

Transition to adulthood for young people with learning disabilities whose behaviour challenges: suggested areas for research

This paper has been compiled following a workshop at the July 2026 Challenging Behaviour – National Strategy Group meeting, ‘Supporting good transitions through life’.

The workshop included family carers, academics, and a range of professionals, who identified areas relating to transition where further research could improve outcomes for young people with learning disabilities whose behaviour challenges and their families.

This paper will be distributed to relevant stakeholders, including academics and research funding bodies.

Specific areas of existing transition practice where further evidence would be useful

Transition coordinators/transition liaison officers in schools

- Transition liaison officer role: provides information about options and legal frameworks, coordinates, provides advocacy for young person and family
- What we need to know: **(how) do outcomes improve if a transition coordinator/transition liaison officer is in place?**
- Related questions: **a) what skills should a transition coordinator/transition liaison officer have?; b) what factors and qualities make a transition workforce effective?**

Providing information to young people and their families about options

- What we need to know: **a) does this improve outcomes for the young person?; b) does this improve the wellbeing of families?**
- Related questions: **a) are there/what are the benefits of meaningfully involving families in transition planning?** (hypothesis – family-led transitions are more successful); **b) what are outcomes like for young people with learning disabilities whose behaviour challenges whose families are unable/less able to advocate for them?**

Economic case

Costing the care provided by families of young people (14-25) with learning disabilities whose behaviour challenges

- Families provide a significant amount of support for their relative, but as the young person grows older and transitions into adulthood, the amount of external support received (e.g., respite/short breaks) can reduce
- Families of young people without learning disabilities whose behaviour challenges would expect that, as their relative approaches adulthood, they would need to provide less hands-on support, but this is not the case for families of young people with (e.g., severe) learning disabilities
- Families frequently request some external support to enable them to continue caring for their relative, but this is often refused on grounds of funding – however, compared to the cost of e.g. an inpatient unit, the cost of providing some additional external support which enabled a family to continue caring for their relative may be negligible
- There is an overall estimate of how much carers save the economy, and there are estimates for the value of care provided by family carers of people with other disabilities or health conditions, but there is not an estimate for the value of support provided by family carers of people with severe learning disabilities
- What we need to know: **what is the economic value of the support provided by family carers of young people (14-25) with learning disabilities whose behaviour challenges?**
 - **How does this compare to the value of care provided by family carers of people with other disabilities and/or health conditions?**
 - **How does this compare to the cost of e.g., residential care, inpatient hospital bed, shared lives schemes?**
- Why this would be useful:
 1. Would enable the value of this support (and the absence were it to stop being provided) to be factored into e.g., social care funding decisions
 2. Would increase recognition of how much support family carers provide, improving esteem
- Complementary research: **qualitative research into what support families say they would need to continue providing support to their relative** (which could then be compared to the amount that families are saving the state and the cost of other kinds of care)

Personal Health Budgets

- What we need to know: **does providing a flexible personal health budget result in improved outcomes for a) the young person and b) their family?**

Improving understanding of transition(s)

Mapping the transitions that children, young people and adults with learning disabilities and their families go through in life

- What we need to know: **a) what types of transition are there?; b) are any of these transitions ‘more successful’ or ‘less successful’ than others (and if so, what factors affect this)?**

What do people understand transition to be?

- People have different concepts of what ‘transition’ is
- This can make it harder to talk about transition as it is understood as different things
- What we need to know: **what does transition mean to a) young people with learning disabilities, b) families, c) different professionals and practitioners? (preference: qualitative research)**

Young people with learning disabilities whose behaviour challenges in residential schools

- Previous research on experiences of transition for young people in residential schools has been carried out (e.g., Beresford and Cavet, 2009; Heslop and Abbott, 2008)
- The above research identified particular issues for young people in out-of-area residential schools – however, there have been subsequent reforms to education and social care (e.g., Children and Families Act 2014, Care Act 2014, Special Educational Needs and Disability Regulations 2014) which could have had an impact on the experiences and outcomes of young people in the years since
- A 2024 study found that being in a residential school was more likely to lead to out-of-area placement in adulthood, and that people with severe learning

disabilities and/or behaviours that challenge were particularly likely to be placed out-of-area following residential school (Tomlinson et al., 2024)

- However, attendees highlighted that there was still insufficient information about the transition experiences of those in residential schools, and in particular about the quality of support these young people receive following transition – this was also identified by Tomlinson et al. (2024) as an area where further research was needed
- What we need to know: **what is support like for young people who have transitioned out of residential school?**

Tackling (systems-generated) trauma and parent-carer blame

Understanding the impact of trauma

- Families and professionals highlighted the impact of trauma on young people with learning disabilities and their families
- Trauma from e.g., past abuse or past poor experiences could impact on transition by decreasing trust in professionals, increasing the needs of the young person, etc
- Poor transitions could also cause trauma for the young person and their family, e.g., through inappropriate support, trauma of having to navigate complicated systems alone, impact of cancelled meetings, etc
- What we need to know: **a) are transition processes traumatic for young people with learning disabilities/their families, and if so, what does this look like?; b) what things can be done to decrease trauma during the transition process?; c) what is the impact of trauma training for e.g., staff, the transition workforce? (e.g., does this improve experiences and/or outcomes for the young person and their family); d) what helps people to recover from trauma?**

Other

Finding out what is important to young people with learning disabilities whose behaviour challenges

- Based on frequent lack of involvement of young people with learning disabilities in their own transition planning (in particular, young people with severe or profound and multiple learning disabilities and/or who are non-verbal), attendees raised importance of finding out what is important to the young person, not just what is important for the young person, during transition

- What we need to know: **what are the best ways of engaging young people with severe or profound and multiple learning disabilities and/or who are non-verbal during transition planning?**¹

What increases wellbeing for young people with severe or profound and multiple learning disabilities whose behaviour challenges?

- Good support should increase the young person's wellbeing
- What we need to know: **what approaches and/or activities are most effective at increasing wellbeing for young people with severe or profound and multiple learning disabilities?**
- Related question: **is there a difference in outcomes for young people and families when approaches are e.g., relational vs deficit-led?** (note: this would involve defining what is meant by these approaches)

What impact does the language used about young people and their families have on the support they receive?

- What we need to know: **a) does the language (e.g. 'difficult', 'demanding') that is used to describe young people with learning disabilities whose behaviour challenges and their families have an impact on the support that they receive?; b) does the use of language by/to professionals and practitioners have an impact on their compassion/empathy towards young people with learning disabilities whose behaviour challenges and their families?**

¹ The [What Matters to Me](#) project engaged with several young people with severe or profound and multiple learning disabilities and complex communication needs. As part of this project, findings relating to what was important to them during transition were identified. The upcoming 'Making It Matter: no voice but a lot to say' project may provide an opportunity to identify further ways to engage with young people.