

Acquired brain injury: A 'hidden' condition schools need to know about

Dr Emily Bennett, Consultant Clinical Psychologist & Dr Gemma Costello, Educational Psychologist, from the National ABI in Learning in Education Forum (N-ABLES)

Over 40,000 children and young people (CYP) in the UK experience some kind of acquired brain injury (ABI) every year (NHS England, 2018). The majority of these will return to the school they attended before their injury or illness, and most will rely on school to play a core role in supporting their rehabilitation and adjustment. Despite this, many teachers and SENCOs report to knowing little about ABI, and schools frequently feel unprepared and ill-informed to manage the new needs presented by a child returning to school after an ABI.

What is an ABI and how does it impact on a CYP's education?

An ABI is an injury to the brain that is acquired after a period of typical development. ABI is identified as the leading cause of death and disability in childhood and can be the result of accident/trauma, infection, illness, stroke, tumour or hypoxic events to the brain. ABIs can range from mild (e.g. concussion) to severe, with the subsequent need for support in school ranging from simple adaptations in the weeks after an injury, to long-term individual support or changes in school placement. Outcomes can impact on children across all domains; changes in behaviour and emotions are common, as are cognitive, physical and sensory difficulties. Many CYP also experience high levels of fatigue; and changes in their social skills and communication.

After an ABI, CYP and their families are often faced with the challenge of adjusting to a 'new normal' in many areas of their lives. Returning to their education setting is frequently cited as one of the most difficult aspects, with many CYP finding school both familiar, yet completely different. Within school or college, childhood ABI can have a significant impact on attendance (Leo et al., 2017), integration, engagement and achievement (Sariaslan et al, 2016). It is also reported that fewer CYP with ABI go on to further study or employment and many report to feeling socially isolated and unable to participate fully in school and in leisure activities.

The nature of ABI means there is the potential for difficulties to be hidden, cumulative and evolving (e.g. Anderson et al., 2011). Educators should be aware that new needs can emerge as the brain develops across childhood; an 8-year-old in a small primary school might present very differently to the same child aged 12 in a busy secondary. Emerging difficulties in executive function, attention and behaviour are common, but also represent changes frequently misinterpreted by school, which may not be linked back to the earlier injury.

So presumably teachers know all about childhood ABI?

Unfortunately not! In fact, clinical and research evidence suggest the opposite is the case. At present in the UK, teachers rarely receive any training about ABI either pre or post qualification. It is unsurprising, therefore, that research indicates the understanding of brain injury amongst educators is poor (Linden et al., 2013; Ettl et al., 2016). SENCOs too have been reported to have little knowledge of brain injury, often holding misconceptions about ABI, and claiming to have had little, if any, training (Howe and Ball, 2017; Bennett, Woolf & Thomas, 2019). A recent study of SENCOs in Nottinghamshire found a significant gap in training was indicated by the majority of those participating in the study. Content analysis of responses was used to identify suggestions for a training programme on childhood ABI. SENCOs felt this should cover what an ABI is and how it impacts on development, classroom strategies, and signposting to resources.

What is the impact of this knowledge gap?

ABI is not mentioned within the Special Educational Needs Code of Practice, and nor is it addressed in initial teacher training programmes. Where ABI is not identified or is misinterpreted, CYP are at increased risk of exclusion, disengagement, and failure to meet their potential. YP with a history of ABI are over-represented in alternative provision, as well as the criminal justice system (Williams et al., 2010, Hughes et al., 2015).

As people leave hospital/treatment settings and return to their familiar and everyday activities they form a better understanding of how changes in their abilities affect their everyday functioning (Turner, Fleming, Ownsworth & Cornwell, 2011). Because so much of a CYP's rehabilitation after brain injury effectively happens at school, a lack of understanding of ABI in the setting can have a significant impact on outcomes.

Concerningly, teachers also report that information about a CYP's ABI is "often not transferred from class to class, teacher to teacher, school to school (Hawley et al., 2002). As a result, there is a risk the CYP gets lost within the system and does not receive the support necessary. Indeed, SENCOs in Nottinghamshire (Bennett et al., 2019) reported to finding it hard (20% said it was 'difficult' and 40% 'extremely difficult') to obtain funding for a child with ABI due to their limited understanding of the impact and ongoing needs, and the lack of awareness of ABI in the wider education and Local Education Authority systems. Families and CYP often articulate the importance of school staff and peers understanding their needs and having the capacity to respond to them in a timely manner, they often acknowledge the challenge this presents to an education system that isn't always resourced to be able to meet a sudden change in needs.

Schools as rehab settings

Despite the challenges acknowledged above, school is arguably the primary provider of ongoing rehabilitation for CYP with ABI. A review of YP's goals in community-based rehabilitation has highlighted the importance of activity and participation, with the majority of YP highlighting the return, reintegration and sense of belonging to their school and peer group, as their primary focus (McCarron et al., 2019).

Schools provide the optimal environment for supporting everyday rehabilitation goals and there is a lot they can do to help. Firstly supporting the CYP to be held in mind during any hospital admission or time away from school can reassure them that staff and peers are holding them in mind and maintains their sense of belonging.

Effective transition to school has been linked to increasing the likelihood of young people staying in education (Todis & Glang, 2008) which, in turn, is likely to positively influence future outcomes and quality of life. An effective transition can be facilitated through attending hospital discharge planning meetings; liaising with professionals, the family and YP, who will all be able to share their understanding of the things that remain meaningful to the young person and to answer any questions you might have about their acquired needs.

The impact of cognitive fatigue on learning and engagement, can be profound if not managed effectively. It is crucial schools develop a transition plan/timetable that considers the cognitive demands of activities and allows for periods of rest and recovery. Processing information at speed can be often be a significant issue for many CYP following ABI; giving them the opportunity to have time to process is particularly important. It can also be helpful to reduce non-essential tasks (e.g. copying of information) to allow them to focus on the core information CYP need to learn.

When developing intervention plans in school it is crucial to monitor their effectiveness over time. Ensuring handover from teacher to teacher, school to school, ensuring that needs and goals are supported as they change or emerge over time.

Teachers and SENCOs can learn more about ABI through a range of excellent resources that are available:

- The Child Brain Injury Trust (CBIT): www.childbraininjurytrust.org.uk/ produce a range of resources and offer training courses (supported by the Eden Dora Trust) for teachers
- NASEN and CBIT publication for teaching professionals: <https://childbraininjurytrust.org.uk/wp-content/uploads/2018/11/ABI-Mini-Guide.pdf>
- The Children's Trust: <https://www.braininjuryhub.co.uk/information-library/return-to-education>
- The Stroke Association: <https://www.stroke.org.uk/resources/supporting-children-after-stroke-toolkit-teachers-and-childcare-professionals>
- The Brain Tumour Charity: <https://www.thebraintumourcharity.org/get-support/children-and-families-service/education-resources/>
- A teacher's guide for CYPs with brain tumours: <https://www.cerebra.org.uk/wp-content/uploads/delightful-downloads/2018/09/Returning-to-school-2015-revised-InDesign.pdf>
- The Encephalitis Society: <https://www.encephalitis.info/Pages/Category/encephalitis-in-children>

References

- Anderson V, Spencer-Smith M, Wood A. (2011). Do children really recover better? Neurobehavioural plasticity after early brain insult. *Brain*, 22;134(8):2197-221.
- Bennett, E., Woolf, E., & Thomas, S. (2019). SENCOs' knowledge of Acquired Brain Injury. (In submission).
- Ettel, D., Glang, A. E., Todis, B., & Davies, S. C. (2016). Traumatic Brain Injury: Persistent Misconceptions and Knowledge Gaps Among Educators. *Exceptionality Education International*, 26, 1-18. Retrieved from <https://ir.lib.uwo.ca/eei/vol26/iss1/1>
- Hawley, C.A., Ward A.B., Magnay, A.R. & Mychalkiw, W. (2004). Return to school after brain injury. *Archives of Disease in Childhood*, 89(2):136-42.
- Howe J & Ball H. (2017). An exploratory study of Special Educational Needs Co-ordinators' knowledge and experience of working with children who have sustained a brain injury. *Support for Learning*, 32(1):85-100.
- Hughes, N., Williams, W.H., Chitsabesan, P., Walesby, R.C., Mounce, L.T.A., Clasby, B. (2015). The prevalence of traumatic brain injury among young offenders in custody: a systematic review. *Journal of Head Trauma Rehabilitation*. 30(2), 94-105.
- Leo, G., Macey, J-A., and Barzi, F. (2017) Educational outcomes for children with moderate to severe acquired brain injury. *Australian medical student Journal*, 8(1):46-50.

Linden MA, Braiden HJ, Miller S. (2013). Educational professionals' understanding of childhood traumatic brain injury. *Brain Injury*, 27(1):92-102.

McCarron, R., Watson, S. & Gracey, F. (2019) What do Kids with Acquired Brain Injury Want? Mapping Neuropsychological Rehabilitation Goals to the International Classification of Functioning, Disability and Health. *Journal of the International Neuropsychological Society*. 25(04): 403-412.

McCusker, C. (2005). An interacting subsystems approach to understanding and meeting the needs of children with acquired brain injury. *Educational and Child Psychology*, 22(2), 18-28.

Sariaslan, A., Sharp, D.J., D'Onofrio, B.M., Larsson, H., and Fazel, S. (2016) Long-Term Outcomes Associated with Traumatic Brain Injury in Childhood and Adolescence: A Nationwide Swedish Cohort Study of a Wide Range of Medical and Social Outcomes. *PLoS Med*, 13(8): e1002103.

<https://doi.org/10.1371/journal.pmed.1002103>

Todis, B., & Glang, A. (2008). Redefining success: Results of a qualitative study of postsecondary transition outcomes for youth with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 23, 252-263.

Turner, B.J., Fleming, J., Ownsworth, T. & Cornwell, P. (2011). Perceived service and support needs during transition from hospital to home following acquired brain injury. *Disability and Rehabilitation*. 33(10): 818-829.

Williams, W.H., et al (2010). Self-reported traumatic brain injury in male young offenders: A risk factor for re-offending, poor mental health and violence? *Neuropsychological Rehabilitation*. 20(6): 801-812.