

Written Evidence submitted by United Kingdom Acquired Brain Injury Forum (TRN0045]

United Kingdom Acquired Brain Injury Forum (UKABIF) & National ABI in Education and Learning Syndicate (N-ABLES) The transition from child to adult health and social care services | May 2026

Introduction

This is a response to the Health and Social Care Committee Expert Panel's investigation into the transition from child to adult health and social care services, on behalf of the *United Kingdom Acquired Brain Injury Forum* (UKABIF) and the *National ABI in Education and Learning Syndicate* (N-ABLES).

N-ABLES was set up, with support from UKABIF, in response to recommendations made in the All-Party Parliamentary Group for ABI's *Time for Change* report. The report pointed to a widespread lack of education about ABI for education professionals, and highlighted problems in identifying the specific educational support needs of brain injured individuals and a lack of liaison between health and education professionals.

Our response focuses specifically on young people with ABI because acquired brain injury poses distinct challenges to the transition from child to adult services – both in terms of the lack of awareness and appropriate, specialist support across the system, and by the very nature of how ABI can impact young people's developmental trajectories and executive function.

Response to Questions

Focus Area	Theme	Question	Answer
1: Timeliness and Pace of the Transition to Adult Services	Effectiveness and implementation	1: How do services identify those who will need to transition to adult services, and what	There is a no national measurement of data relating to Children and Young People with ABI, which presents a fundamental problem for services in identifying those who will require transition.

		proportion start transition planning in year 9? How is this monitored?	There has historically been very little understanding of paediatric ABI, and it is a hidden condition. However, current research indicates that 1 in 37 children have had a hospital admission for a probable illness or injury likely to cause ABI before the age of 18; and 1 in 117 for a definite illness or injury likely to cause ABI before the age of 18 (<i>Kent et al., under review</i>). There is a lack of services - rehabilitation services are patchy and even more so for the paediatric population. Too often, CYP with ABI are missed entirely and therefore do not transition to adult services.
1: Timeliness and Pace of the Transition to Adult Services	Effectiveness and implementation	2: To what extent are transfers from child to adult services managed without gaps in provision? How is this monitored?	Across the country there is a postcode lottery of provision for people with acquired brain injury (<i>APPG for ABI & UKABIF, 2025</i>). Often, there are no appropriate adult services to refer and transition CYP with ABI to. As above, the lack of national data in relation to ABI makes it difficult to monitor the implementation and effectiveness of transition. There is no national monitoring database for children with ABIs.
1: Timeliness and Pace of the Transition to Adult Services	Appropriateness	1: How appropriate are the current expectations on the timeliness and pace of the transition at both the individual and service level?	There is a systemic lack of awareness and understanding of acquired brain injury, including the impact of executive function issues and developmental trajectories for CYP with ABI, which affects the appropriateness of expectations on the timeliness and pace of transition. In relation to executive function, the frontal lobe paradox (a mismatch between what a person is able to explain in a structured, supported situation versus what they are actually capable of doing unsupported in day-to-day life) is not well understood amongst professionals who are not ABI specialists. The dynamic impact of an ABI on a developing brain also differentiates ABIs from other conditions. After childhood ABI, it can be extremely challenging to predict a young person's trajectory

			because of the delicate balance between plasticity and vulnerability within a child's brain, as well as the impact of external and environmental factors on recovery (<i>Bennett, Watson & Costello, 2022</i>). For many young people, acquired needs are initially subtle or hidden, but there is a risk that they will 'grow into' new difficulties as they transition into adult services. At the point of transition, it may not yet be clear which skills will emerge as expected and which may be delayed or challenged. Over time, ABIs can show a 'neurocognitive stall' (<i>Chapman, 2006</i>) which means that difficulties may become more expressed as development continues (often several years after the initial injury). At key stages of neurological development, which often co-occur with ages at which transitions happen, difficulties may become more pronounced as young people fail to meet ongoing developmental milestones (<i>Ylvisaker & Feeney, 2002</i>). Services currently lack the awareness and understanding of ABI to appropriately adapt the timelines and pace of transition for many young people with ABI.
2: Effectiveness of The Transition Process and Cross-Service Coordination	Impact Outcomes and	3: Is there available data demonstrating the proportion of young people who are transitioned to primary care management, for example where there is no specific adult service, or they do not meet the requirements for adult services.	There is a no national measurement of data relating to CYP with ABI, and no data on the proportion of young people with ABI who are transitioned to primary care management where there are no appropriate adult services. Given what is known about the complexity of predicting developmental trajectories for young people with ABI, without robust data collected to track and monitor this group, there is a significant risk that young people with ABI who do not initially meet the requirements for adult services may miss out on transition to those services if their needs later change, or where they have not met the criteria for paediatric services and their needs then emerge or their

			needs are misinterpreted.
2: Effectiveness of The Transition Process and Cross-Service Coordination	Appropriateness	1: Are the current guidelines and guidance in this area appropriate for children and young people, and for the health and social care professionals involved?	No – while current guidance, such as NICE NG43, emphasises a person-centred approach, the lack of awareness and understanding of acquired brain injury across health and social care means that services and professionals struggle to adapt transition planning appropriately for young people with ABI.
4: Workforce and Training	Effectiveness and Implementation	2: How are staff trained to effectively support young people through the transition from child to adult health and social care? What is the standard training offer – is this available to all, and how is this different for	There is currently no mandatory national training on acquired brain injury for non-specialist health and social care professionals working with people with ABI. Training for social workers has been developed through the NIHR-funded Heads Together Brain Injury Social Work Education Platform, and this could be incorporated as a core, mandatory element of social work education.
4: Workforce and Training	Appropriateness	1: Is the level of training and education provided to staff appropriate to the needs of young people at the point of transition.	No – awareness and understanding of the needs of young people with ABI are currently missing from standard training and education provided to staff in health and social care.
5: Enabling Developmentally Appropriate Independence	Impact and Outcomes	2: Across education and employment, community inclusion, health and wellbeing, independent living and housing options, are there areas which	ABI is fundamentally absent from most existing guidance across all services. In education, there is no mandatory training for teachers or SENCOs on ABI. Understanding of ABI across health and social care services is very limited and there is no mandatory training to improve this situation.

		require more or better guidance to enable effective transition?	Homelessness and vulnerability are very high in this population and without a full understanding of ABI these young people are at higher risk.
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