


Understanding barriers and facilitators to long-term participation needs in children and young people following acquired brain injuries: a qualitative multi-stakeholder study

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ABSTRACT

Background. This study focused on exploring the longer-term participation needs of children and young people with acquired brain injury (CYP-ABI) and their families in one region of the UK and identifying the barriers and facilitators of their participation and well-being to inform the development of a behavioural change intervention for clinical implementation.

Methods. Qualitative interviews were conducted with CYP-ABI and parents. Focus groups were created with health, education, care and charity stakeholders. The International Classification of Functioning, Disability and Health (ICF) and the Behaviour Change Wheel (BCW) were used to map needs, barriers and facilitators. **Results.** A total of 10 CYP/parent dyads ($n = 20$) and 17 health, education, care and charity stakeholders were included in this study. Unmet participation needs were mapped to the ICF and barriers/facilitators to the BCW. Significant unmet needs impacting CYP-ABI participation and family well-being were found. Barriers spanned 'Capability', 'Opportunity' and 'Motivation', the greatest being knowledge, skills, social influences, environmental context and resources, social identity and emotion. Facilitators included increasing awareness and understanding, supporting parents, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways.

Conclusion. The long-term impact of ABI on CYP and families' participation and well-being were significant, with barriers spanning every sector and level of society. Implementation of collaborative, cross-sector (education, health and social care) accessible and family-centred care pathways is needed to meet the long-term needs of CYP-ABI and their families, ensuring equity of access. Multi-modal, family-centred, needs-led, theory-based interventions should be co-developed with CYP, families and stakeholders to improve the health and well-being outcomes and the lives of CYP-ABI and their families.

Keywords: acquired brain injury, barriers, children, facilitators, family, implementation, intervention development, participation, well-being, young people.

Introduction

An acquired brain injury (ABI) in children and young people (CYP) is defined as either a traumatic (e.g. a fall or road-traffic collision) or non-traumatic (e.g. a stroke, infection or brain tumour) injury to the brain occurring since birth (McKinlay *et al.* 2016). Traumatic brain injury (TBI) is the leading cause of childhood morbidity and mortality worldwide with an estimated incidence of between 47 and 280 per 100 000 children, depending on the country (Dewan *et al.* 2016). In the UK, approximately 40 000 CYP sustain an ABI annually, with over 9000 cases classified as moderate or severe (NHS England 2013). Physical, cognitive, emotional and/or behavioural impairments can significantly impact

physical and psychological development, quality of life (QoL) and participation outcomes (Anaby *et al.* 2012; de Kloet *et al.* 2015). As such, ABI is conceptualised as a chronic condition with functional changes occurring over a decade after injury (Molteni *et al.* 2021). A scoping review identified extensive unmet and unrecognised needs up to 12 years post-injury, with needs relating to CYP's impairments, parent and family support, return to school and long-term after-care (Keetley *et al.* 2019). Furthermore, there are increased risks of long-term poor health and psychosocial outcomes in adulthood, which present the need for long-term rehabilitation and support (McKinlay *et al.* 2016; Sariaslan *et al.* 2016; Holloway *et al.* 2019; Lindsay *et al.* 2023).

Participation, a key domain in the International Classification of Functioning, Disability and Health (ICF), is a complex multidimensional construct, defined as 'involvement in a life situation' (World Health Organisation 2002). Participation in home, school and community activities is a fundamental right and enhances the well-being of all, including children with disabilities (Imms and Green 2020). However, CYP-ABI and their families report reduced participation and QoL in the years after injury (Keetley *et al.* 2019; van Markus-Doornbosch *et al.* 2020; Allonsius *et al.* 2021; Wales *et al.* 2021; Keetley *et al.* 2022). A cross-sectional survey of CYP-ABI and their parents 1–4 years post-injury found significant long-term impacts of an ABI on CYP participation and both CYP and parent well-being (Keetley *et al.* 2022). Of the CYP participants, 72% had severely restricted participation, and 67% reported reduced health-related QoL. Of the parent participants, 53% reported reduced health-related QoL and family functioning, and 37% of parents screened positive for anxiety/depression. Reduced participation and well-being can isolate families and increase CYP disability (McLaughlin and Coleman-Fountain 2014; Batorowicz *et al.* 2016; King *et al.* 2018; Lindsay *et al.* 2023). Improving survival rates for many childhood ABIs (e.g. brain tumour) means more CYP are living with the long-term impacts of ABIs and require paediatric rehabilitation services and support throughout their life courses (NHS Digital 2023).

Rehabilitation aims to maximise functional recovery and well-being, with participation in individual life contexts (home, school, community) seen as both the means of skill development and the outcome (Wade 1992; King *et al.* 2018; Imms and Green 2020; Resch *et al.* 2020; Anaby *et al.* 2021). Widespread variability in paediatric rehabilitation results in uncertainty regarding the long-term outcomes of CYP-ABI and their families. It is unclear how services should be designed to meet their needs and optimise their participation and well-being (Hayes *et al.* 2017; Wales *et al.* 2021).

Diener *et al.* (2022) described the community reintegration (participation) needs of a small sample of US CYP-ABI and their families. Through qualitative interviews with caregivers of 6 CYP-ABI and 14 outpatient and community providers, they found substantial unmet needs,

including issues related to CYP's impairment and identity, social isolation and a lack of education for parents, peers and teachers. Additionally, they found a lack of coordinated family-centred care and access to funding and resources. Similarly, qualitative interview studies of 14 Australian rehabilitation services for CYP with TBI and spinal cord injury, found multiple challenges to family-centred care delivery, including poor communication and understanding of needs across sectors (Botchway *et al.* 2022; Botchway-Comme *et al.* 2023). Both studies conclude collaborative multi-system interventions and broader-scale system improvements are required to address the needs of CYP-ABI and their families in the long-term. However, to develop interventions that address needs and improve outcomes, a greater understanding of influential factors is required (Keetley *et al.* 2019; Wales *et al.* 2021).

The Medical Research Council's framework for developing and evaluating complex interventions recommends using theory and evidence when developing interventions (Skivington *et al.* 2021). Implementation science offers a pragmatic, systematic and theoretical approach to health-care research that incorporates the use of theories, models and frameworks to guide the process of translating research into an evidence-based practice (Nilsen 2015; Guyatt *et al.* 2021). It draws on a range of theories, such as psychological theories, to help identify and define core components of complex interventions and ensure that the integrity of these are maintained regardless of the context for intervention (Skivington *et al.* 2021). Theoretical frameworks, such as the Behaviour Change Wheel (BCW), help us to understand target behaviour(s), barriers and facilitators to behaviour and mechanisms likely to lead to successful implementation of evidence-based behaviour change interventions (Nilsen 2015; Atkins *et al.* 2017). Additionally, engaging stakeholders using qualitative methods when developing theory-informed interventions ensures the needs, barriers and facilitators to the target behaviour and the real-world context are well understood. This detailed understanding guides intervention development and implementation by ensuring new interventions are acceptable, address the target population's needs, and identify potential implementation barriers and facilitators (Atkins *et al.* 2017).

This study aimed to explore the longer-term participation and well-being needs of CYP-ABI and their families in one region of the UK and to identify barriers and facilitators to participation (target behaviour) and well-being to inform the development of a participation-focused intervention.

Method

Design

We conducted a qualitative exploratory study, using a pragmatic approach and semi-structured interviews with

community-dwelling CYP-ABI and parents, as well as focus groups with health and social care professionals to identify and understand participation needs, barriers and facilitators (Ritchie *et al.* 2014; Atkins *et al.* 2017). Ethical approval was gained from the UK Health Research Authority (REC-20/EM/0258).

Methodology

Two theoretical frameworks informed this study. The ICF biopsychosocial model was used to map the impact of the brain injury on the CYP/family in four domains: (1) 'body functions and structures', (2) 'activity and participation', (3) 'personal factors' and (4) 'environmental factors', as well as to describe participants' unmet participation needs (World Health Organisation 2002). The BCW (Michie *et al.* 2014), which incorporates the COM-B model of behaviour and the Theoretical Domains Framework (TDF), provides a systematic process for using theory and evidence in the design of interventions. It has been used to inform multiple intervention development studies, including physical activity interventions for adolescent girls and adults (Murtagh *et al.* 2018; Truelove *et al.* 2020) and increasing social participation of adult stroke survivors (Gingrich *et al.* 2023). We chose it to guide the design of the intervention and the identification of determinants of the target behaviour (participation), barriers and facilitators to participation; how behaviour change might be achieved; and the context for intervention delivery. The COM-B, at the centre of the BCW, describes sources of behaviour. 'Capability' describes the physical and psychological abilities of a person related to a behaviour; 'Opportunity' is the properties of a person's environment that affect their ability to enact a behaviour; and 'Motivation' describes influences on motivation to perform that behaviour (Michie *et al.* 2014). The TDF, a determinant framework, subdivides the COM-B components and aids a greater understanding of barriers and facilitators at individual, organisational and community levels (Table 1) (Atkins *et al.* 2017).

Participants

CYP-ABI, their parents, as well as health, education, social care and third-sector professionals participated in this study. CYP-ABI and their parents were identified from 95 participants who had completed an earlier survey of participation and QoL outcomes (Keetley *et al.* 2022). CYP were aged 5–18 years with moderate to severe ABI sustained 1–4 years previously (to capture persistent longer-term needs), and they received in-patient care at a regional specialist paediatric neurosciences centre. Survey participants who had expressed interest in being included in a further interview were purposively sampled using a sampling frame (including sex, diagnosis, county, ethnicity, injury severity and deprivation) taken from survey responses and the clinical

Table 1. Behaviour change wheel – COM-B components and TDF domains.

COM-B components		TDF domains
Capability	Psychological	<ul style="list-style-type: none"> – Knowledge – Skills – Memory, attention and decision processes – Behavioural regulation
	Physical	<ul style="list-style-type: none"> – Skills
Opportunity	Social	<ul style="list-style-type: none"> – Social influences
	Physical	<ul style="list-style-type: none"> – Environmental context and resources
Motivation	Reflective	<ul style="list-style-type: none"> – Social/professional role and identity – Beliefs about capabilities – Optimism – Beliefs about consequences – Intentions – Goals
	Automatic	<ul style="list-style-type: none"> – Social/professional role and identity – Optimism – Reinforcement – Emotion

registry data used in the survey (Ritchie *et al.* 2014). A 20% subsample was identified, following the principles of sample adequacy, ensuring cases were 'information-rich', diverse and representative of this heterogeneous population (Vasileiou *et al.* 2018).

Stakeholders representing health, education, social care and charity providers were recruited through existing regional referral networks and persons known to the research team and were invited to participate in a focus group.

Procedure

The study was conducted online using the Microsoft Teams platform. Interviews were completed between August 2021 and May 2022, and focus groups were completed in November 2022. All data were collected online using Microsoft Teams. Participants completed an online consent form before participation, with parents consenting for CYP under 16 years of age. Topic guides for interviews and focus groups included questions aligned to the theoretical framework domains and survey findings. Interview formats and timings were led by the CYP and parents. Interviews commenced with CYP and parents together, with those over 16 years of age being able to choose whether they wanted their parents present or not. CYP participated as much or as little as they wished and were free to leave at any point. Parents were then interviewed alone. All interviews and focus groups were conducted by RK, with the assistance of a co-facilitator (EB) and chat moderator/note taker (MW) for the focus groups. Microsoft Teams chat and whiteboard functions were also used within the focus groups. Interviews and

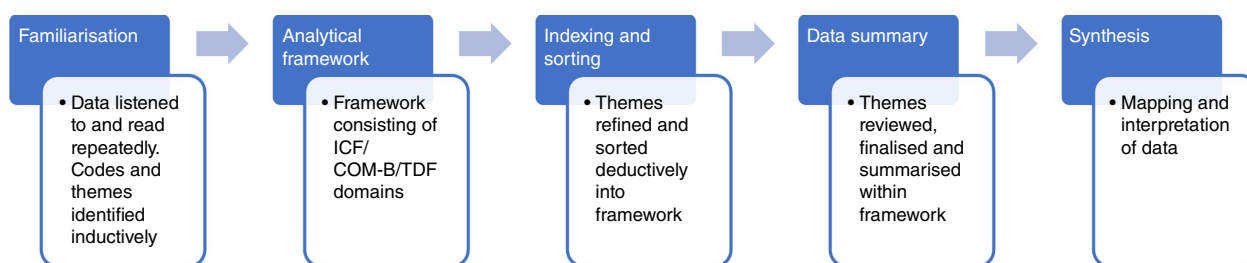


Fig. 1. Data analysis plan (Ritchie et al. 2014).

focus groups were audio recorded and transcribed verbatim by RK or a professional transcriber, with these being cross-checked by RK and a peer researcher (LR). Transcripts and chat/whiteboard contributions were anonymised with pseudonyms or professional roles used to protect participant privacy.

Analysis

Transcripts were imported into NVivo (ver. 12). Data were analysed using a framework analysis, with the domains of the ICF and COM-B/TDF forming the preliminary framework (Fig. 1) (Ritchie et al. 2014; Lawton et al. 2016). Through a systematic and iterative approach, interview and focus group data were analysed separately as two datasets, with codes and themes identified inductively. Themes were then refined and deductively mapped to the framework before synthesising the datasets.

Researcher characteristics, trustworthiness and reflexivity

The lead researcher is an experienced children's neurorehabilitation physiotherapist. Recognising the potential influence of the researcher's perspective, regular consultations with the research team and study steering group (experienced paediatric neurorehabilitation clinicians from the regional centre) were held to validate coding and interpret emerging themes (Saldaña 2016). Field notes were maintained for interviews and focus groups and used during analysis alongside the transcripts for context and reflexivity (Phillippi and Lauderdale 2018).

Results

Eleven interviews and two focus groups were conducted. Ten CYP/parent dyads participated in the interviews. Interviews were adapted where necessary to enable CYP participation and ranged from 13 to 73 min, the shortest was due to splitting one interview into two parts to accommodate the CYP participant's needs. Seventeen stakeholders participated in focus groups lasting 73–78 min. Participant characteristics are shown in Table 2. Key themes identified from the framework analysis relating to unmet participation

Table 2. Participant variables.

			<i>n</i>
CYP	Sex	Male	7
		Female	3
	Age (years)	5–10	4
		11–15	3
		16–18	3
	Diagnosis	Non-traumatic brain injury	7
		Traumatic brain injury	3
	Severity ^A	2–3b (disorder of consciousness–severe disability)	8
		4a–5b (moderate–mild disability)	2
	Length of hospital stay	Median (days)	18.5
		(Range)	(4–102)
	Indices of Multiple Deprivation Quintiles (IMD) ^B	1–2	3
		3	3
		4–5	4
Parents	Mother		10
Stakeholders	Professional		17
	Nurse		3
	Allied Health Professionals ^C and Neuropsychologists (AHPN)		7
	Education professionals and support staff (EPS)		5
	Social care/charity partners (SCP)		2

^ASeverity measured using Kings Outcome Scale of Childhood Head Injury (Crouchman et al. 2001).

^BIMD (measure of relative deprivation for small areas in the UK – 1 most deprived, 5 least deprived) (Ministry of Housing Communities and Local Government 2019).

^CAllied health professionals including acute and community physiotherapists, occupational therapists and speech therapists.

needs and barriers and facilitators to participation and well-being are presented here.

Unmet participation needs

Using the analytical framework, themes relating to participants' needs were deductively refined and sorted into the framework. Participants reported multiple unmet participation needs impacting CYP-ABI and family participation and well-being. Restrictions in participation were reported in every ICF sub-domain of activity and participation at home, school and

community settings, and unmet needs were related to addressing these or accessing support to overcome barriers (Table 3).

Mapping barriers and facilitators to the COM-B/TDF

Barrier and facilitator themes inductively identified included issues related to well-being, support, information and resources (Fig. 2). These themes were deductively sorted into the analytical framework and spanned the COM-B 'Capability', 'Opportunity' and 'Motivation' domains and

Table 3. Participation unmet needs.

ICF participation sub-domains	Unmet needs	Example quotes
Learning and applying knowledge	–Access to additional learning support	'Elijah struggles a bit with his memory and sometimes he struggles with trying to find the right words to say so he'll take a while to answer something to try and get the right words.' (Elijah's Mother)
General tasks and demands	–Support to develop independence in daily routines	'It's more so when he's tired or he's not concentrating...he hasn't got the memory to remember what tablets he has.' (Barney's Mother) 'My mom helps me with like stuff that I need to pack. Or if I need to go over and remember some things.' (Elijah)
Communication	–Support with communication difficulties	'She's lost all her confidence completely now talking to other people. She's looking to me all the time....' (Megan's Mother) 'Banter sometimes can be a bit tricky. The filter's not on and he says what he's thinking out loud, and sometimes that can be, oh my gosh, should he have said that?' (Hamza's Mother)
Mobility	–Developing skills: –Walking –Fine motor skills –Driving car/riding bike	'Because he's struggling with buttons and his tie and laces and what have you.' (Robert's Mother) 'Probably go back to physio try to get some more use in my body.' (Barney) 'Driving, I want to work because I've got a placement with college soon what involves working and driving and it's always been a thing I've wanted to do....' (Jack)
Self-care	–Developing washing and dressing skills –Safety awareness	'It's not the actual journey of knowing the direction that you're going to walk to and from, it's the actual crossings, being aware of whose right is where and being aware of give-ways, being aware of three-way junctions.' (Hamza's Mother)
Domestic life	–Preparing meals	'Because I want to cook things by myself and just get ready if you're not going to be there to cook anything.' (Oscar talking about developing independence at home)
Interpersonal interactions and relationships	–Difficulties with friendships or lack of friends	'He's become a bit of a recluse to be fair.' (Barney's Mother)
Major life areas	–Education: –Developing independence in school –Needs not being understood –Reduced physical activity (lesson-based and playground/breaktimes)	'But once he went up to high school, because Elijah looks fine and he doesn't look like he's had a brain injury, really, you know...and I think they think, oh it's fine and everything's OK when, well no, it's not.' (Elijah's Mother) 'I want her to be outside, to get some fresh air and see her friends, she's not seen anybody; and they were saying, but we can't watch her outside, we can't keep her safe.' (Megan's Mother talking about safety at playtimes)
Community, social and civic life	–Recreation/leisure activities –Support to identify and access appropriate activities –Developing independence within community settings	'That one can be a bit tricky can't it? I don't like you to go too far do I?' (Amelia's Mother talking about her playing outside with friends) 'She is interested in doing something but how do I do that, and you know, what can I do for her and I don't know what I can do for her? I don't know where I can go to get help for her.' (Megan's Mother) 'Buses has come up in our conversations, but she just wants to make sure I'm there safe, that I don't catch the wrong bus and that.' (Jack)

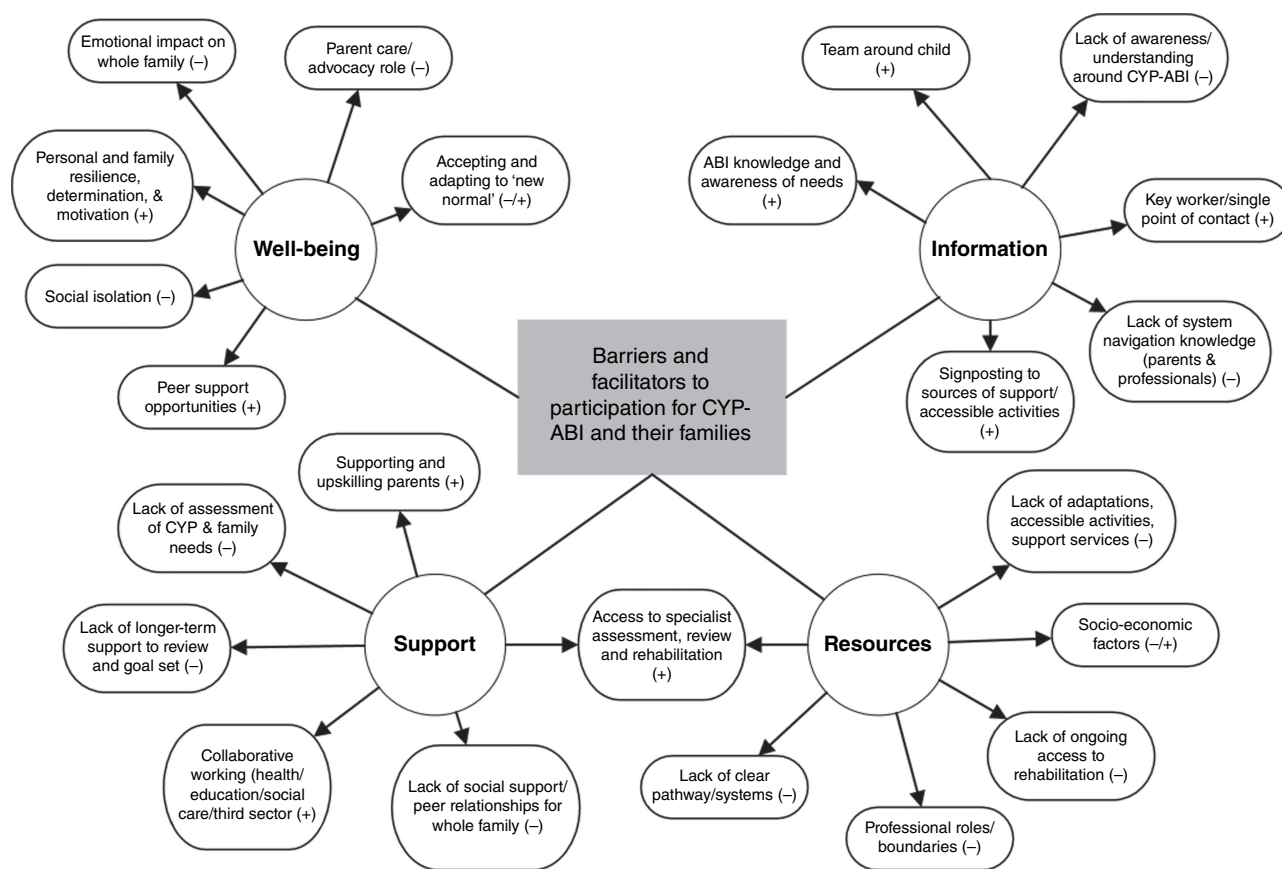


Fig. 2. Barriers and facilitators to participation for CYP-ABI and their families (- = barrier, + = facilitator).

nine of the TDF domains (Table 4). The main barrier and facilitator themes are presented here within their COM-B and TDF domains, with additional themes and quotes presented in Table 4 and Supplementary file S1.

Capability barriers

Knowledge

An overwhelming **lack of awareness and understanding** about the impact of ABI across every level of society caused barriers to participation, especially in school and community settings. Hidden impairments (e.g. cognitive impairments) and new or emerging needs posed particular challenges, especially in education settings and through educational stages.

To address these deficits, parents reported needing to rapidly develop expertise about the impact of ABI and the array of potential effects, which stakeholders also recognised:

They've [parents] never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't

necessarily specialists that they have all this to cope with on a daily basis. (Nurse-2)

Parents described the initial information overload in the acute phase post-injury but the need for more timely information and support in the longer-term.

Parents also reported **system navigation difficulties** and having to learn how to navigate complex health, education and social care systems, which many have no previous experience of:

I feel that school is a category and, you know, social life is a category, and medical is a category and the dots are not joined up for a brain injury, and a brain injury's everything isn't it, it's everything, it's everything in your life. (Megan's Mother)

Similarly, professional stakeholders described systems as hard to understand and navigate, which affected their ability to effectively advocate and access support for families.

Skills

Participants felt that a **lack of long-term monitoring and assessment** was a barrier to accessing the support CYP and families needed:

Table 4. Identified barriers and facilitators mapped to the Behaviour Change Wheel/Theoretical Domains Framework.

COM-B/TDF domain		TDF construct	Barrier/facilitator	Theme	Quotes
Capability	Knowledge	Knowledge (about condition)	Barrier	Lack of awareness and understanding	‘They’re also then going into contexts where there’s also a lack of understanding, so they go back to school, they go back to community settings, where people also don’t understand acquired brain injury and don’t know about making sure that things are accessible...’ (AHPN-7)
			Facilitator	Education and training for families and professionals	‘It’s hard to describe but it’s something that you’ve got to carry on living with. But most people, unless they’ve come across a brain injury, they haven’t got a clue.’ (Robert’s Mother)
		Procedural knowledge	Barrier	Lack of knowledge regarding system navigation	‘And it’s just that education that encouragement that it’s not the end of your life, it’s a challenge, yes, we need to make adjustments and with the help of somebody supporting you, you can move that forward.’ (Nurse-3)
			Facilitator	Support and upskill parents	‘I think training staff, particularly school staff, to feel empowered to know how to adapt their environment...just really subtle approaches that can be used to help children.’ (AHPN-5)
Skills	Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs	‘I just, I feel that school is a category and, you know, social life is a category, and medical is a category and the dots are not joined up for a brain injury, and a brain injury’s everything isn’t it, it’s everything, it’s everything in your life.’ (Megan’s Mother)
			Facilitator	Support and upskill parents	‘...on a really regular basis, a family will come to me and say we’ve got this problem and I’ll think okay, I’ve not got a clue how to sort that out, but you probably know who to ask, to work out the answer, but families just don’t have that, do they?... I think collaboration is so important. That being able to phone a friend. That, well I don’t know what to do about this, but I know who to go to. Again, you’ve got to understand how systems work to know who to go to, which parents often don’t.’ (Nurse-1)
Skills	Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs	‘There’s a lot of unrecognised needs in terms of referrals from education out to community, out to kind of other participatory contexts, but also perhaps from community services as well because, like you say, if the expectation is well they’re getting to school, they’re coping with that, that’s brilliant, but actually they are going to be exhausted, then we’re not thinking, but normally they’d be going swimming or they’d be doing X, Y and Z as well. We’re almost closing their world in a little bit, aren’t we, as a system around that child.’ (AHPN-7)
			Facilitator	Support and upskill parents	‘And so as they’re going through the education process, you may hit a particular aspect of the curriculum or a cognitive step that you

(Continued on next page)

Table 4. (Continued)

COM-B/TDF domain	TDF construct	Barrier/facilitator	Theme	Quotes
	Ability/skill development	Facilitator	Access to specialist assessment and review	want them to take, and suddenly you find that they have lost that knowledge or they can't bridge that gap, or they've lost that function. But you and they don't know that until they reach that benchmark, milestone, challenge what, whatever it might be, so it's a really unpredictable kind of future for them.' (EPS-I)
				'I think for me, it's something about – it probably comes down to money and time and all of those things, about being able to offer longevity of support. This ongoing support for these families, so that they know who they can come back, they can come back and that when new needs are identified, there is something to do about that need, so you can go to the right person and you can offer that support, so sort of the ongoing support, but also the network around that, that allows if I identify a need in a child, to say okay, they need this, I can then refer them to that or I can signpost them to that or I can put them in the right direction.' (Nurse-I)
		Barrier	Lack of ongoing rehabilitation access to address impairments	'As time's gone on, I realise more and more how important it is he gets out there and picks up on those skills, how to talk to people, how to handle situations, how to be more independent.' (Hamza's Mother)
				'There is certainly a frustration around not being able to offer as much as one might like to. So we're very much based on episodes of care in the community. We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need.' (AHPN-I)
	Memory, attention and decision processes	Facilitator	Access to specialist rehabilitation support	'...because if it was just up to me, I would've thought, well other people would think I probably wouldn't drive, I probably wouldn't be riding a bike..., so over the past year the physio, all their help and the support they got me they definitely...I can do things, I can do it or try and do it.' (Jack)
		Barrier	Impact of fatigue	'...personal trainer and that was really, really good for his self-esteem, physical health, and that was really good.' (Jack's Mother)
				'Much more tired, after school and stuff.' (Elijah)
				'If you've got a child who's very, very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask for, almost, because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that.' (Nurse-I)

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Table 4. (Continued)

COM-B/TDF domain		TDF construct	Barrier/ facilitator	Theme	Quotes
Opportun- ity	Social influences	Social support	Facilitator	Education and training regarding managing fatigue	'Managing their fatigue – I don't know if anybody has, that's such an under researched area and actually for schools to manage children and for children themselves actually. I don't know what it's like in the primary sector, I would imagine difficult, but for children to learn how to pace themselves and to manage their fatigues extremely difficult in the school context because of the way that the day works.' (AHPN-7)
				Support with learning	'...he's got an EHCP [Education Health Care Plan] and he's got a one-to-one in each lesson.' (Robert's Mother)
	Environmental context and resources	Environmental stressors	Barrier	Social isolation/lack of CYP peer relationships	'I think they have emotional challenges relating to peer relationships that can be very impactful, particularly if they're in adolescence, but not solely if they're in adolescence.' (EPS-1)
				Lack of peer support for parents/families	'And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.' (EPS-2)
			Facilitator	Peer support for whole family	'For schools this is probably slightly easier, but it's trying to tap into peer support, trying to use the friendship groups that you've got around that child to then encourage their progress from that point of view.' (AHP-4)
					'I think there is some scope and opportunity to do it [online peer support], and we've done some, you know, we haven't done patient led ones, but sibling things, and actually they've worked, if you get it right, they've worked really, really well and you can engage people you know who are geographically a long way apart...so there's, I think possibly the scope to use that and expand that going forward in order to, you know, to get people together that otherwise wouldn't get the opportunity.' (SCP-2)
				'In a regional network it would be a project to look at to find those links for families that come from our area and to link up better both for the children and for their parents as well.' (AHPN-6)	
			Barriers	Substantial parent care and advocacy role	'It does, now obviously it does involve twenty-four-hour care, I mean you know, I was up at 4:00 am this morning, suctioning and things like that, so she does need full assistance with manoeuvring and her mobility's very reduced.' (Charlotte's Mother)
					'I think in terms of brain injury I think there's no consistency of support, the consistency's not there... You don't have any point of

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Table 4. (Continued)

COM-B/TDF domain	TDF construct	Barrier/facilitator	Theme	Quotes
				contact, you don't have one person who can help you with all these things.' (Megan's Mother)
				'I think the families and the young people I worry about more are perhaps those who can't express those things [needs and views] in the same way, or who perhaps don't have that support.' (AHPN-7)
			Lack of clear pathways/ systems (health/social care/ education)	'I think it's really hard because you can see the need, but you don't know where to go....it's where you go, that parent is taking a case manager's role in trying to deal with things but they haven't got that understanding of the system and the professionals involved and they don't have access to it... You need this service but they just – where do you go to get that? It's really hard.' (AHPN-3)
			Impact of COVID-19 pandemic	'I just think, especially because...he's transitioning from child to adult services sort of within the next six months, yeah, six to eight months he'll be transitioning over, I just think the communication needs to be a lot clearer.' (Barney's Mother)
				'He'd only just sort of started with his whole time one-to-one when we went into lockdown, so he sort of fell even further behind.' (Robert's Mother)
				'It stopped everything really. There was no more support. It was all of a sudden, down to you to self-manage. So that was really, really hard work.' (Hamza's Mother)
		Facilitator	Point of contact/support for parents	'I think that's the thing, isn't it? They need somebody that's got that time to look up stuff for them, point them in the right direction.' (Nurse-2)
			Care pathway/policies	'I think national and local pathways and policies...so everybody knows this is what we need to do and that's where they need to go and it would be the same for everywhere.' (Nurse-2)
	Resources/ material resources	Barrier	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)	'I find families find it very difficult to find groups and activities and I find it very difficult to know where to find that information.' (AHPN-3)
				'I'm still waiting for my adaptations to be done...three months ago I emailed the architect that's doing the work on Barney's adaptations and I've still yet to have a response from him.' (Barney's Mother)
				'That's [social care access] a big issue at the moment and I think we've really noticed recently, it's nigh on impossible, it's resource based, isn't it? ...I mean the thresholds are – ...they basically said if

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Table 4. (Continued)

COM-B/TDF domain		TDF construct	Barrier/facilitator	Theme	Quotes
			Facilitator	Information resources	<p>it's not safeguarding, we're not touching it. But this child has a permanent disability.' (SCP-2)</p> <p>'I've definitely experienced socioeconomic difficulties and have really had to work in a bit of a social work capacity.' (AHPN-1)</p> <p>'...some kind of information sheet which said, you've sustained a possible acquired brain injury, these are the symptoms, these are the people that can help you, these are the services that you could be referred to, this is who can help you at school, this, because every single bit of the way I feel like I've had to dig away trying to find which direction to go into, and everyone has their area of expertise, which they've helped me with, but it's been very difficult to connect all the dots up.' (Megan's Mother)</p>
Motivation	Social/professional role and identity	Social identity	Barrier	'New normal'	<p>'The hidden bit in terms of a lot of these children do quite well from their motor skill recovery, but actually it's then – they're walking and talking and look fine. They want to get back to normality, but actually there's still a long way to go.' (AHPN-7)</p> <p>'So they've got to completely re-change and re-focus where they're going. So adapting to the new normal and working out what their expectations need to be now...there's a whole re-shaping of expectations, not only within the child, but also with all the support staff and the parents and staff.' (AHPN-5)</p>
			Facilitator	CYP motivation	<p>'Walking home from school, there is no hard road for me to cross because I've done it before. There was a time last year where my French intervention wasn't on and I deliberately didn't call my parents – I just didn't want to – so I walked it by myself.' (Hamza)</p> <p>'She does try and maintain her independence as much as possible and sometimes I'm a bit guilty of, like for instance, you know, in the bath, I'll get the puffer and the shower gel and I'll go to give her a wash and she'll grab it off me as if to say, I can do that, and she'll do it herself.' (Charlotte's Mother)</p>
		Professional role/boundaries	Barriers	Professional roles and boundaries	<p>'They need somebody that's got that time to look up stuff for them, point them in the right direction, which a lot of clinicians, if you've</p>

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Table 4. (Continued)

COM-B/TDF domain	TDF construct	Barrier/facilitator	Theme	Quotes
Beliefs about capabilities/ beliefs about consequences	Self-confidence/ perceived competence	Facilitator	Collaborative cross-sector working	not got a specialist role, haven't got that time to be doing and helping them think outside the box.' (Nurse-2) 'So some of it, I think, is just awareness of when other professionals can get involved and just that collaborative working, so that people can access more therapy and more of their lives, really.' (AHPN-5)
		Barriers	Lack of parental or CYP confidence	'I would've loved to have taken her swimming...absolutely not... there's a lot of things that I'm confident in, and then there's things like that.' (Charlotte's Mother)
			Lack of insight	Barney's Mother: 'Because I don't know if he's going to have, if he has a seizure, and [he] doesn't understand that.' Barney: 'I could call myself an ambulance.'
			Safety concerns	'I want her to be outside, to get some fresh air and see her friends, she's not seen anybody; and they [school] were saying, but we can't watch her outside, we can't keep her safe...' (Megan's Mother)
Goals	Goals (distal/ proximal)	Facilitator	Access to rehabilitation support	'We could be supporting these challenges with participation that we often see further down the line, we could be supporting that so much more effectively if there was just investment in that longer term perspective, but we often get kind of a huge investment in that acute sort of side, which is really needed but then it thins out, doesn't it?' (AHPN-7)
		Barrier	Lack of support to achieve longer-term goals	'I think most challenges extend into education and other settings as well, because you think about that sudden change of needs of an ABI and the education system is not set up to deal with that. So you know, you've often got kids going back in where they can't get any EHCP. They probably won't even meet the criteria..., but also they've missed the funding pots because it's not the start of term when they had their brain injury.... They're trying to get them back into school to get them participating, to get them seeing friends, to get them doing all those things we want them to do but they can't because they've not got a TA [Teaching Assistant] or they've not got the support and they're having to just juggle things within education because the system is not fit for purpose when you've got that change in needs.' (AHPN-7)
		Facilitator	CYP motivation/goals	'So I think it's more driven by Jack... If he wants to do something then we set a goal that he'll be able to do it.' (Jack's Mother) 'Because I want to cook things by myself and just get ready if you're not going to be there to cook anything.' (Oscar)
				'Maybe because I just like doing sports, I just like being active; and my dream is to be in the [professional sports association] at the moment, so that's what I'm trying to work up to.' (Fred)

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Table 4. (Continued)

COM-B/TDF domain	TDF construct	Barrier/facilitator	Theme	Quotes
Emotion	Affect	Barriers	CYP emotional impact	'Yeah, I'm sick of being inside 24/7.' (Barney)
				'It's a long time of him worrying.' (Elijah's Mother)
			Parental emotional impact	'You think the hospital's going to be the hardest time, but I think it's...I don't even know what sorts of things, but it's when you go home and, like I say, we're nearly four years in...since starting the secondary school, this has probably been the hardest time since, the most challenging.' (Robert's Mother)
		Facilitators	Family impact	'I find that a lot of my families, there can be relationship breakdowns as well and quite often, it tends to be the mum within the family that feels that she needs to take all of this on and then that breaks down relationships. It's a really hard time for them.' (SCP-1)
				'And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.' (EPS-2)
			Resilience/bravery	'So I think you've got to take the positive out of it, because as the trouble is, you're always going to live in the past aren't you, and you never – because I say to myself, I needed to let him ride his bike again, you know, I need to let him go out and see his friends because, you know, I don't want him to stay in the past of the accident as well.' (Fred's Mother)
			Support for families	'There is a need to be brave to do something new, do a new activity, join a new group and that can require a lot of energy and resilience.' (SCP-2)
				'I think there's a lot out there for siblings. Like we use [charity] a lot for siblings but again, doesn't quite allow the young person with a brain injury, depending on their severity, to go to camp.' (Nurse-2)
				'I think maybe just, maybe information about support groups really.' (Robert's Mother)
				'I think, if there's something for people with common experiences that give their tips, I don't know, or professionals that can advise, I think that would be useful.' (Oscar's Mother)
				'We belong to [charity]. They've been absolutely brilliant. Yeah, they've been really, really good, like really quite a good like source of help for me as well.' (Amelia's Mother)

I think it's even harder with ABI seen as such a hidden disability...there's nowhere really to turn because nobody's really understanding what needs we have. (SCP-1)

CYP and parents described the need to address participation barriers by developing skills and strategies to manage them and achieve goals. It was felt this required practice, exposure to new contexts and support from family and rehabilitation professionals. Parents and stakeholders described frustration with the **limited access to rehabilitation** in the years post-injury and saw this as a major barrier to CYP-ABI's development and participation:

I do believe that physio should have continued more for him... Occupational, I believe they could've taken more part in his daily activities, like walking, crossing roads... (Hamza's Mother)

Memory, attention and decision processes

The **impact of fatigue** was discussed by almost all participants as a significant barrier to participation:

If you've got a child who's very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask...because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that. (Nurse-1)

Capability facilitators

All participants identified that targeted education and training for peers, professionals and families across the health, education and social care systems are essential to address the aforementioned knowledge and awareness deficits. These include clear and timely signposting and access to relevant information and sources of support and education (primary care, social care and charitable organisations). Additionally, access to timely and appropriate support from specialists is required to assist schools in understanding and addressing the specific needs of individual CYP.

I think training staff, particularly school staff, to feel empowered to know how to adapt their environment... just really subtle approaches that can be used to help children. (AHPN-5)

Participants recognised the need to support, upskill and empower parents to identify their CYP's needs, navigate complex systems, self-advocate and self-manage. Additionally, they felt long-term access to specialist support is necessary for the assessment of needs and skills, realistic

goal setting and rehabilitation planning to enable CYP participation. A specific need for fatigue management support to enable prioritising or balancing activities more equally across education and sports, hobbies and socialising was identified.

Therefore, interventions need to address the knowledge and skills of those supporting CYP-ABI to ensure they have the capability to advocate effectively for needs to be met.

Opportunity barriers

Social influences

Long periods away from school following ABI and the impact of impairments limiting the ability to go out with friends were viewed as social barriers, impacting pre-injury friendships and resulting in **social isolation**, as well as mental health and well-being concerns:

Those sports and hobbies that you would have done before for that like kind of mental well-being as well as...social interaction that maybe aren't as accessible to you now. (AHPN-6)

Although health professionals felt school was ideally placed to address unmet socialisation needs, education staff disagreed and were very aware that having one-to-one support in school impacted CYP's ability to interact with friends. All participants recognised that their inability to participate in sports and activities also affected their socialisation.

Parents and stakeholders spoke about the **lack of peer support** for parents and siblings. Parents described living with the isolating after effects of their CYP's ABI and how support from peers who understood would be invaluable:

Most people, unless they've come across a brain injury, they haven't got a clue...I suppose maybe speaking to people that actually understand what you're talking about rather than just, 'well, you know, he looks fine'. He is fine, but it is quite isolating and lonely really. (Robert's Mother)

There was also shared concern for siblings of CYP-ABI, the emotional impact on them and the lack of support (including peers) available.

Environmental context and resources

Parents' **substantial care and advocacy roles** were seen as huge issues impacting the whole family. Care needs ranged from assisting CYP with organisation for school to complex healthcare needs and constant supervision. Some parents had stopped working or altered their working patterns

accordingly. None of the families interviewed had employed carers, either choosing not to or because they experienced difficulties accessing care packages.

Parents described their experiences of advocating for their CYP as a 'battle'. Stakeholders were acutely aware of the lack of support and complexity parents managed, voicing concerns regarding its overwhelming nature, particularly for more vulnerable families (e.g. lower socioeconomic status):

I think that's absolutely massive, that sense of feeling very, very overwhelmed and yes, some parents are able to almost do that project management bit themselves, and other parents just are not at all and need someone to project manage for them...Just not knowing which way to turn and which door to open or avenue to go down, really. (AHPN-1)

The **lack of clear pathways or systems** for CYP-ABI added to the care complexity. Transitions between hospital and home, return to education, education stages and into adult services presented major challenges and could occur any time after ABI. Issues faced were often caused by procedural or funding issues regarding CYP's additional support needs:

But once he went up to high school because he looks fine and he doesn't look like he's had a brain injury... You wouldn't even know if you didn't know. And I think they think, oh it's fine and everything's OK when, well no, it's not. And he does need, you know the extra support... (Elijah's Mother)

Stakeholders confirmed systems were structurally inflexible, and they struggled to adapt to sudden changes in needs. The absence of key worker or coordinator roles and difficulties re-accessing health and social care services as new needs emerged compounded this. A lack of communication, collaboration and understanding regarding the needs of CYP-ABI within commissioning and across organisations was reported as a barrier to CYP and schools accessing appropriate support.

I wonder if that's part of the gaps, though...where the professionals can't refer to each other and there's not that kind of ability, is there, to be able to kind of work across departments in the same way. Much as we all want to, I think it is an endless frustration. (AHP-7)

A **lack of resources** available to families was reported as a significant barrier to participation. This included housing adaptation delays, limited appropriate/accessible activities (e.g. community groups/activities), gaps in or lack of services/professional support and individual family socioeconomic factors, which affected a family's ability to engage with support offered (e.g. travel costs):

...financially as well for families because ABI is really difficult for them to fight for in terms of benefits and what fits on that criteria. When it changes circumstances and parents can't work full time or they need long term sickness, it really does kind of put a hold on those finances....and it can make it really difficult. (SCP-1)

Opportunity facilitators

All participants recognised the need to reduce social isolation for CYP-ABI through supporting them to develop friendships both at school and through accessing extracurricular sport or activity clubs. They also felt that increasing opportunities for peer support for CYP-ABI families was important in enabling them to support each other and reduce feelings of isolation.

Participants identified that professionals supporting parents in advocating was important in overcoming opportunity-related barriers. They also felt that a point of contact and access to longer-term, flexible specialist assessment, review and rehabilitation were important.

So having one person that families can go to, that health can go to, that school can go to, to relay information and collaborate care and things can be really useful. (AHPN-6)

Participants also described the need to improve communication and collaboration between health, education, social care and charitable organisations. They felt the development of CYP-ABI care pathways could facilitate this and ensure that the needs of the whole family are recognised and addressed holistically.

Therefore, interventions need to include facilitating opportunities for CYP-ABI and their families to access peer support, social activities and professional support through collaborative care pathways.

Motivation barriers

Social role and identity

Although CYP and parents aimed to return to 'normal', there was a necessity to adjust expectations and adapt to a '**new normal**'. Despite CYP not wanting to be seen as different, stakeholders acknowledged the importance of reshaping expectations. Parents and stakeholders recognised the complexity of changing and emerging needs combined with natural childhood development, expected milestones, comparisons with peers and societal norms:

I would imagine that...the majority of these young people do not want to be defined by this, do they? So, they want

to keep it quiet. And I suspect that's a really big problem for lots of them when they transition to another phase of education or a different school or a different setting where there's no context or background and where they can be afresh or you know, kind of not quite reinvent themselves, but nobody knows, and that sets up another level of challenge. (EPS-1)

Goals

A **lack of support to achieve longer-term goals** was reported. CYP and parents were very clear on desired longer-term rehabilitation goals, with the majority being activity and participation focused (e.g. returning to sports, success at school, socialising with friends, and community independence). Stakeholders recognised that more long-term holistic, participation-focused goal setting is needed and noted limited support available regarding this, particularly after discharge from community therapy services.

I think as health professionals, we almost sometimes dismiss that sort of stuff, don't we, as like the cherry on the top of the cake... We almost don't even think of any of that extended stuff because we're so focused on...do whatever treatment we need to do, let's keep you alive, let's get you sorted, let's get you home. (Nurse-1)

In the UK, education-focused goal setting for children with additional needs should occur within the education system via an Individual Education Plan (IEP) or Education, Health and Care Plan (EHCP). Participants reported mixed success with appropriate goal setting and frustrations regarding the EHCP process for newly acquired or changed needs:

I had a young person that we couldn't get the EHCP off the ground because her needs didn't exist before her brain injury and I'm like well, yes. (Nurse-2)

Emotions

A **lack of support for emotional and mental health** for the entire family unit was described as a barrier to families' well-being and participation.

Although CYP themselves struggled to talk about the emotional impact of their ABI, some were able to talk about what worried or frustrated them. The impact was recognised by parents and stakeholders.

Parents were more open about the emotional impact, describing feelings of trauma, grief, frustration and anxieties about their CYP's safety and/or future:

I worry about everything. I worry about her at comp [secondary school], like at uni, all of that. (Amelia's Mum)

The impact was substantial and continued years after the ABI – something also witnessed by stakeholders.

The impact on the entire family's well-being was a concern. Participants were concerned for the emotional health of siblings, the breakdown of relationships, and of family life becoming fractured, limited or compromised:

It's like we've got our life with the boys...and then we've got our separate existence with Megan. (Megan's Mother)

Motivation facilitators

CYP and family resilience, determination and motivation regarding achieving goals, ongoing skill development and independence were all identified as important facilitators. However, participants felt investment was needed to support families who faced participation challenges:

We could be supporting these challenges with participation that we often see further down the line; we could be supporting that so much more effectively if there was just investment in that longer-term perspective, but we often get kind of a huge investment in that acute sort of side, which is really needed but then it thins out, doesn't it? (AHPN-7)

Accessing emotional support, such as counselling, was reported as a facilitator, although this is not readily available to all. Ensuring families can access emotional support is essential to helping them address the substantial emotional impact of the ABI and adjust to their 'new normal', particularly where families' expectations were unrealistically focused on returning to pre-ABI normal.

Interventions targeting participation need to be personalised to the CYP and families' goals and include emotional support for the whole family to address motivation barriers.

Discussion

This study explored the longer-term participation needs of UK CYP-ABI and their families and barriers and facilitators to participation and well-being to inform intervention development.

Qualitative interviews and focus groups offered unique insights into the needs and challenges those affected by an ABI and service providers face. For this population, unmet needs and barriers span every sector and level of society impacting CYP-ABI participation and family well-being.

Barriers and facilitators to participation and well-being mapped across every Capability, Opportunity, Motivation and Behaviour (COM-B) domain, clearly identifying what needs to change. *Capability* barriers included a lack of understanding and awareness of the impact of an ABI,

particularly within the school and the community. Both parents and professionals lacked knowledge of how to navigate systems and struggled to get their needs assessed or to access ongoing rehabilitation. CYP-ABI and their families needed to be able to (re)access support and information as needs or circumstances changed. Parents needed a point of contact, help to coordinate care and transitions, and upskilling and empowerment to independently navigate systems and advocate for their CYP and family's needs. Case coordinator/management roles have been found effective in assisting adults with other long-term health conditions. In a systematic review of case management interventions, [Hudon et al. \(2019\)](#) identified that interdisciplinary care plans and meetings were important aspects of case management and recommended frequent contact, multidisciplinary team meetings and the development of inter-agency care plans. A CYP-ABI case manager could help to navigate systems, facilitate access to services and offer education, training and mentorship about ABI to healthcare professionals, teachers and schools, thus overcoming some of these capability barriers. Further research should explore the feasibility, utility and clinical cost-effectiveness of CYP-ABI case management.

Increasing knowledge and awareness of the long-term needs of CYP-ABI should be at the heart of any intervention – addressing *capability* and *opportunity* barriers. School is the focal point for CYP and their families, yet it can act as both a barrier and facilitator to participation and well-being. Our findings suggest school is one of the places where the needs of CYP-ABI are least well understood. Training and education of teachers and support staff is key to improving this. Further work is required to investigate the best way of implementing ABI-educational interventions in schools. [Glang et al.'s \(2019\)](#) randomised controlled trial compared an online instructional 'In the Classroom' intervention for TBI to a web-based ABI resource for 100 educators in the US. Statistically significant greater gains in TBI knowledge and application and general self-efficacy were found for the 'In the Classroom' recipients; however, the application of knowledge was not maintained at a 60-day follow-up, indicating the need for ongoing support mechanisms. Further research could build on this study to explore the impact of ongoing support for schools.

Opportunity barriers included CYP-ABI and their families feeling socially isolated and having a lack of peer support. Additionally, participants reported the impact of the substantial parent care and advocacy role, plus the lack of clear pathways, systems and resources, including access to rehabilitation services. Longer-term access to specialist rehabilitation, assessment and review would address barriers across all three COM-B domains. Telerehabilitation interventions have shown promising results in rehabilitation and family therapy and offer great potential to expand access to services ([Kettlewell et al. 2021](#); [Holthe et al. 2022](#)). [Rohrer-Baumgartner et al.'s \(2022\)](#) Child In Context Intervention

offers goal-orientated rehabilitation, using in-person and virtual sessions, and involves coaching, education, training and collaboration with CYP, families and schools. Further research could explore the feasibility of implementing and evaluating this intervention in the UK.

The introduction of integrated collaborative health/education/social care pathways and improving communication between sectors through the development of regional networks could address multiple COM-B barriers. These would facilitate the cross-sector collaboration necessary to support the whole family and facilitate timely return to school and transitions between educational stages and into adult services. [Alderwick et al.'s \(2021\)](#) systematic review of the health impacts of cross-sector collaboration found that although there was little evidence for it improving health outcomes, there was evidence to suggest it improves access to services and patient satisfaction. Additionally, more positive impacts were found for more locally targeted interventions, where interventions link professionals and families, such as home-based rehabilitation ([Fisher et al. 2023](#)) and return to school interventions ([Lindsay et al. 2015](#)). Further research is needed to develop contextually relevant local pathways and networks with clear guidelines, processes, professional networks and communication strategies.

Motivation barriers related to *social role and identity*, *goals* and *emotions* had a huge impact on CYP and family well-being, which in turn, impacted on participation. Interventions are needed that address family well-being through therapeutic support and or meaningful peer support, also tackling social isolation (*opportunity*) barriers. Family system interventions focusing on education, skill building and emotional support may be of benefit, as reported by [Gan et al. \(2010\)](#) in their preliminary evaluation of the Brain Injury Family Intervention. They reported that a small sample of participants (families and clinicians) favourably rated the intervention in terms of helpfulness, importance and satisfaction; however, further research to determine impact on outcomes is required.

The unmet participation needs of CYP-ABI and their families identified in this study are not unique to the UK. CYP-ABI face similar challenges regardless of the health, social care or education system contexts or country, as identified in two scoping reviews and one systematic review ([de Kloet et al. 2015](#); [Keetley et al. 2019](#); [Wales et al. 2021](#)). This study builds on the findings of [Diener et al. \(2022\)](#) and [Botchway et al. \(2022\)](#) and, by following the BCW's systematic process, has uniquely enabled in-depth theoretical analysis and identification of key barriers and facilitators to participation and well-being, identifying where change needs to happen, whose behaviour needs to change and how this might be achieved ([Michie et al. 2014](#)). These findings provide targets for intervention development, highlighting the barriers that need addressing and potential facilitators to do so, such as education and training, support for parents and implementing integrated collaborative

rehabilitation pathways. Intervention development work is underway with stakeholders to identify context-specific solutions, using these findings and the BCW to identify the relevant intervention functions, policies and behaviour change techniques required to ensure effective implementation.

Strengths and limitations

This novel study was conducted with methodological rigour and included the voices of CYP-ABI, parents and varied stakeholders, who offered personal insights into their lived experiences and the complexity of childhood ABI and the issues they face. The use of the ICF and BCW to synthesise and map the findings has enabled a 'system view' and the clear identification of participation needs, barriers and facilitators, which will inform future intervention development (King et al. 2018; Michie et al. 2014).

This study set out to ensure a diverse, representative sample of the spectrum of ABI diagnoses, severity, length of time since injury and socio-demography. However, it was conducted in one region of the UK with a small sample, and hence, findings may not be representative of the broader UK CYP-ABI population. Additionally, recruitment was limited via an in-patient database, and therefore, the findings do not capture CYP-ABI with milder TBIs/concussion not admitted to hospital. With only mothers participating, the findings lack the voice of fathers.

The challenges of recruiting participants who have knowledge of childhood ABI via the National Health Service means there is some dependency on known contacts and networks. Although there is potential for bias in recruiting stakeholders through existing networks and collaborations with research team members, having a research team embedded in the regional clinical service facilitated deeper understanding of the local context, systems and processes, as well as stakeholder engagement.

Interviewing CYP with their parents may have restricted their ability to speak freely; however, this was an ethical requirement for CYP under 16 due to interviewing online and the potential vulnerability of CYP-ABI, and those over 16 years of age all chose to be interviewed with their parents. It is a possibility that those less happy with their outcome may be more likely to participate. However, representation from people whose voices are rarely heard in research, including those from lower socio-economic groups and more severe ABI, may be considered a strength in terms of capturing the most complex and impactful unmet need.

Clinical implications

The findings of this study are important for health, education and social care professionals and commissioners in raising awareness of the needs and barriers that families face in the years after ABI. Clinicians need to be mindful of the wider impact of the CYP's ABI on the whole family

and how family well-being impacts on the CYP's rehabilitation and participation. When commissioning services, the long-term needs of this population must be considered to ensure families can access support for as long as they need it, potentially throughout the CYP's life course.

Conclusion

CYP-ABI have unmet long-term participation needs. They, their families and professionals working with them experience substantial and numerous barriers in attempting to meet these needs and the CYP's goals. Participation and well-being is inextricably linked; participation barriers impact on well-being, and poor family well-being impacts CYP-ABI participation. Therefore, addressing the needs of the whole family is essential. Using an implementation science informed approach in this study has provided a theoretical foundation to the intervention development process and ensured implementation is considered from the very beginning of the intervention development process. This has kept the needs of the population and context for intervention delivery central to the process, informing every stage of development. The next step is to co-develop a multi-modal, family-centred intervention with users that addresses unmet participation needs and improves health and well-being outcomes for CYP-ABI and their families.

Supplementary material

Supplementary material is available [online](#).

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Data availability. The data that support this study will be shared upon reasonable request to the corresponding author.

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Ethics standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

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