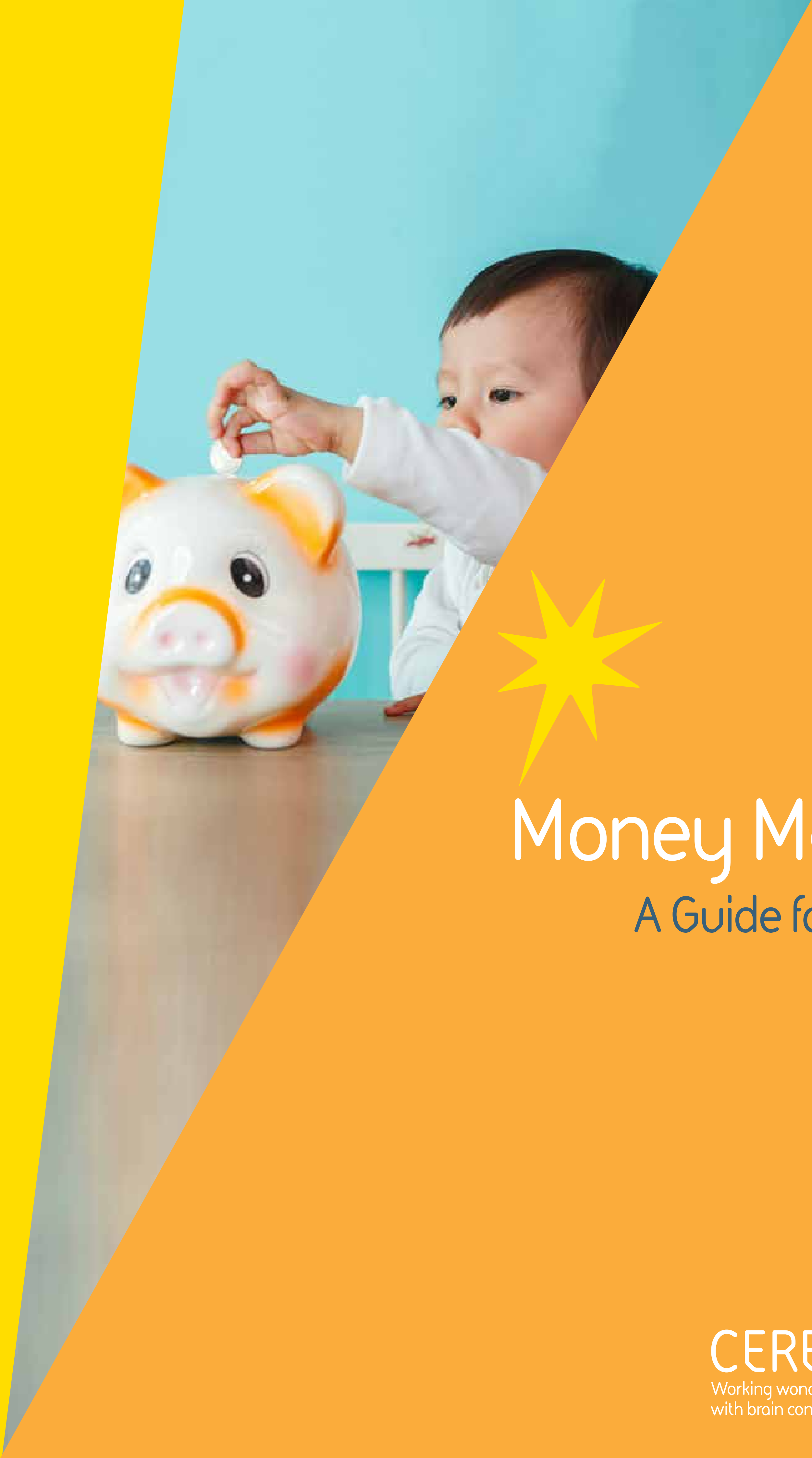


Money Matters

A Guide for Parents

CEREBRA

Working wonders for children with brain conditions

Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It's an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we'll discover together.

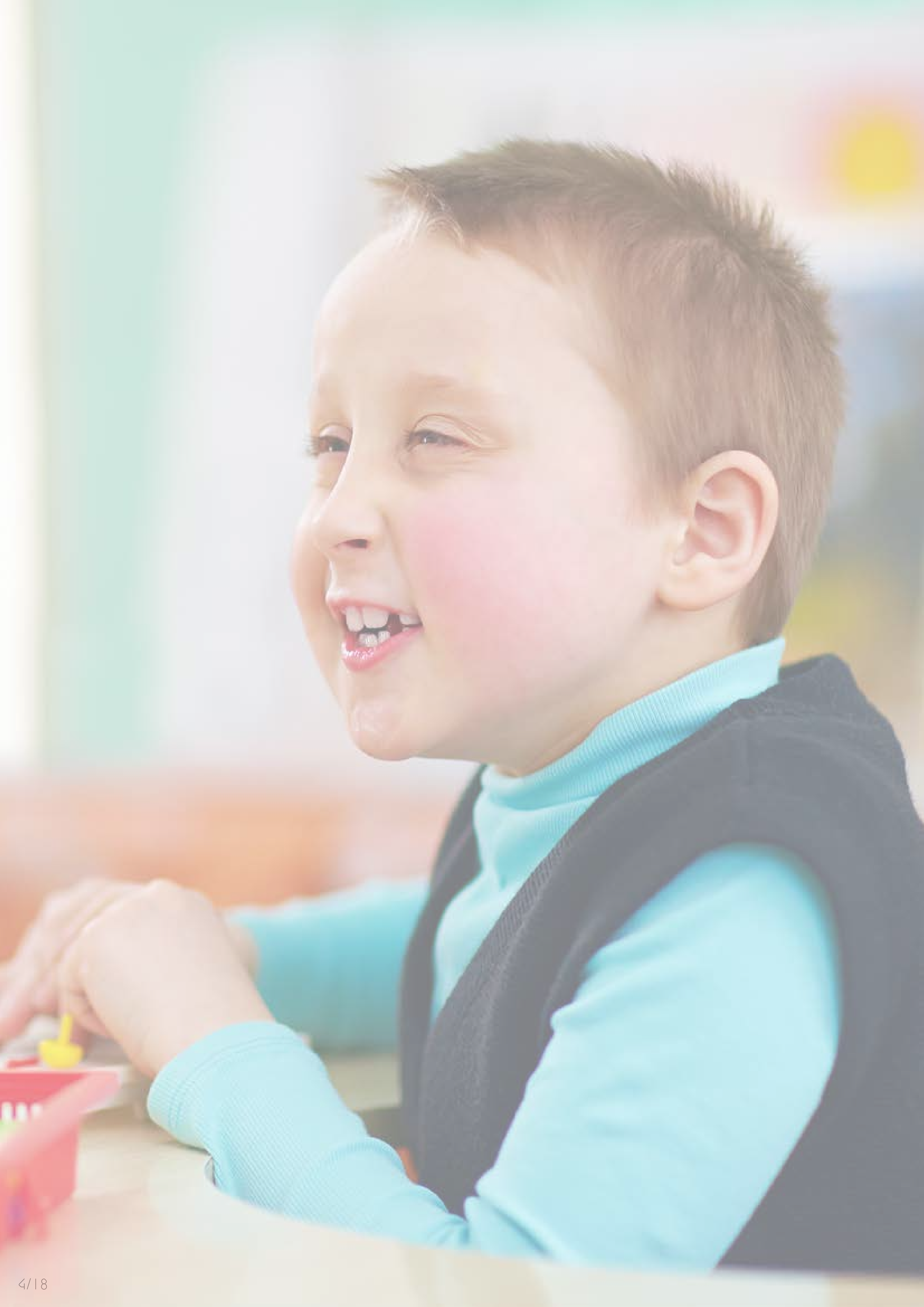
www.cerebra.org.uk

Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides please just text **CERE12** and the amount you want to give to **70070** or give us a call on **01267 244216**. You can also donate online.

Thank you.

Contents



Introduction

This guide has been written for parents of disabled children who want to know what financial help may be available for them and what arrangements they may need to put in place to manage their children's finances from birth and as they get older.

This guide is one of a series of guides published by Cerebra that aim to give parents of children with disabilities and/or special educational needs information on how to get the help and support they need.

Caring for a disabled child costs more for parents and may lead to problems with money and even debt. This guide gives basic information about the main types of financial help available for parents of disabled children and for disabled young people aged 16 and over who may be able to claim benefits and other money in their own right.

This guide covers:

- Benefits
- Other financial help
- Care and support services
- Managing money
- Preparing for the future

The guide gives basic information about these subjects, but you may want to speak to someone who can give you more advice. The Resources section (see page 16) shows you where to get more help and gives links to some useful websites.

Anyone who is caring for a child may be entitled to certain benefits. If your child has extra needs because of a disability, you may be entitled to extra help and/or be able to claim benefits for your child – this will be based on the needs of your child or on the money your family has coming in, or both.

If your child is under 16 they must normally be living with you in order for you to claim benefits on their behalf but special rules apply if your child is in residential care or a residential school.

Foster Carers

Foster carers cannot claim benefits for a fostered child, although the child may still be able to claim Disability Living Allowance (DLA) if under 16 or Personal Independence Payment (PIP) if aged 16 or over. A foster carer can be the child's appointee (see page 13) and help make benefit claims but can't get child benefit for that child. They can get a benefit called carers allowance if looking after a disabled child. If the carer is getting housing benefit or Universal Credit housing element, they are entitled to count a single foster child as requiring a bedroom. See The Fostering Network if you are a foster carer.

When we use the word 'parents' in this guide, it also includes anyone who is caring for a child except foster carers.

Welfare Benefits and Tax Credits

Carers Allowance (CA)

You are entitled to CA if your child receives the middle or highest rate DLA care component and you look after your child for 35 hours a week or more and you earn less than a set amount (£132 per week from April 2022) after deducting tax, National Insurance (NI) and some payments towards a pension and care costs. Receiving CA may also help you to be able to get other means-tested benefits.

Carers Allowance recipients in Scotland are automatically paid a Carers Allowance Supplement twice a year. These are lump sum payments and not increases to the weekly rate of benefit.

Child Benefit (CHB)

A non means-tested benefit for each child you are caring for.

Although not means-tested, child benefit can be taxed if you or your partner earn more than £50,000. The amount you pay can be between 1% and 100% of the child benefit received (100% rate applies if you or your partner on their own earn more than £60,000 a year or more).

In Scotland, recipients of eligible benefits can also apply for the Scottish Child Payment. Currently this is paid for children under the age of six, but is planned to be extended to all children under 16 by the end of 2022. It is currently £20 per week for each eligible child, planned to rise to £25 per week by the end of 2022.

Disability Living Allowance (DLA)

DLA is the main benefit for your child if they need extra care, supervision or watching over as a result of a disability or health problem for the past 3 months and will do so for at least the next 6 months. You will have to show that your child needs more attention than a non-disabled child of the same age. The DLA care component is paid at a low, middle or high rate; you get one of these rates depending on how much help they need.

DLA is normally only payable for a disabled child who is 3 months old or over. However, if your child is born with a terminal illness and may die within 6 months, the DLA care component can be paid from birth.

Getting DLA can also mean that you may be able to get Carer's Allowance (see above).

If your child needs help to get around they may also be able to get DLA mobility component which is paid at two rates, lower and higher.

The higher rate can be claimed for children aged 3 years or over who:

- are unable to walk; or
- are virtually unable to walk (they have severe difficulties walking); or
- are severely visually impaired; or
- are deaf and blind; or
- are severely mentally impaired and also have severe behavioural problems; or
- have such difficulty in walking that the effort would be dangerous to their health.

The lower rate DLA mobility component is paid for children aged 5 or over who can walk but need extra supervision and guidance outdoors because of their disability but do not qualify for the higher rate mobility component.

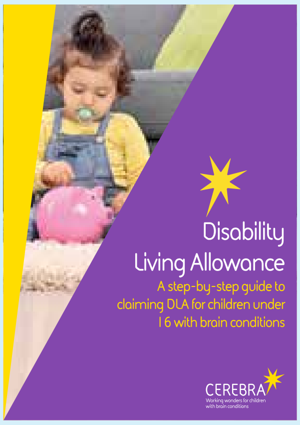
If you get the higher rate mobility component you can use it to pay for a new car through the Motability scheme (www.motability.co.uk), and may also be able to get free road tax for a vehicle used for taking your disabled child out.

In Scotland, DLA has been replaced by Child Disability Payment which works in a similar way although the claim form is very different.

All existing DLA recipients in Scotland are scheduled to be transitioned to Child Disability payment by the end of 2023. For more details see Contact's Benefits & Financial Help Guide in our Resources section at the end of this guide. Claims can be made through Social Security Scotland at www.socialsecurity.gov.scot

Note: DLA for people aged 16 to 64 has been replaced by the Personal Independence Payment (PIP) – see below.

In Scotland, a young person has the option to remain on DLA, or Child Disability Payment, until their 18th birthday.



For more details about DLA see our DLA Guide - available to download from our website

New Style Employment and Support Allowance (ESA)

The old-style, income-based ESA has been replaced by Universal Credit. The 'New-Style' ESA is contribution-based and therefore young people are very unlikely to be eligible as it is based on your national insurance contributions paid during the last two full tax years. It is a benefit for people unable to work due to long-term illness or injury.

Note: See Universal Credit.

Housing Benefit (HB), Council Tax Support (CTS), Income Support (IS) and Tax Credits

These benefits have been replaced by Universal Credit (see page 8) unless you have reached the state pension age (for HB & CTS) or are in very rare exceptional circumstances.

Personal Independence Payment (PIP)

Since 2013 disabled young people can no longer claim Disability Living Allowance (DLA) once they turn 16. If your child is already getting DLA before they turn 16, you will get a letter inviting you to claim PIP. You must reply to that letter, even if you have been given a lifetime award of DLA, as PIP replaces that. If your child is not getting DLA before they turn 16, they should make a new claim for PIP on reaching 16.

PIP is similar in some ways to DLA – it is not means-tested and is not based on National Insurance. PIP has two components, Daily Living (instead of Care) and Mobility. There are two rates of each component.

You complete a claim form and then have a face-to-face assessment.

For more information on PIP go to https://contact.org.uk/wp-content/uploads/2021/03/PIP-guide.pdf.

In Scotland, PIP is being replaced by Adult Disability Payment which is due to be rolled out for new claimants from Summer 2022 onwards. More details of how it differs from PIP will be available from Social Security Scotland nearer the time.

Universal Credit (UC)

Universal Credit has replaced the majority of 'legacy benefits' (e.g. Income Support, Tax Credits). Generally you need to be aged 18 or over to make a claim, but some 16/17 year olds are able to claim UC if they are pregnant or have children or are awaiting a work capability assessment and have medical evidence.

Like the legacy benefits it has replaced, UC is a means-tested benefit and so the amount you receive depends on your income and capital (money in the bank and assets); as well as other factors such as who is in your household, what their capacity to work is, whether you have childcare responsibilities, housing costs etc.

UC is claimed by setting up an online Universal Credit account at www.gov.uk/apply-universal-credit. This is followed by an interview at your local job centre when you will need to bring in evidence (of income, savings, rent etc) to support your claim. Any UC awarded to you will be paid monthly in arrears.

Other Financial Help

Blue Badge Parking Scheme

This scheme, run by local authorities, lets people who can get a Blue Badge park in disabled parking spaces, nearer to where they need to be.

There are three ways you may be able to get a Blue Badge for your child:

The entitlement rules vary somewhat between the 4 nations of the UK, so to check eligibility you should go to https://www.gov.uk/government/publications/blue-badge-can-i-get-one/can-i-get-a-blue-badge

Also note that there is a £20 fee for a blue badge in Scotland and £10 in England. It is free in Wales and Northern Ireland.

16 – 19 year olds Bursary Fund

The bursary scheme is for students in England only and it is up to the college or school where your child is studying if they can get it or not. However, disabled 16-19 year olds qualify for £1200 a year if they get both Disabled Living Allowance (or Personal Independent Payment) and Universal Credit (or ESA). For more information go to www.gov.uk/1619-bursary-fund/overview

Child Trust Fund (CTF)

The CTF was a long-term tax-free savings account for all children born between 1 September 2002 and 2 January 2011, and for whom Child Benefit was being paid. If your child already has a CTF account, the money belongs to your child and they can get to it when they reach 18.

If you wish, you, your family and friends can carry on paying up to £9,000 a year into your child's CTF account. It is possible to convert CTF's into Junior ISA's which may give better rates of tax-free interest. Speak to an independent financial advisor if your child has a CTF and might want to change to a Junior ISA. This won't affect the means-tested benefits you get for your child. See https://www.gov.uk/child-trust-funds for more information.

Council Tax discounts

Council Tax Discounts only apply in England and Wales and are area specific. To find out if it is possible to get a council tax discount where you live, enter your postcode at: https://www.gov.uk/apply-for-council-tax-discount

Disabled Facilities Grants (DFG)

You may be able to get a DFG from the local authority to help pay for changes to your property to meet the needs of your disabled child.

This is not mean-tested if the application for a DFG is on behalf of a disabled person under the age of 19.

Other grants (some means-tested) may be available for work on your house, including the Scheme of Assistance in Scotland.

For more information see our Disabled Facilities Grants factsheet https://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-disabled-facilities-grants/

Disabled Students Allowance (DSA)

Disabled students in higher education in England only may be able to get DSA to help pay for extra support or equipment they need because of their disability.

For further information, see https://www.gov.uk/disabled-students-allowances-dsas.

Education Maintenance Allowance (EMA)

EMA is only available in Wales and Scotland for young people who are still in education after school leaving age and are part of a family who have a low income. They must be going to school or college regularly and meet the targets agreed with their school or college. For more information see https://www.studentfinancewales.co.uk/fe/ema.aspx.

Please note that different schemes exist in Jersey, Guernsey and the Isle of Man.

Family Fund

This fund gives grants to families, mainly those on low incomes, who are caring for a disabled child or young person (aged 17 or less) with complicated extra needs, or children and young people with a serious illness. To claim for a grant, you must show proof that you are getting means-tested benefits and meet residency criteria.

A family can only try to get one grant in each 12-month period unless there are special circumstances like an emergency relating to a disabled child. The fund has its own rules for what counts as disability. Grants are for things that you can't get from people like the health board, social services etc, like washing machines, fridges, clothing, sensory toys, computers or family breaks.The rules for grants in Wales, Scotland and Northern Ireland are slightly different. See the Family Fund website for details www.familyfund.org.uk.

Health Benefits

Parents who are getting Income Support, income-based Jobseekers Allowance or income-related Employment and Support Allowance, (all now replaced by Universal Credit for new claimants), may also be able to get free prescriptions (in England – they are free at source elsewhere), dental treatment and other health costs, help with fares to hospital, vouchers for milk, vitamins, fruit and vegetables for pregnant women, nursing mothers and children up to 4 years of age. They may also be able to get a £500 Sure Start maternity grant for their first child, or subsequent multiple births (Pregnancy & Baby payment in Scotland) – see www.gov.uk/sure-start-maternity-grant.

Note: The Department of Works and Pensions Social Fund for emergency payments known as community care grants and crisis loans stopped in April 2013, and was replaced by discretionary local welfare assistance schemes from local councils. For further details contact your local authority.

In Scotland, parents can apply for Best Start Grants. There are two sorts available, Pregnancy and Early Learning. Those in receipt of eligible benefits can also get Best Start Foods cards which are prepaid cards allowing them to purchase essentials such as milk and healthy foods from participating outlets. More details are available from Social Security Scotland.

School-related costs

If you are getting means-tested benefits and your disabled child is at school or pre-school nursery, your child may be able to get free school meals. You may also be able to get help with transport costs to and from school. These schemes are also administered by your local authority.

Travel costs

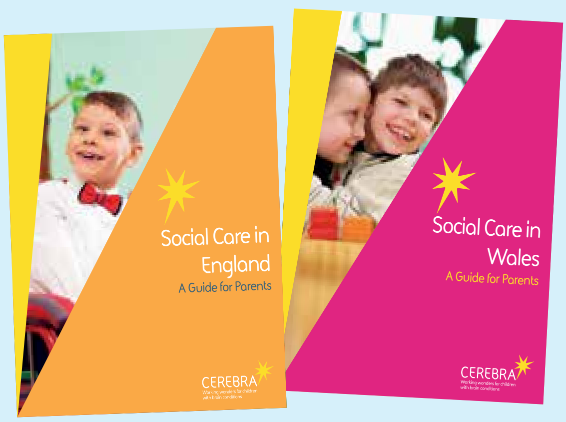
Children getting the middle or higher rate DLA care component and/or higher rate DLA mobility component may be able to get free or cheaper bus or rail travel, and possibly reduced costs for someone accompanying them.

Find out more about school transport in our School Transport guides

Care and Support Services

Disabled children and young people who need care and/or support to be independent are entitled to an 'assessment' by their local social services/children services department, which must then put things in place to meet any assessed needs. Often this support is actually given by the local authority. However, if you want to, you can ask that the local authority makes a regular payment to you, so that you can purchase the services for your child, instead of the local authority doing things for you themselves. These payments are known as 'direct payments'. Some local authorities also make 'personal budgets' available. These payments do not affect the welfare benefits you get.

If you are caring for a disabled child or young person, you are entitled to a Carer's Assessment from social services (which could be done at the same time, or a different time, as your child's or young person's assessment) to see if you can get any services to make caring easier for you. This could mean a break from caring, respite care for your child, the provision of adaptations or equipment and/or a direct payment to meet your own assessed needs.



Please see our Social Care in England or Social Care in Wales Parent Guides for more information on social care and support.

Children aged under 16

You are entitled to claim benefits for any child you are caring for and no special arrangements need to be in place. It is important to include details of your child's disability in the claim. You must tell the office that pays your benefits about any changes to your child's circumstances.

If you share care with another parent, you will have to decide which parent has responsibility for the child, usually based on who gets the child benefit.

You are usually able to help your child manage normal amounts of savings, for example by opening a bank account or savings account for them. However, if your child has a lot of savings (for example, from an inheritance or an award of damages) and has a mental disorder or learning disability which means they cannot make decisions about managing their own money and that they probably still won't be able to manage their money when they are an adult, then legal arrangements should be made to look after your child's property and money. In the case of damages, awards or settlements, the court's approval will be required and the court will decide how the money should be looked after. In other cases, and in any event when your child is approaching 16, an application should be made to the Court of Protection under the Mental Capacity Act 2005 (MCA 2005) for an order showing how your child's money should be looked after. You should ask the Court of Protection to appoint someone, called a 'deputy', with the power to make decisions about money for your child. You (or another family member) are likely to be appointed as your child's deputy, although in some cases a professional deputy may be appointed. Deputies are supervised by the Office of the Public Guardian, and the level of supervision needed will depend on individual circumstances. (see Resources section on page 16 for information on MCA 2005).

Children aged over 16

Young people aged 16 and older are able to claim benefits and financial support themselves. How your child's money is looked after is an important question as they transition into adulthood, and the arrangements needed will depend on whether they have the ability to look after their own money or if they need someone else to look after things for them.

It could be that all your child needs help with is what to claim and when and how to open a bank account to pay their money into (see below). They may also need advice about paying for any care services they may need. But if they are not able to make decisions about their money or about claiming benefits, arrangements must be put in place for someone else to do this for them once they reach the age of 16 – these arrangements are shown below. Anyone making decisions for them will need to comply with the principles and provisions of the Mental Capacity Act (MCA 2005) and in particular, to act in their best interests. (see Resources section on page 16 for information on MCA 2005).

Young people who can look after their own money

Young people aged 16 and older are presumed to be able to make their own decisions unless there are reasons to doubt this.

Any young person getting benefits or other payments will need their own bank account. Banks vary in the type of accounts they offer and whether they offer on-line banking. Many offer a basic bank account for paying in benefits and other income, paying bills by Direct Debit and taking out money at cash machines with a cash card, but with a limit on the amount by which the account can be overdrawn (usually £10). This can be a useful first step for young people. Most banks make specific arrangements to ensure their services are usable by disabled people – you should be able to find details on the bank's website.

To open an account, proof of identity will need to be shown to the bank, such as a passport and proof of address, for example an official letter from a government department or local authority saying that you can get welfare benefits. Proof of identity from your child's workplace or school or college may also be accepted.

Young people who cannot look after their own money

If a young person aged 16 or over is unable to make certain decisions for him or herself, an assessment of their capacity should be done in accordance with the Mental Capacity Act (MCA 2005) and the MCA Code of Practice. (See Resources section on page 16 for details on the MCA 2005). The MCA 2005 provides the legal framework for making decisions on behalf of people aged 16 or over who are unable to make such decisions for themselves. Anything done for, and any decision made on behalf of, a person without capacity should be done or made in the 'best interests' of that person.

Your child will probably qualify for DLA/PIP (and possibly Universal Credit) and be able to get care services from the local council, as mentioned earlier. However, they will need someone else, such as you or a carer, to claim and look after the benefits and services for them, as described below.

(i) Claiming benefits – appointeeship

If your child is aged 16 or over, and only gets social security benefits, and is not able to claim and manage those benefits themselves, then the Department of Work and Pensions (DWP) will need to appoint someone, called an 'appointee', to claim the benefits and use them for your child. You can ask to be made an appointee for your child or, if you don't want to do this, you can suggest to the DWP who might be the best person to be the appointee, such as another family member.

To become an appointee, contact the DWP and explain that your child needs your help to look after their benefits. A DWP officer will visit to check that your child needs an appointee and that you are able to do it and will complete the BF56 appointeeship form with you. If the officer thinks this is a suitable arrangement, the DWP will confirm your appointment on Form BF57, which you can then use to prove that you are your child's appointee.

As an appointee, it is your job to claim their benefits, use the money on your child's behalf, and have a duty to report any changes in your child's circumstances which may affect their benefits. As an appointee you should open a separate bank account in your own name on behalf of your child (known as an 'appointee account') for the benefits to be paid into. Appointees have no right to deal with any savings or capital owned by the young person unless they have formal authority (see (iii) below).

For further details see https://www.gov.uk/become-appointee-for-someone-claiming-benefits.

(ii) Direct Payments and Personal Budgets

If your local authority is making a direct payment in relation to you for your child, it is usually paid to you. However, if your child is aged 16 or older they are allowed to manage their own direct payments so long as they are able to do so. If your child is over 16 and is unable to manage direct payments, the payment can be made to a 'suitable person' instead, who could be someone who is already allowed to deal with the person's affairs (such as a deputy – see below) or anyone the local council says is 'suitable' (usually you or a carer). The 'suitable person' must then choose the services to meet your child's needs and arrange for them to be provided and paid for using the direct payment.

The same sort of arrangements can be made to deal with personal budgets on behalf of your child if they are not able to make arrangements for themselves, including for example setting up an account managed by a suitable person, or by trustees, on their behalf.

(iii) Managing other income, savings and capital

If your child is aged 16 or older and is not able to deal with their own affairs and has income other than benefits or has savings, or has had an inheritance or an award of damages, then you will need to get formal authority to deal with their property and affairs on their behalf and in their best interests.

Where there is an on-going need for financial decisions to be made on your child's behalf, and they will probably still not be able to look after their money when they are an adult, the Court of Protection can be asked to make someone a deputy to make decisions about money for them. The court is likely to make you or another family member your child's deputy, although sometimes a professional deputy (like a solicitor or accountant) may be appointed. Deputies are supervised by the Office of the Public Guardian, and the level of supervision needed will depend on individual circumstances.

In rare cases, if your child is aged 18 or over and has the capacity to understand that they may need help to look after their affairs, they may be able to make a lasting power of attorney (LPA) appointing you or someone else as their chosen attorney to deal with financial affairs on their behalf. However, quite a high level of understanding is needed to make an LPA and choose an appropriate attorney, which is why this is a rare option for young people with brain conditions.

Preparing for the future

You might want to put things in place for your child after your death or in case you are no longer able to care for them as they get older and become adults.

The main way to do this is to make a will, but you need to be careful about the effect of any inheritance on your child's finances like benefits and entitlement to services.

One solution might be to make a discretionary trust in the will to appoint trustees to manage funds on behalf of your child. You can decide who the trustees will be and decide what should happen to any money left after your child's death. You can also leave a detailed letter of wishes providing guidance on how the trust should be used for the comfort, support and maintenance of your child.

There are other things you can do, including making a lifetime discretionary trust to be in effect while you are alive. Some trusts made for the sole benefit of disabled people (known as trusts for 'vulnerable beneficiaries') get special tax treatment which means the disabled person may have to pay less tax. The law relating to wills and trusts for disabled people is a complicated area – you will probably need to seek independent legal advice.

The charity Mencap has a Wills & Trusts service which can advise you further and recommend solicitors who specialise in making wills, trusts and discretionary funds for children and young people with disabilities. See https://www.mencap.org.uk/advice-and-support/wills-and-trusts-service.

Resources

Welfare Benefits

Contact

The charity Contact offer a free helpline for parents and families with disabled children as well as regularly updated information on 'rights and entitlements' on their website:

https://contact.org.uk/advice-and-support/benefits-financial-help/

Disability Rights UK

https://www.disabilityrightsuk.org

Citizens Advice

https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/

Turn 2 Us

https://www.turn2us.org.uk/Your-Situation/a-young-person-aged-16-18

Other Financial Help

Child Trust Fund

https://www.gov.uk/child-trust-funds

Care and Support Services

Mental Capacity Act 2005–Code of Practice:

www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf

Making and registering a Lasting Power of Attorney:

www.gov.uk/power-of-attorney

Information for deputies:

www.gov.uk/become-deputy

Advice on becoming an appointee for someone claiming benefits:

www.gov.uk/become-appointee-for-someone-claiming-benefits

Making Decisions on Behalf of Someone:

https://www.gov.uk/make-decisions-for-someone

Making and registering a lasting power of attorney:

www.gov.uk/power-of-attorney/make-a-lasting-power-of-attorney

Making a will:

www.gov.uk/make-will

Trusts for vulnerable beneficiaries:

https://www.gov.uk/trusts-taxes/trusts-for-vulnerable-people

Information About The Authors

Penny Letts (OBE) is a policy consultant and trainer specialising in mental health and capacity law. She is Editor of the Elder Law Journal (Jordans), a contributor to Court of Protection Practice 2011 (Jordans, 2011) and Assessment of Mental Capacity (Law Society/BMA, 2010). She was Specialist Adviser to the Parliamentary Select Committee on the Draft Mental Incapacity Bill and prepared a major part of the Mental Capacity Act Code of Practice. Penny was formerly Law Society Policy Adviser on Mental Health and Disability (1987-2001), a Mental Health Act Commissioner (1995-2004) and a member of the Administrative Justice and Tribunals Council (2002-2013).

Jo Honigmann is Chief Executive of The London Centre for Children with Cerebral Palsy, having previously been a partner of Just Equality, which specialised in discrimination, disability and education law and policy. Having practised as a solicitor for several years, in both private practice and the not for profit sector, Jo has worked as a legal and policy consultant since 2008. Projects have included drafting Equality Act 2010 education guidance as part of a small consortium for the Equality and Human Rights Commission and for the NHS. During her career Jo has been responsible for a university's policy and provision for it's disabled students. She has written, trained and presented on education and discrimination law and policy to a wide range of specialist audiences. Jo chaired the Law Society's Mental Health and Disability Committee from September 2008 to September 20010 and has been a member of the Committee since 2003. She has an MSc in Disability Management in Work and Rehabilitation.

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Dafydd Williams is a former welfare rights advisor who spent nine years as a parent support worker and training officer with Cerebra and currently works with the NHS Wales Integrated Autism Service. He reviews our successful DLA Guide and has formerly given advice to a member of the Senedd on benefits issues, as well as helping hundreds of families through every stage of the claims process including representing them at tribunal. A parent of a young person with autism himself he has written, and delivered training courses and workshops on welfare benefits to parents and professionals.

The findings of this report are those of the author, not necessarily those of Cerebra.

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Working wonders for children with brain conditions

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