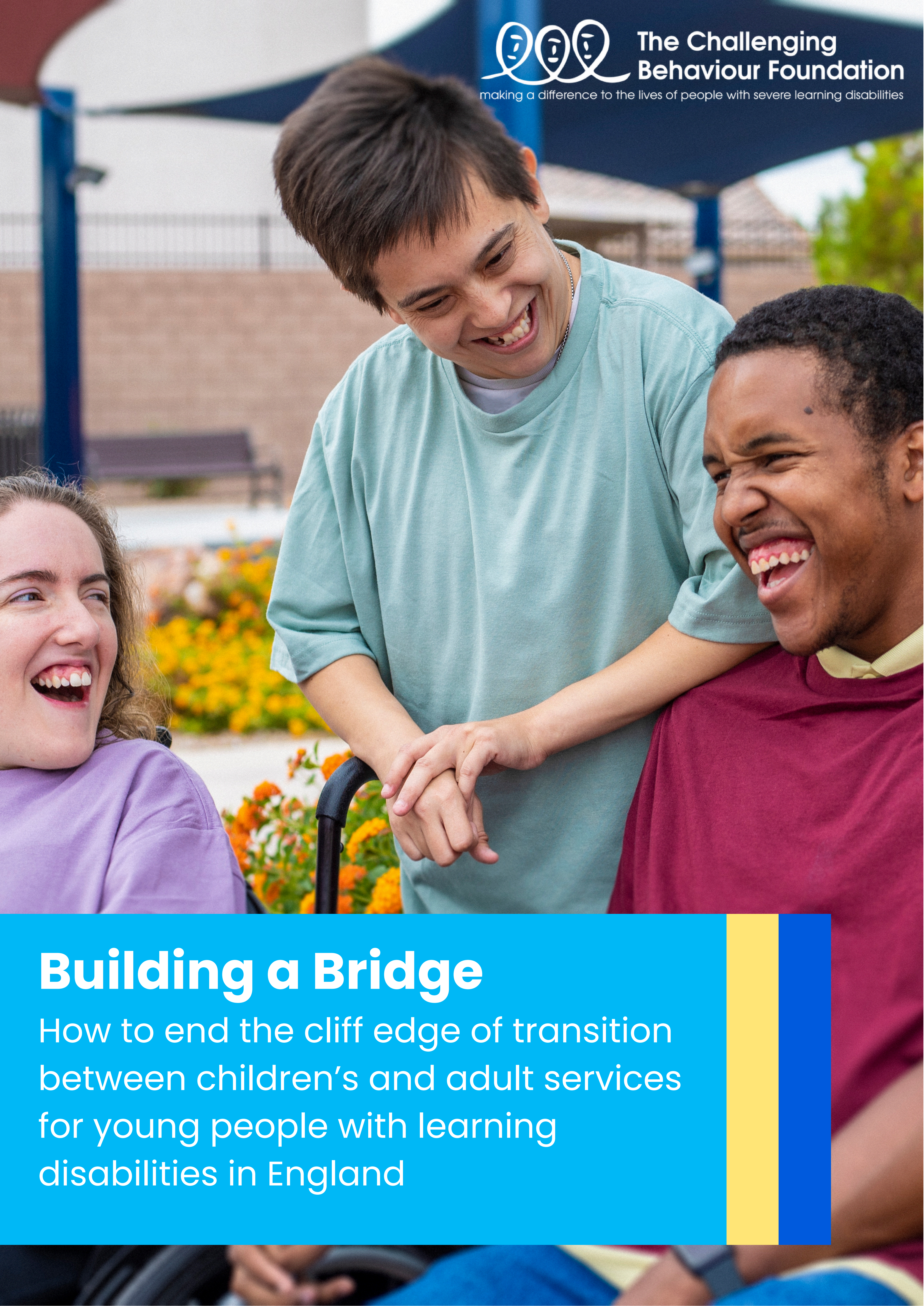
The Challenging Behaviour Foundation
making a difference to the lives of people with severe learning disabilities



Building a Bridge

How to end the cliff edge of transition between children's and adult services for young people with learning disabilities in England

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1. Forewords

"Becoming an adult should be a time of growing independence and opportunities. For parents, it often marks a natural shift in relationships—stepping back as young people move on.

For young people with learning disabilities and their families, this should be no different. Yet, too often, the opposite is true. As young people move into adulthood, essential opportunities and support fall away. Many families find themselves facing greater uncertainty and increased pressure.

Family carers are frequently left to step in and fill the gaps. They take on more caring responsibilities while trying to navigate a complex adult system that operates under an entirely different legal framework from children's services. For young people who need lifelong support, the suddenness and scale of change can be deeply damaging. Established routines are disrupted, trusted relationships are lost, needs go unmet, and rights that should be upheld are too often overlooked.

This should not be the experience of turning 18. Adulthood should never come as a surprise. We must do better.

We need to understand transition from the perspective of young people with learning disabilities and their families. This report starts from that point. It identifies the systemic problems that create the "cliff edge" and considers how to build the bridges to prevent it. With the right planning, support, and accountability, young people can access the opportunities they are entitled to—and families can be families, not substitutes for the state."

Jacqui Shurlock
Chief Executive, The Challenging Behaviour Foundation

"As a family carer of young people with learning disabilities, the transition from childhood into adulthood can be an incredibly confusing and daunting process. With so many parts of the system changing at once, it can feel overwhelming and difficult to navigate.

This is such an important point in young people's journeys, shaping what the rest of their life will look like. We need services to work together in partnership, with the family placed firmly at the centre, to make it a success for them.

Our relatives need more time than others to prepare and cope with change. Yet too often, a lack of early planning and joined-up thinking means support is left until the last minute, leading to poor outcomes and unnecessary distress.

When planning support for young people with learning disabilities, the focus is frequently put on the practical side of the care they need. Whilst this is essential, it does not take into consideration what makes a meaningful life—what brings happiness, purpose, and joy. Support must be genuinely person-centred, with a life-long approach that recognises the individual beyond their needs.

As families, we know our relatives best and know what they need. However, too often we are not listened to, or the right kind of support does not exist. Like any family, we want our loved ones to have fulfilling, happy, and independent lives as they move into adulthood—but we have to fight so much harder to achieve this".

Polly, family carer
Co-Chair, Challenging Behaviour – National Strategy Group, Transition Subgroup

2. Background

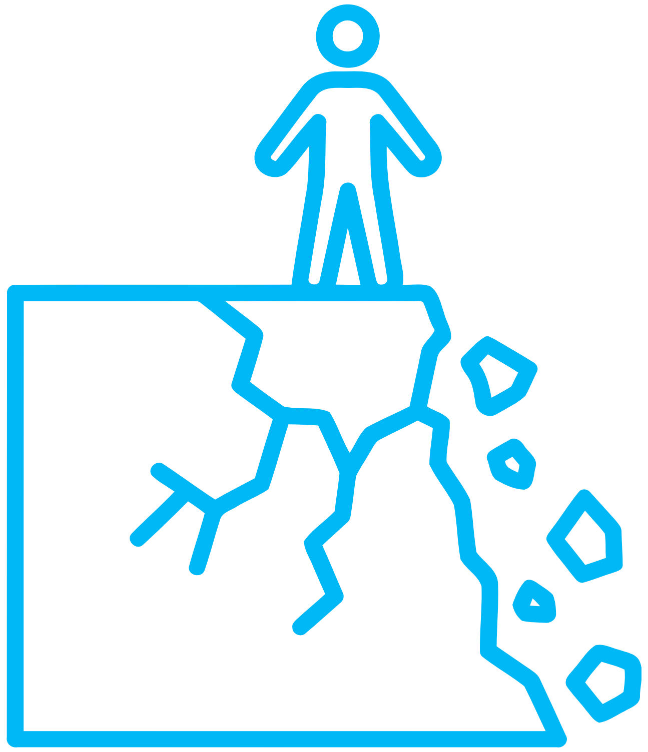
What is transition?

‘Transition’ can mean any time of change, but it often means the process of moving from child to adult services and support. Transition should be a time of opportunity and excitement for young people as they look ahead to their future, but too many young people with a learning disability instead experience a ‘cliff edge’.

In England, young people with learning disabilities are entitled to support from a range of children’s services, including education, children’s social care, and paediatric healthcare. As they approach adulthood, there needs to be a transition from the children’s services that they have been receiving support from to adult services – such as further education and/or employment, adult social care, and adult health services.

In developing the 2016 guidelines ***Transition from children’s to adults’ services for young people using health or social care services***, NICE found that there *“is much evidence about the nature and magnitude of the problems of transition from children's to adults' services but very little on what works”*[1]. **10 years on, families and professionals continue to report that they are not aware of much good practice around enabling positive transitions to adulthood for young people with learning disabilities whose behaviour challenges**[2].

This report looks at what we know about transition from children’s services to adult services for young people with learning disabilities – what works, what doesn’t, and why. Drawing on policy, research, and examples of good practice, the report demonstrates how professionals and services can work with young people with learning disabilities and their families to get the transition from children’s to adult services right – setting out what is possible and providing examples of how this can be achieved.



Transition: what should be happening

Young people with learning disabilities in England have rights related to transition to adulthood under several different laws and pieces of guidance.

Legal framework

Two of the main pieces of legislation that set out what should happen as a young person with a learning disability reaches adulthood are the **Special Educational Needs and Disability Regulations 2014** (which are associated with the **Children and Families Act 2014**) and the **Care Act 2014.** There are also two main pieces of guidance that accompany these pieces of legislation: the **Special Educational Needs and Disability Code of Practice** and the **Care and Support Statutory Guidance.**

The **Special Educational Needs and Disability Regulations 2014** say that:

> *Where the child or young person is in or beyond year 9, the EHC plan must include within the special educational provision, health care provision and social care provision specified,* ***provision to assist the child or young person in preparation for adulthood and independent living”***
>
> Section 12 (3)

This means that if a young person has an Education, Health and Care Plan (EHCP), from year 9 onwards, their annual review must cover planning for transition to adulthood.

Under the **Children and Families Act 2014**, *“preparation for adulthood and independent living”* includes finding employment, where the young person will live, and how they will be supported to participate in society. Chapter 8 of the **Special Educational Needs and Disability Code of Practice**[3] says that the review should include the following things:

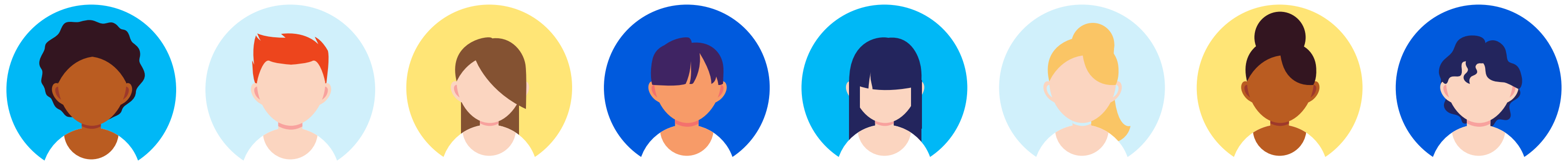
- Support to prepare for **higher education and/or employment**, including training options such as supported internships, and how to find and do a job
- Support to prepare for **independent living**, including decision-making, where they want to live in future, who they want to live with and what support they will need – looking at local housing options, housing benefits, and social care support
- Support in maintaining **good health** in adult life, including *“effective planning with health services of the transition from specialist paediatric services to adult health care”*
- Support in **participating in society**, including how to find out about social and community activities, opportunities to engage in local decision-making, and support to develop and maintain friendships and relationships

The **Care Act 2014** says that:

> *Where it appears to a local authority that a child is likely to have needs for care and support after becoming 18, the authority must… assess –*
> 1. *Whether the child has needs for care and support, and if so, what those needs are, and*
> 2. ***Whether the child is likely to have needs for care and support after becoming 18, and if so, what those needs are likely to be"***
>
> Section 58 (1)

This places a duty on the local authority to assess young people who are likely to need support as an adult to find out what these needs are before they reach adulthood. However, currently there is no set age when the process must start; the statutory guidance only states that this should be done when it is of "*significant benefit*" to the young person. Alongside this, the **Care and Support Statutory Guidance** (which gives more detail on how the Care Act should be applied) says that "Local authorities must not allow a gap in care and support when young people and carers move from children's to adult services"[4].

Other relevant legal rights and duties include a duty on local authority under the **Children Act 1989** and the **Children (Leaving Care) Act 2000** to "*prepare and maintain a Pathway Plan for every eligible care leaver, setting out the full package of support they will require as they transition into adulthood*"[i].



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[i] Young people with learning disabilities will be considered 'children in care' or 'looked after children' if they are under the care of a local authority, including if they are accommodated under Section 20 of the Children Act (which does not remove parental responsibility). This includes young people who are in residential special schools, and some young people who access short breaks.

Policy and Guidance

The **NICE quality standard on *Transition from children's to adults' services*[5] (2023)** sets out six 'quality statements' – the key things which should be in place or should happen during transition to adult health and social care services.

1 Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9

2 Young people who will move from children's to adults' services have a coordinated transition plan

3 Young people who will move from children's to adults' services have an annual meeting to review transition planning

4 Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer

5 Young people who are moving from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer

6 Young people who have moved from children's to adults' services but do not attend their initial meetings or appointments are contacted by adults' services and given further opportunities to engage

In 2015, NHS England, the Local Government Association (LGA), and the Association of Directors of Adult Social Services (ADASS) published ***Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition***[6], which sets out what support should be in place for children, young people and adults who have a learning disability or are autistic.

While not specifically about transition to adulthood, this guidance sets out several points that are particularly relevant to transition:

Education and Employment

"Everyone should have access to education, training and employment (including supported internships) which they can access within their local area"

Housing

"Choice about housing should be offered early in any planning processes (e.g. in transition from childhood to adulthood, or in hospital discharge planning) and should be based on individual need and be an integral component of a person's person-centred care and support plan"

Advocacy

"In addition to the legal right to advocacy, people should also be offered non-statutory advocacy, which should be available to them either at key transition points and/or for as long as they require at other times in their lives"

Coordination

"Everyone should be offered a named local care and support navigator or keyworker to coordinate and ensure timely delivery of a wide range of services set out in the person centred care and support plan, working closely with the person and their families/carers where appropriate and ensuring a consistent point of contact"

The 2026 NHS England guidance **Supporting young people to transition into adolescent and adult services**[7] sets out what integrated care boards (ICBs), providers and clinical teams should do to enable "safe and effective transition between services".

Integrated Care Boards should:

- Support and commission services to jointly develop healthcare transition model, so that there are no gaps in care
- Provide training on adolescent healthcare and transition, and ensure this is completed

Providers should:

- Proactively identify young people who are due to transition
- Have written policies that say which service(s) hold clinical responsibility for treating young people aged 16-17

Clinical Teams should:

- Start preparing young people for healthcare transitions no later than age 14
- Co-develop a strengths-based healthcare plan with the young person
- Provide a named worker to coordinate care
- Include parents and carers
- Make reasonable adjustments

Between 2014 and 2022, the Department for Education funded a national **Preparing for Adulthood (PfA) programme**, delivered by NDTi[8]. This programme provided support to local authorities to improve transition services and joined-up working, focusing on the four key outcomes of 'employment', 'independent living', 'community inclusion' and 'health'.

Local authorities were encouraged to:

- Develop a personalised approach, including using person-centred practices
- Work with young people, families, and other key partners to develop a shared vision
- Develop post-16 options and support that lead to employment, independent living, good health, friends and relationships and community inclusion
- Raise aspirations by sharing information and good practice

Young people with learning disabilities may also be eligible for children's continuing care and/or adult continuing healthcare. The ***National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care***[9] and the ***National Framework for Children and Young People's Continuing Care***[10] include guidance on what should happen during transition.

National Framework for Children and Young People's Continuing Care (2016)

- All children or young people with a package of continuing care should have a multi-agency plan for an active transition process to adult or universal health services or to a more appropriate specialised or NHS Continuing Healthcare pathway
- There should be a single key contact for families of a young person approaching transition

National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (2022):

- Children's services should identify young people who are likely to be eligible for adult NHS Continuing Healthcare when the young person is 14, and notify whichever integrated care board will be responsible for them as adults
- Integrated care boards should ensure that adult NHS Continuing Healthcare is represented at all transition planning meetings for young people whose needs suggest they may be eligible for adult Continuing Healthcare
- When a young person turns 17, the relevant ICB should determine in principle whether they will be eligible for adult Continuing Healthcare, so that packages of care can be commissioned in time for their 18th birthday

Key Message

Transition planning should:

- **Start early**
- **Involve health, education, and social care working together**
- **Be well-coordinated – with a named person responsible for this**
- **Fully involve the young person and their family**

The gap between policy and practice

Despite the legal frameworks, policies and guidance setting out what should be happening to support young people with learning disabilities to transition from children's to adult services, too many young people experience a "cliff-edge" – where support from children's services falls away, but adult services do not take over.

What policies/legislation say

"Timely plans need to be made by health and social care staff for their transfer of their support and care from children to adult services so that this transition can be smooth and stress free for the young person and their family"[11]

– Local Government Association

"Professionals from different agencies, families, friends and the wider community should work together in a coordinated manner around each young person"[4]

– Care and Support Statutory Guidance

"Good transition plans take a holistic look at the needs of the young person, including aspects of education and employment"[12]

– Royal College of Paediatrics and Child Health

"Use person-centred approaches to ensure that transition support treats the young person as an equal partner in the process and takes full account of their views and needs"[1]

– NICE

What is happening

Between 2017 and 2020, only 3% of young people with learning disabilities and/or who were autistic had begun the process of transition from children's to adult mental health services by the age of 14[13]

- Soper et al., 2022

3%

"Parents were particularly concerned by inadequate and often last minute transition planning by LAs, the absence of a multi-agency approach to this, and the lack of local services for their children to return home to"[14]

- Lenehan and Geraghty, 2017

"Many young people and their families are left in the dark about the future until very late in the day"[15]

- Kaehne et al., 2018

"It is clear that NICE guidance around transition is repeatedly ignored from commissioning to practice across services"[16]

- Shanahan et al., 2020

"The flexibility in the current framework can delay planning which, if it had been started earlier, would have enabled a smoother transition to adult social care"[17]

- Law Commission, 2025

3. What issues do young people with learning disabilities and their families face during transition?

Transition does not start early enough

> **"I just remember I felt the whole transition was rushed... there are so many things we need to make sure that are in place and it takes a long time to put those things in place"**
>
> Lina, family carer

Under the **Children and Families Act 2014**, and the associated **Special Educational Needs and Disability Regulations 2014**, planning for adulthood must be covered as part of a young person's EHCP review from year 9 (age 14) onwards. Social care is required to be part of a young person's annual review if the young person receives social care support; however, there is not a corresponding duty to begin planning for social care transitions at age 14 under the **Care Act 2014**. There is also no statutory duty around healthcare transitions, although the **NICE quality standard on Transition** from children's to adult services says that it is good practice to begin planning in year 9.

Although transition planning is supposed to begin at age 14, families supported by the Challenging Behaviour Foundation tell us that this is not happening. Instead, the process does not begin until much later – in some cases, not starting until just before their relative's 18th birthday, or when they are already an adult.

> **"To be frank our transition was a complete nightmare and I cannot think of anything positive to share. Emily* was in the hospital system at the time and was completely overlooked by the funding authority, she was not known to adult services at all. Emily was hospitalised while under the care of child services and adult services only became aware of Emily when the hospital she was in closed within 10 days. Emily was 18 at the time."**
>
> Family carer
> **name changed*

This is backed up by the research evidence. A 2022 study which looked at the experiences of 67 young people with learning disabilities who moved from children's mental health services to adult mental health services found that for **65 out of the 67 young people, transition planning had not started by age 14**[13].

Similar delays in beginning transition were also found by the National Confidential Enquiry into Patient Outcomes and Death in a 2023 review of transition[18], and by reviews of transition in education and social care[19] - including young people who still did not have a transition plan despite being due to leave school imminently[20].

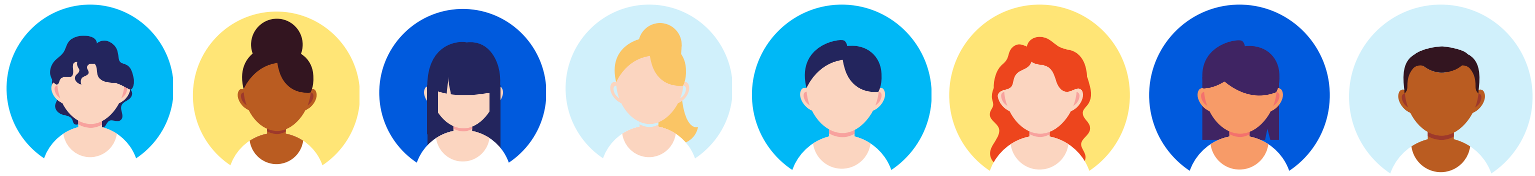
Transition planning doesn't just support the young person and their family to know what will be happening in their future; it is also a mechanism for the local area and services to identify who will need support and what support will be needed. When transition does not begin early, local areas are unable to plan effectively, including developing any services that are not currently available. This can lead to unsuitable placements which don't meet the young person's needs and are more likely to break down[21]. This matters, not only because the young person should be receiving the right support and isn't, but also because when a placement breaks down, people with learning disabilities are more likely to be admitted to hospital or to other more restrictive settings[22].

Why does transition begin so late?

Research consistently identifies that a major reason that transition planning begins late is because of a lack of resources – both in terms of the resources needed for planning a transition, and the resources for the support that a young person will need as an adult[21,15,20].

Because health and social care services don't have a statutory duty to begin transition planning at age 14, this lack of resources can make it harder for them to get involved in transition planning until much closer to a young person's 18th birthday[23].

This lack of resources could also be linked to local areas or services not having a transition pathway in place. For example, in its 2023 review, the National Confidential Enquiry into Patient Outcomes and Death found that healthcare transition began late because the hospital had no transition service in nearly 20% of cases[18].



Transition is not well-coordinated

The process of transition from childhood to adulthood for young people with learning disabilities involves lots of different people and organisations, including (but not limited to):

- The young person themselves
- Their family
- Education – such as schools, local authority education teams, colleges
- Healthcare – such as paediatricians, GPs, specialists, Child and Adolescent Mental Health Services (CAMHS), Adult Mental Health Services, the integrated care board
- Social care – such as local authority education teams, social workers, support workers
- Housing – such as local authority housing teams, housing providers
- Employment services – such as supported internship services or careers advice
- Department for Work & Pensions – as benefit entitlements change at 18

The research evidence shows that transition from childhood to adulthood for young people with learning disabilities is often not well-coordinated. A review of transition from children's to adult health services for young people with complex conditions, including learning disabilities, found no evidence of coordination between teams in 68% of reviewed cases[18]. A lack of coordination in the transition process is also cited by family carers of young people with learning disabilities, who describe it as one of the most significant issues during their relative's transition[24,25].

> **"I was asked questions relating to his birth, developmental milestones etc, all of which I had gone through when he was a child with children's social care. Apparently, although we were in the same local authority, information from children's services didn't transfer over to adult services."**
>
> Family carer

Why is transition poorly coordinated?

There are many organisations that need to be involved in transition planning, and these have different processes, rules, and eligibility criteria[26]. One part of this is that education, health and social care, as well as children's services and adult services (e.g. CAMHS and Adult Mental Health Services) use **different terminology and different systems**, which can make it harder to share information as part of transition, and for adult services to plan support for young people who are transitioning[27,28].

This is made worse by the fact that, while multiple people and organisations need to be involved in transition planning, there is often no one with specific responsibility for coordinating this involvement. Multiple research studies have found that **fragmented responsibility for coordinating transition results in worse outcomes for the young person**[29,30].

Young people and their families are not meaningfully involved

Despite it being a central theme in policy and guidance, young people with learning disabilities and their families are frequently excluded from transition planning[31,25,32]. Transition is often driven by 'what works for services', rather than being person-centred and looking at what matters to, and is best for, the young person[24,25,33].

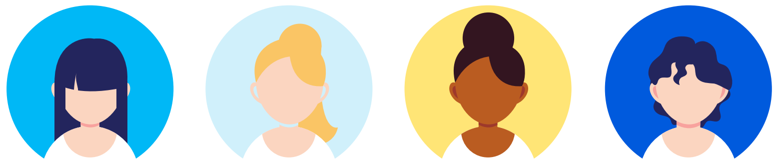
> **"Build relationships before you build timetables."**
>
> Carys, young person and member of the Kids Advisory Panel[ii]

The exclusion of families becomes particularly significant once a young person has turned 18. Compared to the more family-centred children's services, adult services focus on the individual without necessarily involving families[15]. This can be a particular issue for young people with learning disabilities, particularly young people with severe or profound and multiple learning disabilities, who may lack capacity to make some of the decisions affecting their lives. The research shows that families do not have enough information about the legal changes that take place when their relative becomes an adult, and that services do not always have enough information about mental capacity laws, which in some cases leads to poorer care[34,35].

> **"When these transitions do not involve meaningful consultation with children, are not effectively planned for, or are not properly supported, they can be disruptive and traumatic for the child or young person."**
>
> - Children's Commissioner, 2024[36]

Why are young people and their families not meaningfully involved?

Young people with severe or profound and multiple learning disabilities, who may be non-verbal or have complex communication needs, are particularly likely to be excluded from transition planning[33], for example because of the resources (both financial resources, and time) that are needed to do this. However, the fact that a young person with a learning disability has complex communication needs does not mean that their views and preferences do not matter and cannot be found out as part of transition planning. By working with the young person and those who know them well – for example, their family and people who support them – it is possible to gain an insight into what matters to them as part of transition planning[37,33].



[ii] The Kids Advisory Panel amplifies the voices, experiences and expertise of young people with special educational needs and disabilities

Some young people with learning disabilities face greater challenges during transition

While the research shows serious issues that can impact all young people with learning disabilities, it also shows that some young people with learning disabilities are particularly at risk of poor transitions.

Young people with learning disabilities who are living out-of-area (in a different local authority or integrated care system to where their home or 'original' address is) in residential schools – primarily because the support that they need is not available in their local area – can face additional barriers when transitioning to adulthood.

The geographical distance between the residential school and the teams in the young person's home area, who have responsibility for transition planning, makes it harder to 'know' the young person and to engage with them and their needs as part of transition planning[21]. It can also lead to a disconnect between local services and the young person, making it harder to identify what support is needed and what the young person's wishes are[38]. In some cases, this results in the local area waiting until the young person has left school and returned to the family home before beginning the assessment and planning process, resulting in gaps in support[21]. Residency rules (for example, for determining a local GP), can also make it harder for young people who are living out-of-area prior to or during transition to get the right support[25].

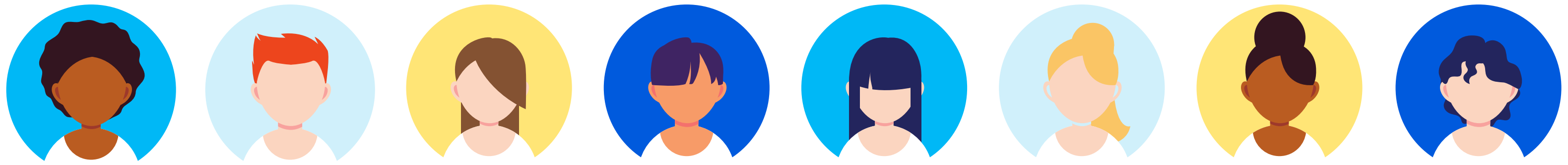
Young people with learning disabilities from minoritised ethnic groups face additional challenges during transition. For example, the poor coordination and lack of involvement of young people with learning disabilities and their families is made worse when support and services do not consider the cultural needs, religious needs, or language needs (e.g., need for an interpreter) of the young people and their families[32]. A 2013 study found that not speaking English as a first language is an additional barrier to fully participating in transition processes, with this contributing to less awareness of future options, increased difficulty taking an active role in planning, and difficulties with filling out forms to access services and benefits[39].

Stereotypes and assumptions about young people with learning disabilities from minoritised ethnic groups and their families can lead to failures to provide appropriate or person-centred support. For example, a family carer interviewed as part of the *We Deserve Better* report highlighted difficulties getting services to support or plan her son's transition to supported living because of the assumption (based on stereotypes of Asian families) that he would stay living at home permanently; however, this was not what she wanted, and no professionals had tried to find out what her son's views were[40].

4. The consequences of poor transitions

The research evidence highlights the problems with the current system. But when transition from children's services to adult services does not work effectively, it can have wide-ranging repercussions for young people with learning disabilities and their families.

> **"Laura* had a transition social worker who had just qualified and it was her first case involving a transition. The transition was worked on by all parties and during this time we visited many day services. The one we chose as most suitable for Laura agreed for her to attend but only if they had 1:1 [support for her]. At the last minute, the funding authority said no and we were no longer able to proceed. All of the hard work everyone had invested was wasted and no one listened to Laura's needs.**
>
> **We had to prove that certain options wouldn't work. The funding authority chose a day service they thought would work better and suggested that 1:1 would "suppress" Laura. The day service failed Laura as she was too challenging which left Laura at home for months whilst I fought for her to have the right support. I still believe the transition from education to adult services would have worked if Laura's needs had been taken into account. Sadly the need to prove it didn't work only caused behaviours that became irreversible for her."**
>
> Family carer
> **name changed*



Out-of-area placements

While out-of-area placements for children and young people can contribute to issues with transition planning, poor transitions can also result in young adults with learning disabilities living out-of-area following their transition to adult services.

Like many children and young people with learning disabilities who are sent to out-of-area residential schools prior to transition to adulthood, young adults with learning disabilities are often sent out-of-area or remain there following an earlier out-of-area placement because there aren't suitable services available in their local areas[41,42]. A review of people with learning disabilities in Scotland who were living in out-of-area placements found that 77% of people living out-of-area were doing so because of a lack of specialist services locally, while for a further 11%, specialist services were available locally but did not have sufficient capacity[22]. Out-of-area placements are also often more expensive[43].

77%

of people were living out of area not by choice, but because their local areas did not have specialist services locally[22]

Living out of area can have a significant impact on people with a learning disability. Being far away from their home area, including their families, friends and familiar places, can weaken these relationships, causing "real harm"[44]. Families supported by the Challenging Behaviour Foundation have shared the impact of having to travel long distances to see their relatives, including that the time taken to travel means that they are not always able to visit as much as they would like.

Alongside the impact on relationships with family, friends, and their local area, being out-of-area can also cause problems with safeguarding and oversight of support. A study by the Tizard Centre on behalf of Kent County Council found that people with learning disabilities living in Kent who were from other areas were more likely to experience multiple types of abuse in residential care settings, and to be more likely to be abused by staff than those who were originally from Kent[45]. Multiple safeguarding reviews have also highlighted that being out-of-area can put children, young people and adults with learning disabilities at risk of abuse and harm because of weaker oversight from their local area[46,47].

Health inequalities

Children, young people and adults with learning disabilities face a range of health inequalities throughout their lives.

Health issues faced by people with learning disabilities

Young people (13-24) with learning disabilities are

SIGNIFICANTLY MORE LIKELY

to experience health issues than young people without learning disabilities[48]

Children with learning disabilities are

4.5x

more likely to have a mental health problem[49]

People with learning disabilities are

2x

as likely to have a diagnosis of anxiety[50]

Adults with learning disabilities are

10x

more likely to be blind or partially sighted[51]

Young adults with learning disabilities are

2x

as likely to be obese[52]

People with more severe learning disabilities are likely to have

MORE HEALTH ISSUES

than people with milder learning disabilities[53]

In 2023,

40.2%

of deaths of people with a learning disability were avoidable – **nearly double** the general population[54]

Families we support tell us that when their relative is nearing transition, there is a 'gap' where they can no longer access children's services (or are not seen as a 'priority' because of their age) but they are not yet eligible for adult services. This gap has been known about for over 20 years[55], but has not been closed – meaning that young people with learning disabilities cannot access the physical and mental health care that they need. Alongside this gap in eligibility based on age, delays in identifying where a young person will live when they leave school can prevent them from being registered with a local GP (and therefore being able to access healthcare) because of GPs' geographical eligibility criteria[21], creating another knock-on effect on health.

This is particularly a problem for young people with learning disabilities because of their increased likelihood of physical and mental health issues which can often need long-term care.

The evidence also suggests that transition-age young people with learning disabilities are **more likely to experience mental health problems**, with a 2017 UK-wide study finding that 19–24-year-olds with learning disabilities were more likely than 13–18-year-olds to have a mental health problem[48].

Young people with learning disabilities from minoritised ethnic groups can also experience the 'double discrimination' of being disabled and being from a minoritised ethnic background[56]. A 2011 study of found higher levels of unmet healthcare need – including paediatrics, neurology, clinical psychology, speech and language therapy, occupational therapy, physiotherapy and dietetics – reported by family carers of young people with learning disabilities from South Asian backgrounds, compared to those from White backgrounds[32].

> **"Given that health in the young population with intellectual disabilities is so poor, it is crucial that transition between child and adult health services is carefully planned in order to ensure that existing health conditions continue to be managed and emerging mental health problems are minimised."**
>
> - Young-Southward et al., 2017[48]

Inpatient hospital admissions

The Transforming Care programme was set up in 2012 to address the high numbers of people with learning disabilities and autistic people in mental health hospitals – even though many did not have a mental health condition and were there because the right support wasn't available in their communities. However, progress has been slow, and too many people are still going into hospital and staying there for far too long. In April 2026, there were 2105 people with learning disabilities and/or who are autistic in hospital, and the average amount of time people had spent in hospital was 4.7 years[57].

Poor transitions to adulthood are one of the key reasons why people with learning disabilities are admitted to hospital[58]. The NICE guidance on ***Challenging behaviour and learning disabilities***[59] highlights some of the environmental factors that can increase the likelihood of behaviour that challenges, including "changes to the person's environment (for example, significant staff changes or moving to a new care setting)" and places where "staff do not have the capacity or resources to respond to people's needs". The common drop in levels of support available once a young person transitions to adulthood, disrupted continuity of care, and support arranged by adult services that doesn't meet the young person's needs can all be factors in increased behaviours that challenge, contributing to young people experiencing crisis and breakdown of their living situations. The Challenging Behaviour Foundation has supported many families where failures in transition planning led to their relative being admitted to hospital, when better planning could have avoided this.

> **"From the age of 16, conversations were instigated by his school at every annual review attended by the local authority about transitioning to adult services but nothing concrete ever came out of these discussions. In his last year I started to look at options as we were given no guidance. The school, with my support, then had to serve notice on him when he was coming up to 19 as the local authority were still showing no signs of transitioning him.**
>
> **He ended up being sent hundreds of miles away to a semi secure type unit. He was away from all of his family and although I went up every weekend to see him, he clearly found the environment very difficult. I found a placement in a supported living unit in Cornwall, a place we visit on holiday with him regularly. There was still nothing suitable in the local area at that time."**
>
> Family carer

What does the data show about transition-age people with learning disabilities and autistic people in mental health hospitals?

200 under-18s in hospital

445 18–24-year-olds in hospital

INCREASE OF 112%

More than 1 IN 5 of people with learning disabilities and autistic people in hospital are aged 18–24

NHS Digital Assuring Transformation data, published May 2026[57]

> **"For children and families, the onset of adolescence and puberty, as well as the transition period between child and adult services, was a key time when things could go wrong. These changes were often not planned for early enough, or were not successful because of a lack of a joined-up approach between local social care and education services, and families did not feel supported through these periods."**
>
> - Care Quality Commission, 2020[58]

> **"Prevention always costs less – emotionally, financially, and educationally – than crisis intervention"**
>
> Tobias, young person and member of the Kids Advisory Panel[iii]

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iii.The Kids Advisory Panel amplifies the voices, experiences and expertise of young people with special educational needs and disabilities

Impact on families

> **"The way it impacted me was quite horrific really and I ended up having a mental breakdown. There was no time to process, there was no support around me."**
>
> Lina, family carer

Research on how families of young people with learning disabilities experience transition highlights the serious negative impacts that poor transition has. Parents report that the process of transitioning from children's to adult services means that the support that they and their relative received from children's services – for example, a paediatrician who has worked with the child and family for many years and has built a positive relationship with them – falls away, leaving them to have to navigate a new set of professionals and relationships[24]. The absence of a named contact, transition coordinator, or transition navigator means that families are often placed in the position of having to bring together the different professionals and services that should be involved in transition, identify options for their relative's future, and ensure actions are taken forward – in many cases with limited information, support or guidance[60].

The consequences of this are that families feel isolated and stressed[61]. In many cases, differences in eligibility criteria and service availability means that transferring from children's services to adult services results in less support, even though support needs may not have changed (or could have become more significant). Reducing support, such as short breaks or replacement care, doesn't only impact the young person, but also has significant physical and mental health implications for their family[34,62]. In interviews, parents highlight limited access to statutory support, for example from local authorities, with families then relying on informal support including other parents[61]. Alongside these health implications, families having to act as coordinator can also lead to them having to reduce their working hours or give up work entirely – with a particular impact on single parents and mothers – which in turn increased financial hardship[34,25].

Key Message

Poor transition planning has serious consequences for the health and wellbeing of young people with learning disabilities and their families.

5. Getting transition right – how can it be done, and how do we know it works?

While young people with learning disabilities and their families face significant issues during transition to adulthood, there are steps that can be taken to address these. This section sets out what is known about good practice in transition to adulthood for young people with learning disabilities, alongside case studies that put these principles into action.

What types of transition service are there?

Models of transition services for disabled young people or young people with health conditions vary significantly between areas. Some areas have a distinct transition team (e.g. Highland Council and NHS Highland's Joint Transition Service, which covers 14–25-year-olds with disabilities). In other areas, responsibility for transition sits either within children's services or adult services. There are also examples of joint meetings or clinics that bring together children's and adult services, particularly for healthcare transitions (e.g., Royal Devon and Exeter Hospital piloted 'Pathways clinics' to transfer care for young people with complex needs from their consultant paediatrician to a consultant adult physician, which also brought together a range of other professionals including from education and social care[63]).

Evidence from people working within different local authority models of transition services suggests that having a dedicated transition team, as opposed to where transition sits within existing children's or adult services, helps facilitate multi-agency working and provide better support to young people and their families[23]. However, evaluation of different transition models is limited, and there is a need for a stronger evidence base on what models of transition service are most effective.

Overarching principles of good transitions

The research on transition identifies several key principles or factors that help make transition to adulthood better for young people with learning disabilities and their families. For example, Heslop et al. (2002) identified the 'five Cs' of a good transition experience[64]:

COMMUNICATION

Open, honest and respectful communication between agencies, and between agencies and families; young people have access to independent advocacy

COORDINATION

Different parts of the system (including education, health and social care) work together effectively, including carrying out joint assessments and having a joined-up strategic approach for ensuring that there is the right support in place

COMPREHENSIVENESS

All young people have an effective transition plan; all staff have received race and disability equality training; young people with learning disabilities have the same ability to realise their aspirations as young people without learning disabilities

CONTINUITY

Young people and their families have access to key workers throughout transition; transition from children's to adult services is seamless, with no gaps in eligibility/support

CHOICE

Young people and their families are involved in the transition process; there is access to appropriate information on potential options; young people have a range of options, including housing and employment, in their local area

Specific actions that improve transition

Starting planning for transition to adulthood early

Currently, transition planning starts too late. Because of this, young people and their families experience significant anxiety and stress, as they don't know what the future holds or what support will be in place. Late transition planning also contributes to the likelihood of the wrong support being put in place, or to gaps in support, which can lead to crisis.

> **"emergency placements cause great distress and can result in people being moved too far from family/familiar surroundings"**
>
> Family carer

However, young people, families, and professionals all highlight that starting transition planning earlier either helps, or would have helped, overcome some of the issues with transition. For example, a review of transitions to adulthood for disabled young people (the majority of whom had learning disabilities) who were in out-of-area schools found that when adult social care teams became involved in transition planning earlier (on average a year earlier than they typically would), this led to "fewer rushed or last minute placement decisions" and "a reduction in the use of interim placements"[21].

Beginning transition planning early doesn't mean that transition will be happening immediately, but it does make it possible to start thinking about what support will be needed and whether anything needs to be done to put this in place.

Starting transition planning early means that it is possible to plan in a more person-centred way and for local areas to prepare; when this doesn't happen, young people and their families are often not properly involved and the options that are available might not meet the young person's wishes or needs[65]. Young people with learning disabilities often need more time to get to know new people or situations, which makes it even more important that transitions are planned early and changes are gradual, not a 'cliff edge'[34]. Informing and involving young people and their families in transition planning – which cannot be done well, particularly for young people with more complex needs, if it is rushed – also reduces anxiety and stress[61,26].

Key Message

Make sure transition planning starts by age 14 in education, health and social care to overcome delays

Making sure transition is coordinated

> **"If someone was there supporting you and kind of guiding you through the situation, that would have really helped"**
>
> Lina, family carer

Research shows that poor coordination during transition can have serious negative impacts on young people with learning disabilities and their families.

A common theme in the literature is the need for a named transition coordinator. These can be called different things, including 'named worker' (NICE guidance), 'transition key worker', or 'transition navigator'. Transition coordinators:

- Act as the link between young people, their families, and the different practitioners involved in supporting them
- Proactively coordinate transition support
- Help the young person and their family to navigate the process of transition and the different services that should be involved
- Support and advocate for the young person

While many young people and their families have not had access to a transition coordinator, those who have had access have highlighted this as a key support during transition[24], and those who have not frequently say that they wish that a transition coordinator had been available[34,16,64]. Reasons for this include having a single point of contact and the ability to build up a longer-term relationship, as well as reducing the pressure on families to act as the coordinator[60].

> **"I had someone who would fight my corner... a safe person I could go to."**
>
> Carys, young person and member of the Kids Advisory Panel[iv]

Reviews of services or programmes where transition coordinators have been in place also show improved outcomes for young people with learning disabilities, particularly young people who need support from multiple services or who may experience greater difficulties in advocating for themselves[26,23,66]. While many of these services or programmes had other components as well as the transition coordinator, transition coordinators are often singled out as key factors in improved transitions. Professionals also highlight that having someone act as a transition coordinator is beneficial and improves transition, both for the young person and their family, but also for the different professionals involved[34,25].

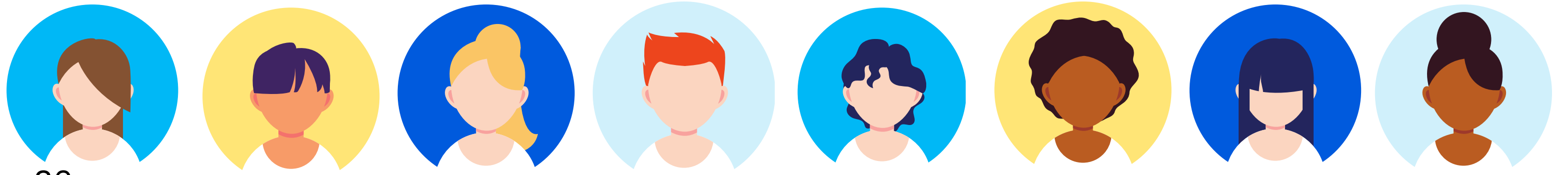
[iv] The Kids Advisory Panel amplifies the voices, experiences and expertise of young people with special educational needs and disabilities

The Real Opportunities project

The Real Opportunities Project[67] ran in 9 local authorities in Wales between 2011-2014, with the aim of improving transition to adulthood for young people (14-19) with learning disabilities and/or who were autistic. A key part of this project was the 'Transition Key Worker', who "liaised with families, provided advice and information on future options, and connected with all relevant professionals and agencies to fulfil the person's plan". The evaluation of the project's impact found that "roles such as Transition Key Worker are central to the success of a person centred approach".

Key Message

Having a transition coordinator leads to better outcomes for young people with learning disabilities and their families



Meaningfully involving young people with learning disabilities and their families

Making sure that young people and their families are fully involved in transition is extremely important, not only because of the principles of self-determination, choice and control, but also because involving young people and their families results in better outcomes[26].

> **"Buying him his own house with support from our family has proved to be the most ideal option for him. Although there have been ups and downs with his care, he is proud of his house and we are reassured that unlike previous breakdowns in care where he had to leave his home and familiar environment, he has a long-time place to stay."**
>
> Family carer

However, the research – and the experiences of families – shows that this is currently not happening enough. Young people with learning disabilities and their families should be fully involved in transition planning, and given the opportunities to share their views and shape their futures.

Young people with learning disabilities and their families can be meaningfully involved in transition planning by:

- Making sure transition planning begins early and that young people and their families are involved from as early as possible[32,60], including building a relationship with the young person and their family in advance of formal transition planning meetings[55]
- Giving clear and accessible information to the young person and their family[15,66]
- Providing support and advocacy to young people and their families, to help them to engage and make their views heard[60]
- For young people with severe or profound learning disabilities, who have little or no speech and may have complex communication needs, using a mixed-method approach of finding out background information, observations, direct engagement, and working with people who know them well to find out what is important to them[37,33]

Key Message

When young people with learning disabilities and their families are given the right information and support to be involved in transition planning, this results in better outcomes

Case Study : The Treloar Transition Team

About Treloar's:
Treloar's is a charity that provides education, therapy and care to children and young people with physical disabilities, including children and young people who also have learning disabilities. Based in Hampshire, Treloar's has a school and a college, providing education and support to children and young people aged 4-25.

Treloar Transition Team:
At Treloar's, transition is understood as a long-term, relational process rather than a single event. The Transition Team works alongside students, families and professionals from the point of entry into college through to life beyond Treloar, ensuring that preparation for adulthood is purposeful, coordinated and centred on each young person's aspirations, strengths and needs.

The Transition Team provides consistent oversight and coordination throughout a student's placement. For every student, a named transition practitioner works closely with the multidisciplinary team (MDT) to maintain a clear and up-to-date transition focus within daily practice, EHCP outcomes and annual review processes. Transition planning is live and ongoing, with clear targets embedded in learning and behaviour plans and regularly reviewed with the student. This ensures that progress towards adult outcomes, such as future living arrangements, care and support, employment or meaningful daytime opportunities, remains visible and purposeful throughout a student's time at Treloar's.

A core part of the team's role is building strong partnerships with families. Transition practitioners meet regularly with parents and carers, ensuring they understand the transition process, feel supported to navigate statutory systems, and are meaningfully involved in decision-making. Meetings are offered in advance of annual reviews to prepare families, clarify priorities and ensure that student and family views are reflected clearly in Section A of the EHCP. Where students do not yet have have an allocated social worker or Integrated Care Board (ICB) case manager, the Transition Team supports families to make referrals and engages proactively with local services. As part of Treloar's wider transition offer, the College also hosts events such as Treloar's Future Fest, which brings together students, families and external providers to explore post-college options, ask questions, and gain a clearer understanding of the pathways and support available beyond Treloar.

The Transition Team also plays a central role in multi-agency coordination. Practitioners chair and minute multidisciplinary team (MDT) meetings, coordinate assessments, and act as a consistent point of contact for education, health and social care partners. Joint meetings with social care and health commissioners are arranged at increasing frequency as students' progress through college, supporting early conversations about future provision, funding pathways and placement options. This coordinated approach helps prevent last-minute decision-making and reduces the risk of young people and families experiencing a "cliff edge" at the point of leaving college.

As students move into their later years at Treloar's, transition work becomes more intensive and forward-facing. Students and families are supported to explore potential post-college placements, with practitioners facilitating communication with providers, arranging visits where appropriate, and coordinating further assessments at Treloar's to inform placement decisions. The Team supports careful handover planning, including sharing detailed transition information, enabling receiving providers to observe students within the Treloar environment, and ensuring continuity of support and understanding.

Transition does not end on a student's final day. The Transition Team maintains contact with students and families for up to six months post-leaving, offering follow-up support, attending joint meetings if required, and assisting with information sharing to support placement stability. This continued involvement reflects Treloar's commitment to positive, sustainable outcomes beyond college.

Overall, the Treloar Transition Team provides structure, continuity and coordination across a complex landscape of services. By starting early, working collaboratively and keeping the young person and their family at the centre of planning, the team supports students to move on from Treloar's with clarity, confidence and the best possible foundations for adult life.

Eva's* story:

Attending Treloar's College as a weekly boarder enabled Eva to thrive both socially and developmentally and helped her family to see what might be possible for her as she grew in confidence and independence. Through building trusting relationships with staff and seeing first-hand the significant benefits Eva gained from interacting with her peers in a residential setting, her parents were able to explore future living options that they had not previously thought possible.

Eva and her family were supported to begin meaningful conversations about life beyond Treloar's by Eva's Student Progress Coordinator, who researched and arranged visits to a wide range of potential placements, and by attending the college transition event Future Fest. In total, the family visited 12 different potential future living options before identifying one that they felt would be the most appropriate and supportive environment for her. The Student Progress Coordinator then worked closely with the family to arrange regular transition planning meetings with Eva's ICB case worker, ensuring that all key professionals were involved and that decisions could be made collaboratively. As a result of this early planning and coordination, Eva's transition was agreed during the spring term.

This early agreement was vital in allowing sufficient time for a robust and carefully planned handover from Treloar staff to the staff at Eva's new home, including opportunities for her new support staff to shadow Eva and gain a thorough understanding of her routines, personality, preferences and support needs within a familiar environment. This approach helped to ensure continuity of care and consistency of support, significantly contributing to Eva experiencing a smooth and well-managed transition.

> ***"The work that [Treloar staff] do is outstanding, highly professional, thoughtful and they go above and beyond every day to ensure that each individual pupil's needs are met. We have had the most brilliant service from the transition team. With their help, we have got Eva into our first-choice home, and we now feel that we all have a future ahead of us."***
>
> Eva's family

*name changed

Case Study: CBF Family Support Team

About the CBF Family Support Team:

The CBF Family Support Team provides information and support to families about the needs of their relative with a severe learning disability. The team helps parents, siblings or other close relatives of children, young people or adults with severe learning disabilities who display behaviour that challenges to navigate the complex health, education and social care systems. As well as providing casework and information support, families are also able to access peer support through the CBF Family Carer Email Network, transition-related resources on the CBF website, and the CBF Podcast 'Challenge Accepted' - the third series of which focused on transition to adulthood.

Michael and Paula's story:

Paula, the mum of a 17-year-old with a severe learning disability and multiple serious gastrointestinal issues, contacted the CBF Family Support Team because her son Michael was displaying a range of behaviours that challenge and was at risk of injury. When Paula contacted the Family Support Team, she and her partner were burnt out and she was living with constant anxiety about her son's pain being triggered, causing behaviours that challenge.

At the time, Michael was under the care of the Chronic Pain Team and had a dedicated multidisciplinary team around him, but there was no clinical input to explore the links between Michael's pain, anxiety, and challenging behaviour. Michael's care was further complicated because he was on the cusp of transitioning to adult services, but poor coordination between children's and adult services left him with key gaps in support:

- Michael's local CAMHS service closed his case as they believed his behaviours were solely related to pain, not to mental health issues, but the adult community learning disability team (CLDT) said that they were unable to support Michael until he turned 18
- Referrals to specialist services like Continence, Urology, and Colorectal were refused due to age limits within children's services, although the adult Gastroenterology service accepted him
- Michael did not have access to specialist behaviour support
- There was no keyworker who could act as a liaison or coordinator of the different services that Michael needed to access

The Family Support caseworker wrote to CAMHS and the CLDT on the family's behalf, highlighting that unless they worked together, Michael would experience a gap in support until he turned 18. The caseworker also supported Paula to make a formal complaint about CAMHS's decision to close Michael's case, and helped the family to advocate for urgent, coordinated action to address Michaels's pain and self-injury at a multidisciplinary team meeting. Immediate actions identified at the multidisciplinary team meeting included input from the CLDT, specialist behaviour support, access to continence services, and the allocation of a keyworker, and a request was made for adult services to become available prior to Michael's 18th birthday as a reasonable adjustment to prevent him from falling into the gap between children's and adult services.

Michael was eventually accepted onto the Dynamic Support Register, with the assurance that a keyworker would be allocated and that he would be admitted to hospital to investigate his gastrointestinal issues – but despite these promises, treatment continued to be delayed until the Family Support caseworker helped Michael's family to escalate his case to the CEO of their local NHS Trust. Within 3 days of this escalated complaint, a learning disability nurse and occupational therapist from the CLDT visited the house and Michael was assigned a keyworker.

Michael and Paula's story highlights not only the current failures in the system – for example, the serious impacts of poor coordination on the young people who fall into a gap between children's and adult services – but also the importance of having someone who can act as a coordinator and liaison, so that young people and their families do not have to navigate the system themselves.

Family Support Service caseworker

Case Study: Ategi Shared Lives, Buckinghamshire

About Ategi:
Ategi is a charity that provides social care support, including operating Shared Lives schemes. Shared Lives schemes provide support within family homes for adults with support needs, such as learning disabilities.

They match people with trained Shared Lives carers, who share their home and family life with the individual; helping them work towards their goals and supporting them to be more independent, whilst living positively in the community. Ategi support people with a range of different disabilities, including people with severe learning disabilities and dual diagnoses.

Juliet, Charles, Bell, Chloe, Emma and Kelly's story:
Back in 2009, Juliet and Charles began the assessment process to become Shared Lives Carers with Ategi to enable them to continue supporting two foster children that had lived with them from a young age: Bell and Kelly. Both Bell and Kelly have a diagnosis of a learning disability and were assessed by the local authority to be eligible for Shared Lives arrangements. After a few months of going through the assessment process, including comprehensive training on areas such as safeguarding and mental capacity, Juliet and Charles were approved as Ategi Shared Lives Carers, and the Shared Lives arrangements for Kelly and Bell were established. Kelly and Bell were relieved to learn they could stay with Juliet and Charles, who they consider to be their parents.

Juliet and Charles have supported many other foster children, and two of these have also now transitioned over to Ategi Shared Lives arrangements. These are siblings Emma and Chloe. Emma has a diagnosis of Autism, Learning Disability and Epilepsy, and Chloe has a diagnosis of ADHD, and a Learning Disability. Ategi has supported the family throughout their journey, providing unwavering reassurance and stability against a backdrop of systemic delays and uncertainty. For example, although Emma's placement was considered a 'done deal', social services did not actually confirm her placement until the day of her 18th birthday.


Bell and Magic the rabbit


Chloe and Juliet

Ategi continue to support Juliet, Charles, and the people that they support in shared lives arrangements. They are visited regularly by an Ategi Coordinator where they can catch-up on how the arrangements are going, share any concerns they may have, as well as any positive outcomes. Juliet and Charles have an annual carer review with their allocated Coordinator and bi-annual arrangement reviews.

They are supported to complete regular Shared Lives+ modules, including Oliver McGowan training. Crucially, support does not end after a short period; it continues throughout the transition period to adulthood and beyond.

Continuing to live with Juliet and Charles after reaching adulthood has given Bell, Kelly, Emma and Chloe a safe and nurturing family environment and enabled them to live fulfilling lives in their local community, including participating in Morris dancing, self-defence, and volunteering. The four young people have continued to develop life skills, including cooking, with support from Ategi to help identify goals. In the future, Bell, Kelly, Emma and Chloe would all like some more pets to add to an already impressive collection of fish, rabbits, guinea pigs, birds, a dog and a tortoise, and Emma is looking forward to visiting Wales again.


Juliet, Emma and Kelly

“Having been a foster carer with my husband for many years, I suddenly realised that the young people we cared for as our family for a long time would have to move on. I thought it was very important to think of the future of Bell, Kelly, Emma and Chloe. However, they were extremely upset about the thought of moving on to a different home and leaving the family that they lived in for so many years happily. Leaving foster care can be very daunting especially when you're looking for a new place to call home. They had all had extremely difficult childhoods causing a huge amount of both physical damage, trauma, and mental health issues; to just tell them to leave would have been a nightmare. My husband and I were not willing to accept this, as it was so important that they felt safe and secure, and that their deep needs had to be met and understood.

After a great deal of research and thought, I decided to ask for help to look around, as it was all new to me, and just to see what possibilities were available. They had been part of our family for a long time.

We wanted to create a sense of security and understanding, which was so crucial for them. It's not just giving them a home; it's building trust and sense of belonging. I researched several companies and met with them to see how they could support Bell, Kelly, Emma and Chloe. I found this very difficult as I knew their needs very well, and I had to ensure that their needs were met. After interviews with several companies, I began to feel agitated and very worried, but on my last meeting with a company called Ategi Shared Lives, I felt a feeling of warmth and kindness, plus hope. They showed to be extremely professional and kind and thoughtful. This was what I was looking for.

We both knew that we wanted them to stay with us as our family, and the help Ategi offered was amazing: someone to offer good sound advice and always be available if needed.

Bell, Kelly, Emma and Chloe warmed to Ategi immediately and happily we all settled down into a comfortable environment. We understood the importance of sharing our lives and were joined by an assistant dog, which has helped us come through all of our problems and help them settle down again.

We are so pleased to have gone forward with Bell, Kelly, Emma and Chloe, and to see them progress. They are our family and we enjoy every day – thank goodness we found Ategi Shared lives. Ategi works with us, not against us. Bell, Kelly, Emma and Chloe speak highly of Ategi and it’s very important to them: it has changed their lives and given them hope.”

Juliet

6. Recommendations

1 Improve joint working by introducing a **national, cross-departmental plan for transition, co-produced by young people with learning disabilities and their families**

Transition is disjointed, with different parts of the system working in different ways and to different timescales. Beyond this, the fact that transition needs to cover so many different parts of the system – including health, education, social care and housing – as well as children's and adult services, means it isn't clear who has overall responsibility for transition policy.

A national, cross-departmental plan for transition – which should at a minimum involve the **Department for Education**, the **Department of Health and Social Care**, and the **Ministry of Housing, Communities and Local Government** – is needed to make sure that there is a united approach to transition across these different parts of the system. The plan should be co-produced by young people with learning disabilities and their families, so that their voices and experiences are at the centre.

2 Make sure all young people and their families have access to a **named transition coordinator**

The overwhelming evidence is that families are having to take on the role of coordinating their child's transition to adulthood without support or information and alongside many other caring responsibilities – with serious impacts on their health and wellbeing. A named transition coordinator would not only improve outcomes for young people and their families by bringing all of the different parts of the system together, but would also reduce this pressure on families.

3 Introduce a **statutory age of 14 to begin transition planning**

Currently, transition planning starts too late. In its recent review of disabled children's social care, the Law Commission recommended that the Care Act 2014 should be amended so that there is a statutory duty that planning for transition to adult social care must begin by the time a young disabled person is 14. As the evidence in this report shows, when transition planning begins late, this doesn't just cause stress for the young person and their family but also means that adult services are not sufficiently ready to support the young person – which results in inappropriate services and gaps in support. A statutory age of 14 would mean that local authorities would be better able to identify young people who will be making the transition to adulthood, assess their needs, and ensure that the right support is available for when they become adults.

4 **Strengthen the evidence base for 'what works'** in transition for young people with learning disabilities

Ten years on from NICE first highlighting the lack of evidence about 'what works' in transition, there is still a very limited evidence base of successful approaches to supporting young people with learning disabilities during transition to adulthood in England. To build a better evidence base and to provide models of 'what works', research should be taken forward and transition services and approaches should be evaluated to show what the short and long-term impacts on young people with learning disabilities and their families are, and which provide the best outcomes.

5 **Address the increased inequalities** faced by young people with learning disabilities from minoritised ethnic groups

The intersection of disability and ethnicity, and the 'double discrimination' caused by this, means that young people with learning disabilities from minoritised ethnic groups face additional challenges during transition. There should be a specific focus on addressing these barriers.

Opportunities to improve transition

Improving young people's experiences of the transition to adulthood will require coordinated action, but there are several proposed and ongoing systemic shifts that could support this:

- The Independent Commission on Adult Social Care led by Baroness Casey will be looking at how social care should be structured and what a National Care System should be – thinking about how disabled young people enter the adult social care system and the interaction between children's and adult services should be a key part of this.
- Reforms to education and the SEND system should include a focus on supporting transitions to adulthood for young people with learning disabilities, including the role of the education system in facilitating successful transitions.
- Reforms to the health system, in line with the 10 Year Health Plan and NHS England's functions being moved to the Department of Health and Social Care, are an opportunity to think about how health and social care works, including for young people with learning disabilities. The move to neighbourhood health is a particular opportunity to think about how health services should be structured and provided, including better ways of supporting young people as they transition to adulthood.

7. Conclusion

Transition from childhood to adulthood is a complicated time for all young people, but for young people with learning disabilities, there are additional barriers that can make it even harder. While there are many policies and pieces of guidance out there that are meant to make transition smooth and seamless, the reality for young people with learning disabilities and their families is that this is not yet happening in practice.

This report brings together evidence about what transition is currently like for young people with learning disabilities and their families – the problems they face, the impact that this has on them, and what things can make this better. The *Getting Transition Right* section includes examples of ways that people and organisations have worked to overcome common issues with transition, so that young people with learning disabilities and their families have a smoother transition with better support, that others can learn from.

The recommendations build on the evidence and these examples of practice to set out actions that Government should take. We urge the Government to act on these recommendations, so that they can make a real difference to the lives of young people with learning disabilities who are going through transition to adulthood.

Call to action

“The process of care and support planning for transition to adulthood comes at a time when a lot of change takes place in a young person's life. Well-managed transitions cannot prevent all of this disruption, but can reassure people and their families that there is continuity in their support, based on a shared understanding of their care needs and what matters to them as individuals.

Effective and early person-centred transition planning is essential to help young people and their families prepare for adulthood. However, instead, even if transition assessments are completed, they are often not implemented or are “trimmed” without any consultation in order to prioritise solely the cost of support. Basic key information – such as how to contact new teams, and when they will visit – are not always clearly communicated to the person or their family in advance of their move.

High level strategic leadership, commitment and coordination are vital to bring about change. Across the local authority there needs to be leadership and commitment to a whole family approach, with protocols in place across a wide range of local partnerships to enable services to be coordinated and responsive to the needs of young people and carers in their transition to adulthood.

Implementation of the recommendations in this report is vital to prevent any further decline of our children’s lives. Like many families who care for a child with a severe learning disability we struggle to get through the week, so thinking beyond the present day or having time to research and navigate the next steps is really challenging.

I would like to see leaders shift the focus on to four key outcomes:

- Family, friends, relationship and community
- Living arrangements
- Good health
- What makes the person happy and how they want to spend their time

Young people with a learning disability don’t transition to a service, they transition to a life. The services should be there, at the right time, to support their transition; ending the predominately poor transition experience, and bringing everyone involved on the same page and thinking about what really needs to happen.”

Oana, family carer

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