

# FASD AND TRANSITIONING TO ADULthood

## – a guide for parents and carers



### WHAT is this Factsheet about?

This factsheet has information about:

- The steps you might take during the teenage years to support and prepare your teenager for adulthood.
- What transition planning is, and the Local Authority's legal obligations towards young adults and their carers.
- Needs and capacity assessments - what to look out for.
- Options for supported living.
- The legal routes (power of attorney, appointee, deputy) to support your young adult to manage their affairs.

There are helpful links throughout this factsheet.

### KEY POINTS:

- Be proactive and prepare for adulthood from age 13 onwards, don't wait until your child turns 18.
- Consider whether your teenager might need help managing their affairs post 18. Look at the options, discuss them with your teenager and agree a plan.
- During the teenage years document and keep all assessments from different professionals in a file to ensure capacity and need is properly understood in adulthood.
- Be aware of the vulnerabilities of your teenager and how the hidden nature of their disability can impact need and/or capacity assessments and refer 'experts' to FASD resources.

### UNDERSTAND your rights

#### FASD and the teenage years

Parenting a teenager can be challenging and parenting a teenager with FASD can be particularly difficult as they transition into adulthood.

You may expect your teenager to remain at school and be living at home, safe with you after turning 18. Or, your teenager may be out of school, known to the police and you may have serious concerns about how they will keep themselves safe and out of trouble as an adult.

Whatever your situation, experience shows the best way to protect and prepare your teenager with their transition into adulthood is to **start early and be proactive**.

#### What is a transition period?

The period from age 13/14 until a teenager turns 18 is called the **transition period** and this is the period where you still have parental control and can think about and take active steps to put safeguards and scaffolding in place before your teenager turns 18.

#### What happens legally at 18 years old?

At 18, your teenager is legally an adult and parents/carers lose all parental rights. This means that an 18 year old can buy cigarettes and alcohol, hold a credit card and a loan, buy fireworks, view, rent or buy pornographic material, pawn goods in a pawn shop, place a bet in a betting shop or casino, ride a motorbike above 125cc with a licence, get married without parental permission, serve on a jury, vote, and go to prison if found guilty of a criminal offence.

#### The importance of proactive planning for adulthood

Many teenagers with FASD will, with a little support, transition to adulthood with few problems. However, statistics indicate that individuals with FASD are particularly vulnerable. At 18 years old, an individual with FASD may be

articulate and outwardly 'able' but might have the comprehension and emotional maturity of a 6-year-old, the social skills of a 7-year-old, an 8-year old's understanding of money, and the living skills of an 11-year-old. A teenager with FASD may want to fit in and be easily led. This profile makes an individual with FASD susceptible to exploitation and crime. The tendency for individuals with FASD to express themselves well often hides their complex needs, meaning their vulnerabilities can go unrecognised by the authorities who have a legal responsibility to support and protect them.

#### Transition assessments

During the teenage years, you may want to ask the Local Authority (LA) for a transition assessment. This will look at what care and support needs are likely after your teenager turns 18. Under s58 of the Care Act 2014, a transition assessment must take place if your child is likely to need care and support after they have turned 18 and if it would be of 'significant benefit' for an assessment to be carried out.

The explanatory notes of section 360 of the Child Care Act 2014 makes clear that teenagers under 18 have a legal right to have their needs assessed by way of a 'transition assessment' if they meet the s58 criteria above, even if they are not known to children's social services or if they have not previously met the EHCP criteria.

There is no specific age a transition assessment should be carried out, but it is recommended to do so when it will significantly benefit the individual, and not to leave it until they turn 18.

Under s363 of the Care Act 2014, if the LA does not comply with a request to carry out an assessment, it must explain why in writing and provide information and advice about what can be done to prevent or delay the development of needs. Your LA should include transition assessments in their Local Offer.

## UNDERSTAND your rights

Following the assessment, the LA must say whether the national threshold for help in Section 2 of the Care and Support (Eligibility Criteria) Regulations 2015 has been met. If it has, then the LA should create a personalised support package and a personal budget. You may find it helpful to look at the FASD & Multi-Agency Services Factsheet.

The Care Act 2014 places a legal duty on LAs to provide or arrange services that promote independence for disabled people. This includes offering personal budgets and direct payments allowing individuals to choose how their funding is spent, including the option to use direct payments to hire a Personal Assistant (PA).

### EHCPs and transition planning

An EHCP can be a helpful tool as your child transitions into adulthood because it is not limited to school settings but can also support a young person's participation in apprenticeships, traineeships, and supported internships. These post-16 learning options can be tailored to the young person's needs and aspirations, with the EHCP ensuring that the necessary support and funding is in place.

An EHCP can remain in force until the end of the academic year in which someone turns 25 (section 46 Children and Families Act 2014). EHCPs can remain in place even if a child or young person is not in a formal college setting. SEN charities have raised concerns about LAs illegally terminating EHCPs post-16 by arguing (incorrectly) that on reaching adulthood, needs are no longer educational but 'social'. You can find out your rights here. If your child does not have an EHCP, you may find it helpful to read this FASD factsheet on EHCP's.

### EHCP transition assessments

For young people with an EHCP, transition assessments should be carried out within the annual EHCP process.

A LA has a legal duty (regulation 20(6) and regulation 21(6) of the SEN and Disability Regulations 2014) to make sure that **from year 9** at school (13 or 14 years olds), the annual review meeting considers what provision is required to help a child prepare for adulthood and independent living.

From year 9, reviews should focus on how young people with SEN can be supported towards greater independence and employability, including independent living, maintaining good health in adult life and participation in society. The EHCP should identify what action should be taken, and by whom, (paragraph 8.11 of SEN and Disability Code of Practice (the Code)). Paragraph 8.10 of the Code has some useful examples.

*LAs should consider the need to provide a full package of provision and support across education, health and care that covers five days a week, where that is appropriate to*

*meet the young person's needs* (paragraphs 8.39 and 8.40 of the Code). The Code confirms that five-day packages of provision and support do not have to be at one provider and could involve amounts of time at different providers and in different settings. It may include periods outside education institutions with appropriate support.

### Transitioning from children's to adults' services

If your child already receives support from child health and social care services or the Children's Disability Team, then this will often stop at age 18 and services will be provided by adult services. This transition period can be destabilising and confusing for young adults and their families as staff and routines change. Health, education and care is often not joined-up and young people can fall between the gaps when transitioning from children's to adults' services.

As early as year 9, consider what support your child currently receives and start to question how that service will transition to adult services. It should be an ongoing process rather than a single event. According to s66 Care Act 2014 and the explanatory notes, support from the LA's children's services, including provision of an existing EHCP, must continue until adult provision has started, or until a person is assessed as ineligible for adult care and support.

### Care-experienced children, Special Guardianships, Kinships and transitioning to leave care

The LA has a legal duty to provide specific support for looked-after or certain previously looked-after children at age 16 and beyond. The law is complicated because the support a LA legally must provide depends on the legal status of the child. You will need to work out whether the child is an *eligible child*; *relevant child*; *former relevant child*; or *other qualifying care leaver*.

For example, previously 'looked after' children aged 16 to 20, who ceased to be 'looked after' on the making of a Special Guardianship Order, AND are either still being cared for under the Special Guardianship Order (16 or 17 year olds); or the Order remained in force until they reached 18 are 'qualifying care leavers' and may be eligible for leaving care advice and assistance services under the section 24(1A) of the Children Act 1989.

Coram child law advice explains the difference. Click here for a helpful page.

### Pathway Plans

A pathway plan is a document that helps young people prepare for leaving care and living independently. It is a legal document that outlines the support they'll receive from the age of 16 and is based on a needs assessment. It must be reviewed at least every 6 months until the child turns 21 years of age, or beyond if they remain in education.

## Personal Adviser

Section 3 Children and Social Work Act 2017 requires a LA to provide personal advisors to care leavers up until they reach the age of 25. Statutory guidance on this can be found [here](#). A personal advisor is someone who offers advice, support and information to make sure the young adult is ready to leave care and live independently. Their job is to assess need, identify goals and help to overcome any challenges. They will also contribute to the pathway plan and make sure it's carried out correctly. The legal guidance LAs must follow can be found [here](#).

## Supported living for young adults

As your teenager transitions into adulthood, you may be starting to think about whether they will be able to live independently. The transition assessments referred to in previous paragraphs should consider independent living. It is helpful to get an FASD informed neuropsychological assessment or to update an existing one ahead of this time to inform the referral process.

### Supported living accommodation

If your teenager is thinking of moving away from home, they might want to consider [supported living accommodation](#) where they can live alone or in shared accommodation specifically designed for adults with care and support needs. Supported living accommodation is defined in [s5 of the Care and Support \(Ordinary Residence\) \(Specified Accommodation\) Regulations 2014](#).

### Shared Lives scheme

Under the [Shared Lives scheme](#) your young adult will live with a 'carer' and shares family and community life with them. This can involve living with someone on a full-time basis or just for day support or overnight breaks. The law and a good explanation of Shared Lives can be found [here](#).

### Staying-put for children in foster care

A foster child has a right to stay with their foster families past the age of 18, if the foster family and foster child agree. This is known as 'staying put'. The LA has a duty under [the Children and Families Act 2014, part 5 Welfare of Children, s98](#) to monitor the arrangement and to provide advice, assistance and support (including financial support) to maintain the 'staying-put' arrangement until the care leaver reaches the age of 21.

## EVIDENCE is key - documenting needs

During the teenage years, proactively build a clear picture of their needs so you can understand and provide evidence of need when you are trying to get support for your young adult. Most decision making in the LA is carried out by a panel who will use the evidence before them to make decisions. Written evidence is key.

Any person carrying out assessments should be

FASD-informed and if they are not, send them resources and ask them to contact FASD alliance charities for input ahead of the assessment.

If your young adult does not have a diagnosis but you suspect FASD, you can still use assessments to show need.

Some of the suggested assessments below are easier to access than others and it may depend where you live. Some may be funded by the Adoption & Special Guardianship Fund [ASGF], some by your LA as part of an EHCP assessment [LA –EHCP], or your LA's local offer [LA – LO] or by the NHS as a referral from your child's GP or paediatrician [NHS]. All can be provided privately if you have the funds.

- **A FASD informed neuropsychological assessment** is a comprehensive evaluation of a person's developmental and cognitive functioning. It will assess intellectual ability, memory, executive, aspects of language, cognitive and adaptive functioning, and can help predict what support may be needed in adulthood. Unfortunately, this assessment is only available through private funding but if you cannot access a full neuropsychological assessment, there are many ways to show need to help build a picture. Consider using the following:
- **A Wechsler Intelligence Scale for Children test (WISC-V Test)**. This test may form part of an FASD neuropsychological assessment, or an ASGF multi-disciplinary assessment (see below) or an assessment by an educational psychologist (see below). The test measures IQ but also a range of cognitive abilities, including verbal comprehension, perceptual reasoning, working memory, processing speed and fluid reasoning. [NHS] [ASGF][LA-EHCP].
- **An educational psychologist** will assess your child at school as part of an EHCP needs assessment (and may carry out a WISC-V test). You do not need consent from the school, nor do you need a diagnosis. There is further information on the [FASD & EHCP Factsheet](#).
- **Assessments to diagnose FASD** will necessarily involve some assessment of functioning and adaptability, and written paediatric reports can be helpful. [NHS]
- **Suggestibility assessments** can be used by psychologists to assess suggestibility. They can be helpful in showing vulnerability and susceptibility as part of a capacity assessment or if involved in the criminal justice system.

### Other evidence

Below are other reports you may want to obtain to show evidence of your teenager's needs. Explain to the therapist you require a robust report to document your teenager's needs so they can access support now or in the future and they will often be happy to support this.

- **Post-adoption support social worker – general support**
- **Sensory integration OT** [NHS, ASGF]
- **Play-therapy** [ASGF] [LA – EHCP]

- **Multidisciplinary trauma and attachment assessments** which involve a holistic assessment of neurodiverse needs including FASD. [ASGF]
- **Occupational therapy** [ASGF] [LA-EHCP][NHS]
- **PALMS** Positive behaviour, autism, learning disability and mental health service [NHS]
- **CAMHS** Child and Adolescence Mental Health Service [NHS]
- **Speech and language therapy** [LA - EHCP] [NHS]

## Taking control/helping your young adult with affairs post 18

There are three main formal routes to support your young adult and each will depend on:

- What they need support with; and
- Whether they have mental capacity

### A Power of attorney

A Power of Attorney is a legal document to allow you to manage affairs and make important decisions on behalf of your young adult (the donor). Your young adult will have to agree to you being their attorney. **You may want to discuss and plan this with your young adult before they turn 18, but you can only enter into a power of attorney once your young adult turns 18 years old.**

### General Power of Attorney (GPA)

A General Power of Attorney, also known as an Ordinary Power of Attorney, is usually used for specific and time-limited actions (e.g. selling a property), but can also be very helpful for individuals who need help with their affairs as it allows one or more persons to make decisions on an individual's behalf. It is only valid while an individual has mental capacity to make their own decisions.

A GPA will set out clearly what the attorney can do and when. It is helpful because, unlike an LPA (see below), it does not need to be registered and is legally effective as soon as it is signed. However, as it is not registered, the donor can 'revoke' (end) the GPA at any time. It will end automatically if the donor loses mental capacity.

### Lasting Power of Attorney (LPA)

A LPA can be useful if an individual needs help to manage their affairs. It is a legally binding document that is registered with the Office of the Public Guardian (OPG). It takes up to 20 weeks to be registered so you may want to discuss this with your child before they turn 18 and, depending on your circumstances, you may want to consider a GPA (which does not need to be registered to be effective) whilst you wait.

Once registered, an LPA remains in force, but it can be revoked or overridden by the donor (if they have mental capacity) by applying to the OPG.

There are two types of LPA:

**A property and financial affairs LPA** to make decisions about money and property, such as managing a bank account, paying bills, managing benefits. This can be used while someone has mental capacity, or drafted to come into force *only* if the donor loses mental capacity in the future.

**A health and welfare LPA** gives someone the power to make decisions about things like medical care and daily routine but can only be used when someone loses mental capacity.

You can create an LPA online and apply for it to be registered. Or you can download the forms and apply by post. The OPG will check the LPA before they register it. You must show your LPA document or a certified copy every time you act on their behalf.

### Apply to become an appointee

You can apply to manage your young adult's benefits by applying to become their appointee. As an appointee you do not have the power to manage their entire finances, only specific benefits. Where to apply depends on the benefit they are claiming or want to claim, but once an appointeeship is confirmed, it should apply to all DWP benefits.

The DWP may arrange to visit to assess if an appointee is needed and may also interview you to make sure you're a suitable appointee. You will need to fill out an appointee application form (Form BF56). If the DWP believes your young adult has mental capacity to agree to you becoming an appointee, they will seek your young adult's consent to you acting as appointee on their behalf.

If the DWP agrees your appointeeship you'll be sent Form BF57 to confirm you've been formally appointed. You're not the appointee until this happens. An appointeeship is reviewed every few years.

### Apply to become your child's deputy

You can apply to become someone's deputy if they lack mental capacity under the Mental Capacity Act 2005 (MCA). In practice it is often difficult to prove that someone with FASD lacks mental capacity under the MCA (see below). There are 2 types of deputyship and the application process is different for both:

1. personal welfare, where you can make decisions about their medical treatment and care
2. property and financial affairs, where you can make decisions about their money and property

You'll need to apply to the Court of Protection to become a deputy. You can apply for one type of deputyship or both. The application process is different for each.



## The Mental Capacity test – does my young adult lack mental capacity?

There are certain decisions an individual can only agree to if they have mental capacity. Other decisions can only be made on someone's behalf if they are assessed as lacking mental capacity. It is often confusing to work out whether someone has mental capacity.

The MCA applies to people aged 16 and over. The MCA starts with the assumption that *everyone* has mental capacity and if an individual is struggling, then they should be helped to make their own decision rather than have the decision made for them. Making an unwise decision doesn't mean someone lacks capacity.

Under the MCA, a person lacks mental capacity if they cannot do 1 or more of the following:

- understand the information relevant to the decision
- retain that information for long enough to make the decision
- use or weigh up that information as part of the process of making the decision
- communicate their decision in any way

Even if someone is deemed to lack full capacity, those making decisions on their behalf must act in their best interests, and their wishes, aspirations and views should be considered and included in any best interests meeting.

### Who carries out assessments under the Mental Capacity Act?

The Act is designed to empower those in health and social care to assess mental capacity themselves, rather than rely on expert assessments by psychiatrists or psychologists. Although, in cases involving complex or major decisions, a professional opinion from a GP, a consultant psychiatrist or psychologist is often appropriate. All assessors should consider the Mental Capacity Act 2005 Code of Practice (the Code) and the NICE Guidelines On Decision Making And Mental Capacity (the Guidelines).

4.51 of the Code states that *if the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition). Contact your local FASD Alliance for details of FASD trained clinicians local to you.*

Assessments of capacity are time and decision-specific. So, a person may lack capacity in one area, like managing finances but have capacity in other areas. This means that different people will be involved in assessing someone's capacity to make different decisions at different times.

If there is a disagreement, the Court of Protection will decide whether a person has mental capacity and the person who is challenging the assessment can apply directly to the Court of Protection by submitting expert evidence using a

COP3 Form. You do not need a solicitor, but you may want to seek legal guidance.

### Capacity and needs assessments for individuals with FASD

As your young adult transitions into adulthood there may be various assessments of need and capacity. This may be a formal transition assessment or a mental capacity assessment for an LPA, or it could be what seems like an informal 'chat' by social services for supported living.

Often, these capacity assessments and needs assessments are carried out by social service safeguarding teams, the police, government agencies (such as the DWP), and even professionals, (such as GPs) who have no, or very little understanding of FASD. Assessors often do not have the skills or experience or knowledge to dig deeper to recognise that abilities are often superficial, and as a result may not accurately assess capacity, especially if your young adult is articulate and comes across as capable. For example, your teenager may be able to physically cook, clean, wash, book an appointment, self-medicate, but **ONLY** by being adult led and supervised and when being engaged.

Lived-experience shows that the 'hidden' nature of FASD can sometimes lead to significant risk to individuals with FASD as the 'experts' deem a teenager with FASD to have capacity in situations where they may not. The individual may be left in a vulnerable situation without the support they need and the carers may be accused of being overbearing. **Those who carry out capacity and needs assessments on individuals with FASD should have specific training to understand the nuances of the disorder and interpret behaviours accurately.** You should refer the assessor to your local FASD UK Alliance organisation for input if they are not appropriately trained in FASD and they need support.

### Deprivation of Liberty

The liberty of an adult aged 18 and over can only be taken away in very specific situations. The MCA calls this a 'deprivation of liberty'.

Being deprived of liberty means that someone is prevented from doing anything without continuous supervision. A deprivation of liberty should only be used if it's the least restrictive way of keeping someone safe.

If an individual aged 18 and over is in a hospital or care home, liberty can normally only be taken away if health professionals use the procedures called the Deprivation of Liberty Safeguards (DoLS) which provide a legal framework to balance the need for care and treatment with the fundamental right to freedom and autonomy.

If an individual is aged 16 or over, lives at home, in supported accommodation or in a shared lives placement it is only the Court of Protection who can decide to deprive someone of their liberty. The Court will appoint deputies to act on the individual's behalf if they are unable to make decisions about personal health, finance or welfare.

## MYTHBUSTERS

**My daughter has suspected FASD but no diagnosis, how do I collect evidence of need to ensure she gets help as an adult?**

You do not need a diagnosis to build up evidence of need. Any assessments showing difficulties are helpful whether from school, a pediatrician, CAMHs or other, so consider the list of 'evidence' in this factsheet. If you have access to the ASGF fund, contact your post-adoption team and access the support set out in this factsheet.

**Social services carried out a capacity assessment on my son and decided he had capacity to make his own decisions, but they had no knowledge of FASD. I disagree with the outcome.**

Refer the assessor to paragraph 4.51 of the Mental Capacity Act 2005 Code of Practice, send them any relevant assessments and encourage them to contact a FASD alliance partner for advice

explaining why you disagree with the outcome. If they refuse, then ask for an independent review or raise a formal complaint. If you are still unhappy you can complain to the Local Government and Social Care Ombudsman. If this does not resolve the issue you may need to challenge the decision by judicial review, and you should seek urgent legal advice.

**My teenager does not have an EHCP and is academically doing well, but he will struggle to live without support due to his poor memory and living skills and I am worried about him.**

An EHCP can be requested for children and young people up to the age of 25 and SEN includes a broad range of learning difficulties so you may want to seek advice from [IPSEA](#). Your child does not need an EHCP to qualify for a s58 transition assessment. The LA must carry out an assessment if your child is 'likely' to need care and support after they turn 18 and it would be of 'significant benefit'. Ensure you collate evidence that your child is likely to need care and support post 18 to help with your request.

## HOW can I enforce my rights?

**If you are refused a transition assessment**

- ☐ Write to your LA asking them to provide written reasons why they are not carrying out an assessment. If you are still not happy with the decision, you are entitled to complain to your [local council](#).

**If you are told you do not meet the threshold for help.**

- ☐ Ask your LA to provide a written explanation of the assessment. Tell the assessor why you are unhappy about their decision and why. If you cannot resolve the issue informally, ask your assessor/check your LA website for information on making a formal complaint.

**Independent review, monitoring officer**

- ☐ If a complaint does not work, write to your LA to ask for independent review or contact your LA's [monitoring officer](#).

**Local Government and Social Care Ombudsman**

- ☐ If you have already done all the above, contact the [Local Government and Social Care Ombudsman](#).

**Concerns about abuse, harm or exploitation of your teenager or young adult**

- ☐ If you are concerned someone misusing your young adult's money or making decisions that are not in the best interests of the person they're responsible for you can raise a concern with the [OPG](#).
- ☐ If you have concerns about someone else having decision making powers over your young adult you can [Apply to search the Office of the Public Guardian Register](#) to check if someone has another person acting on their behalf.

**Applying to the Court of Protection**

- ☐ If you want to appeal an action or decision made under the Mental Capacity Act you can apply to the [Court of Protection](#).

## KEY LEGISLATION AND GUIDANCE

- [Mental Capacity Act 2005 and Mental Capacity Act - Code of Practice](#)
- [Government Guidance - Mental Capacity Act: making decisions](#)
- [Care Act 2014 and Care Act statutory guidance](#)
- [The Children Act 1989 guidance and regulations - planning transition to adulthood for care leavers](#)

## HELPFUL LINKS

- [Gov UK - Care Act factsheets - how the Care Act and supporting guidance place duties and responsibilities on local authorities about care and support for adults.](#)
- [NHS - moving from children's social care to adults' social care](#)
- [Gov UK - Apply for an assessment by social services](#)
- [Council for Disabled Children: A Housing and Support booklet](#)
- [Mind - complaining about health and social care](#)
- [Gov UK - Leaving foster or local authority care](#)
- [Coram child law advice - Services for children leaving care](#)
- [Government guidance on making decisions for someone](#)
- [Social Care Institute of Excellence - Assessing capacity under the MCA](#)
- [tri.x - Mental Capacity Act 2005 - managing disagreement](#)
- [Mind - About the Court of Protection](#)
- [Independent Provider of Special Education Advice \(IPSEA\) - Annual reviews in year 9 and beyond](#)
- [The Law Society - find a solicitor. Check here to see if you are eligible for legal aid](#)
- [FASD UK Alliance](#)