

Transition to Adulthood



Transitioning from children's services to adult's services is a critical time for young people with a learning disability – it is crucial to get this right

1

Ensure that there is a coordinated approach to transition to adulthood, bringing together children's and adult's services and the different parts of the system to work collaboratively together

Currently, there are significant issues with transition planning for young people with a learning disability. Transition planning is supposed to begin early, involve both children's and adult's services, and bring together the different parts of the system – Education, Health, Social Care, and Housing, for example – with the young person and their family to create a plan for the future.

But too often this doesn't happen – in some cases, adult services have only 'found out' about a young person with a learning disability a few days before their 18th birthday. The planning process is often complex, confusing, disjointed and hard to navigate.

**“
In my experience nothing happens to prepare for adulthood! No one knows my son or has met him, and no one responds to emails about transition planning especially about independent living.**

Family Carer

Investing in transition planning at an early stage leads to positive outcomes for young people and their families. Failing to plan early can result in crisis situations including inappropriate admissions to inpatient mental health services, acute hospital wards and inappropriate out of area placements at distance from family and friends. There is often a heavy price to pay for the failure to plan both in terms of trauma to the young person and their family as well as increased financial costs due to the person requiring more intensive crisis support.

Transition is seen by young people with a learning disability and their families as a 'cliff-edge' – where rather than getting the right support, they fall off.

To address this 'cliff-edge', planning needs to start early and extend up to the age of 25 years. When young people transition to adult services, a lack of employment opportunities and meaningful activities, including the opportunity to socialise with peers, is often reported (particularly for people with complex needs).

Professionals and services should work collaboratively and maintain open channels of communication with the young person and their families. The means of communication should be tailored to the specific needs of the individual so that their voice can be heard and included in decision making processes. Too often the voice of the young person is not central to the process and families report being ignored and excluded. Family carers of a person with a learning disability often provide continuous and lifelong support to their relative and know and understand their needs best.

People with severe learning disabilities may be non-verbal and use alternative means of communication, so require staff who are trained in augmentative and alternative communication. Adapting the means of communication to suit the needs of the individual would enable them to fully understand and be included in decision making. A transition coordinator should work alongside other members of staff to deliver person-centred support and ensure that the individual and their family are fully included in each stage of the transition planning process.

Find more information and examples about person-centred, community support [here](#)

The Department for Education and the Department of Health and Social Care need to:

Write to all a) local authorities and b) integrated care boards to highlight the importance of starting transition planning early

Facilitate a transition community of practice including sharing examples of good practice and high quality training

Introduce a Transition Coordinator who is trained in augmentative and alternative communication and will help explain people's options, entitlements and rights, focusing on what is possible, not just available e.g. bespoke packages of care and support

Amend the Care Act 2014 to introduce a statutory age for transition planning

2

Under the Care Act 2014, local authorities are required to carry out an assessment of young people's support needs and prepare plans to meet needs if these are likely to extend beyond their 18th birthday. Planning should start when there is "significant benefit" to the child to do so. The Law Commission are currently consulting on a proposal to change the law to introduce a statutory age for transition planning.

Investing in transition planning at an early stage will improve outcomes and reduce crisis situations.



The Department for Education and the Department of Health and Social Care need to:

Amend the Care Act 2014 to introduce a statutory age for transition planning and ensure that there is a named social worker to lead the assessment and planning process and co-ordinate with other agencies

Ensure that transition support services extend to 25 years (on a case by case basis)

3

Introduce a national, cross-departmental plan for transition that is co-produced with young people with learning disabilities and their families

The Kids report '[Off the cliff edge](#)' calls for the government to publish a coordinated, national and cross-departmental plan for transition. The Minister for Special Educational Needs and Disability (SEND) should work together with named leads from relevant departments, including but not limited to the Department for Education, the Department for Health and Social Care, the Ministry of Housing, Communities and Local Government, and the Department for Work and Pensions. These key figures should co-produce this plan alongside young people with a learning disability and/or autistic people and their families, so that they are fully included in the planning process.

This plan should include an action to develop national standards that all local areas should adhere to. It is essential that any local areas who do not follow these standards are held accountable. We recommend that Ofsted and the CQC jointly review local areas' adherence to the national standards.

More information and guidance:

- CBF information packs: [Planning for Adulthood – Challenging Behaviour Foundation](#) and [Transition Planning](#)
- Kids: [On the Cliff Edge](#)
- [Transition Information Network](#)
- What Matters to Me: [Transition Poster](#)
- Cerebra's Transition Guides for [Professionals](#) and [Families](#)
- Local Government Association: [Preparing for Adulthood – Young People with a Learning Disability and Autistic Young People](#)
- NHS England Keyworkers: [Children and young people keyworkers](#)

Named leads from relevant departments need to:

Work together alongside young people with SEND and their families to publish a cross departmental national plan for transition

Develop national standards for transition support and practice, including around data sharing, to avoid the need for young people and their families to repeat information multiple times

Ofsted and CQC need to:

Jointly review local areas and ensure that they adhere to the national standards