



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 toolkit to help advocates, professionals and carers support disabled children with the transition from children’s to adult’s services.

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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. The most common issues encountered may 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 one 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. Sorting out 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 a young person is experiencing some of the barriers and issues identified above (section 2) then these should be raised with children's services. You can support a young person who is struggling or not getting the right support by doing or supporting the young person to do the following:

- 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/the young person. 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 the young person's assessments and plans and check them.
- Ask that the young person is able to go and visit/see any accommodation, schools, colleges or activity centres they have been offered. This will help the young person make an informed choice about whether they are suitable, and will also help you to challenge unsuitable options later. Young people should try to avoid ruling out anything that they haven't seen as it is hard to either accept or challenge a provision without this first-hand experience.

There is a jargon buster (section 5) and information on young people's legal rights (section 6) below which will also help you.

If the above steps are not successful then usually a young person or their advocate would share the young person's ongoing concerns with the allocated social worker. If needed a young person's concerns should be escalated to a manager to make sure that they are acknowledged and properly addressed. However sometimes this will not be enough.

All young people in transition have the right to make a complaint about the support they are getting (or not getting) from the local authority. Young people with disabilities have the same right to make a complaint as any other young person. They should be supported to exercise this right.

4. making complaints

Try to make the young person's complaint as clear and brief as possible, and stay focused on their unique needs and preferences, and their rights. If there is a lot of background detail you could consider attaching this as a separate chronology, to keep the complaint as clear and concise as possible. Where possible the young person's words or how they may communicate their feelings and views should be used in the complaint. It's important that the complaint represents the young person's wishes, feelings and rights, rather than your personal or professional view of their best interests.

We have produced a simple template to help you write a complaint on behalf of a disabled young person if they do not have an adequate transition plan.

Dear complaints manager, (*insert name*)

Formal complaint on behalf of: *Insert YP's details (e.g. Sam Jones, DOB 3/5/2000, 28 Somewhere Road)*

Briefly explain here your relationship to the young person: *(e.g. I am Sam's mum/carer/advocate/school teacher/key worker etc. and I have known him for him for X years. I am making this complaint on Sam's behalf because he asked me to/he doesn't have an understanding of the transition process due to his learning disability/he isn't able to communicate/write this complaint himself etc.)*

Very brief description of the young person's current situation and needs *(e.g. Sam is a 17/18 year old young person with a learning disability/complex health needs/autism etc., who has been living at his current home/foster care placement/residential school etc. for X years and requires support/prompting/supervision with tasks such as.... I have observed that Sam particularly enjoys/engages in/ smiles/vocalises during outdoor activities/access to the community/family contact/sensory activities etc.*

Specific complaints:

Examples:

- *Sam turns 18 on X date/ is already 18 years old and is likely to need care and support, but no transition assessment has been undertaken in accordance with the Care Act 2014.*
- *Sam will have to leave his placement in X months' time but there is no plan in place for where he will live*
- *Sam has complex needs but there is no transition plan in place for how Sam will manage the move/change of carers etc.*
- *Sam has no allocated social worker/care coordinator/leaving care personal adviser (if he is a care leaver) to oversee his transition plan.*
- *There is no identified educational placement/daytime activity programme for Sam*
- *The proposed new placement/care package will not be safe for Sam/meet his*

needs because ...

- *The proposed new placement/care package lacks access to ... which are clearly activities and opportunities Sam enjoys and has access to currently.*

etc.

*Don't forget to describe here how this will impact the young person's everyday life/wellbeing and why you are concerned on their behalf. It is also useful to **number** your complaints to keep things clear and structured.*

Outcomes requested:

e.g.

- *An urgent Transition assessment in accordance with the Care Act*
- *A transition meeting with all relevant agencies/professionals*
- *An identified placement to meet Sam's needs*
- *A robust care package to meet his needs*
- *A written transition plan with timescales*
- *An allocated worker to support with...*
- *Funding for....*
- *A programme of educational/community activities*
- *An interim plan*

*Etc. Again, it's useful to **number** each outcome.*

We look forward to hearing from you within 10 working days.

Kind regards

Contact details

You want to be sure that the young person's complaint is properly dealt with. The best course of action is to send the complaint to the complaints manager or officer at the local authority responsible for the young person's care. If you are unsure who to contact at the local authority you can call or check their website.

It is important to send your complaint to the complaints manager, rather than complaining direct to the social work team. This is because there are processes and timescales for responding to complaints about young people and it's the complaints managers' responsibility to ensure these are followed.

For more information about young people's right to make a complaint and how these complaints should be handled you can look at the Coram Voice website please see: www.coramvoice.org.uk/young-peoples-zone/complaints or the Government's guidance: <https://www.gov.uk/government/publications/childrens-social-care-getting-the-best-from-complaints>.

All children in care, care leavers and many children in need should be able to access independent advocacy support to make a complaint. You can find out how to help a

young person can access advocacy support with Coram Voice's help below (section 7).

5. 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.

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.

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

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.

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.

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.

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 accommodation and deprivation of liberty.

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.

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.

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 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.

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).

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.

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

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.

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.

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 entitled to a PA as well as a transition/adult Social Worker.

Transition assessment: An assessment in accordance with 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.

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.

6. 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>

7. Still having problems?

It's important to seek out support when this is needed to make sure that a young person's transition meets their needs. You can do this by considering the following:

- If a young person is struggling have their voice heard, or to understand their rights, they should be supported to ask for an advocate. For referrals, information and signposting about advocacy, call the Coram Voice's **Always Heard** service on **0808 800 5792** or visit our website at 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

Written by: Emma Robinson, Specialist Advocate for Children and Young People with Disabilities

Coram Voice | Coram Campus | 41 Brunswick Square | London WC1N 1AZ
Phone: 020 7833 5792. Registered Charity Number 1046207 Company Reg. No. 3050826

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