about who's the best person to ask. It needs to be someone who is both 'on their side' and understands how their disability impacts on everyday life. This can be a friend, support worker, or health, education or social care practitioner. Most often we think it's likely to be you, their parent or carer.

It's really worth preparing for this meeting. Start keeping a diary so you can illustrate what your child can do and the help they need.

A young person may not have had much involvement in writing their PIP claim and even if they have, the last time either of you looked at it will have been months ago. So read through it again, together.

Spend a bit of time rehearsing: take turns asking and answering 'open' questions. 'Can you tell me about how you would make a cup of tea?', 'How did you get here today?' but don't practise too much!

Assessments may happen at your home or at an assessment centre. If you need to travel, plan how you will get to the venue. If a young person is very anxious it may even help to practise the journey and 'stake out' the building a few days before. Check for accessibility.

Travel expenses will be reimbursed: keep receipts or note mileage if you come by car. Parking charges are covered too.

On the day, arrive in good time. Make sure you are both as comfortable and feeling as calm as possible.

We understand you can make a record of what is said at the meeting but you have to be able to give a copy to the assessor

and it makes sense to say well in advance if you'd like to do this.

The healthcare professional who does the assessment will want to see for themselves how what is written on the PIP form matches up with the young person they are meeting.

If a young person struggles to 'follow' the thread of a conversation or is likely to misunderstand what other people say, you will need to act if you notice this is happening. Doing this in a clear, positive way: repeating and phrasing questions more simply, using words they know, checking back they really understood the question and everyone else has understood what the young person is trying to explain, will help the assessor spot how easily things can go wrong.

Often a young person will have a very good idea about what is difficult for them and how they manage. But even so, some may say what they think the healthcare professional wants to hear. You will be able to add to and comment on what a young person says if you feel their own perception of their abilities is unrealistic. It helps to give real examples of occasions when a young person hasn't had the help they needed and things haven't gone well or routine daily activities didn't get done at all.

It's important the assessment goes at a comfortable pace and it's OK to ask for a break, if a young person needs one.

Be aware that the healthcare professional will observe and note everything: from whether a young person lets a door go in your face as you come into the room, to how they put their coat on.

If there is any sort of physical examination, a young person should not feel pushed to do more than they can safely manage

or anything that is painful. Agree beforehand how they will tell you or signal that they cannot carry on.

Towards the end of the assessment, the healthcare professional should give a summary of their findings and ask if there are any questions or if there is anything more you would like to add. Later they will write a report and send it to the DWP.

The decision about whether to award PIP, at what rates and for how long is made by the DWP. You will be contacted by letter about the outcome.

### **What happens if you do not agree with a decision?**

The outcome letter will explain what to do next if you do not agree with a PIP decision and about time scales. The first thing to do is contact the DWP: you can do this over the phone.

Say what it is that you do not agree with and why. It may be that you feel a young person should be entitled to the enhanced rate for the mobility component rather than the standard rate. Or maybe you disagree with the length of the award. Always be aware that when you ask for a claim to be looked at again, the DWP can look at both components as well as the length.

If no award has been made at all, you should get a phone call from the DWP to explain why. You should ask that another decision maker look again at the claim: this is called requesting a re-consideration. The DWP must do this, if you ask. Ask for copies of all the information, including any reports submitted by the healthcare professional. This can help you build a case. Say you will write to give detailed reasons why you disagree.

Go through this paperwork carefully: notice if there is any difference of opinion between what you put on the claim pack and the healthcare professional's report, if any evidence has

been disregarded or if you need to gather more reports to support what you say. Ask for extra time if you need it and say when you will write back to them. Otherwise a decision may be made straight away.

The right to appeal a PIP decision only arises once a different decision maker has reviewed all the information and you have the outcome in writing. Hopefully, the first decision will be revised in your child's favour and you won't need to go to appeal. If it isn't all is not lost!

Whether or not the decision is changed, you will get a mandatory reconsideration notice. You will need this to appeal. You now have one calendar month to submit your appeal. Appeals are made directly to an independent Tribunal. You will need to fill in a SSCS1 notice of appeal. You can download this from [www.gov.uk](http://www.gov.uk) website or by ringing the DWP on 08457 123456 to get one posted out.

Say clearly what part of the decision you disagree with and why. Keep a copy. Send it back within the timescale.

You will get a pre hearing questionnaire. It's best to opt for a face to face hearing, your chances of an outcome in a young person's favour is much greater if you do.

You do not need to take someone like a solicitor to represent your young person. Experience of DLA appeal tribunals tells us that parents and carers are generally best placed to 'tell it how it is' and say it from the heart.

If you have any more supporting evidence, send it in at least a week before the hearing. If you only get a report the day before, take it with you and explain about this. In our experience the Tribunal panel will accept evidence on the day.

Hearings are informal and you will be able to comment on and add to what your child says. It's always best to prepare again as you did for the face to face assessment with the healthcare professional.

## **EMPLOYMENT AND SUPPORT ALLOWANCE**

Employment and Support Allowance (ESA) is a means tested benefit paid to people whose ability to work is limited by ill health or disability.

Most claims are started over the phone, so call 0800 055 6688 or text on 0800 023 4888 and ask for a claim pack. You can download form ESA1 from [www.gov.uk](http://www.gov.uk) or pick up a form from your local JobcentrePlus.

### **Who can claim?**

A disabled young person may be able to get ESA if they're 16, 17 or 18 even if they're still at school or college. They cannot be in 'full time education' for 21 or more hours a week. But most college courses take up less than 21 hours and teaching hours that are significantly differentiated are not counted (because a young person has severe learning difficulties for example). From the age of 19 there are no rules about the hours and type of study.

A young person can claim ESA from 16, but they have to have had a limited capability for work for 28 weeks before ESA can be paid. These 28 weeks can be before their 16th birthday. So plan ahead and get a medical certificate or 'fit note' six months before your child's 16th birthday, so ESA can be paid straight away. Alternatively, your GP may be willing to back-date a medical certificate.

As a full time student, a young person can only get ESA on the grounds of low income (income related ESA) if they are getting DLA, PIP or armed forces independence payment.

A young person cannot get income-related ESA if their savings or capital is above £16,000. Their benefit will be affected if they have savings of more than £6,000 (£10,000 if they live in a care home).

Remember, if a young person claims ESA, you won't be able to claim child related benefits for them. You'll need to think about what works best for your household. There are rules about who counts as a child for Tax Credit purposes: you can check this at HM Revenue and Customs (HMRC) at [www.hmrc/taxcredits](http://www.hmrc/taxcredits) or call the Tax Credit Helpline on 0845 300 3900.

The principle underpinning ESA is that everyone should have the opportunity to work and if they're able to, people with an illness or disability should get the support they need to move into work or work-related activities. So the assessment framework looks at what the young person can do, as well as what they can't do.

When a young person makes a claim for ESA there is an initial assessment period. This is about 13 weeks but can be longer. During this phase they will be sent a Work Capability Assessment form. You need to return this within four weeks.

The Work Capability Assessment (WCA) form is laid out rather like a PIP claim pack. You are assessed on your ability to carry out 17 'physical, mental, cognitive and intellectual activities'. Any 'limitation' must arise from an illness or disability, or as a direct result of treatment (eg chemotherapy, or a body brace).

Each activity has with it a list of related descriptors of increasing difficulty, the more complex the task you can

perform, the fewer points you will be awarded. More than one descriptor might apply but you can only pick up one score from each type of activity: whichever is the highest. You score when you are not able to carry out the activity described.

You automatically pass the test if you score 15 points from any one activity. Points are added up across different parts of the test and you are also deemed to have limited capability for work if your total reaches 15.

Disability Rights UK have a useful guide including information on eligibility, all the activities, descriptors and points attached to these. You can download it for free from [www.disabilityrights.org.uk](http://www.disabilityrights.org.uk)

Our advice is to apply the same principles to filling in a WCA form as you have to completing DLA or PIP claims. It's like starting all over again: don't assume that because a young person gets DLA or PIP, they will get ESA.

Give the claim pack the time and attention it needs! Say as much as you can to describe in detail what a young person can do and what they cannot. Give examples. Send evidence to support what you say. If the assessor is persuaded from the initial information and evidence you supply that a young person has 'limited capability for work' they will automatically be placed in a 'support group'. In many cases the assessor will seek further information.

Most young people will be asked to attend a face to face 'work focused' interview. The assessor who undertakes the interview will want to see for themselves how what is written on the WCA form matches up with the young person they are meeting.

Prepare for this meeting in the same way as you would a PIP face to face assessment.

Following this meeting, young people who are awarded ESA will be placed in one of two groups:

**The ‘Support’ group**

Young people with the most complex needs join the ‘support group’ and won’t be expected to attend regular interviews or work towards getting a job (although they can volunteer to do so if they want).

**The ‘Work-related activity’ group**

Most disabled young people will fall into this group and will need to take part in work-focused interviews, in return for ESA and focused support.

The aim is that over time and with the right help, most disabled young people can be supported to move into work. This group of young people risk getting their benefit cut if they miss appointments without good reason. If your son or daughter falls into this group, they may need your help to be in the right place at the right time.

See Chapter 8 on ‘Employment and Volunteering’ for more information about support into training and employment.

More able young people, who do not pass the ESA assessment and are no longer in education or training, will be encouraged to apply for Job Seeker’s Allowance (JSA).

**What happens to benefits that parents are already claiming if their child claims ESA?**

**Child Benefit**

If a young person claims ESA, parents are not entitled to claim Child Benefit, even if their child is still at school.

If your child doesn’t claim ESA or a training allowance, you can continue to claim Child Benefit for children aged 16 and under 20 who are at school or college in non-advanced education and studying more than 12 hours a week. You can also continue to claim Child Benefit if you’re responsible for a 16 to 19 year old who’s registered with the Youth Employability Service, in unpaid work-based learning and for 19 year olds on some training courses.

If your child has left school, college or approved unpaid training and they’re not claiming ESA, you can keep claiming Child Benefit until the first Sunday after the last day of February, May, August or November - whichever falls first after the date they left. If your child leaves school, college or training but returns to education you may be able to apply for Child Benefit again.

Parents of 16 and 17 year olds who leave education or training and are registered with the Youth Employability Service, but not claiming ESA, may be entitled to Child Benefit for the following 20 weeks. Parents need to write and ask for Child Benefit to continue.

**Child Tax Credit (CTC)**

Parents are not entitled to claim Child Tax Credits (CTC) if their child claims ESA in their own right. But otherwise, you can claim CTC for children up to the age of 20 if they’re in full-time education, studying up to ‘A’ level or an equivalent standard, or if they’re in unpaid work-based training.

If you have a child who gets any rate of DLA or PIP, CTC should include an extra disabled child element. If your child gets DLA at the high rate for personal care or PIP at the enhanced rate for daily living you may also be able to claim an additional severely disabled child element. These credits are in addition to the tax credits available to other families.

CTC is more generous than other benefits. Maintenance payments and most other benefits and allowances, including Social Fund payments, are disregarded as income when HM Revenue and Customs (HMRC) calculate your entitlement. Carers Allowance is counted as income though - so be sure to say if you are claiming it.

If your child's entitlement to DLA or PIP changes, tell HMRC as soon as possible. If you aren't claiming CTC and think you may be entitled, call the Tax Credit Helpline on 0845 300 3900.

### **Parents' Income Support (IS)**

Income Support (IS) is for people who aren't required to sign on for work and don't have enough money coming in to cover basic living expenses. In general, parents getting IS or Job Seekers Allowance (JSA), Local Housing Allowance (LHA) and Council Tax Benefit (CTB) will see changes to their own benefits if their child claims benefits as an adult, so it's worth getting advice.

Once a young person claims ESA or JSA in their own right their parent will:

- Have to sign on for work - unless they are also disabled
- Lose the disabled child premium element of IS or JSA they were claiming
- Lose the family premium element of IS or JSA - if the disabled young person is the youngest or only child
- Lose the disabled child premium of any LHA they're entitled to claim

There are exceptions though: parents are still eligible for IS if they're on a low income and care for someone who gets the middle or highest rate of DLA for care, or if they get Carers Allowance. They also continue to get IS for eight weeks if that person stops getting DLA.

## **CARERS ALLOWANCE (CA)**

Carers Allowance (CA) is a weekly payment for anyone who spends at least 35 hours a week looking after someone with an illness or disability, but isn't paid to do it. The person they look after must be getting the middle or higher rate of DLA or either rate of the daily living component of PIP. If someone other than you cares for your teenager, they can claim the benefit instead. Even if your child is at school or college, many parents will 'clock up' more than the required 35 hours a week. Only one person can claim CA for your child and you can only claim CA once, even if you care for more than one person who's getting DLA or PIP.

You can claim CA and earn up to £100 a week after deductions (tax, National Insurance and other allowable deductions). This amount is revised every April and is correct for the year 2013/14. Up to half your earnings can be disregarded if you pay someone who's not a 'close relative' to look after your child. You can claim CA even if you are getting DLA, PIP or Attendance Allowance yourself. CA is taxed and counted as income if you claim other means tested benefits.

It's worth claiming CA even if you are on IS because although CA is deducted from your IS, claiming it protects your pension and makes you eligible for a Carer's Premium - so the amount of IS you get will increase.

The process for claiming CA is simple and quick. Call the Carer's Allowance Unit on 0845 608 4321 or text on 0845 604 5312 for a claim pack, or claim online at [www.dwp.gov.uk](http://www.dwp.gov.uk)

## **UNIVERSAL CREDIT**

Universal Credit (UC) is a radical new approach to welfare benefits. It is an integrated means tested benefit for people in or

out of work. UC will replace many familiar benefits, and includes allowances for adults, additions for children, childcare costs, limited capability for work, caring and most importantly housing costs.

At the time this handbook goes to print in February 2014, UC has only been launched in a few places in other parts of the country. The plan to roll out UC is behind schedule but on its way. At some point, there will be no more new claims for Income Support, Income based Job Seekers Allowance, income related Employment and Support Allowance, Tax Credits or housing benefit and anyone claiming these and reporting a change of circumstances or a break in their claim will be moved to Universal Credit.

Until UC is introduced locally we cannot be sure about its impact, but it is likely that some families will be worse off. If, by the time you read this book, UC is being rolled out in this area, contact Amaze for advice as we will have more detailed information as soon as it becomes available.

For more information about Universal Credits visit [www.gov.uk](http://www.gov.uk)

## OTHER SOURCES OF FINANCIAL HELP

See Chapter 10, 'Travel and getting about', for details on travel and transport schemes and concessions, including Motability. For information about Direct Payments (DP) and funding for adaptations in the home, see Chapter 9, 'A Place to Live'.

Once your child is 18, you may be able to apply for a **Carers' Grant** from the council. It can help if you want to take a break and need a temporary increase in a care package, or a short stay somewhere else for your son or daughter while you're away. The grant can also help towards the cost of a holiday, travel

costs, days out with the person you care for, or for leisure, adult education, or support to help you stay in employment. You'll need a carer's assessment to be eligible (see page 141) Call the Adult Social Care Access Point on 01273 295555 or email [accesspoint@brighton-hove.gov.uk](mailto:accesspoint@brighton-hove.gov.uk) for more information.

Some charitable organisations make grants for specific purposes like holidays or buying a special piece of equipment. You'll find details in a directory called 'A Guide to Grants for Individuals in Need'. The Carers Centre, Amaze and Jubilee Library have copies.

Your child won't be eligible for a Compass Card once they reach the age of 20 - but as a parent, it's likely you'll be eligible for a free **Carers' Card**, a leisure incentive card launched to promote the health and wellbeing of carers in the city. See page 144 for more information.

## FURTHER HELP WITH DISABILITY BENEFITS

Amaze helpline staff can offer advice and practical support or we may also be able to offer you individual help to make a claim. We have a small team of volunteers who can make home visits and help you and your teenager think about how to make a strong case. If you find writing stuff down is hard, that's OK too - our volunteers are happy to fill the forms in. The service is usually only available in term time. Call the Amaze helpline for more information.

Once your child turns 20 we won't be able to support you anymore but there are quite a few local and national organisations, such as the Fed, MACSS and the Citizen's Advice Bureau who can offer similar benefits and financial advice and support to disabled adults or their carers. Find their details in the Contacts section at the back of this book or call the helpline for more info.