

Returning to education after childhood acquired brain injury: Learning from lived parental experience

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Abstract.

BACKGROUND: Returning to education (RtE) after an acquired brain injury (ABI) can be stressful for children/young people (CYP) and families. While much can be done to support RtE, there has been limited exploration of the lived experience of parents/carers about what can both help and hinder the process.

OBJECTIVE: The aim was to understand more about RtE from parents' perspectives to inform best practice and facilitate improvements in service delivery.

METHODS: A service evaluation explored parent/carer views about the RtE process and the support received from healthcare professionals at a regional centre in the UK. Questionnaires ($n = 59$) were sent to parents of patients treated for an ABI in the last two years.

RESULTS: 31 parents (response rate = 51%) completed the survey. Results highlight the many challenges of RtE. Thematic analysis of responses revealed six key themes: Parental mindset and growth; What do they need know?; Specialist support and information; Talk and share; Challenges of new and hidden needs; and Don't forget them!

CONCLUSION: Parents offer crucial insight into the challenges of the RtE process. Their feedback highlights important factors for service development and reminds professionals of the key components of an effective return.

Keywords: Acquired brain injury, return to education, parents, children, young people, ABI, neurorehabilitation

1. Introduction

Acquired brain injury (ABI) is a major cause of childhood disability, with around 40,000 new ABIs sustained by children and young people (CYP)

in the United Kingdom (UK) annually (National Health Service England, 2013). Effects can potentially impact all aspects of a CYP's functioning (Braga et al., 2005; McKinlay et al., 2016), and even mild injuries can affect CYP participation in usual activities (DeMatteo et al., 2015). Attending school is their primary occupation, and educational settings provide important contexts for ongoing neurorehabilitation after ABI (Glang et al., 2013), immersing

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CYP in natural, experience-rich environments to help them relearn skills and compensate for acquired difficulties. Furthermore, when asked about key rehabilitation goals after ABI, the majority of CYP highlight reintegration to school and regaining a sense of belonging to school and peer groups as their primary focus (McCarron et al., 2019). Returning to education (RtE) after ABI should, therefore, be an important focus for hospital discharge planning and support.

As childhood ABI is often a sudden event, a timely and proportionate response is required from education settings to ensure successful reintegration, accommodating changed or acquired needs. Despite this, both clinical and research evidence suggests that teacher and Special Educational Needs Coordinator (SENCo) knowledge and understanding of ABI is limited (Bennett et al., 2022; Ettl et al., 2016; Howe & Ball, 2017; Linden et al., 2013). Few, if any, receive training about ABI, and many report being unaware of a pupil's ABI history (Davies et al., 2013; Hawley et al., 2004). Many teachers describe limited communication with hospital teams (Hartman et al., 2015), a focus on community rather than school interventions (Lindsay et al., 2015), and feeling ill-prepared in supporting RtE (Hartman et al., 2015). They also commented on limited information on possible long-term sequelae (Hawley et al., 2004). Recent research with teachers emphasized a need for both basic training about ABI and child-specific professional development with specialist input (Bate et al., 2021). A report to the UK parliament highlighted gaps in training and knowledge within education, identifying the need for clearer pathways supporting RtE after ABI (Barnes et al., 2018).

This lack of awareness and appropriate support can have a dramatic effect on RtE, and subsequent attendance, integration, engagement and achievement (Leo et al., 2017). Without effective support, CYP with ABI are at risk of adverse outcomes including mental health difficulties, poor educational outcomes and career prospects, and increased likelihood of welfare reciprocity (Sariaslan et al., 2016). As the impact of ABI can present differently across development with emerging difficulties in executive function, attention and behaviour common (Anderson et al., 2011), teachers are often faced with an evolving picture of need. There is a risk the ABI is therefore forgotten, unrecognised or misinterpreted, particularly where behaviour that challenges becomes an issue. Inevitably, these CYP are in turn more likely to be seen in child and adolescent mental health services

(CAMHS), alternative educational provision settings and the youth justice system, where rates of ABI are reported to be high (Williams et al., 2015).

Given the importance of effective RtE, it is crucial that experiences of those encountering the process are explored and their views considered within service planning and development. While research shows that schools rely on parents to inform them about a brain injury (Hawley et al., 2004), there has been very limited exploration to date of the lived experiences of parents supporting CYP back into education after ABI, particularly regarding the nature of support they needed and received (Andersson et al., 2016).

1.1. Study context

The Brain Injury Living Life (BRILL) team at Nottingham Children's Hospital works with CYP admitted with ABI, providing an evidence-based model of inpatient intensive neurorehabilitation and early supported discharge to smooth transitions to home and local community services (Keetley et al., 2020). CYP are supported by Paediatric Neuropsychology and a Brain Injury Specialist (BIS) or a Neuro-oncology Outreach Nurse Specialist (NOONS). Schools are proactively involved in this transitional process with flexible support offered to help them receive a CYP back at school, including staff training specific to the CYP's injury, stage of development and rehabilitation progress to date. While this process is largely successful, team observations and anecdotal feedback from families suggest not every return goes as smoothly as hoped. This study therefore sought to understand factors which may help or hinder RtE, from the parental perspective.

1.2. Study purpose

A service evaluation was devised to explore lived experiences of parents and carers supporting their CYP's RtE after ABI, and to provide information for future service development and improvement. The study aimed to gather information about the RtE process, and seek qualitative views on the following questions:

- a. What do parents feel have been the main challenges in supporting their CYP to return to education post-ABI?
- b. What do parents believe helped?
- c. What advice would parents offer other families?

d. What key points would parents want people in education (e.g. teachers and SENCos) to remember when working with pupil with an ABI?

2. Method

2.1. Participants and procedure

Parents of CYP seen by neurorehabilitation service within the previous 2.5 years (October 2017 to March 2020) were contacted by email or text ($n = 60$). A link was provided to a 42-item questionnaire devised by the Paediatric Neuropsychology Service, BIS and NOONS, and administered via Survey Monkey. Questions requested demographic and brain injury information, and explored the experience of RtE from the parent's perspective, asking them to reflect on what felt challenging and helpful within this phase of their child's rehabilitation (Table 1).

2.2. Data analysis

Descriptive, exploratory analysis of quantitative data was conducted with statistics including mean, standard deviation, and percentages. Thematic analysis was used to analyse qualitative responses to study questions flexibly and inductively, describing this

information in rich detail and searching it for patterns (Braun & Clarke, 2006). Thematic analysis followed Braun and Clarke's (2006) framework. After data immersion by all authors, EB and AF generated initial codes and text exemplars manually to organise data with items of similar meaning. All authors re-read data to check codes were meaningful, generating additional codes and regrouping where relevant until consensus was reached. Codes were then collated into themes and subthemes through discussion and mapping, identifying relevant data extracts (Table 3). Themes were reviewed and refined to ensure coherence between data and agreement between authors, then defined and named before finally preparing the written evaluation. At all stages, study questions were used as a reference point and the thematic analysis framework was used to respond to these dynamically.

3. Results

3.1. Demographics

Thirty-one parents/carers (response rate = 52%) completed the survey. 61% of their children were male ($n = 19$) with CYP age ranging from five years to 18 years-old at the time of survey completion. All were at least six months post-injury or illness and had returned to education. Prior to their ABI, 90% of

Table 1
Examples of Question Types and Methods of Analysis

Question type	Category	Question examples	Method of analysis
Closed questions	Demographics and injury/illness characteristics	What is your child's gender? How old was your child when they had their ABI? How long was their stay in hospital?	Quantitative (descriptive statistics)
	Impact of ABI	What has changed for your child because of their ABI? Select all that apply (e.g. thinking and learning; levels of fatigue; friendships and relationships with teachers, friends and family) Is your child classed as having special educational needs? Is this the result of their ABI?	Quantitative (descriptive statistics)
Open questions	RtE information	Did your child return to their original education setting after their ABI? How long after your child's ABI did they return to school? On return to school did they return a. full time or b. part time?	Quantitative (descriptive statistics)
	Experience of the RtE process from the parent's perspective	What have been the main challenges in supporting your child to RtE post ABI? What are the things that helped? What advice would you offer to other parents? What is the one thing you want people in education (e.g. teachers and SENCos) to remember when working with a pupil with an ABI? Please use this space to add any other comments relevant to your experience of your child RtE	Qualitative (thematic analysis)

Table 2
Demographic Information and Injury Details

Demographic variables	Number
Gender: boys; no. (%)	19 (61%)
Age at injury (years): mean <i>SD</i> (range)	10 5.6 (2–17)
Age at injury	
0–4	2
5–8	7
9–11	9
12–15	11
16–18	2
Injury/illness characteristics	
Length of stay in hospital (days): mean <i>Mode</i> (range)	16 14 (0–64 days)
Cause of brain injury	
Concussion/mild TBI	3
Mod/severe TBI	12
Stroke/AVM	3
Brain tumour	6
Infection	4
Hypoxia	1
Unsure	1
No response	1

186 children had been in mainstream education ($n = 27$).
187 Two children attended independent schools (7%), one
188 CYP was in a special school setting, and one parent
189 did not provide an answer. Further demographic and
190 injury details are outlined in Table 2.

191 3.2. RtE information

192 All CYP except one returned to their previous
193 education setting after their ABI (97%). RtE took
194 between 0 and 40 weeks, with a mean re-entry time
195 of 9 weeks; only one CYP returned immediately after
196 discharge. Fifteen (48%) children missed more than
197 seven weeks of schooling, while 9 of these (29%)
198 missed more than 12 weeks. Twenty-nine percent
199 required home education before returning to school,
200 and 77% of children returned part-time ($N = 24$) on
201 school re-entry; eleven parents said their CYP only
202 attended for half days in the first stages, 6 reported
203 they attended for just a few hours, and some children
204 did as little as an hour. With regard to re-joining
205 lessons, 58% joined their previous lessons, 6% completed
206 their lessons separately to peers (e.g. in the
207 learning support area) and 23% learned across both
208 environments; 13% transitioned into new settings
209 (e.g. moving from primary to secondary school) so
210 could not answer this question.

211 3.3. Impact of ABI and support needed

212 Parents ($n = 29$) reported a high number of changes
213 in their child's abilities and needs post-ABI,

214 illustrated in Fig. 1. The five highest rated changes
215 included levels of fatigue (86%, $n = 24$), ways of
216 behaving (76%, $n = 22$), thinking and learning (72%,
217 $n = 21$), feelings about things (emotions) (72%,
218 $n = 21$) and communication (59%, $n = 17$). Changes in
219 at least three areas were reported for 24 (83%) CYP,
220 and in at least five areas for 17 (59%). As a result
221 of these changes, 48% of CYP were described by
222 parents as having special educational needs (SEN),
223 although only 29% had an Education, Health and
224 Care Plan (EHCP) and only 16% of parents reported
225 the school had applied for additional funding to support
226 their child. Two young people were reported to
227 have been excluded from school since their ABI. Parents
228 frequently reported changes in their child's levels
229 of happiness in school pre and post-ABI (see Fig. 2).

230 3.4. Thematic analysis

231 Six main themes were identified, summarised in
232 Fig. 3. Themes and subthemes are described and illustrated
233 below; parents are identified by their response
234 number to the survey (e.g. P1).

235 3.4.1. Parental mindset and growth

236 One of the key emerging themes addressed the
237 changed role and mindset parents felt they had
238 to 'grow into' after their CYP's ABI, developing
239 resilience, patience and perseverance to manage the
240 many challenges presented throughout RtE. Parents
241 also spoke of their role in advocating for their child,
242 particularly in the absence of knowledge about ABI
243 within the education setting. The need for self-
244 kindness in taking on this 'new' role was widely
245 described and supports themes in previous research
246 about learning to be a 'new parent to a different child'
247 (Tyerman et al., 2017).

248 3.4.1.1. Taking on the role of expert and advocate

249 Many parents described feeling a need to help school
250 understand their child's new needs and push for
251 appropriate support, including requesting meetings,
252 making judgements about when the CYP should
253 return to certain activities, and challenging schools
254 when provision was not forthcoming. Parents highlighted
255 difficulties "getting enough help for him in
256 school and getting his EHCP" (P30), and sometimes
257 required a strong stance to challenge the school,
258 reflecting previous research of the stressful nature of
259 parenting a CYP with a brain injury (Brown et al.,
260 2013): "it took time, determination and sometimes
261 confrontation to get what we believed our daughter
needed" (P10).

Table 3
Samples of Text Used to Develop Codes and Build Themes

Codes	Sample of coded text	Theme
<ul style="list-style-type: none"> ● Parental need to build resilience ● Parent learning to become an advocate for their child ● Perseverance in the face of challenges and knowledge gaps ● Parents needing to be patient/kind to themselves, their child and school 	<p><i>“My determination to not give up”</i></p> <p><i>“Don’t give up, keep pestering the system until you are happy your child’s needs are being met”</i></p> <p><i>“To persevere with getting things put in place for their child. Seek advice on what’s available”</i></p> <p><i>“Don’t expect too much too soon, and just accept one day at a time”</i></p>	Parental mindset and growth
<ul style="list-style-type: none"> ● The essential role of specialists ● Utilising the available ABI networks and information ● Liaison between ABI professionals and school 	<p><i>“The Brain Injury Specialist gave us that knowledge and was very helpful about how to handle behavioural changes”</i></p> <p><i>“Get a list of support groups, charities, websites and contact details and most importantly a contact for help and advice”</i></p> <p><i>“The links between the medical and ABI teams and school are essential to ensure a successful return to education”</i></p>	Specialist support and information
<ul style="list-style-type: none"> ● Need for new types of support from school ● Need for adjustments within school/the classroom ● The need for bespoke support ● Need for schools to give time and display patience/empathy towards the child ● School’s knowledge & understanding of ABI 	<p><i>“Be patient with the school as this may be new for them too”</i></p> <p><i>“Reduced hours, regular breaks”</i></p> <p><i>“the school have used visual aides for maths and have recently tried short bursts of work”</i></p> <p><i>“be more empathetic as this could easily be your child so treat and support these pupils how you would want your own child to be treated and supported”</i></p> <p><i>“School taking time to understand the holistic nature and impact of the ABI was important”</i></p>	What do they need now?
<ul style="list-style-type: none"> ● Communication between everyone playing a part in the RtE ● Liaison with family & child – holding them at the centre ● Liaison with professionals to understand new needs 	<p><i>“He has up to 10 teachers per day and no one seems to communicate with each other to understand him”</i></p> <p><i>“Involve the child in the planning process to support their understanding . . . the ‘done to them’ approach does not help”</i></p> <p><i>“Try to get behavioural advise as soon as possible. It is not only about the physical effects but also longer term recovery of personality”</i></p>	Talk and share
<ul style="list-style-type: none"> ● ABI as a hidden disability ● Consideration of longer-term needs ● Child’s new needs post-ABI ● Anxiety within the child and their system 	<p><i>“Just because they look like every one else doesn’t mean they think/react like everyone else”</i></p> <p><i>“take note and implement recommendations from the BIS and parents, and to maintain these over the long term of recovery not to forge them after the first few weeks”</i></p> <p><i>“He shouts and swears at times which is all post ABI”</i></p> <p><i>“The worries and fears of how school will be with them and getting them into school when they are so nervous”</i></p>	Challenges of new and hidden needs
<ul style="list-style-type: none"> ● Changes to inclusion and participation ● Difficulties with peers ● The need for others to help facilitate friendships ● Challenges associated with the amount of school missed 	<p><i>“Dealing with his exclusions from activities whilst his blood clot dispersed”</i></p> <p><i>“the effect on her friendships because of her apparent bluntness, and lack of consideration of other people’s feelings”</i></p> <p><i>“Seek out and find special friends who your child can connect with who will support them”</i></p> <p><i>“Completing the education to the best of their ability whilst acknowledging the work he missed is so vast”</i></p>	Don’t forget them!

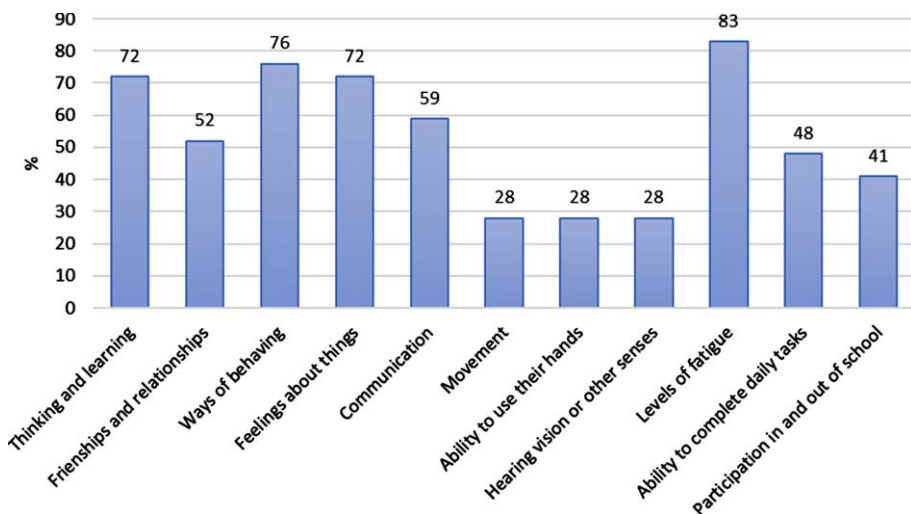


Fig. 1. Areas of Function that have Changed for CYP as a Result of ABI.

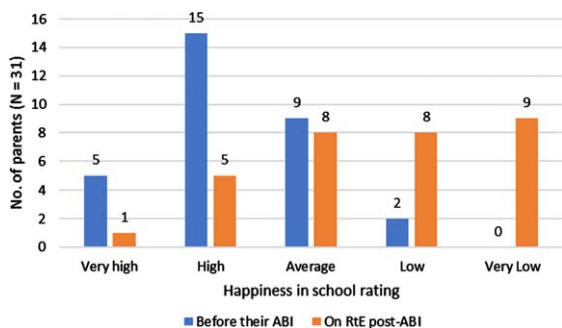


Fig. 2. Parental Ratings of their Child's Happiness in School Pre-ABI and on Return to Education Post-ABI.

P10's comment that "it has been a very difficult journey of two and half years to get to our current situation of having an EHCP and support in place. It's taken too long", highlights the need to persevere. This was also illustrated by the 56% of respondents who advised other parents to have perseverance when advocating for their child: "It's a long fight to get help but don't give up, even when it seems no one is listening" (P25).

Additionally, the process of becoming an expert advocate in their CYP's ABI was highlighted as a challenge, with parents describing needing time "for me to get to know and understand the 'new X' and be able to explain this to others" (P27), while also "Having to ask for support to be put in place but not knowing what can be offered and not being given a choice of different options" (P18).

3.4.1.2. *Stay strong, be patient and be kind to yourself* In response to the many challenges acknowledged in supporting their child's RtE after ABI, 52% highlighted the importance of self-kindness. Parents emphasized that patience was key, advising other parents that having an understanding that RtE may not be sorted immediately was crucial to looking after themselves and their child:

Don't expect too much too soon, and just accept one day at a time, and then make sure you communicate with school and keep checking in with your child that they feel they are being listened to and adequately supported. (P27)

Be patient with your child and yourself. Take it one day at a time. Be kind to yourself as you will be learning new things along with your child. (P2)

Finally, many parents reported the need for resilience, with one feeling the eventual progress in gaining support for her CYP was down to "my determination to not give up" (P16). Parents were able to recognise how their own strength and growth had been important, but also spoke about the "battle" (P10) to get the right help for their CYP while still processing the trauma of what had happened.

3.4.2. *Specialist support and information*

Parents reflected on the role of collaboration with health and education professional networks, and the value ABI-specific support could add to education staff during RtE and beyond. This reflects

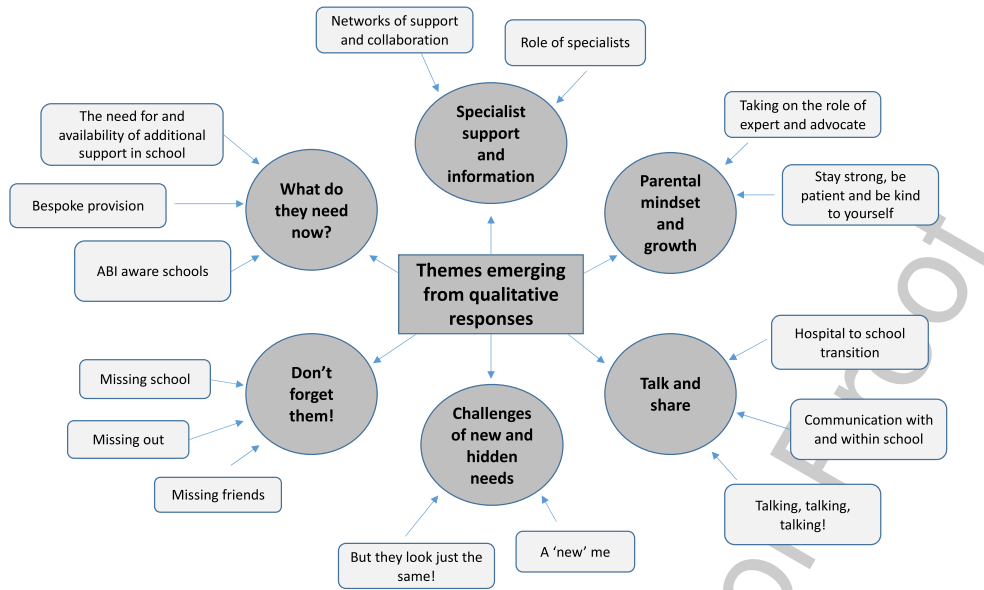


Fig. 3. Subthemes and Themes Emerging from Parental Qualitative Responses.

recommended best practice of seamless care, with education staff understanding their role in the CYP's rehabilitation (Andersson et al., 2016; McKinlay et al., 2016) to enable appropriate support for both CYP and family (Hartman et al., 2015).

3.4.2.1. Role of specialists Specialists from multiple acute care and neurorehabilitation disciplines were highlighted as “knowledgeable sources” (Hartman et al., 2015) for education staff to tap into, with P23 advising schools “take note and implement recommendations from the Brain Injury Specialist and parents and maintain these over the long term of recovery not forge[t] them after the first few weeks”. P10 noted “The epilepsy nurse was amazing. She became our voice at school”, supporting their attempts to advocate for their CYP, while other parents noted the crucial roles of the neuropsychologist (P19), and BRILL/hospital team (P14, P21). Some parents, however, noted that specialist advice was not followed, and exhorted education staff to take on specialist advice offered:

I would've liked teachers to follow the advice of the clinical psychologist report, by giving him time to process the subject matter prior to each lesson and understand how fatigued he would be. (P22)

3.4.2.2. Networks of support and collaboration In addition to advising education staff to “work with

and seek advice from the family to learn what the child's capabilities are and what support they can put in place individually for them” (P22), parents noted the value of having networks of support around them and their child: “the links between the medical and ABI teams and school are essential to ensure a successful return to education” (P20). Parental views echo recommendations for education staff to be proactive in working alongside health professionals from an early stage after the child's injury (Savage et al., 2005), and reflect national recommendations encouraging professional network support (for example, Paediatric Stroke Working Group, 2004).

When asked what advice they would offer other parents, survey respondents emphasised the importance of building and using the available network, including third-sector organisations: “Work with the ABI support teams to deliver advice to school. Be informed and draw on the information... available through The Children's Trust and other sources” (P20). Having “a list of support groups, charities, websites and contact details and most importantly a contact for help and advice” was also advised (P10), and in reflecting back on their experience over time, parents noted the importance of drawing on networks, even if support does not seem essential initially:

In the beginning agree to all help and support offered by children's trust for support groups and a support worker or whatever else they offer, even

if you think you won't need it... you will need to be sure you have support long-term. (P16)

3.4.3. What do they need now?

The need for schools to be responsive in meeting a CYP's new needs after ABI in appropriate and timely ways was raised by all parents, encompassing wide-ranging aspects including adjustments and bespoke approaches for supporting changed educational needs, recognition of the additional time, patience and empathy CYP may require, and the importance of underpinning these by ensuring schools have comprehensive knowledge and understanding of ABI. These subthemes reflect previous recommendations exploring the experiences of individuals with ABI and their families (Norman et al., 2022) and current practice recommendations (McKinlay et al., 2016).

3.4.3.1. The need for and availability of additional support in school For many parents, getting enough support from school for their CYP following their ABI was a challenge, with P10 noting that, "initially, it was just awful... Having no support and being totally ignorant of what we were dealing with". The relationship with the previous theme of network collaboration was highlighted in this subtheme, noting that where this was dysfunctional, "the battles with funding and lack of cohesive support from all the experts together, initially made getting support in place very difficult" (P10). Underlining the need for parental resilience noted earlier, several parents described feeling let down when the school did not action agreed provision:

... School staff gave promises and agreed to give support to my daughter on return to school when in meetings with myself and Brill team, but never followed through with agreed support when my daughter actually returned to school... the whole experience was disheartening. (P16)

Another parent discussed challenges faced when progressing through the education system where there was "a lack of records from her time in Year 5... [and the challenge of] making sure that the right information is handed over from primary school" (P18).

Conversely, parents also discussed wider aspects of school culture deemed helpful when accessing support for their CYP in school, with positive experiences including "school involvement, meeting his friends, meeting head teacher" (P1) and "feeling safe

and supported in school, by staff who are informed and understanding" (P20), and recognising the benefit when an "EHCP was sorted very quickly" (P30). Where schools were viewed as meeting needs well, parents were very positive, with P9 saying "the school were superb and I don't feel I could have asked for more" and P10 describing a good transition to secondary education where "the secondary school... have done everything in their power to support us... and our daughter".

3.4.3.2. Bespoke provision Support packages were considered more effective when they were "suitable for the child, and agreeable with them" (P11). Such adjustments included, "visual aids for maths and... short bursts of work, repeating what he has already done to help him retain the information" (P13), "rest and not too many expectations" (P7), "reduced hours, regular breaks" (P29), "brain breaks, completing revision work and then minimal work" (P3), adjustments to managing "behavioural changes" (P23), and a holistic approach to "managing the day" (P24). This was reinforced by P20's documentation of beneficial bespoke arrangements:

Teaching staff support – reassurance and guidance, weekly meetings with head of year, re-starting the school year, 1:1 subject teaching, new friendship group, counselling, exam access arrangements, and school taking the time to understand the holistic nature and impact of ABI. (P20)

Some parents highlighted the role of one-to-one support: "having a TA (teaching assistant)... work solely with him... helped with communication and they know what signs to look for when he becomes fatigued or losing concentration" (P22).

3.4.3.3. ABI aware schools 57% of parents highlighted the impact of a school's depth of knowledge and understanding of ABI on the nature and efficacy of educational support, noting a link between a "lack of understanding in handling change of behaviour and... of support / interest / action by the school" (P23). While the role of specialists in giving detailed information about a CYP's neurorehabilitation progress and new needs is identified in a previous theme, this subtheme of ABI aware schools acknowledges the responsibilities schools have to proactively deepen their knowledge of ABI to support RtE. P29 requested staff to:

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462 ... please research as much as you can to pro- 509
 463 vide the best support and not to be afraid of being 510
 464 honest about particular doubts and concerns ... I 511
 465 would have preferred honesty instead of avoid- 512
 466 ance and putting obstacles in my child's way to 513
 467 return to school. (P29) 514

468 P22 wished all educators working with students 515
 469 with ABI would "gain knowledge and understanding 516
 470 of how an ABI can affect a child's learning and the 517
 471 day to day struggles for them and their whole family", 518
 472 and P19 noted inconsistencies in awareness between 519
 473 those who had received training and those who had 520
 474 not: "some [staff] are brilliant, some think he is just 521
 475 being naughty like others in the class". Parents felt 522
 476 a deeper understanding of ABI would help teachers 523
 477 appreciate the need to "give them time" (P3), with 524
 478 "an abundance of patience and not always adhering 525
 479 to social norms" (P22). The need for this empathetic 526
 480 approach towards CYP with ABI during RtE was 527
 481 eloquently described. 528

482 This is very confusing for the pupil, more chal- 529
 483 lenging than they let on. So be more empathic as 530
 484 this could easily be your child so treat and support 531
 485 these pupils how you would want your own child 532
 486 to be treated and supported. (P16) 533

487 3.4.4. *Talk and share* 534

488 Parents emphasized the importance of communi- 535
 489 cation between hospitals, parents, and schools as well 536
 490 as amongst teaching staff, with this theme acting as 537
 491 a foundation to all other identified themes. 538

492 3.4.4.1. *Hospital to school transition* The impact 539
 493 of poor communication during RtE was highlighted 540
 494 starkly by one parent, whose CYP was not initially 541
 495 referred to BIS or BRILL: 542

496 ... there should have been some direct communi- 543
 497 cation between hospital and school. School knew 544
 498 nothing about what had happened or what should 545
 499 be in place and simply relied on asking us what 546
 500 they needed to do. (P10) 547

501 Others, however, felt well supported, encouraging 548
 502 educators to communicate with "hospital staff to find 549
 503 out what help is available within the NHS, they are 550
 504 amazing and offer support beyond diagnosis" (P14). 551

505 3.4.4.2. *Communication with and within school* The 552
 506 need for strong, open communication between par- 553
 507 ents and schools was also important, with P10 554
 508 commenting that "lots of contact and communication 555

509 is vital"; conversely, parents found RtE extremely 510
 511 stressful when there was "little communication from 512
 513 school" (P15). Where possible, many parents recom- 514
 515 mended keeping channels of communication open 516
 517 and working alongside the school to ensure their 518
 519 child's needs were being met: "Make sure you com- 520
 521 municate with school and keep checking in with your 522
 523 child that they feel they are being listened to and 524
 525 adequately supported" (P27); "Keep communication 526
 527 open with the school and don't be afraid to speak up 528
 529 for your child remember...you know them best" (P2). 529
 530 One parent also believed: 531

532 Communication and cooperation with school is 533
 534 key. Be brave and don't let your anxiety trans- 535
 536 fer to your child. Work with the ABI support 536
 537 teams to deliver advice to school. Be informed 537
 538 and draw on the information about ABI ... Look 538
 539 after yourself! (P20). 539

540 One particular challenge highlighted was internal 541
 542 school communication, with one parent describing 542
 543 how, "he has up to 10 teachers per day and no one 543
 544 seems to communicate with each other to under- 544
 545 stand him" (P7). Reflecting on the time since their 545
 546 CYP's ABI, parents emphasised the fundamental 546
 547 importance of communication on transition between 547
 548 schools, with some parents noting risks: 548

549 For secondary school – making sure the right 549
 550 information is handed over from primary school 550
 551 but again I had to request a meeting with safe- 551
 552 guarding lead to make sure they were aware of 552
 553 my child's difficulties. (P18) 553

549 3.4.4.3. *Talking, talking, talking!* Several parents 554
 550 also acknowledged the importance of communication 555
 551 in supporting their own and the CYP's adjustment 556
 552 following ABI, including during RtE. One recom- 557
 553 mended, "Talk (find safe people to talk to) about how 558
 554 you feel and what you are going through. Allow your 559
 555 child to do the same" (P2). Parents recognised the 560
 556 importance of "Talking, talking, talking. Letting him 561
 557 know it's OK to feel the way he feels" (P2), and of 562
 558 using this to "still have some banter in order to make 563
 559 them realise they are still the same child as they were 564
 560 before" (P15). 565

566 3.4.5. *Challenges of new and hidden needs* 567

568 Foundational to RtE approaches, the often 'hidden' 569
 569 nature of new needs linked to ABI was a clear theme 570
 570 within parent responses, and the challenges these 571
 571 needs created when not always evident to others. 572

3.4.5.1. *But they look just the same!* When asked what they wished SENCOs/teachers would remember about ABI, 43% of survey respondents highlighted its ‘hidden disability.’ P25 wished to remind teachers that “just because they look like everyone else doesn’t mean they think/react like everyone else,” while P24 wrote, “they look ok on the outside, but often there are still many challenges happening internally.” Others commented, “it’s a hidden disability. The child may look fine, but they don’t always feel fine. They may not have the capacity to say . . . ” (P20), “they may look physically fit but are maybe struggling with the way they now think” (P19) and:

Just because my son looks fine, his brain gets tired and he needs breaks. He needs more time to finish tasks and he needs more time to recall. Just because they are back at school doesn’t mean they are back to normal. The trauma has an impact and they need support and kindness (P17).

One parent emphasised the conflict this caused with school, “until the brain injury specialist went into school they were clueless and I think it’s easy for them to forget that because he looks ok doesn’t mean the ABI isn’t there (P13).

3.4.5.2. *A ‘new’ me* The specific impact and challenges of a CYP’s new ABI-linked needs on settling back into an education system were strongly and eloquently illustrated by parents within this subtheme:

Getting teachers to understand his behaviour, some are brilliant, some think he is being naughty like others in the class. He is easily led and makes poor decisions, some teachers think it’s his choice. He shouts and swears at times which is all post-ABI. (P19)

Expanding on changes listed in Fig. 1 above, and reflecting other studies reporting numerous post-ABI difficulties across a range of domains (Babikian & Asarnow, 2009; Keenan et al., 2018; Wilkinson et al., 2018), parents noted their CYP’s new needs included “reading books” (P28); anxiety, low mood, emotions and confidence, (P31, P17, P2, P1); behaviour (P23, P19); memory (P26); concentration (P4) and fatigue (P24, P29, P27, P7, P9, P4, P3). One parent described changes in more detail, highlighting “fatigue, anxiety – in particular in relation to keeping up with the workload and perceived teachers’ expectations. Pacing – learning to manage fatigue” (P20), while another said, “the fatigue and memory loss has been very difficult. He struggles to retain

information in all subjects . . . maths especially” (P13). P1 described changes to her son’s “confidence, his appearance, his independence”, while others described changes in personality: “they are not the person they were, they’ve changed . . . they quite often lack insight . . . they may react differently in certain situations and seem ‘odd’” (P10); “It is not only about physical effects but also the long-term recovery of personality” (P23).

3.4.6. *Don’t forget them!*

The final theme emerging from the qualitative data related to the challenges encountered by parents while supporting their CYP’s participation and inclusion. As highlighted in recent research (Keetley et al., 2021; Wales et al., 2021), parents reported changes in participation relating to school engagement, maintaining friendships and peer relationships, and involvement in extra-curricular/community activities.

3.4.6.1. *Missing school* Missed school was noted by some parents as a current and ongoing challenge in supporting their child’s RtE, reflecting that learning has continued for other students while the CYP with ABI has been unable to attend:

Completing the education to the best of their ability whilst acknowledging the work he missed is so vast that he will not be able to catch up. Having to encourage him to complete homework whilst fatigued from being at school all day and fitting in extra-curricular activities and health appointments. (P22)

Another parent faced challenges with their CYP’s attendance after ABI as “she does not want to go to school” (P12), and P26 described how her son continued to “miss a day here and there . . . as he was exhausted”. While adjusted hours were valued by some parents (see bespoke provision subtheme above), P2 saw this less positively, commenting that the need for a phased return meant her child struggled to “attend school for longer.”

3.4.6.2. *Missing out* Many parents felt participation had changed for their CYP post-ABI, and several linked this to fatigue. P2 stated, “fatigue can play a huge part in obstacles”, and P22 noted the impact of this on leisure time and learning (see P22 quote above). P17 described the challenges “dealing with exclusions from outdoor activities whilst his blood clot dispersed and . . . judging the timing of return to

653 activities . . . anxiety of certain sports means he does
 654 not want to take part". Others highlighted problems
 655 "resuming sport activities (P20), "requiring surgery
 656 before he can participate" (P19), and being "unable to
 657 go in the playground" (P13). In addition to physical
 658 restrictions due to medical needs, one parent spoke
 659 honestly of the parental impact on participation by
 660 encouraging parents to "let go a little, as difficult as it
 661 is . . . let them do things for themselves to make them
 662 feel normal" (P15).

663 *3.4.6.3. Missing friends* Facilitating and maintain-
 664 ing peer and social relationships also presented a
 665 participatory challenge for many CYP after ABI: "For
 666 the first few months the main challenge was [child]'s
 667 emotional needs, and the effect on her friendships
 668 because of her apparent bluntness, and lack of con-
 669 sideration of other people's feelings. Total lack of
 670 diplomacy" (P27). P2 also described the "change in
 671 friendships," while another mentioned the "impact
 672 on former social relationships" and the challenge of
 673 having to form a "new friendship group" after old
 674 relationships broke down (P20). However, many par-
 675 ents also spoke of how peer relationships had been
 676 crucial in assisting the RtE:

677 Having one close friend who accepted [child] just
 678 as she was, and didn't judge even if [child] said
 679 upsetting things. Also time . . . time for me to get
 680 to know and understand the 'new [child]' and be
 681 able to explain this to others. (P4)

682 Many advised other parents to encourage and facil-
 683 itate friendships in a way they may have not needed
 684 to before the ABI. Parents suggested, "seek out and
 685 find special friends who your child can connect with
 686 who will support them" (P22), "Arrange for them to
 687 meet one or two of their closest friends so they get
 688 that feeling of care back" (P27).

689 4. Discussion

690 The findings from this service evaluation highlight
 691 the importance of hearing the voices and wisdom of
 692 parents supporting their children to RtE post-ABI.
 693 Parents of children aged two to 17 years of age
 694 at injury described the process of RtE after ABI.
 695 The majority returned to their previous education
 696 setting but over three quarters of the CYP experi-
 697 enced changes in at least three areas of function, and
 698 nearly half were described as having special educa-
 699 tional needs. Thematic analysis of the 31 completed

700 questionnaires identified six main themes: parental
 701 mindset and growth, specialist support and infor-
 702 mation, what do they need now, talk and share,
 703 challenges of new and hidden needs, and don't for-
 704 get them. In line with study purposes and within
 705 each of these themes, parents clearly articulated the
 706 many challenges they faced when supporting their
 707 child's RtE, and acknowledged these often existed
 708 even where health service provision was good.
 709 Their reflections illustrated strategies and approaches
 710 which were helpful, offered rich advice for other
 711 families, and together the themes provide clear key
 712 points for schools to remember when supporting RtE
 713 after ABI. Implications of these findings for local and
 714 wider service provision and planning are discussed
 715 below.

716 4.1. Multisystem support

717 Results highlight the essential role played by pro-
 718 fessionals with ABI expertise and experience in
 719 supporting effective and child-specific information
 720 sharing, consultation and guidance during RtE, offer-
 721 ing insight into the recovery trajectory and anticipated
 722 longer-term difficulties to inform support strategies.
 723 Part of this must involve upskilling parents, CYP, and
 724 teachers alike via psychoeducation, to ensure they too
 725 can be effective advocates for the CYP's new support
 726 needs. It is important, therefore, that health service
 727 commissioners are aware of key health services and
 728 roles essential for supporting a successful RtE, and
 729 the potential personal and economic costs of not facil-
 730 itating this, including increased risk of parental and
 731 CYP mental health difficulties. Indeed, evidence sug-
 732 gests where rehabilitation and school reintegration
 733 are successful, CYP are better able to participate in
 734 secondary education (Todis & Glang, 2008) and thus
 735 occupation in the future, reducing the recognised risk
 736 of possible dependency on services and benefits in
 737 adulthood (Sariaslan et al., 2016).

738 As well as ensuring the availability of ABI-specific
 739 health service provision to support RtE, teachers,
 740 SENCOs and the wider education system must be
 741 knowledgeable and well-equipped for supporting
 742 CYP with ABI. This study showed huge disparity
 743 in school awareness of ABI, with negative or pos-
 744 itive impact on RtE as perceived by parents: this
 745 reflects previous research recognising greater needs
 746 for parental advocacy when schools are viewed as
 747 lacking in training or refusing services (Burke &
 748 Hodapp, 2016). The paucity of training on ABI is
 749 recognised by health and education services alike

and well-documented in the literature (Andersson et al., 2016; Barnes et al., 2018; Bennett et al., 2022), yet driving change remains challenging, particularly in the UK where SEND systems are increasingly focused on broad areas of need rather than specific conditions (Department for Education (DfE), 2014). However, given the sudden and dramatic changes presented by ABI, the risk of hidden disabilities and the potential for emerging needs across development, ABI training for all teachers is essential, with input from specialists around individual needs as required. This gap is emphasised in the All-Party Parliamentary Group on ABI's report to the UK Parliament, states, "All education professionals should have a minimum level of awareness and understanding about ABI" (UKABIF, 2018, p22); this is now reflected in the key aims of the National ABI in Learning and Education Syndicate (N-ABLES, 2018).

4.2. *Recognising complexity*

The issue of hidden and complex needs after ABI, and the challenges associated with fatigue are also emphasised in parental responses. As shown above, many CYP in the study had a range of difficulties and 83% of CYP had at least three areas of deficit post-ABI. Research also demonstrates high levels of pre-existing vulnerabilities/comorbidities in the ABI population including ADHD (Eme, 2014; Hoarea & Beattie, 2003; Max et al., 2004; Yeates et al., 2021), and many CYP also face ongoing medical complications/treatments which may create additional needs or further RtEs, for example, ongoing oncology treatments, hydrocephalus, arteriovenous malformation and cavernoma management. Parents remind us that it is essential to create child-centered pathways and systems responsive and adaptive to the complexity of individual needs, ensuring CYP can continue to make educational progress at intensities and levels suiting their recovery, progress with neurorehabilitation and emerging development.

Participation should also remain a central focus within support, as CYP are often excluded on many levels post-ABI. This need for participation to be considered within conceptualisations of disability/function and across all rehabilitation contexts is highlighted within the International Classification of Functioning, Disability and Health (World Health Organisation, 2001), and in emerging research addressing outcomes of paediatric ABI (Câmara-Costa et al., 2020; de Kloet et al., 2015; Thompson et al., 2016). Given changes in identity, needs and

participation, it is also important pathways into timely mental health support are identified and strengthened.

4.3. *Supporting parents*

The role of parental advocacy in supporting RtE is a clear theme from this study, and reflects research highlighting that rehabilitation understood and delivered by families is often most effective (e.g., Braga et al., 2005). However, given that parents described the effort and time required to embrace and 'grow' into this new role, it is crucial that the vulnerabilities of such reliance on parents, and the risk of increased inequity in RtE experiences, are acknowledged. Effective parental advocacy is enhanced, for example, in families with higher socioeconomic and education backgrounds (Burke & Hodapp, 2016; Lalvani, 2012), whereas parents with different cultural and language backgrounds or inexperience of navigating school and special educational needs systems may find advocacy more challenging (Bacon & Causton-Theoharis, 2013; Rosetti et al., 2020; Savage et al., 2005). Hospital teams also recognise that emotional trauma of a child's ABI (for example, an accident which parents may also have been involved in) may have a negative impact on parental ability to absorb new information and advocate successfully on their child's behalf. Thus, the system cannot be wholly reliant on parents, particularly in the early stages after injury, but instead needs to support parents to share their learned expertise: it is, therefore, essential that hospital/specialist teams are involved in RtE, education staff receive adequate training, and parental mental health is considered within service provision.

4.4. *Reducing regional variation*

It is important to appreciate parent voices represented in this evaluation are the experiences of parents who had support of ABI professionals, yet RtE was still challenging in most cases. The authors recognise that in some parts of the UK, there would be no neuropsychology/neurorehabilitation team or BIS/NOONS to offer support, and it is likely the RtE process would be additionally stressful and challenging for families. The recent work of N-ABLES attempts to begin addressing this inequity with the production of best practice guidance, ABI RETURN, which informs educators and families about how best to help. ABI RETURN addresses many of the key principles highlighted by this evaluation, outlining

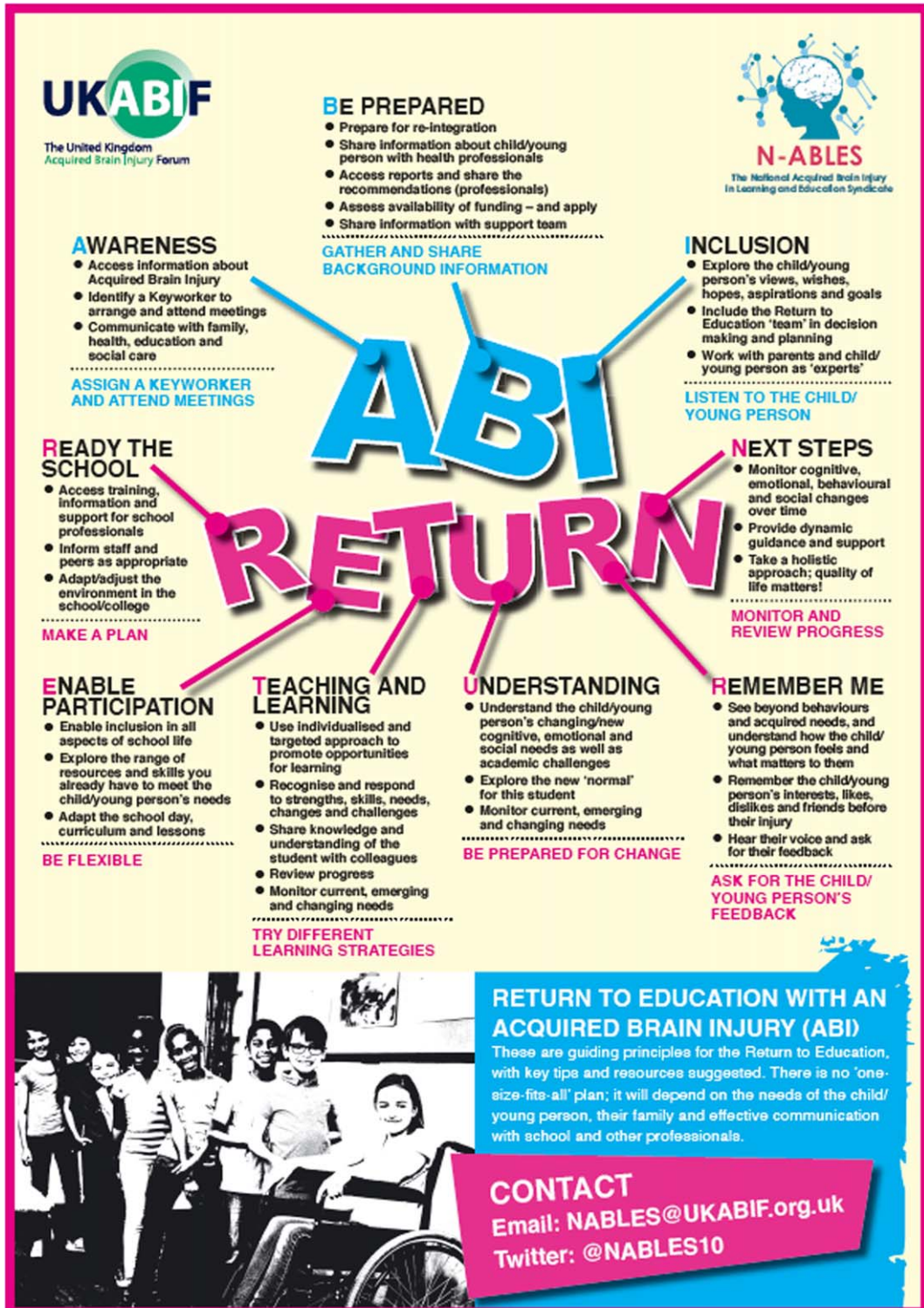


Fig. 4. N-ABLES ABI RETURN Best Practice Guidance.

848 nine key ways to support RtE, centered around com- 895
 849 munication and training, planning and preparation, 896
 850 flexible and dynamic responses within the system, 897
 851 CYP and family-centred working, and participation 898
 852 and inclusion (see Fig. 4) (UKABIF, 2021). 899

853 4.5. Strengths, limitations and future research 900 854 directions 901

855 Strengths of this service evaluation include cham- 902
 856 pioning the voice of parents with lived experience, 903
 857 within one regional system in the UK. This is helpful 904
 858 for service improvement within the specific system, 905
 859 and for wider learning about the key themes and 906
 860 gaps acknowledged. Limitations of this approach, 907
 861 however, mean that it is representative of this one 908
 862 area only and some findings may not be applica- 909
 863 ble to all UK contexts, or further afield. Research 910
 864 to explore experiences across other parts of the UK, 911
 865 with and without specific ABI RtE support, would 912
 866 be beneficial to ensure comprehensive understand- 913
 867 ing of needs and identify good practice more widely. 914
 868 Future research might also explore how hospital or 915
 869 neurorehabilitation teams might best equip families 916
 870 for knowing their rights and advocating within the 917
 871 education system. Research should also be broadened 918
 872 to explore the experience of teachers and education 919
 873 teams and their interaction with RtE pathways. The 920
 874 voice of CYP should also be sought to understand 921
 875 their experiences and understand what is important 922
 876 to them as they RtE after ABI. Next steps would 923
 877 be to investigate how support continues through- 924
 878 out a CYP's educational career once initial RtE has 925
 879 been completed, the role of neurorehabilitation pro- 926
 880 fessionals across hospital and community contexts in 927
 881 supporting this, and the effectiveness of structured 928
 882 pathways in supporting RtE. 929

883 5. Conclusions 930

884 This service evaluation set out to learn from the 931
 885 perspective of parents with lived experience of sup- 932
 886 porting their CYP's RtE after ABI. Their comments 933
 887 and insights have highlighted areas of good practice, 934
 888 and deepened understanding of aspects of RtE which 935
 889 are important for health and educational profession- 936
 890 als to improve, including communication, network 937
 891 support and awareness of ABI across these, and 938
 892 consideration of parental confidence and wellbeing. 939
 893 Despite better understanding of these issues and pos- 940
 894 itive progress regarding best practice guidance, there 941

remains a challenge as to how to disseminate best 895
 practice on a broader, national level to ensure appro- 896
 priate and timely RtE support for CYP after ABI. 897
 Ideally, dissemination and delivery supported on a 898
 multisystem level by the UK government, DfE, and 899
 local health, education, and social care partnerships 900
 would ensure schools are trained and aware of their 901
 roles in RtE after ABI. In the longer-term, this evalu- 902
 ation also makes it clear that consistent, well-defined, 903
 child- and family-centered pathways for RtE are 904
 needed, with involvement and investment from both 905
 health and education. 906

907 Declaration of interest 908

The authors have no competing interests to declare. 909

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918 Ethical considerations 919

This study, as a service evaluation, was exempt 920
 from NHS Ethical Board approval. It was approved 921
 by the NHS Trust as a service evaluation. 922

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