

CB-NSG November 2025 – Transition to Adulthood

Summary of workshop discussion and agreed actions

Discussion

“I find it confusing and frustrating, and I’m a professional working within the service.”

What are the barriers to smooth, effective, and person-centred transitions from children’s to adult services?

1. Use of different systems in children’s and adult services, and between e.g., NHS and social care

Attendees highlighted that often different computer systems are used by a) children’s and adult services, and b) health, social care, education, and other (e.g., housing) services. This prevents information about the young person/their family being shared/exported/accessed easily and quickly by different services.

The impact of this is that pressure is put on families, who are repeatedly asked the same questions about their relative. Attendees raised that this can contribute to the trauma that young people with learning disabilities and their families experience.

“I find that really frustrating because I don’t like asking people the same questions all the time, but sometimes you have to do it because the information is lost or you can’t find it.”

“I’d have really interesting experiences meeting parents for the first time and saying, so, tell me about this person, and you’d just see them sigh and know that they’d had to do that speech and explain the situation to 30 other professionals before.”

A similar issue is that children’s and adult services can use different eligibility criteria. An example given was that adult mental health services often have different (tighter) criteria for accessing support than child and adolescent mental health services (CAMHS), meaning that young people who had previously received support from CAMHS were not transitioning over to adult mental health services.

2. Transition processes not beginning early enough

“We might do a brief assessment at 16, 17, but then they tend to go on a waiting list to be picked up by someone, and sometimes that’s not until they’re 18 or unless there’s a need. So I think we’ve had several cases come through as a crisis and they’ve

already turned 18 because they've got no package and they're at home and their education package finished, they've got no social care package and they are just at home with family, and then they come in as a crisis."

Attendees stated that, from their experiences, transition planning is not beginning early enough. It was felt that 14 should be the absolute latest that transition planning should begin, which aligns with the recommendation made by the Law Commission in their review of disabled children's social care.

When transition planning begins too late, the impact on the young person and their family is significant. If this delay results in a package of support not being put in place in a timely manner, then the young person/their family care can experience a crisis – if this occurs, attendees highlighted that usual interventions, such as behavioural support plans, can be less effective or insufficient (due to the young person/their family already being in crisis, whereas these interventions are designed to provide support that helps to prevent a crisis from occurring in the first place). Consequently, more restrictive measures such as medication or a change of placement are being used, when this could have been avoided had planning taken place earlier.

One serious impact of delays to transition planning raised by attendees is that young people (18-25) are overrepresented in inpatient services.¹ It was suggested that this is particularly the case for young people who had previously been in out-of-area residential schools.

3. Systemic inflexibility

Attendees shared experiences where systemic inflexibility prevented young people from receiving person-centred support, even in cases where their health was at risk. Young people on the cusp of turning 18 were highlighted as being at particular risk of falling between the gaps of children's and adult services – this is because, if the (health) issue cannot be resolved quickly, children's services (particularly if they are under pressure) often do not see the point in opening a case when the young person is likely to stop being eligible to receive support from them before the issue is resolved, while adult services are unable to take on cases where the young person is not yet 18.

"[A young person] had lots of people involved in the MDT and people who wanted to do things, but the system just didn't let them do the things that they wanted to do. You

¹ As of November 2025, people aged 18-24 made up nearly a quarter of adults with a learning disability and/or who are autistic in inpatient units (435/1820, 23.9%) [Statistics on people with a learning disability and autistic people in mental health hospitals from Assuring Transformation: Data tables - NHS England Digital](#)

know, the adult’s system wouldn’t let them start working with the person until they were 18, and he was 17, so he had a few months to go, and CAMHS weren’t really seeing him as a priority.”

As well as inflexibility relating to age, attendees also highlighted a lack of flexibility around the kinds of support that young people can receive, and where/how it is provided. Attendees stated that there can be a “black and white” mentality when local authorities are planning where a young person receives support, with parents put in the position of deciding whether they want their young person to live with them all the time, or away from them all the time, instead of considering whether it would be possible to provide some support in the family home and some support outside the family home.

Related to this, attendees also highlighted inflexibility around young people’s access to respite. Respite was given as an example of support that can help transitions go smoothly, but attendees shared that some respite providers are reluctant for a young person’s regular support workers to accompany them to the respite location, even when this continuity of care would benefit the young person (for example, if the young person has complex needs and/or behaviour described as challenging). Being flexible about what ‘counts’ as respite can also help – an example was given of someone who, because ‘standard’ respite would not meet their needs, is supported by their regular support workers to stay in an accessible caravan. This meets their needs, and the needs of their family carer(s), and has enabled this person’s living situation to remain stable and supportive; however, when this has been shared with other local authorities as an example of how other specific individuals could be supported more creatively, there has been pushback along of the lines of “not being a holiday provider”.

4. Lack of health/social care involvement

While noting that attendees in these workshops are not necessarily a representative sample, some attendees shared their experiences that health and social care are less involved in transition planning than education. These attendees also drew comparisons to EHCPs being primarily led by education professionals with limited input/engagement from health and social care.

What is needed to ensure that transition from children’s to adult services goes more smoothly?

1. Named transition lead

Attendees agreed that having a specific, named person who can act as a transition lead would:

- a) Reduce the pressure on families of having to coordinate their relative’s transition from children’s to adult services (on top of caring for them);
- b) Facilitate communication between different professionals, and between these professionals and the family; and
- c) Improve information retention and sharing

Attendees highlighted that there are people who currently carry out similar roles, for example pastoral care/family liaison officers – however, it was raised that in many cases this role is attached to a school, with the young person/their family losing access to this once they leave the school. Attendees also highlighted high levels of turnover in advocacy roles which, without strong handover processes, can result in the knowledge and relationship that has been built up being lost.

“I know that there are some fantastic advocates for young people, both in the teaching support they’re getting and from the local authorities, but there’s also a high level of attrition there. And those people can suddenly just disappear and the relationship they built up and information sharing just evaporates.”

Concerns were also raised that having a transition lead that is too closely aligned with one of either education, health and social care could make it difficult to bring all parties to the table and create a holistic and person-centred transition plan.

This transition lead should therefore **bridge the gap between children’s services and adult services by continuing to work with the young person and their family after their 18th birthday** to ensure that the transition is going smoothly. They should also have **sufficient knowledge of education, health, and social care to be able to draw all the parts of the system together.**

2. Access to respite

Alongside **agreeing with the Law Commission’s recommendation that transition planning should begin by 14** at the latest, attendees suggested that access to respite could support young people with transitioning to adulthood. Respite not only provides young people and their families with additional support (including a break from caring responsibilities), but also provides an opportunity for young people with complex needs to experience being supported in different locations and/or by someone who is not their family carer; it was suggested that this could help prepare the young person for future transitions.

Working together to improve transition to adulthood – Actions

Existing information and support for young people with learning disabilities whose behaviour challenges and their families

Attendees struggled to find examples to share. It was felt that this exemplified the issues with transition from children's to adult services. Attendees did however identify that good practice looks like **regular meetings, open communication** from the beginning of the process, and **being flexible**.

Key systemic issue(s) that need to be tackled by the CB-NSG and other partners in relation to transition

Attendees identified **the disconnect between different parts of the system – lack of communication, use of different processes and systems, poor coordination, and disagreements over responsibility for paying** (rather than putting the needs of the young person and their family first) – as the key issue that needs to be addressed.

Practical solutions which could be implemented in the short-term to make a difference

Attendees identified:

- a) **Using the same computer systems/recording processes**, so that information can be identified and shared more easily
- b) Being willing to **think outside the box**, and in particular, to **take risks** where these may significantly improve a young person's quality of life

Thank you to Gemma Harpum (CBF), Heather Harper (Kids) and Charles Mollet (Kids) for facilitating this workshop, and to all attendees for their contributions.