



It is vitally important that all young people (including those with disabilities) are supported to achieve the best possible outcomes as they move into adulthood. Without the right support this transition can become more difficult and stressful than necessary, having a negative impact on the young person's wellbeing, happiness and progress. For that reason Coram Voice have produced this tool kit to help advocates, professionals and carers support disabled children with the transition from children's to adult's services.

If you need to contact us with any questions about this information, our details are listed in section 5, on page 6.

## **1. The ideal transition**

In an ideal world, every child with a disability would experience a smooth a transition to adult's services, which would include:

- Discussions about transition starting early/from year 9
- Different agencies/organisations working jointly together and with the young person/family to ensure a smooth transition.
- If a child is likely to need care and support from adult services after turning 18, a transition assessment should be completed within a reasonable timescale, and at a point in time when it is most likely to benefit the young person and carer.
- A lead professional to coordinate the transition process
- The child or young person should be involved in planning for the future, and their wishes and feelings should be listened to.
- Written assessments should be kept up to date and the young person and/or carers should be involved in reviewing them.
- A situation should not arise where children's services stop funding and support, but adult's services haven't taken over yet: There should never be a gap in services.

- If a disabled young adult is also a care leaver, they will be entitled to leaving care support such as a Personal Adviser, Pathway Plan and Setting Up Home Allowance.

## 2. Common barriers and issues.

Although some young people will be fortunate enough to experience a well-planned, smooth transition, for some this is not the case. Some of the most common issues encountered will include:

- Lack of forward planning leading to last minute and rushed decision making.
- Drift: Plans being made but not acted upon in time
- Assessments (such as EHC plans and Care Act/Transition Assessments) not completed in good time
- Processes (such as panel meetings) can seem hard to understand and as if they are creating extra barriers
- Disagreements between different organisations about who is paying for what: e.g. a council saying another council has a duty to provide accommodation, or Health teams and Social Care teams within once council disagreeing about which agency should fund care and support.
- Difficulties in finding the right placement, school or support provider for a young person with complex needs, and concerns about how much this will cost.
- Disagreements between carers/young people and professionals about what is in a young person's best interests.
- Lack of leaving care support for disabled young adults who are also care leavers (if a disabled young adult is also a care leaver, they will be entitled to leaving care support such as a Personal Adviser, Pathway Plan and Setting Up Home Allowance).

## 3. Jargon Buster

The transition process can feel complicated, even for the professionals involved. As a young person or carer the language of transition can be hard to understand, so we have provided a jargon buster. Not all of these terms will apply, but you may hear some of them at meetings, or they may be referred to in assessments.

- 1. Transition assessment:** An assessment under the Care Act 2014 for children, carers and young carers which must be carried out if there is significant benefit in doing so, and if a child is likely to have needs for care or support after turning 18.
- 2. Eligible need:** An adult or carer's need for care and support as defined by the

Care Act 2014. This has to be arising from a physical/mental disability or illness, meaning they are unable to achieve 2 or more specific listed outcomes and consequently there is an impact on their wellbeing

3. **Care and support plan:** A plan produced following a Care Act needs assessment, which details a person's needs and how these needs will be met. The plan should ensure the person's wellbeing is promoted and that they can achieve their desired outcomes.
4. **Funding/Allocation Panel:** An internal process/meeting which many councils choose to use following a social worker's assessment, where a group of people at the council decides whether they should agree the funding for a care package.
5. **EHCP (Education health and care plan):** A plan for children and young people aged up to 25, identifying provision needed to meet their special educational needs. (Has replaced statements of SEN and S139 Learning Difficulty Assessments).
6. **EHCP Co-production meeting:** A term some local authorities use to describe a meeting where a parent/young person can review a draft EHCP and can discuss/have input into what is included.
7. **MCA (Mental Capacity Assessment):** An assessment to decide whether an individual (over 16) has the capacity to make a particular decision at a particular time, because they are affected by an illness or disability. The assessment determines whether a person is unable to understand, retain or weigh up the relevant information to make a decision, and whether they can communicate their decision.
8. **Best interests meeting:** A meeting for a person who has already been assessed as lacking capacity, to consult the people involved in the person's life, on whether they feel a particular action or decision is in his or her best interests
9. **DOLS (Deprivation of Liberty Safeguards):** Extra safeguards for people in care homes or hospitals who are 'deprived of their liberty' because they are being continuously supervised and not are not free to leave. The deprivation of liberty may be unavoidable and for a good reason (e.g. to keep someone safe) but if so it still needs to be authorised.
10. **COP (Court of Protection):** The court which deals with decisions or actions taken under the mental capacity act. When there is a disagreement that can't be settled any other way about what is in a person's best interests, then the court makes a decision. This includes disputes about deprivation of liberty.
11. **PA (Personal Adviser):** The worker allocated to a care leaver to provide advice, ensure that the support in their Pathway plan is implemented and coordinate the provision of services. Remember: A disabled adult can also be a care leaver and if so, they are be entitled to a PA as well as a transition/adult Social Worker.
12. **CCG (Clinical Commissioning Group):** This is an NHS body of local health professionals who make commissioning and funding plans and decisions for health services in a specific area.
13. **Continuing healthcare:** People with long-term complex health needs can be assessed as qualifying for free care and support which is arranged and funded by the NHS. This is known as continuing healthcare.

- 14. Direct payments:** Payments from adult social care. They enable people who have been assessed as eligible for care and support to choose and buy the services they need themselves, instead of getting them arranged by the council.
- 15. CQC:** The Care Quality Commission The independent regulatory body for health and social care in England. They monitor, inspect and regulate services (such as hospitals and care homes) to make sure they meet standards of quality and safety.
- 16. Advocate:** A professional advocate will support a young person to know their rights and ensure that their wishes and feelings are heard. There are different types of advocates who may support you during a transition. This could include a Youth Advocate or Children's Rights Officer, a Care Act Advocate or an Independent Mental Capacity Advocate. In addition, friends, carers or other professionals may advocate more informally on behalf of the young person.

Remember social care professionals have a responsibility to explain clearly what they are saying and doing to young people, carers and other professionals. If you don't understand what they are saying ask them to explain or be clearer.

#### **4. What the law says:**

It always helps to know your rights! Here is a list of some of the relevant legislation/guidance, and some of the key points about transition.

##### **The Care Act (2014) Statutory Guidance says:**

- Local authorities must carry out a transition assessment of anyone in the 3 groups when there is significant benefit to the young person or carer in doing so, and if they are likely to have needs for care or support after turning 18
- Transition assessments should be carried out in a reasonable timescale. Local authorities should inform the young person or carer of an indicative timescale over which the assessment will be conducted and keep them informed.
- There is a duty on local authorities to provide an independent advocate to facilitate the involvement in the transition assessment where the person in question would experience substantial difficulty in understanding the necessary information or in communicating their views, wishes and feelings – and if there is nobody else appropriate to act on their behalf
- Local authorities must not allow a gap in care and support when young people and carers move from children's to adult services.
- The full guidance can be found at:  
<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

**The Special educational needs and disability code of practice: 0 to 25 years (2015) says:**

- For a young person with an EHC plan, the local authority should ensure that the transition to adult care and support is well planned, is integrated with the annual reviews of the EHC plans and reflects existing special educational and health provision that is in place to help the young person prepare for adulthood.
- Local authorities must ensure that the EHC plan review at Year 9, and every review thereafter, includes a focus on preparing for adulthood
- The full guidance can be found at:  
<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

**The Children Act 1989 guidance and regulations Volume 3: planning transition to adulthood for care leavers says:**

- Care leavers with complex needs, including those with disabilities, may transfer direct to adult services and the pathway plan will need to ensure that this transition is seamless and supported
- Local authority responsibilities towards disabled care leavers are the same as for all other care leavers
- Because of their additional needs, some young people may draw on a number of services, receive support from several professionals and have multiple plans. The local authority must ensure that these processes are streamlined as much as possible and roles and responsibilities discussed with the young person and their carer(s).
- Each disabled young person will have their own individual aspirations, hopes, needs and wants. Whilst different services will have their own eligibility and access criteria, they must work together to adopt a holistic approach based on assessment of individual needs informed by each young person's wishes and feelings.
- The full guidance can be found at:  
<https://www.gov.uk/government/publications/children-act-1989-transition-to-adulthood-for-care-leavers>

**5. Still having problems?**

Even with the help of people who know their rights, the transition for a young person with a disability doesn't always go to plan. If you know a young person who is struggling or not getting the right support, here are some things you may want to try:

- Ask for a meeting with all of the different people/organisations involved in the transition planning process. This can be especially useful if there are disagreements between different organisations. Make sure someone is taking

minutes and that they will be shared with you. However it can also help to take your own notes of key points/actions.

- Send clear, brief emails to keep a record of your concerns/if you feel things are not being done properly
- Request written copies of your assessments and plans and check them.
- Ask to go and visit/see any accommodation, schools, colleges or activity centres you have been offered. Try not to rule out anything that you haven't seen: This will help you to make an informed choice about whether they are suitable, and will also help you to challenge unsuitable options later.
- Make a formal complaint to the council's complaints department if you can't resolve your issues. Make sure your complaint is clear, not too long and that you list what outcomes you want at the end. For further information please see: [www.coramvoice.org.uk/young-peoples-zone/complaints](http://www.coramvoice.org.uk/young-peoples-zone/complaints)
- If you are a young person struggling to make your voice heard, or understand your rights, ask for an advocate. If you know a young person who cannot request an advocate themselves, because of their disability, you can do this on their behalf. For referrals, information and signposting about advocacy, call the Coram Voice's **Always Heard** on **0808 800 5792** or visit our website at [www.coramvoice.org.uk/alwaysheard](http://www.coramvoice.org.uk/alwaysheard).
- If you have a question about the information in this toolkit, or need more general advice, you can contact Coram Voice on the number above, and ask to speak to Emma Robinson, the Specialist Advocate for Children and Young People with Disabilities. However if your issue is urgent, please speak to the Always Heard service if Emma is not available.
- If things have gone very wrong with the transition plan, you may be able to get help and advice from a solicitor. Further information can be found at [www.childrenslegalcentre.com/get-legal-advice](http://www.childrenslegalcentre.com/get-legal-advice)

**Always Heard:** The National Advocacy Safety Net and Advice Service for Children and Young People

**Freephone:** 0808 800 5792

**Online:** [www.coramvoice.org.uk/alwaysheard](http://www.coramvoice.org.uk/alwaysheard)

**Written by:**

**Emma Robinson, Specialist Advocate for Children and Young People with Disabilities**

Coram Voice (formerly Voice for the Child in Care)

Gregory House, Coram Campus, 49 Mecklenburgh Square, London WC1N 2QA.

Phone: 020 7833 5792.

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