



Moving into Adulthood & Getting a Life

Money Matters

About these guides

The '**Moving into Adulthood and Getting a Life**' guides are a series of guides, written *by* and *for* families of young people with learning disabilities. However, some of the information contained in them may also be helpful for families of other disabled young people or those who have additional or special educational needs.

Each guide covers the many issues that families have to think and know about during the stage when their child is preparing for adulthood. This stage is often referred to by services as 'Transition'.

- **Getting Started:** Starting point. 10 top tips, 'Jargon buster'.
An introduction to person centred thinking, planning and approaches. The start of the preparing for adulthood stage. The Year 9 review. Person centred thinking tools.
- **Education Matters:** Further education - Staying on at school or going to college. Residential colleges. Adult education and lifelong learning
- **Money Matters:** Benefit changes at 16. Managing money. The Court of Protection
- **Social care matters:** Personalisation and choice and control. Personal budgets. 'Just enough support'
- **Finding the right support:** What support are you looking for? Finding support providers. Checking out support providers. Employing your own staff. Keeping safe
- **Becoming an adult:** The Mental Capacity Act. Supported decision making
- **Health Matters:** Staying healthy and safe. Health action plans. Personal Health Budgets
- **Social Life, Having Fun, Friends & Relationships:** Social life and having fun.
Growing up – sex and relationships. Where to look for activities. Staying safe online. Circles of Support.
- **Finding a job:** Work experience. Volunteering. Supported Employment.
- **Finding a somewhere to live:** Independent living. Supported living.

All of the guides stem from the belief that all young people, whatever their ability are capable of achieving a good quality of life as an adult.

As parents we know that our children are all different. They are unique individuals with their own gifts, talents, difficulties and challenges. The "one size fits all" approach has never worked for young people and families like ours and so throughout this guide we have included information about how you can tailor the support your child needs and wants to live a good life. This approach is called **person centred planning** and everything in this series of guides centres around person centred thinking, planning and approaches.

Contents

- Introduction
- Personal Independence Payment (PIP)
- Employment and Support Allowance (ESA)
- What is an appointee?
- Becoming a Deputy under the Court of Protection
- Where to get further advice and help

Introduction

Although your child will not legally become an adult until they are 18 it's important to note that adult disability benefits start when they are 16 years old.

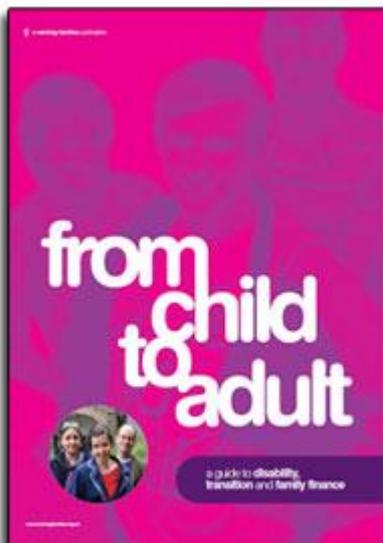
The benefits system is extremely complex. We have included some of the major benefits in this guide and suggestions of where to get further information but, we can't stress enough how important it is to obtain specialist benefits advice *before* your child turns 16 in order that they don't miss out on any entitlements.

When your child reaches 16 they may be able to claim benefits in their own right. However, you need to be aware that if they do you will lose any benefits you receive for them as your dependent (e.g. child benefit) As parents of disabled children you may be used to getting extra money to help you to meet some of the additional costs of caring for your disabled child. These benefits often become part of the household budget and so it's not surprising that many of us worry about benefit changes and how they might impact on the household. If your son or daughter is living at home, and especially if your family claims income related benefits, it's important to get specialist benefits advice to work out what makes the most financial sense for your household at this time.

Top Tip:

All young people are meant to become less financially dependent on their parents when they become adults and this is the same for young disabled people. Make sure they are receiving everything they are entitled to.

A guide to disability, transition and family finance



Working with Families have produced this [free transition booklet](http://www.workingfamilies.org.uk/admin/uploads/from%20child%20to%20adult.pdf), to help understand how family finances are affected when a disabled child becomes an adult. <http://www.workingfamilies.org.uk/admin/uploads/from%20child%20to%20adult.pdf>

The booklet includes sections for parents and carers and disabled young people. It answers questions such as: how are family finances affected when your disabled child becomes an adult? When is it most advantageous for a young person to start claiming their own benefits? Can you change your working hours to fit with your disabled young person's new regime?

Most parents will have been claiming Disability Living Allowance (DLA) for their children but, at 16 all new eligible claimants will move onto a new benefit called the **Personal Independence Payment** or PIP. You can check when your child is due to change from DLA to PIP by visiting the [Direct Gov website](http://www.direct.gov.uk) -

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) replaced Disability Living Allowance (DLA) from April 2013 for people aged 16-64 with a health condition or disability. Further information about PIP can be found [here](https://www.gov.uk/pip-checker/y) - <https://www.gov.uk/pip-checker/y>

How similar is PIP to DLA?

PIP seems similar to DLA in many ways. It's not means-tested, nor based on national insurance contributions and can be paid to those both in and out of work. In addition:

- It has two separate components - a mobility component based on a person's ability to get around, and a daily living component based on their ability to carry out key activities necessary to participate in daily life
- There are special rules for the terminally ill
- Those getting the enhanced rate of the mobility component of the PIP will be able to make use of the Motability scheme;
- An award of the daily living component will open the way for a carer to claim carer's allowance.

New rules and new assessment

PIP uses an entirely new set of criteria to decide whether someone qualifies for the benefit, and if they do, the rate they will be paid. The way in which your PIP is assessed will also be very different to DLA. As well as having to complete a claim form, most people will be asked to attend a face to face assessment undertaken by a health care professional. This will not be your own GP but a health professional working on behalf of the Department of Work and Pensions.

Qualifying for PIP?

PIP uses a points-based system to decide whether someone qualifies for the benefit, and if so, at what rate. It's proposed that the individual will receive points depending on the level of difficulty they experience in the following areas:

- preparing food
- taking nutrition
- managing therapy or monitoring a health condition
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally
- reading and understanding signs, symbols and words
- engaging with other people face to face
- making budgeting decisions
- planning and following journeys
- moving around.

The number of points they score in the last two categories will be added together to decide if they get the mobility component, and at what rate. The scores in the other categories will be added together to decide whether they get the daily living component.

Further information:

Contact a Family Has produced a free guide for parents *Personal Independence Payment, Universal Credit and other benefit changes* is available from their free phone helpline. It contains further details about the scoring system that will be used in deciding whether your child will qualify for PIP. **Call the free national helpline 0808 808 3555, Monday to Friday, 9.30am-5pm.**

Employment and Support Allowance (ESA)

Employment and support allowance replaced Incapacity Benefit in 2008. Anyone over 16 who has an illness or disability affecting their ability to work may be eligible for ESA.

There are two types of ESA – contribution based and income related but the latter is more relevant to young people who have not paid sufficient National Insurance contributions. Income related ESA depends on the person's income and savings and is payable to young people not in school or equivalent education, nor in full time advanced education (what counts as full time varies for 'further education' and 'higher education' and for the type of tuition – seek advice from the course provider). However young people receiving DLA while at school or in full time advanced education may also be eligible for income related ESA.

People claiming ESA have to undergo a detailed 'Work Capability Assessment' to see if they qualify, unless they are terminally ill or receiving chemotherapy. People refused ESA have the right to challenge that decision at the First-tier Tribunal (Social Entitlement) where many refusals have been overturned.

In some cases young people can be eligible for ESA when they are still in full time education. To find out whether your son or daughter is eligible for this benefit, contact your local job Centre Plus, visit the Department for Work and Pensions (DWP) website at web: www.dwp.gov.uk or telephone the benefits advice line on 0800 055 6688

<https://www.gov.uk/employment-support-allowance>

Managing money

At 16 a young person is entitled to claim benefits in their own right, even if they still live at home with you. Claiming benefits at 16 can be the first time young people have to think about their ability to manage their own money and the benefits and financial support that are available depend on whether they are still in education, looking for, or in, work and the severity of their disability. How their money is managed will depend on whether the young person has the capacity to manage their own finances or whether they need someone else to manage their affairs on their behalf.

In some circumstances, all that young people need to know is what to claim when and to open a bank account into which their benefits can be paid. They may also need advice about using direct payments or personal budgets to pay for the support they need.

Young people who are able to manage their own money (*but, may need some help*)

If a young person is able to manage their own finances then, just like the rest of us they'll need to have their own bank account. Banks vary in the type of accounts they offer and whether they offer on-line banking. Many banks offer a "basic bank account" into which benefits and other income can be paid, bills paid by Direct Debit and money withdrawn at cash machines with a cash card, but with a limit on the amount that can be taken out (usually £10). This can be a helpful first step for young people who are just learning to manage their own money. Most banks have also made arrangements to ensure that the services they offer are accessible to disabled people and you can find out more about this on the bank's website.

Many young people may not feel ready to take on the responsibility of managing their own finances and ask their parents to look after their money for them. Some young people will never be able to manage their own money and in both these situations parents take on the role of "Benefits Appointee"

What is an Appointee?

An Appointee is someone who acts on the young person's behalf in all social security matters. This includes telling the Department for Work and Pensions (DWP) about any changes in their circumstances, banking any benefit money and using the money for the benefit of the person.

Before an Appointee is agreed, the DWP should arrange to visit both the disabled young person and whoever is making the application on their behalf (often the parent). They then have to agree that the young person is unable to act on their own behalf. If you don't get a letter from the DWP to ask whether you will be your child's appointee make sure you ring them a couple of months before they turn 16

If the young person lacks capacity to make relevant decisions about their finances or to claim benefits, arrangements must be put in place for someone else to do this on their behalf once they

Top Tip:

It's important that you are aware that these benefits belong to the young person and not to you. It's a good idea to set up a separate bank account for the young person's benefits (if they don't have one already)

reach adulthood. Anyone making decisions on behalf of a young person aged 16 or above will need to comply with the Mental Capacity Act 2005 ('the MCA 2005') - (read more about the Mental Capacity Act in the "**Becoming an Adult**" guide) and in particular, to act in the young person's best interests. For benefits purposes usually becoming an Appointee is enough as the bank account can be opened in the parents name or be paid into an existing account. In Oxfordshire however, if a young person receives a Direct Payment to pay for their support this can only be paid into a bank account in their name. If the young person lacks the capacity to manage their affairs then you will need to consider becoming a Deputy under the Court of Protection.

Becoming a Deputy under the Court of Protection

The Court of Protection deals with all issues relating to people who lack capacity to make specific decisions, for example concerning financial or serious healthcare matters. It will look at cases where the person's carer and healthcare worker or social worker disagree on what are the person's best interests. See the [Becoming an Adult](#) guide for more information about the Mental Capacity Act

The Court of Protection has specially trained judges to deal with decisions relating to personal welfare, as well as property and financial affairs.

See Web: www.publicguardian.gov.uk

Having Lasting Powers of Attorney differs from being a Court Appointed Deputy through the Court of Protection, in that, your son or daughter needs to have the mental capacity to understand and be able to give their consent for you to make decisions on their behalf.

Lasting Powers of Attorney

Lasting Powers of Attorney (LPAs) replace Enduring Powers of Attorney (EPAs). LPAs will give vulnerable people greater choice and control over their future and enable people to choose someone they trust to look after their affairs if necessary.

LPAs cover personal welfare as well as finance and property decisions. As they can only be used after they have been registered with the Public Guardian, they will be under more scrutiny and ensure that any decisions made on behalf of people lacking capacity are in their best interests.

To find out more visit web: <https://www.justice.gov.uk/about/opg>

Now, this all sounds really complicated and official and actually we know from experience that it is. However, like everything else to do with raising a disabled child you can get advice and help with this (if you know where to look) and we recommend that you do. The helpline at The Office of the Public Guardian is very helpful and your child's Care Manager should also be able to help and advise you.

Person Centred approaches to consider and tools to use

Everyone should have choice and control about how they spend their own money. Even if someone is unable to manage their own money there may be other ways to help them be more in control. This could be something as simple as making sure they have their *own* purse or wallet in their *own* bag.

How people need to be supported to manage their own money should be included in their decision making agreement. For more information click on this link - [Decision Making Agreement](#)

Example of Decision making agreement:

List of decisions and how I make them (Lucy)

Decisions in my life	How I must be involved	Who makes the final decision?
What I eat	I choose what food I buy and I need to be given a choice between two things in the evening.	Lucy
Where I go in the day time	Ask me regularly if I'm happy at day centres and if I'm happy with what I do on days when I'm at home	Social services – (funding body) say yes to places but Anna would make the ultimate decision if she said she didn't want to go.
What I wear	Ask me what colour I want to wear today	Lucy
Who I'm friends with	Talk to me about my friends and how I'm getting along with them	Lucy
How I travel	Ask me regularly if I'm happy with my transport	Funding bodies and staff
What tablets I take	Tell me it's time to take my tablets	Doctors but ultimately Lucy if she refused – this would lead to a specific decision making record
How I spend my money	Show me choices and count money out with me so I can see if it matches how much I need to buy whatever it is I want	Lucy but this is somewhat dictated by things that are out of her control like rent and bills etc. however she signs her cheques so makes the final decision

Where to get further help and advice

A number of organisations produce really useful guides to benefits so it's worth checking out their websites.

Mencap have produced a number of useful guides and these are also free to download from their website. These include guides to:

- Bank accounts Factsheet: An introduction to bank accounts for people with a learning disability <https://www.mencap.org.uk/sites/default/files/documents/Opening%20a%20bank%20account.pdf>
- Capacity and housing tenancies: Explaining what a housing tenancy is, issues of capacity and the law surrounding housing tenancy and how it might apply to a person with a learning disability.

<https://www.mencap.org.uk/capacity-housing-tenancies-factsheet>

The British Banking Association have also produced this useful booklet which explains more about managing money on someone else's behalf <https://www.bba.org.uk/publication/leaflets/4162-2/>

Local advice can be found by visiting the Carers Oxfordshire website here

Dosh - supports people with a learning disability to be more independent with their money. – see web: <http://www.dosh.org/>

If your child has an Autistic spectrum disorder then the **National Autistic Society (NAS)** have produced their own guidance <http://www.autism.org.uk/living-with-autism/benefits-and-community-care.aspx>

Disability Rights UK have produced a free guide to making a claim for PIP <http://www.disabilityrightsuk.org/personal-independence-payment-PIP>

Further information can be found at the **Gov UK** website (formally Direct Gov) the **Department for Welfare and Pensions (DWP) website** <https://www.gov.uk/government/organisations/department-for-work-pensions>

Department for Work and Pensions, a guide for Agents, Appointees, Attorneys and Deputies - <https://www.gov.uk/government/publications/procedures-for-dealing-with-agents-appointees-attorneys-deputies-and-third-parties>

The Money Advice Service: Help with managing money if you, or someone you care for, lacks mental capacity - <https://www.moneyadvice.service.gov.uk/en/articles/if-the-person-you-want-to-help-has-lost-mental-capacity>

The Transition Information Network - provides links to a range of information about money matters <http://www.transitioninfonet.org.uk/resources/money.aspx>

Information about Benefit changes



United Response and Inclusion North have produced these useful “Easy Read” booklets about the changes to welfare benefits.

[United Response Booklet can be downloaded here](#)

[Inclusion North Booklet](#)

Local Advice Centres

Barton Advice Centre (BAC) is an independent community advice and information centre, providing services to individuals who live locally in Barton, Headington and Risinghurst and throughout Oxfordshire. BAC provides specialist advice on welfare benefits, debt and general advice on a wide range of other issues. They also offer assistance to fill claim forms, negotiate with the Department for Work and Pensions or other outside agencies like fuel, water board, banks, creditors and housing. BAC is part of a network of advice centres in the City that includes

The Agnes Smith Advice Centre, Donnington and Rose Hill Advice Centre, Oxford Citizens Advice Centre and the Chinese Advice Centre.

Donnington & Rose Hill

Advice Centre, The Cabin, The Oval Rose Hill, Oxford OX4 4SF
Phone 01865 438634, Fax 01865 438643

Oxford Citizens' Advice Bureau

95 St Aldate's
Oxford OX1 1DA
Phone 0870 2200608

Agnes Smith Advice Centre

96 Blackbird Leys Road
Blackbird Leys
Oxford OX4 6HS
Phone 01865 770206, Fax 01865 771585

Fax 01865 202715