



Factsheet

Transition to Adulthood in England
for parents/carers of children with a
learning disability



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 give us a call on **01267 244216** or donate at <https://cerebra.org.uk/get-involved/donate/>.

Thank you.

Transition to Adulthood in England for parents/ carers of children with a learning disability

Aims

This short guide aims to highlight the importance of transition in the lives of children with learning difficulties, provide information about what is involved and help you navigate and access the information, support and resources that are available.

Key points

- What is transition and why is it important?
- Why it's important to manage your child's transition
- How to develop a transition strategy
- What happens if my child has an Education, Health and Care (EHC) plan
- Parental Responsibility/Mental Capacity Act 2005
- What must public bodies do?

What is transition and why is it important?

The move from being a child to becoming an adult is a very significant change in the lives of all young people. However, many young disabled people and their families find it a particularly difficult and challenging experience. It is often described as 'falling off a cliff'. A big part of the reason for this is that the support and services they receive will move from those focusing on children and their families to those dealing with adults. This process is known as 'transition' and can be particularly stressful due to a range of factors such as the number of different agencies and professionals involved (e.g. education, social services and health) and the way working practices differ between children and adult services.

No two young disabled people are the same. They will have different needs and aspirations and make choices which may well change over time. So, it is important that the transition process prepares young people to help make these important life choices: whether it's to go to university or to move on and leave the family home to live independently or work towards a chosen career. It is also important that young people are well supported and provided with the right information at the right time to make these choices. All transition meetings should involve the young person as much as possible and focus on their needs and what they want to do – this is known as person-centred planning.

If a local authority thinks that your child is likely to have care needs when she turns eighteen they must assess her if they think it will be of 'significant benefit' to her. It must do this even if she isn't already receiving services or even if she hasn't been assessed in the past. So, if you believe that your child will continue to need care services or start to need care services when she turns eighteen you have the right to ask for an assessment.

Find out how to request an assessment in our [Social Care Guide](#).



If your child is receiving care services, once the transition process is at the stage where your child's case is being transferred from children to adult services her care will continue to be provided by children's services until adult care and support is in place and ready to take over. Support should only stop if an assessment by adult services can demonstrate that it no longer needs to be provided. It's also worth noting that only a few moves from children's to adult services will actually take place on the day of someone's 18th birthday. In most cases it'll be a staged process taking place over several months or even years. This continuation of children's services into adulthood can also happen in order to avoid the transition to adult services coinciding with other stressful events such as exam periods.

You'll be able to find out more about transition in your area from your local authority's local offer which you'll be able to find on their website.

The following provide useful information on the transition process with links to many useful resources for you to explore including advice on housing, adaptations, and health:

- Transition Information Network - <https://councilfordisabledchildren.org.uk/transition-information-network>
- Preparing for adulthood - www.preparingforadulthood.org.uk
- Care and Support Alliance - <http://careandsupportalliance.com>
- British Association for Supported Employment - www.base-uk.org
- Learning Disability England - www.learningdisabilityengland.org.uk
- Royal College of Nursing - <https://scadmin.rcn.org.uk/library/subject-guides/children-and-young-people-transition-to-adult-services>
- Access to Work - www.gov.uk/access-to-work
- Council for Disabled Children - <https://councilfordisabledchildren.org.uk>

While these provide more targeted information:

- Down's Syndrome Association - <https://www.downs-syndrome.org.uk/wp-content/uploads/2021/04/Planning-for-adulthood.pdf>
- National Autistic Society - <https://www.autism.org.uk/advice-and-guidance/topics/transitions/making-decisions>
- SENSE - www.sense.org.uk/content/getting-result-information-pack
- National Deaf Children's Society - www.ndcs.org.uk/professional_support/transition.html
- Young Minds (Guide to Transition for Parents and Carers) - <https://youngminds.org.uk/media/1705/transitions-guide-for-parents-email-version.pdf>
- Diabetes UK (Health) - www.diabetes.org.uk/Guide-to-diabetes/Teens/Me-and-my-diabetes/Transition-to-adult-clinics/
- The Children's Trust Brain Injury Hub - <https://www.thechildrenstrust.org.uk/brain-injury-information/info-and-advice/approaching-adulthood/transition-to-adulthood>
- Together for short lives - www.togetherforshortlives.org.uk/assets/0001/0439/TfSL_Stepping_Up_-_Transition_Care_Pathway_6.pdf

Why it's important to manage your child's transition

Transition is notorious for being a particularly stressful process. In a perfect world all families would be given a key worker to act as a co-ordinator between everybody involved. But, unfortunately, in practice this doesn't always happen making a difficult situation worse.

Some local authorities have 'transition workers' who can be really helpful and supportive but they often have extremely large workloads and limited availability. Staff turnover can also be an issue: you may find that professionals who have been helpful and understand what you and your child want to achieve may leave the school or care team during the transition period leaving you high and dry, sometimes at a crucial time.

One way to overcome these potential difficulties is to be your own transition key worker and project manage the transition process yourself.

How to develop a transition strategy

The following are suggested key points to bear in mind throughout the transition process:

- **Have a goal:**

It's never too early to start thinking about transition. If your child has an Education, Health and Care (EHC) plan the annual review at Year 9, and every review after that, must include a focus on preparing for adulthood: but there's nothing to prevent it being considered in earlier reviews.

You will need to think about a wide range of issues such as whether your child wants to go on to further or higher education, where he would like to live and what activities he would like to do. This will help you when you attend the first transition meeting, because you and your child can tell the professionals what you want to achieve.

Remember that social care and health services may prefer to leave the planning to when your child is aged 17 plus. However, starting the planning this late is likely to make it difficult to get the right level and range of support by the time your child reaches 18.

This is particularly important if your child wants to attend a post-16 independent specialist college. For this reason, you need to ensure that the planning starts well in advance so by the time your child is 18 the support that your child needs in areas such as education/training and accommodation as well as health and social care, is in place.

- **Identify different options that you want to explore:**

At the beginning of the process, do not worry whether what you want is feasible. If costs are involved, your plan may well be resisted, but at this initial stage it is important that you and your child focus on what you think is the best plan for your child entering into adult life.

Think about what your child wants and is capable of achieving. For example, is independent living possible, or will they need social care support services in special housing (sometimes called 'supported living')? Or will your child need a residential care placement—if so is there a suitable one near to the family home? Does your child want to go on to higher education? Does he need independent living skills?

Make notes on the different aspects of your child's life that you need to plan for e.g, where to live, education/employment, leisure, friends, social life and specific needs, such as health care.

- **Project manage:**

You are going to have to manage a medium term project (a bit like restoring a building). You will need to get various experts to work together; you will need them to agree to work to deadlines and then ensure that they keep to these deadlines.

You will need to keep records and to remind the experts of what needs to be done in each phase and by when. If the experts give explanations which you find unconvincing, you may need to challenge these.

You will also need to be clear on 'costs'. Generally, councils and NHS bodies must meet the needs of a disabled young person or adult: needs are fundamental and costs are secondary. Vague statements about 'funding panels' or 'cost caps' should be challenged and always clarified in writing.

- ◆ If you feel that you do need to challenge any of the public services you are dealing with you may find our [Accessing Public Services Toolkit](#) useful as it explains how to make a complaint. We have also written some [template complaint letters](#) for common problems which you can adapt to your own situation.

- **Gather as much information as you can:**

The areas of law and policy relevant to disabled young people's transition to adult services and support are wide-ranging and in many cases, complex and overlapping. This may all seem overwhelming, but there is information that will help you to get to grips with the issues.

In addition, do not be afraid to ask – when professionals tell you something that you are not clear about, ask them to give reasons for their views/decisions. In some cases you may need to obtain specialist advice and/or information.

You can get information and support from a number of organisations:

- ◆ Every local authority must have an Information Advice and Support Service to provide free information and support including transition and you can find details of yours here – <https://councilfordisabledchildren.org.uk/information-advice-and-support-services-network/find-your-local-ias-service>;

- ◆ Detailed guidance on the Care Act 2014 at www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance.

- **Persevere:**

You may need to remind the relevant professionals what you want to achieve and why you think this is the best plan for your child. Be prepared to follow up your requests at meetings with written requests, diarise action points and remind agencies of what they promised to do and when.

If you're considering a placement in a post-16 independent specialist college you'll find useful information at the National Association of Specialist Colleges (NATSPEC) website – <https://natspec.org.uk/>.

What happens if my child has an Education, Health and Care (EHC) plan?

As mentioned above, the annual reviews of EHC plans must include a focus on transition from Year 9 onwards. Chapter 8 of The Special educational needs and disability code of practice: 0 to 25 years, www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf, explains how the government intends the process to work. And it says that transition planning must be built into the revised EHC plan and should result in clear outcomes being agreed that are ambitious and stretching and which will prepare young people for adulthood.

For further details on EHC plans, including how social and health care should be treated please see the following:

- Our Education in England: A Guide for Parents - www.cerebra.org.uk/help-and-information/guides-for-parents/education-health-and-care-ehc-plans-education-in-england-a-guide-for-parents/
- SOS!SEN - www.sossen.org.uk/admin/resources/ehcps.pdf
- IPSEA - www.ipsea.org.uk/what-you-need-to-know/ehc-plans

Careers Advice

Schools must ensure all pupils, included disabled pupils, are provided with independent careers advice from year 8 (12-13 year olds) to year 13 (17-18 year olds) and the government have issued guidance explaining what they need to do - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/672418/_Careers_guidance_and_access_for_education_and_training_providers.pdf.

Similarly, six form colleges and further education colleges must also arrange independent careers advice and they have their own guidance - www.gov.uk/government/uploads/system/uploads/attachment_data/file/417426/Careers_Guidance_College_Guidance_March_2015.pdf.

In addition, the National Careers Service has a helpline for information and advice about jobs, careers and training for children aged 13 or older - www.gov.uk/careers-helpline-for-teenagers.

Parental Responsibility/Mental Capacity Act 2005

Transition to adulthood involves an important but often unappreciated change in how decisions are made for young people.

Parental responsibility and the power to make decisions for your children isn't a constant right, but diminishes as they get older and reach a sufficient level of understanding and intelligence to understand the consequences of decisions relating to them.

This can become a particular issue for those young people who don't have the 'mental capacity' to make a specific decision. For instance, they may not be able to give permission for a medical operation to go ahead.

Mental capacity means being able to make your own decisions. Someone lacking capacity because of a learning disability, for instance, cannot do one or more of the following:

- Understand information given to her about a particular decision
- Retain that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate their decision

We all make decisions, big and small, every day of our lives and most of us are able to make these decisions for ourselves, although we may seek information, advice or support for the more serious or complex ones. For many people their capacity to make certain decisions about their life is affected either on a temporary or a permanent basis. A person with a learning disability may lack the capacity to make major decisions, but this does not necessarily mean that they cannot decide what to eat, wear and do each day.

The Mental Capacity Act 2005 applies to anyone aged 16 plus and in certain cases it allows professionals to make a decision in the best interest of someone they believe lacks the capacity to make the decision for themselves.

Parents often report feeling 'shut out' of the decision-making process when their child with a capacity impairing learning disability reaches 16. Many parents assume that as they are their child's 'next of kin' they will continue to have formal legal authority to make decisions on their behalf – unfortunately, as pointed out above, they are wrong.

Unless you have some specific legal authority many health and social care decisions you thought you'd have been making for your child will be made by professionals. Although this can feel very unsettling you do have the right to be consulted over these decisions. Sometimes this can lead to disagreement with the professionals concerned. If this happens to you and the problem can't be easily resolved you should consider taking legal advice as soon as possible.

In some cases you may need to consider applying for Lasting Powers of Attorney or deputyship: information about these possibilities can be found here: <https://www.mencap.org.uk/sites/default/files/2016-06/Mencap%2527s%20Guide%20to%20Lasting%20Powers%20of%20Attorney%20%281%29.pdf>.

The following will give you more information and explain the ins and outs of the Act:

- Cerebra's Decision Making, Confidentiality and Sharing Information: A Guide for Parents - www.cerebra.org.uk/help-and-information/guides-for-parents/decision-making-confidentiality-and-sharing-information/

- Disabled Children: a legal handbook (3rd edition) – Chapter 7 (Decision-making: the legal framework) and Chapter 10 (Transition to adulthood) - <https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-3rd-edition> (The chapters on this webpage can be downloaded free of charge).
- Mencap's Mental Capacity Act Resource Pack - www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf
- Mental Capacity Act Code of Practice - www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

And you can learn more about parental responsibility in this House of Commons briefing paper - <https://commonslibrary.parliament.uk/research-briefings/cbp-8760/>.

Money

Managing finances is an important aspect of transition. Your child may only need some help to open his own bank account or advice on what benefits he is entitled to claim and how to go about claiming them. However, he might not be able to manage his own affairs in which case he'll need somebody else to manage them for him.

The following resources contain information and advice on a variety of financial issues including benefits, charging for social services, direct payments, personal independence payments (PIP) and becoming an appointee:

- Our Money Matters: A Guide for Parents - www.cerebra.org.uk/help-and-information/guides-for-parents/money-matters/
- Our DLA Guide - www.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/

- Contact's Money Matters - https://contact.org.uk/wp-content/uploads/2021/03/money_matters_england_and_wales.pdf
- Contact's Personal Independence Payment (PIP) and other benefits at 16 - https://contact.org.uk/media/1039341/pip_guide.pdf

If you think that your child has been incorrectly refused PIP or has been awarded the wrong amount you can check it with the following tool which will also help you write a letter to ask for assessment to be reconsidered:

- PIP Mandatory Reconsideration Request Letter Tool - www.advicenow.org.uk/pip-tool

What must public bodies do?

It is useful to be aware of what the law says public bodies like the health, education and social services must do. This section has been taken from our Accessing Public Services Toolkit which contains useful advice for challenging public bodies should you disagree with their decisions or they aren't doing something you think they should be doing.

In all of their actions, including the transition process, public bodies – like all of us – must obey the law. If the law says local authorities are under a duty to assess the needs of carers (which it does) then it is simply unlawful for an authority to say 'we don't do carers' assessments'. If the law says that a local authority must meet the 'eligible' needs of a disabled person regardless of how much these may cost (which it generally does) – then an authority has to do this, even if it protests that it is short of money. Public bodies must 'act reasonably': this is a 'principle of public law'. One of the best ways of deciding what is reasonable is to ask yourself the question: "in this particular situation what would a reasonable person do?" Reasonable people don't have magic wands – but they do try to resolve problems as sensibly and as quickly as they can; reasonable people listen to what is said and make decisions; reasonable people 'do the best that they can'.

Generally that is all the court and Ombudsmen ask of public bodies.

Reasonable authorities (for example):

- **Make decisions on the basis of the relevant evidence.** They take into account all the available evidence before making a decision and don't ignore (or refuse to consider) relevant considerations.
- **If the evidence is 'largely one way' then reasonable authorities make decisions on this basis.**
- **Disregard irrelevant factors.** A local authority that decides not to provide support because 'its budget has been spent' will be taking into account an irrelevant factor (i.e. the state of its finances) if the law requires the need to be met regardless of resources (which it generally does).
- **Don't have 'blanket policies'.** Authorities are allowed to develop general policies for the way certain situations are handled, but these policies cannot be fixed – there must always be discretion to depart from them. So an authority can say (for example) that in general it will make direct payments at a rate of £13.00 per hour for personal care assistance. However if this is shown to be an inadequate rate in a particular case, it must be prepared to increase the amount. If it refused – saying that this was the maximum – then this would be unlawful. Lawyers refer to this as 'fettering a discretion'.
- **Give reasons for their decisions.** Authorities should give reasons for decisions which have significant consequences – especially if there is competing evidence. In such cases the reasons need not 'be elaborate... but they should be sufficient to enable a person to understand in broad terms why the decision was reached.

- **Act without delay.** Public bodies must act without delay. What amounts to 'unreasonable delay' will depend on how urgent the need is and the harm that delay may cause. Often it is not difficult to identify unreasonable delay, particularly when the public body has missed its own deadline. In some cases the law/guidance lays down specific timescales (for example, in England assessments of disabled children should be completed within 45 working days – and the English Ombudsman expects that assessments of adults' needs should take no longer than 6 weeks).

Monitoring Officer

If you are challenging the decision made by your local authority, such as one made by a social worker or someone in the SEN department, you may wish to contact the local authority's monitoring officer. The monitoring officer is a senior lawyer who is responsible for seeing that the local authority doesn't break the law. Most complaints made to local authorities are not routinely considered by their lawyers: they are dealt with by officers in the particular department. In many cases once they are aware of the situation the monitoring officer will explain to their departmental colleagues that they have misunderstood the law/applied an outdated policy etc. You'll be able to get the monitoring officer's name and contact details from your local authority. We would advise that you make it clear that you are contacting them in their capacity of monitoring officer and not in some other role they may have.

Information about the author

Derek Tilley is currently working as part of the Cerebra Research Team and is the father of a young lady who happens to have Down's syndrome. As a result of his dealings with public services he has had a long interest in supporting parents with disabled children access their legal entitlements. Firstly, in the area of special educational needs with IPSEA and SNAP Cymru Parent Partnership Services before moving into the area of direct payments with Diverse Cymru. During this period Derek served as a third sector representative on the Cardiff Disabled Children's Strategy Development Group and the Cardiff Autism Strategy Development Group. He recently successfully completed an MSc in Social Science Research Methods at Cardiff University and is carrying out a PhD under the supervision of Professor Luke Clements of Leeds University exploring issues related to the reoccurring problems parents of disabled children have obtaining their rights from the education, health and social services.

Information about the reviewer

Julie Wade is the Deputy Manager for the SEND Information, Advice & Support Service at Coventry City Council.

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

First edition: 2018

This edition: 2021

Review date: 2024



Working wonders for children with brain conditions

Postal Address

Cerebra
The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA31 3LW

Tel: 01267 244200

Freephone: 0800 328 1159

www.cerebra.org.uk



Registered Charity no 1089812 Company no. 4336208