DSUK
Down Syndrome UK

Future Pathways

Part 2: Funding Adult Life



Introduction

Money is where many families feel most anxious about adult life.

Questions we hear often:

"Will my son or daughter have to pay for support?"
"What happens to their benefits?"
"What is a direct payment, and do I want one?"
"How much will they be left with to live on?"

This part explains how funding works, what to expect and which questions to ask. You do not need to become an expert.
You need to know what the key terms mean, what the council should explain to you, and when to ask for help.



Important: this guide covers England only
This guide is based on the Care Act 2014 and its regulations, which apply in England only. Social care, charging and direct payment rules are different in Wales, Scotland and Northern Ireland. Separate guides for those nations are being produced. If you live outside England, please don't rely on this guide.
Figures in this guide are for April 2026 to March 2027. Many amounts change every April. Always check the latest figures on GOV.UK before relying on any number here.
The examples in this guide are typical situations, not real people.

Please read: this is not financial or legal advice. This guide is general information, shared in good faith by parents and Down Syndrome UK from our own experience and research. Rules and figures change, and every family's situation is different. Always check with the right organisation, and take professional advice, before making decisions.

Key terms

Term	Plain English meaning
Personal budget	The amount of money the council calculates it costs to meet the person's eligible needs, as set out in the Care and Support Plan.
Direct payment	One way of taking a personal budget: money paid to the person (or someone acting for them) to arrange their own support.
Financial assessment	The council's check of income, savings and costs to decide what, if anything, the person pays towards support.
Charge / contribution	The amount the person pays towards the cost of their support.
Disability Related Expenditure (DRE)	Extra everyday costs caused by disability, which the council should take into account.
Minimum Income Guarantee (MIG)	The minimum amount of income a person must be left with after charges.
Personal Assistant (PA)	A person employed directly to provide support.
Appointee	Someone authorised by the DWP to manage a person's benefits (see Part 4).

How the money actually flows

These terms are confused all the time, so here is the whole picture:

1. **The council assesses needs** (Part 1) and decides which are eligible. Money plays no part in this decision.

2. **The council writes a Care and Support Plan** explaining how needs will be met.

3. **The council works out a personal budget:** the cost of meeting those needs.

4. **A financial assessment** works out what the person can afford to pay, if anything. This is the person's contribution.

5. **The council pays the rest**. Council contribution = personal budget minus the person's contribution.

6. **The personal budget is delivered** in one of three ways: managed by the council, managed by another organisation on the person's behalf, or paid as a direct payment. The budget can also be a mix of these.

The three things people mix up:

	What it is	Who it concerns
Personal budget	The total amount needed to meet eligible needs	Always produced, however support is delivered
Direct payment	A way of receiving a personal budget as money	Optional
DRE and MIG	Protections within the charging calculation	Affect how much the person pays

Eligibility is separate from all of this: **a person is not turned down for support because they have money**. They may be asked to pay for some or all of it.

The order matters. Needs must be assessed first, whatever the council's budget. The council can consider cost when deciding **how** to meet eligible needs, but not **whether** to meet them.

Two separate pots of money

The personal budget: money for their support	The care contribution: your young person's money
What the council spends on your young person's support	What your young person pays towards their support, from their own income
Paid as a direct payment, or managed by the council so you never see it	Worked out by the financial assessment
Ring-fenced: it can only be spent on the support in the plan	Paid to the council, or into the direct payment account
Not counted as their income or savings	
You're entitled to know how much the support costs	
Unspent direct payments can be clawed back, so keep enough to cover the support in the plan	

These are worked out separately.

Stage 4 in detail: the financial assessment

What does it mean?

The council can charge for non-residential support (such as support at home or in the community). The Care Act says it must follow national rules, and it must leave the person with **at least the Minimum Income Guarantee after charges**. A council may be more generous than the national rules but not less.

The financial assessment looks at:

- Income, such as benefits and pensions
- Capital, such as savings and some investments
- Disability Related Expenditure (DRE), which reduces the income the council can charge against

Some things are disregarded (ignored), including:

- all earnings from work, however much. But any savings built up from earnings do count
- the mobility part of PIP or DLA

Savings: how much is too much? (2026/27)

Universal Credit and social care charging use different savings limits:

Your young person's savings	Universal Credit	Social care charges
Under £6,000	Ignored	Ignored
£6,000 to £14,250	UC reduced by £4.35 a month for every £250 (or part of) over £6,000	Ignored
£14,250 to £16,000	UC reduced (as above)	£1 a week counted as income for every £250 (or part of) over £14,250
£16,000 to £23,250	**No UC**	£1 a week for every £250 (or part of) over £14,250
Over £23,250	**No UC**	**Pays the full cost of their care**

What this looks like:

- £10,000 saved: UC goes down by £69.60 a month (16 × £4.35). No effect on care charges.
- £20,000 saved: no UC at all. For care charges, £23 a week is counted as income.

Good to know:

- It's your young person's savings that count, not yours.
- PIP isn't means-tested, so it has no savings limit.
- The UC limits are for a single person. If your young person lives with a partner, their savings are added together.
- Councils can set higher limits for support at home. Ask.
- Money held in a properly set-up trust may not count. This is why leaving money directly to your young person, or building up their savings, can backfire. See Part 4, and take advice from a STEP solicitor.

The Minimum Income Guarantee (MIG)

The MIG is the least the law says your young person **must be left** with each week after care charges, to pay for everyday living: food, bills, clothes, activities, and **board if they live at home**. It is set nationally each April.

For 2026/27, the amounts for working-age adults rose by 7%. For people over Pension Credit age, they rose by 3.8%.

Person	Weekly MIG basic amount (2026/27)
Single adult aged 18 to 24	£95.40
Single adult aged 25 to Pension Credit age	£120.40
Member of a couple (one or both aged 18+)	£94.55

Plus disability premiums where the person would qualify for them under Income Support rules:

Premium (single person)	Weekly amount (2026/27)
Disability premium	£51.55
Enhanced disability premium	£25.15
Carer premium (if applicable)	£55.25

Who gets the premiums?

The **disability premium** usually applies if your young person gets PIP (either part, any rate) or DLA. The **enhanced disability premium** usually applies if they get the enhanced rate of PIP daily living or the highest rate of DLA care. Some councils also accept LCWRA or the ESA Support Group, so ask. **Many young adults with Down syndrome qualify for both**. Check the financial assessment includes every premium they're entitled to: if one is missing, the MIG is too low and the charge too high.

An illustration: a single adult aged 25 who qualifies for the disability premium would have a MIG of £120.40 plus £51.55, which is £171.95 per week. With the enhanced premium too, it would be £197.10. This is a simplified illustration. How the premiums apply depends on the person's benefits and circumstances.

Councils can set a MIG higher than this, and some do. Ask what your council does.

Disability Related Expenditure (DRE)

DRE means **extra costs that arise because of disability**, which are not met by the council. If the council counts disability benefits as income, it should also take account of these costs. Ask for it to be done properly.

Examples of DRE that may be relevant for adults with Down syndrome:

Health and body	Home and daily life
Ear wax removal	Extra heating above a typical bill for your size of home
Foot care	Air conditioning or cooling, if they can't regulate their temperature
Private physio or speech and language therapy not available on the NHS	Extra laundry, replacement clothing and bedding
Private hearing, vision or dental care	Communication aids, apps, devices and specialist equipment
Specialist skin products, such as antimicrobial washes for skin conditions	
Monitoring equipment, community alarms	Taxis where public transport isn't safe or practical; special diets

Fuel for journeys in the care plan: if the plan says your young person should go to activities they can't reach by public transport, the fuel for those journeys may count as DRE, especially if all of their PIP mobility goes on a Motability lease. Councils often dispute this, so keep a mileage log of journeys linked to the plan and quote the plan's wording. General mileage is much harder to get accepted.

Having a PA at home: if your young person has full-time or sleep-in support, ask about the extra household costs it causes: water (toilet, shower, washing machine), toilet roll and household supplies, electricity and heating while PAs are there, and extra laundry such as bedding for sleep-in staff. Some councils accept these and others don't, so evidence them and ask.

Some councils use a **standard allowance** for DRE and others assess it individually. If the standard allowance does not reflect your costs, **ask for an individual assessment** and **keep receipts, bank statements and a simple list of regular costs**.

Tip: keep a running list in the Notes app on your phone, adding costs as they happen.

Something that's easy to miss: DRE is not automatic. Many families are never asked about it. If you have not been asked, say so in writing.

Getting DRE agreed

- DRE is decided by the **financial assessment team**. They're finance staff, not disability experts, so they need evidence.
- They look first at the **needs assessment and the Care and Support Plan**, so make sure the needs behind each cost are written in there.
- They may ask for medical evidence. Notes recorded at the annual learning disability health check help.
- Compare costs with a typical household, for example an average energy bill for your size of home.
- If a cost is turned down, ask why in writing and ask for a review.

One family's story.

A young woman with Down syndrome follows a special diet, which costs much more than a typical weekly shop. Her support worker kept the receipts, and her mum compared the cost with a standard shop. They sent the receipts to the council's financial assessment team, and the answer came back within one day: her contribution fell from **£16.11 to £4.17 a week**. That's **£620.88 a year** back in her pocket.

What to expect

- A form or home visit asking about income, benefits and savings. Some councils do this online or by phone.
- A **written decision** showing how any charge was calculated, including MIG and DRE.
- Charges are **never more than the cost of the support** being provided.
- You can ask for a **review** if your circumstances change, such as new costs, a move, or a change in benefits.
- If you do not provide the information the council asks for, it may assume the person can pay in full. Respond promptly, or ask for more time.

If you disagree

- Ask for a **full breakdown** of how the contribution was calculated.
- Ask for a **review** (and ask how to request one).
- Provide evidence of extra costs.
- Use the council's **complaints procedure**. If unresolved, the **Local Government and Social Care Ombudsman** can look at it.
- Ask for **advice** from Down Syndrome UK (including Access Ava on our website), Citizens Advice, Contact, Scope or Mencap.



Benefits and charging

Benefits are separate from social care but they affect each other. This is one of the areas families most want clear answers on.

Benefit	Who it's for	Amount
PIP daily living	From 16. Not means-tested, not affected by work or savings	Standard £76.70 / enhanced £114.60 a week (£306.80 / £458.40 every 4 weeks)
PIP mobility	From 16. Help with getting around	Standard £30.30 / enhanced £80.00 a week (£121.20 / £320.00 every 4 weeks)
Child Benefit	Stops on 31 August after the 16th birthday, unless they stay in full-time non-advanced education (up to 20)	£27.05 a week (eldest or only child); £17.90 for each additional child
Carer's Allowance	You, if you care 35+ hours a week and they get PIP daily living	£86.45 a week (earnings limit £204 a week)
Universal Credit standard allowance	Single, under 25 / 25 and over	£338.58 / £424.90 a month
UC health element (LCWRA)	Existing claims and protected groups / most new claims since 6 April 2026	£429.80 / £217.26 a month
New Style ESA	Based on National Insurance contributions	£75.65 (under 25) / up to £95.55 (25 and over) a week, or £145.90 in the Support Group

Watch the timing

- PIP and Carer's Allowance are **paid every 4 weeks**.
- ESA is usually paid **every 2 weeks**.
- Universal Credit is paid **once a calendar month**.
- Social care charges and the MIG are worked out **weekly**.

To turn a weekly amount into a monthly one: × 52 ÷ 12.

(There are 13 four-week periods in a year, so 4-weekly amounts aren't the same as monthly ones.)

How benefits count in the financial assessment

Benefit	How it may interact with charging
PIP	The daily living part is usually counted as income, with DRE allowed. The mobility part is ignored.
Universal Credit or ESA	Counted as income, except UC's housing element. Rent that UC doesn't cover may be allowed as a housing cost.
Housing Benefit / UC housing costs	Help with rent, including in supported housing (Part 3)
Carer's Allowance	Paid to the carer, not the person, so it isn't counted in the young person's assessment

Key points:

- **Claim at the right time.** The move from DLA to PIP at 16, and then to adult benefits, needs planning. Missed or delayed claims can cause hardship.
- **ESA:** only New Style ESA is open to new claims; the old income-related ESA has been replaced by Universal Credit. New Style ESA depends on National Insurance contributions, isn't affected by savings, and can be paid alongside UC (it's counted as income for UC). Most families are more likely to encounter Universal Credit than New Style ESA, although ESA may be relevant for some adults who have worked and built up enough National Insurance contributions.
- **UC from 16.** In some cases a young person can claim UC in their own name from 16, but the family then loses Child Benefit. Get a benefits check first.
- **Check the person is receiving everything they are entitled to**. A **benefits check** through Citizens Advice, Contact, Scope or a welfare rights service, or the Turn2us online calculator, can be valuable.
- **New claims to the UC health element changed on 6 April 2026**. For most new claims it's now £217.26 a month, about half the £429.80 paid on existing claims and to protected groups. Many older websites still quote the higher figure, so check which applies to your young person.
- **Who manages the money?** Many adults with Down syndrome manage their own benefits with support. Others have an appointee. See Part 4.

Working while on Universal Credit

- There's **no hours limit** on UC. **If** your young person gets ESA rather than UC, "permitted work" must be **under 16 hours a week**. (UC is paid monthly with an online journal; ESA is a separate benefit, usually paid every two weeks. Check award letters if you're not sure).
- If UC includes housing costs, your young person can earn **£427 a month** (about 8 hours a week at the National Living Wage) before UC is affected. Without housing costs, it's £710 a month (about 13 hours a week at the National Living Wage of £12.71).
- Above that, UC goes down by **55p for every £1** earned, so they **keep 45p** of every extra £1.
- **PIP isn't affected by working**. Earnings are ignored in the social care financial assessment.
- **LCWRA**: working doesn't automatically end it, but a big change in hours can prompt DWP to review it. The review looks at what the person can and can't do, but work can be used as evidence. Someone earning above roughly 16 hours a week at the National Living Wage (about £203 a week, or £881 a month, at £12.71 an hour in 2026/27) usually can't be newly assessed for LCWRA, but people getting PIP are exempt from that rule. If LCWRA stops and is later awarded again, it may only be paid at the lower new-claim rate, so get advice before increasing hours.

Example, with housing costs: a young man on UC with housing costs works 16 hours a week at the National Living Wage, earning £881.23 a month. That's £454.23 over his £427 work allowance. 55% of £454.23 = £249.83, so his UC goes down by £249.83. **He's £631.40 a month better off by working.**

Example, without housing costs: a young woman whose UC doesn't include housing costs, for example because she lives at home, works the same 16 hours a week, earning £881.23 a month. That's £171.23 over her £710 work allowance, so her UC goes down by £94.18.
She's £787.05 a month better off by working.

Work almost always pays, but check first.

Get a benefits check before starting a job or increasing hours, particularly in these situations:

- **If they get ESA rather than UC:** going over the permitted work limits (under 16 hours, plus an earnings limit) can stop ESA altogether, not gradually.
- **An LCWRA review:** if more hours prompts a review and DWP decides they no longer qualify, they'd lose the health element (£429.80 or £217.26 a month).
- **Housing Benefit** in supported living: it's means-tested too, so more of each extra pound can be withdrawn, though they should still come out ahead.
- **Help linked to low income**, such as Council Tax Reduction or help with health costs, can reduce as earnings rise.
- **The costs of working**: travel, lunches and work clothes. Access to Work can help with travel and support costs.
- **Savings building up** past the UC or care charging limits.
- **The family's benefits:** if a 16 to 19-year-old leaves education to work, parents may lose Child Benefit and related support.

Personal budgets

What does it mean?

Everyone whose eligible needs are met by the council gets a personal budget. It isn't optional: what you choose is how it's managed. The exceptions are when there are no eligible needs, when family willingly meets all the needs, short-term reablement, and NHS Continuing Healthcare (below).

A **personal budget** is the council's calculation of the cost of meeting the person's eligible needs. It must be written into the Care and Support Plan, showing:

- the **total** cost of meeting needs
- the **amount the council** will pay
- the **amount the person** will pay (if any)

Why does it matter?

A personal budget is not just a number. It is what makes choice possible. It should be **enough to meet the needs in the plan**, and should reflect the person's outcomes, not just a standard package.

Three ways to take a personal budget

1. **Managed by the council.** The council arranges services. Least choice, least admin.
2. **Managed by another organisation** (sometimes called an Individual Service Fund). A provider or other organisation manages the money and arranges support following the person's wishes.
3. **Direct payment.** Money paid to the person (or someone acting on their behalf) to arrange support themselves.

You can **mix** these: for example, a direct payment for a PA plus council-arranged day services.

What to expect

- You should be told about all the options, not only the council's preference.
- You should be given a plain-English explanation of how the budget was calculated.
- The budget should be enough to meet eligible needs. If you think it is not, you can ask for it to be looked at again.
- Budgets should be reviewed at least annually and when circumstances change.

NHS Continuing Healthcare (CHC)

- For adults whose needs are mainly health needs (a "primary health need").
- Most people with Down syndrome won't qualify, but a few with complex health needs may, now or later in life, for example with advanced dementia.
- If eligible, the NHS pays for all their care and support. There's no means test and no contribution.
- Support can be taken as a personal health budget, including as a direct payment.
- It starts with a short checklist, then a full assessment if needed. Ask the GP, social worker or hospital team.
- If needs are mixed, care can be jointly funded by the NHS and the council, and the person may still contribute to the council's part.

Something that's easy to miss:
A personal budget calculated from "hours of care" can leave out what makes the real difference, such as transport costs, activity costs or support to try something new. Ask how these have been included.

Direct payments

What does it mean?

A direct payment is money paid by the council **so the person can arrange and buy their own support**. It gives greater control and flexibility. It also brings responsibility: you become an employer, or a commissioner of services, and you must keep records.

What can it be used for?

Direct payments can be used to meet the needs set out in the Care and Support Plan.

Examples include:

- employing a Personal Assistant
- using a care agency
- paying for community activities, travel training or support at work or college
- short breaks

It cannot normally be used for a permanent place in a care home, or for things not connected to the plan.

Example: one young man's direct payment can be used flexibly for activities that matter to him, such as cycling, skiing, yoga and groups. It can't be used for food, or for accommodation and travel on family holidays. His maths club is funded through his EHCP instead, because it counts as education.

Important rules

- The person (or someone acting for them) must **agree** to a direct payment.
- If the person lacks capacity to decide about a direct payment, a **“suitable person”** (often a family member) can receive and manage it for them. If they have capacity but need help, they can **nominate** someone to manage it. The council should explain how. Part 4 explains capacity and decision-making.
- Direct payments to a **family member living in the same household** are usually not permitted, but councils can allow it in exceptional circumstances.
- The council may ask for r**ecords or accounts** and may check how money is spent. Unspent funds can sometimes be reclaimed.
- A direct payment is **not a benefit** and does not affect benefits.

Often works well when...	May be harder when...
The person knows what support they want	You do not yet know what support suits them
Family or friends can help with the paperwork	You are already stretched
There are PAs or local providers who fit	Local PA supply is poor
You want flexibility around work or college	You prefer a ready-made service

Neither choice is "better". You can **start** with the council arranging support and **move** to a direct payment later (and the other way around).

Employing Personal Assistants (PAs)

Many families find a PA, someone who works for the person and supports them to live the life they want, is the most flexible and person-centred way to use a budget.

What employing a PA involves

When you use a direct payment to employ a PA, you are an employer. In practice this means:

- writing a job description and contract
- recruiting (interviews, references, checking right to work)
- a DBS check for the PA. It isn't a legal requirement, but it's strongly recommended. You can't usually apply for an enhanced check yourself; your council or direct payment support service may be able to arrange one.
- payroll, tax and National Insurance
- pension auto-enrolment where applicable
- holiday pay and sick pay, and at least the National Minimum or Living Wage
- employer's liability insurance
- managing and supporting your PA, including cover for holidays and illness
- planning and managing rotas, which is very time-consuming

What support costs

Type of support	Typical cost
Support from an agency or provider	£25 to £30 an hour (covers the company's running costs)
PA employed directly through a direct payment	£12.71 (the National Living Wage) to £16.50 an hour
Day opportunities, for example 10am to 3pm	£75 to £80 a day (about £15 to £16 an hour, in a group)

Based on one family's experience in Warwickshire. Rates vary by area.

Employed or self-employed?

Councils usually prefer PAs to be **employed**. If a PA is self-employed, expect the council to ask for evidence: their tax registration, insurance, and an employment status check (IR35 if they work through their own company). If HMRC decides they're really an employee, you could owe their tax and National Insurance. HMRC's free online "Check employment status for tax" tool can help.

Three ways to manage support

	Pros	Cons
Payroll service (most councils offer one)	They handle payroll and HR for you	Less flexibility
Running payroll yourself	Huge flexibility	Very time-consuming. You deal with HR issues and an employer's responsibilities
Supported living provider	The provider organises everything	The budget is usually paid to the provider, so you lose control over how support is arranged

Help is available

- Many areas have a **direct payment support service** or **payroll service** that helps with these tasks. Ask your council. Some costs may be included in the budget.
- **Skills for Care** and other organisations produce guidance and templates for PA employers.
- You can use an **agency** instead if you prefer.

Using a care agency at home

If your young person lives in their own home or the family home, their personal budget can pay a **CQC-registered home care agency**. With a direct payment, you choose the agency.

Pros	Cons
The agency recruits, trains and employs staff	Less say over who comes, and staff can change often
They cover sickness and holidays	Higher cost: around £25 to £30 an hour
No payroll or HR for you	Fixed rotas and minimum visit lengths
Useful in a crisis or while you recruit PAs	Some focus on personal care, not activities, work or friendships

Questions to ask an agency:
What's your CQC rating? What experience do your staff have of learning disability and Down syndrome? Will it be a small, consistent team, and can we meet staff and help choose them? Can you support activities, work and friendships? What's the minimum visit length? How do you cover sickness and missed visits? How will you communicate with us? What are all the costs, including travel time, mileage and notice periods?

A tip from experienced families

Think about **personality, shared interests and age** when recruiting a PA, not just experience. A person who shares a love of music or football may open more doors than someone with a long CV. Involve the person with Down syndrome in choosing.

Safeguarding

Employing someone brings people into the person's life. Use references, probation periods and clear boundaries, and be alert to **exploitation or "mate crime".** If you have concerns, contact your council's adult safeguarding team.

Planning and negotiating: one parent's approach

One mum shared how she prepares for social care meetings. Her approach works for any family.

1. **Start with the "why"**. Before costing anything, she wrote down what her son's week needed to achieve: skills for the rest of his life, age-appropriate activities, high expectations, his specific needs, and his ambitions.

2. **Give every activity a purpose**. For example: booking and paying for tickets (independence, IT, maths); planning meals (healthy eating, quantities); food shopping (money skills); cooking real meals (independence, measuring); lunch with a friend (friendship); delivering sessions at work (work skills, confidence). Assessors are far more likely to agree to an activity when they can see what it achieves.

3. **Colour-code the week**. She used one colour each for independence, education, work and social activities, so the balance was obvious at a glance. The colours match the Care Act outcomes.

4. **Cost every slot**. Support hours × the PA's hourly rate, plus any activity fee, with weekly and annual totals using realistic numbers of weeks. Keep support, activity and travel costs separate.

5. **Expect to negotiate, and keep both versions**. Her activities request went from £13,572 a year to £7,471 agreed. Mileage (£4,410) and personal leisure costs moved to her son's own money (£5,031 a year), maths club moved to his EHCP, and snow sports were reduced from 40 to 30 weeks.

6. **Know who pays for what:**
   - **Direct payment:** disability-specific activities and support
   - **Your young person's own money:** mileage, leisure memberships, season tickets, cinema and theatre
   - **EHCP:** anything that counts as education

Tip: disability-related costs your young person pays themselves, such as extra mileage, may count as DRE in their financial assessment.

Worked examples (illustrative)

These are made-up examples to show how the calculations work.
Real calculations vary by council and individual circumstances. Always ask for the written working.

Note: *Josh's and Sally's examples use the UC health element for existing claims (£429.80 a month). For most new claims since 6 April 2026 it's £217.26 a month, which would lower their income and their care contribution. Check which applies.*



Jordan: how a charge is worked out

Jordan, aged 24, lives with his parents. His Care and Support Plan includes PA support for work, travel training and weekly community activities.

1. What can Jordan afford to pay? (weekly)

	£
Jordan's income counted for charging	£230.00
Less: MIG (aged 18 to 24, with disability premium: £95.40 + £51.55)	– £146.95
Less: DRE agreed (extra laundry, taxis, heating)	– £30.00
Most Jordan can be asked to pay	**£53.05**

2. Who pays for his support? (weekly)

	£
Personal budget (cost of his support)	£400.00
Jordan pays	£53.05
Council pays	**£346.95**

Without the DRE assessment, Jordan would pay £83.05 a week. This is why DRE matters.

Josh: renting, with full-time support

Josh is 24 and rents a private home, with full-time support paid for by his personal budget. He gets the enhanced rate of both parts of PIP; his mobility part goes straight to Motability for his car. He has no earnings.

Money in (monthly)	Full award	What Josh receives
Universal Credit (including £850 for rent)	£1,618.38	£1,618.38
PIP daily living (enhanced)	£496.60	£496.60
PIP mobility (enhanced)	£346.67	£0 (goes to Motability)
Total in	**£2,461.65**	**£2,114.98**

Money out (monthly)	
Rent	£1,250.00
Care contribution	£54.21
Total out	**£1,304.21**

Left for everyday living: £810.77 a month (about £187 a week).

How Josh's care contribution is worked out (weekly):

	£
UC counted (£768.38 a month, not the housing part)	£177.32
PIP daily living (enhanced)	£114.60
Income counted	**£291.92**
Less: MIG (under 25, both premiums: £95.40 + £51.55 + £25.15)	− £172.10
Less: DRE	− £15.00
Less: rent UC doesn't cover (£400 a month)	− £92.31
Care contribution	**£12.51 a week (£54.21 a month)**

What's left is, in effect, Josh's MIG plus his DRE.
If his rent were fully covered by UC, he'd pay £104.82 a week instead. Without his £15 DRE, he'd pay £65 a month more.

Sally: living at home

Sally is 20 and lives with her parents. She goes to a day service three days a week, paid for by her personal budget, and pays her parents board. She gets the same benefits as Josh: the enhanced rate of both parts of PIP, with her mobility part paid straight to Motability for her car. She has no earnings.

Money in (monthly)	Full award	What Sally receives
Universal Credit (no housing element)	£768.38	£768.38
PIP daily living (enhanced)	£496.60	£496.60
PIP mobility (enhanced)	£346.67	£0 (goes to Motability)
Total in	**£1,611.65**	**£1,264.98**

Money out (monthly)	
Board to her parents	£300.00
Care contribution	£454.22
Total out	**£754.22**

Left for everyday living: £510.76 a month (about £118 a week).

Care contribution: income counted £291.92 a week (UC £177.32 + PIP daily living £114.60; the mobility part is ignored), less MIG £172.10 and DRE £15.00 = **£104.82 a week** (£454.22 a month). Board isn't usually deducted: it comes out of her protected MIG. Councils treat board differently, so ask yours.

Compare Sally with Josh: *they get exactly the same benefits. The only difference is that Sally pays board at home and Josh pays rent. Sally pays a much higher care contribution, because she has no rent shortfall to deduct, and her board comes out of her protected MIG, so she's left with less.*



Old and new claims: what difference does it make?

From 6 April 2026, the UC health element for most new claims fell from £429.80 to £217.26 a month. Here's how that changes Sally's and Josh's examples:

- **Sally lives at home** with her parents. She's 20, pays £300 a month board and has no rent to pay.
- **Josh rents his own home**. He's 24, rents a 2-bed home for £1,250 a month, and UC pays £850 towards his rent.
- **Both get the same benefits:** enhanced PIP daily living, and enhanced PIP mobility paid straight to Motability. Both are under 25, with the same MIG and DRE. The only difference is board versus rent.

Monthly	Sally at home: existing claim	Sally at home: new claim	Josh renting: existing claim	Josh renting: new claim
UC health element (LCWRA)	£429.80	£217.26	£429.80	£217.26
Total money received	£1,264.98	£1,052.44	£2,114.98	£1,902.44
Board (Sally) or rent (Josh)	£300.00	£300.00	£1,250.00	£1,250.00
Care contribution	£454.22	£241.67	£54.21	£0
Left for everyday living	**£510.76**	**£510.77**	**£810.77**	**£652.44**

Living at home (Sally): the lower UC is balanced out by a lower care charge (£55.77 a week instead of £104.82), so she's left with about the same.

Renting (Josh): once his care charge reaches £0, every pound of lost UC comes out of his living money. He's about £158 a month worse off, and below the MIG and DRE that are meant to protect him.

Ask whether your young person falls into a protected group that still gets the higher rate.

Who still gets the higher rate?

People already getting LCWRA before 6 April 2026 (as long as it continues without a break), and new claimants who are terminally ill or meet the Severe Conditions Criteria.

Monthly (existing claim)	Josh, renting	Sally, at home
Housing cost	Rent: £1,250	Board: £300
Help from UC	£850 housing element	None: UC doesn't pay housing costs for someone living with parents
What they pay themselves	£400 rent shortfall	£300 board
Allowed in the care calculation?	Yes: the £400 shortfall is deducted, cutting his care charge by £400 a month	No: board comes out of her protected MIG
Care contribution	£54.21	£454.22
Left for everyday living	**£810.77**	**£510.76**

- The council effectively gives Josh his rent shortfall back through a lower care charge, so he keeps his full MIG and DRE.
- **The money stays in the family:** Sally's £300 goes to her parents' household, towards food and bills. Agree a fair amount based on what it actually costs you.
- **Councils vary**, so ask yours how board is treated.
- With the new-claim rate the gap is smaller, because Josh's care charge falls to £0, so he can't get all of his rent shortfall back.

Checklist: before the financial assessment

- [ ] Do we know which benefits the person receives, and are they correct?
- [ ] Have we collected recent statements, award letters and savings information?
- [ ] Have we written down regular extra costs caused by disability (DRE)?
- [ ] Have we kept receipts?
- [ ] Are the needs behind each disability-related cost written into the needs assessment and Care and Support Plan?
- [ ] If they live at home, have we agreed a fair amount of board?
- [ ] Do we know the council's capital limits and MIG policy?
- [ ] Have we asked whether the council uses a standard DRE allowance, and whether it can be assessed individually?
- [ ] Do we understand how the decision was calculated, and have we asked for it in writing?
- [ ] Do we know how to ask for a review if circumstances change?

Questions to ask your council

1. How was the personal budget calculated, and is it enough to meet all the eligible needs in the plan?
2. What are the options for taking the budget (council-managed, third party, direct payment)?
3. What help is there to manage a direct payment and employ a PA?
4. What are your capital limits, MIG rate and DRE policy?
5. How are benefits counted?
6. How do we ask for a review of the budget or the charge?



Myth-busters

"She's better off not working."

Almost never true. Work almost always pays, but get a benefits check before starting a job or increasing hours. Earnings don't affect PIP and are ignored in the social care charge. Universal Credit only goes down by 55p for each £1 earned above the work allowance, so she keeps at least 45p of every extra £1. For example, a young adult working 16 hours a week at the National Living Wage is £631.40 a month better off if their UC includes housing costs, or £787.05 if it doesn't.

"If he has savings, he won't get any support."

Eligibility is decided without considering money. Savings may mean paying towards support, depending on the amount.

"A direct payment will affect his benefits."

It does not. A direct payment is not a benefit and is not counted as income.

"The council has set the charge, so we can't challenge it."

You can ask for a breakdown, a review and for DRE to be considered.

"A personal budget means we have to employ staff ourselves."

No. You can have the council or another organisation manage it, or use it to pay for support from an agency or day service.

"If she gets a job, the council will take her wages."

No. Earnings are ignored in the social care financial assessment, however much someone earns.

They do affect Universal Credit, but she'll keep 45p of every extra £1 above the work allowance.



What comes next?

Part 3: Housing and Support explains housing options, supported living, Shared Lives and how housing costs and benefits fit together, with illustrative financial examples.



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