

"COMMUNICATION AND CO-OPERATION":

Hearing the Voices of Parents to Improve Return to Education after Childhood ABI

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Introduction

Each year around 40,000 new ABIs are sustained by children and young people (CYP) in the UK. The majority of children will return to their school after ABI, and educational settings are recognised as an important context for ongoing neurorehabilitation (Glang et al., 2013). Despite this, both clinical and research evidence suggests that the knowledge and understanding about ABI of teachers and, indeed, of Special Educational Needs Coordinator (SENCO)'s is limited (Bennett et al., 2022; Ettel et al., 2016). Lack of awareness and understanding of ABI in the school system can make the RtE process highly stressful for CYP, families and teachers alike. There is also the risk of adverse outcomes, including poorer attendance, integration, engagement and achievement within education (Leo et al., 2017). Given the importance of an effective RtE, it is crucial the experiences of those going through the process are explored and their views considered within service planning and development.

To date, there has been limited exploration of the lived experiences of parents supporting their CYP back into education after ABI, particularly regarding the nature of support they received and needed.

Aims

A service evaluation was devised to explore the lived experiences of parents and carers supporting their CYP's return to school after ABI, and to provide information for future service development and improvement.

Methodology

Parents of children seen at a regional centre in the UK within the previous 2.5 years (October 2017 to March 2020) were contacted by email (n = 60). A link was provided to a 42-item Survey Monkey questionnaire devised by the Paediatric Neuropsychology Service, Brain Injury and Nurse Specialists. Quantitative data was analysed using descriptive statistics. Thematic analysis was used to analyse the qualitative responses following Braun & Clarke's framework (2006).

Results

31 parents/carers (response rate = 52%) completed the survey. 61% of children were male (n=19) and ages ranged from five years to 18 years-old. All but one child returned to their previous school after their ABI (97%). Mean school re-entry was 9 weeks. 15 (48%) children missed over 7 weeks of schooling. Parents (n=29) reported numerous changes in their child's abilities / needs post-ABI.

The five highest rated changes included levels of fatigue (86%, n=24), ways of behaving (76%, n=22), thinking and learning (72%, n=21), emotions (72%, n=21) and communication (59%, n=17). 24 (83%) of children had reported changes in at least three areas, and 17 (59%) in at least five.

The emerging themes from the qualitative responses are captured in the diagram below.

Themes

Parental Mindset and Growth

- Taking on the role of expert and advocate
- Stay strong, be patient and be kind to yourself

Specialist Support & Information

- Role of specialists
- Networks of support and collaboration

What Do They Need Now?

- Need/availability of additional support in school
- Bespoke provision
- ABI aware schools

Talk and Share

- Hospital to school transition
- Communication with and within school
- Talking, talking, talking!

Challenges of New and Hidden Needs

- But they look just the same!
- A 'new' me

Don't Forget Them!

- Missing school
- Missing out
- Missing friends

Discussion

The results highlight a number of key areas that represent crucial considerations in a successful RtE after ABI. The essential role played by professionals with expertise and experience in supporting RtE is of particular importance within service provision, development and commissioning. Parents particularly valued the effective sharing of information, consultation and guidance on support needs, and insight into the trajectory and longer-term difficulties associated with certain ABIs. Feedback also highlighted how parents are often required to embrace an advocacy role for their CYP and described how many felt it took time to 'grow' into this new role. This leads to important reflections about the benefits and risks of reliance on parental advocacy. Indeed, future research might explore how hospital / rehabilitation teams might best equip families for advocating and knowing their rights within the education system. The need for teachers, SENCOs and the wider education system to be knowledgeable and well-equipped for supporting CYP with ABI is also evident across all parental responses. Finally, the issue of hidden and complex needs after ABI are also emphasised in responses, with 83% of CYP experiencing three or more areas of deficit post-ABI. Parents remind us it is essential we create pathways and systems responsive to individual needs, which ensure CYP can continue to make progress in their education. Participation should also remain a central focus within support, as CYP are often excluded on many levels post-ABI.

Conclusions

The findings from this service evaluation highlight the importance of hearing the voices and wisdom of parents supporting their children to RtE post-ABI. Parents clearly articulate the many challenges faced, and acknowledge these often exist even where provision from the health service is good. Parents emphasise the need for strong and open communication between professionals, educators and the family, and remind clinicians and teachers that the child and their new needs should always remain at the centre of any planning, with a familiar professional to attempt to address potential anxieties.

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