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Enabling participation in children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development

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Enabling participation in children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development

Rachel Keetley [1,3]
PhD Student – Centre for Rehabilitation and Ageing Research / Clinical Specialist Children's Physiotherapist

Joseph C Manning [2,3]
Professor of Nursing and Child Health (Clinical-Academic)

Jade Kettlewell [4]
Senior Research Fellow and NIHR SPCR Post-Doctoral Fellow

Jane Williams [3]
Consultant Paediatrician – Neuro-disability

Emily Bennett [3]
Consultant Neuropsychologist

Victoria Lyon [5]
Patient and Public Involvement Representative

Kathryn Radford [1]
Professor of Rehabilitation Research – Centre for Rehabilitation and Ageing Research

[1] School of Medicine, University of Nottingham, [2] School of Healthcare, University of Leicester, [3] Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust [4] School of Primary Care Research, University of Nottingham, [5] PPIE Representative

Corresponding author: Rachel Keetley
Centre for Rehabilitation and Ageing Research
School of Medicine
University of Nottingham
Nottingham
rachel.keetley2@nuh.nhs.uk

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Abstract

Objective: To co-design and develop an intervention to promote participation and well-being in CYP-ABI and family caregivers.

Design: A complex intervention development study including a scoping review, mixed methods study, co-design workshop and theoretical modelling.

Setting: Community dwelling participants in one geographical region of the UK

Participants: Children and young people with acquired brain injuries and their parents, health, education, social care and charity professionals

Results: The intervention development process using a theory driven and evidence informed approach, combining the Behaviour Change Wheel (BCW) (COM-B and Theoretical Domains Framework) and the Person-Based Approach (PBA) is described. Findings from the scoping review and mixed methods study were analysed and synthesised using the framework method and the International Classification of Functioning, Health and Disability (ICF) and the BCW. Evidence of identified participation needs, barriers and facilitators was presented at the co-design workshop, with key barriers being lack of knowledge and understanding, lack of parental and family support, and a need for cross-sector collaboration and communication. Stakeholders identified potential solutions and intervention ingredients (such as the need for education for families and schools regarding long-term impact of ABI, and longer-term practical and emotional support for families). Findings from the workshop were analysed using the framework method and synthesised with previous findings using the BCW. The BCW and PBA guided the theoretical modelling of the intervention which included identifying guiding principles – highlighting key design objectives that were then mapped to intervention functions and behaviour change techniques, resulting in a logic model for the 'ABI-Participate' intervention.

Conclusion: A systematic process using a theory-, evidence- and person-based approach resulted in an intervention, grounded by an in-depth understanding of CYP-ABI participation needs, barriers and facilitators, ready for feasibility testing.

Strengths and limitations of this study:

- Involving CYP, parents and stakeholders from across health, education, social care and charity sectors at every stage of this research ensured their views and needs remained at the centre of the process and the intervention.
- Use of a theory, evidence and person-based approach ensured a detailed and rigorous intervention development process and a theoretically and contextually informed complex intervention.
- The findings from this study may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home.
- Feasibility and effectiveness testing is now required.

Keywords: Children and young people, Acquired Brain Injury, Participation, Wellbeing, Intervention

Background

Sustaining an acquired brain injury (ABI) as a child or young person can lead to an array of physical, cognitive, emotional and behavioural sequelae which can impact on participation in life situations and wellbeing (1). Outcomes within this population are heterogeneous with a range of influential factors such as injury severity, location, age at injury, premorbid abilities and personal, socioeconomic and environmental factors, e.g. family functioning (2, 3). Many children and young people (CYP) experience persistent or life-long effects, which impact on physical and psychological development, quality of life (QoL), educational achievement and social inclusion. These continue to emerge months or years after the event as developmental, education and social demands increase (4-7).

The International Classification of Functioning, Disability and Health (ICF) defines participation as involvement in life situations, which enhances wellbeing. It is both a fundamental right and essential part of child development (8, 9). Research has shown that participation is associated with improved quality of life, social competence, educational success, future life outcomes, and overall well-being of CYP with and without disabilities (10-12). CYP with ABI (CYP-ABI) and their families have reported experiencing participation restrictions, negatively impacting on their wellbeing with extensive unmet and unrecognised needs found to persist up to 12 years post injury (1, 13-16). Additional responsibilities associated with caring for a child with additional needs have resulted in increased parental stress, social isolation, financial hardship, and emotional impact on the whole family, including siblings (2, 17).

Rehabilitation following an ABI aims to enable individuals to achieve optimal levels of participation by reducing the impact of difficulties and maximising wellbeing, activities of daily living, functional ability, and social integration (18, 19). However, international variability in paediatric rehabilitation provision and follow-up leads to uncertainty regarding long-term CYP-ABI outcomes and the best way to provide long-term support (7, 20). Additionally, identifying and addressing individual family psychosocial and systemic issues is essential to ensure rehabilitation interventions can be effective (4). The literature recommends family-centred rehabilitation care models, collaborative multi-system interventions and long-term regular follow-up. However, it remains unclear what components should be included and how these should be delivered to meet the needs of CYP-ABI and optimise participation and wellbeing (21-25).

Rehabilitation interventions are typically complex with multiple needs and factors to be addressed (24). Complexity is defined by the number of interacting components, the range of possible outcomes, the need to tailor the intervention to different contexts, and dependency on the behaviours of those delivering and receiving the intervention (26, 27). This complexity makes them difficult to implement, with factors likely to affect implementation needing to be considered and addressed in their development. Intervention development demands an understanding of these factors and the context for delivery and therefore engagement with stakeholders.

When developing interventions that aim to result in a behaviour change (e.g., increasing parental confidence to support their CYP-ABI), it is important to understand the target behaviour, its influences and the context for delivery, as well as identifying mechanisms of change and resources required (28). The Medical Research Council's (MRC) framework for developing and evaluating complex interventions recommends the use of theory and evidence when designing an intervention (26). Drawing on existing theories, such as the Behaviour Change Wheel, can help identify important and relevant factors and inform the content and delivery of an intervention (29, 30). Evidence from previous research can help define the problem, understand context, and identify target behaviours. Uncertainties or gaps in the literature can be addressed using primary data collection, such as quantitative surveys to assess outcomes or qualitative interviews and focus groups to gain deeper understanding of needs, barriers and facilitators (28). Engagement with stakeholders through primary data collection is essential to ensure population needs and context are understood and guide intervention design and implementation into real-world practice (31).

We describe the intervention development process for the ‘ABI-Participate’ intervention using an integrated theory-, evidence- and person-based approach (28). This approach ensured a pragmatic, systematic, rigorous intervention development process was adhered to. The process necessitates stakeholder engagement and an in-depth understanding of behaviour, its barriers and facilitators, and how implementation of an intervention could change behaviour (30, 31). The aim was to co-design and develop an intervention to promote participation and well-being in community dwelling CYP-ABI and family caregivers.

Theoretical frameworks

We integrated the Behaviour Change Wheel (BCW) and Person-Based Approach (PBA) in our intervention development process. The BCW was selected as the most appropriate theory for developing our intervention for CYP-ABI as it provides a systematic process using theory and evidence to develop interventions (32). It incorporates the COM-B model of behaviour which aids description of how *capability, opportunity* and *motivation* influence *behaviour*, and the Theoretical Domains Framework (TDF) which subdivides the COM-B components to aid greater understanding of barriers and facilitators at individual, organisational and community levels (32, 33). Once these have been identified, the BCW leads developers through a process identifying the components required for the intervention – intervention functions to target the behaviour and barriers, policies to support intervention delivery and behaviour change techniques, the specific strategies designed to change behaviour which are the active, observable, replicable and irreducible ingredient of an intervention – i.e., the proposed mechanism of change (32) (Table 1).

Table 1: Behaviour Change Wheel components and definitions (32)

COM-B Components *(for any behaviour to occur there must be capability, opportunity and motivation to do it)*		**TDF Domains** *(integrative framework synthesising key theoretical constructs)*	**BCW Intervention Functions** *(broad categories of means by which an intervention can change behaviour)*	**BCW Policy Options** *(types of decisions made by authorities that help to support and enact the interventions)*	**Behaviour Change Technique (BCT) Taxonomy Groups** **(16 groups containing 93 BCTs)** *active component of an intervention designed to change behaviour)*
Capability	Psychological	- Knowledge - Skills - Memory, attention, and decision processes - Behavioural regulation	- Education - Persuasion - Incentivisation - Coercion - Training - Enablement - Modelling - Environmental Restructuring - Restrictions	- Guidelines - Environmental/Social planning - Communication/Marketing - Legislation - Service Provision - Regulation - Fiscal Measures	- Goals and planning - Feedback and monitoring - Social support - Shaping knowledge - Natural consequences - Comparison of behaviour - Associations - Repetition and substitution - Comparison of outcomes - Reward and threat - Regulation - Antecedents - Identity - Scheduled consequences - Self-belief - Covert learning
	Physical	- Skills			
Opportunity	Social	- Social influences			
	Physical	- Environmental context and resources			
Motivation	Reflective	- Social/professional role & identity - Beliefs about capabilities - Optimism - Beliefs about consequences - Intentions - Goals			
	Automatic	- Social/professional role & identity - Optimism - Reinforcement - Emotion			

The PBA, designed for the development of health-related behaviour change interventions, integrates well with the BCW and provides a process for combining stakeholder co-production with mixed-methods research (34). It ensures that the views of individuals who will interact with the intervention (i.e. key stakeholders) are included throughout, increasing the likelihood of the intervention being successfully implemented in real-world practice. Guiding principles are formulated, describing the key intervention design objectives which can be mapped to BCW intervention functions and behaviour change techniques. This theoretical modelling process facilitated the development of a logic model to describe the intervention, planned mechanisms of change, resources required and impact on outcomes (35).

Methods and Results

Using the GUIDED framework for reporting intervention development (36), we describe the methods and results for each stage of the intervention development process following the BCW/PBA process as depicted in Figure 1.

INSERT FIGURE 1

Stage 1 – Understanding the target behaviour

To understand the target behaviour, the problem needs to be defined, target behaviour selected and specified, and barriers and enablers identified. A scoping review of the literature and primary mixed methods research was conducted to address this aim.

A. Synthesis of relevant literature – Scoping Review

A scoping review was conducted to identify relevant literature regarding the needs of CYP-ABI and their families and whether needs were met, unmet or unrecognised. The methods and findings of this are reported elsewhere (13). Four themes were found regarding needs related to CYP's impairments, parent and family support, return to school and long-term after-care. Needs were mapped onto the ICF, with a substantial proportion of needs relating to participation and contextual factors. The impact on parents and family and the lack of communication, collaboration and long-term follow-up were key findings. A lack of awareness and understanding underpinned all reported needs and led to many needs being unrecognised. Recommendations within the majority of the articles reviewed included the need for specialist follow-up and integrated care pathways that are CYP and family centred. However, there were gaps in the literature. The voice of the CYP themselves was limited, there was a lack of focus on personal factors such as psychological and emotional needs for the CYP and families, a lack of focus on community participation, including recreation and leisure activities, and a lack of data regarding outcomes and needs within a UK NHS context. These findings led to the development of a mixed-methods research study.

B. Mixed methods research study

An exploratory sequential mixed-methods study was designed to explore the long-term participation and wellbeing needs of CYP-ABI (5-18 years) and their families, one to four years after injury, in one geographical region in the UK.

The study consisted of a quantitative cross-sectional survey which explored participation and wellbeing outcomes and goals of CYP-ABI and their parents. Qualitative interviews and focus groups were conducted with CYP-ABI, parents and stakeholders to explore needs, local context, and barriers and facilitators in more depth. We began recruitment in March 2021 with all surveys, interviews and focus groups completed by November 2022. Ethical approval was gained from the UK Health Research Authority (REC-20/EM/0258). The methods and findings from each of these studies are summarised below and reported fully elsewhere (16, 37)

Quantitative Study

Survey results demonstrated the significant long-term impact of an ABI on CYP participation and both CYP and parent wellbeing; 72% of CYP had severely restricted participation, 67% had reduced HRQoL (16). Around half (53%) of parents reported reduced HRQoL and family functioning and 37% of parents screened positive for anxiety/depression. Relationships were found between CYP participation and HRQoL and parental HRQoL and family functioning. CYP and parents reported goals that mapped to the activity and participation domains of the ICF, demonstrating the importance of these activities to their wellbeing.

Qualitative Study

The qualitative study involved CYP-ABI and their parents who had participated in the survey and health, education, social care and charity stakeholders. Significant unmet participation needs were found, impacting CYP-ABI and family wellbeing (37). Barriers and facilitators, mapped to the BCW, spanned *'capability, 'opportunity' and 'motivation'*. The greatest barriers aligned to the TDF domains of knowledge, skills, social influences, environmental context and resources, social identity and emotion. Identified facilitators included increasing awareness and understanding, supporting parents, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways.

C. Mapping of current service provision

Current service provision and pathways were mapped out of the information provided by stakeholders and members of the research team and study steering group who work within the clinical service (Supplementary file 1). This demonstrated the complexity of communication and referral routes from acute to community health services and between health, education and social care providers, the lack of provision or capacity of long-term specialist support services and collaborative care pathways.

D. Synthesis of findings

Following the PBA and BCW intervention development process, the findings of the literature review and mixed-methods research were collated and synthesised using the framework method of analysis and the ICF, COM-B and TDF. This enabled us to define the problem in behavioural terms, identify the target behaviour and identify and specify barriers and facilitators (Supplementary File 2). This also allowed us to consider what needs to change and at what level. Specifying the barriers provided clarity regarding those that were individual factors (CYP/family), external organisational level (health/education systems) and community level (society) factors. Although there were individual factors with every CYP-ABI and family experiencing unique circumstances, there were many commonalities and a multitude of external factors that impacted on families in similar ways. The 'behavioural diagnosis' was then used to inform the design of the intervention with four key issues identified:

1. Reduced CYP-ABI and family participation and wellbeing - support needed to enable participation and improve wellbeing by addressing unmet needs.
2. Lack of practical, psychological and emotional support for parents - support needed for parents to enable them to navigate systems and processes and support their CYP.
3. Lack of understanding and awareness - training and education needed for those who support CYP-ABI across health, education, social care and community sectors.
4. Lack of cross-sector collaboration – a need to improve communication and collaboration between sectors and access to support in the years after ABI.

A complex intervention was required to target key issues that are common across the CYP-ABI population whilst also providing individually tailored support to meet the specific needs of CYP and their families.

Stage 2 – Identify intervention options

The next stage in the BCW process was to link the ‘behavioural diagnosis’ (Supplementary File 2) with intervention functions likely to be effective and policy categories that can aid implementation (32).

As we had identified a large number of barriers and facilitators, there was a need to prioritise which were to be targeted. We therefore consulted CYP, parents and stakeholders on this and asked for their help in generating potential solutions.

A. Co-Design Workshop

An experience-based co-design workshop with multiple stakeholders (CYP, parents and health, education and charity professionals) was held in person in July 2023. The aim was to co-design and develop an intervention to promote participation and wellbeing in CYP-ABI and family caregivers. The objectives were to present and confirm the key issues identified, discuss priorities and generate possible solutions and identify local context-specific barriers/enablers to intervention delivery (35). The data collected informed the guiding principles and theoretical modelling of the intervention. Ethical approval was gained in May 2023 (REC-20/EM/0258).

Procedure:

Participants were recruited from those who participated in the interview and focus group study with an invitation to attend the workshop sent by email. Additionally, members of the research team, study steering group (healthcare professionals from the acute neurorehabilitation team) and a Patient and Public Involvement (PPI) representative were present at the workshop to both contribute and assist with facilitating groups.

All participants provided written consent/assent prior to the workshop, with parents consenting for CYP under 16 years alongside their CYP’s assent. An external facilitator (AH) ran the workshop on the day, to allow the research team to listen and document discussions.

The four main issues identified from the previous research, and the aims of the workshop were conveyed to the participants by the researcher (RK). Three break-out groups discussed solutions focused on the main issues, each group was facilitated by a member of the research team and study steering group (KR, JM, DC, MD). Parents and professionals were divided between two groups, one focusing on parental support and the other on cross-sector collaboration/pathway. A separate group for the CYP was supported by a facilitator, a PPI representative (VL) and play specialist (AP). A range of resources were provided to each group – paper, post-it notes, pens and Lego. The 'draw, write, tell' technique was used within the CYP group with the facilitators ensuring CYP's artwork or verbal contributions were well described in written form (38). The groups reconvened and each fed back to the whole group, where potential solutions were discussed.

The workshop findings were collated and analysed by RK using content analysis to code and categorise the data to the COM-B/TDF using the framework method of analysis (39, 40). The findings and themes were discussed with the research team and study steering group to validate coding and ensure rigour.

Findings

In total, 17 participants attended the workshop including four CYP aged 6-17, four parents (mothers), eight health, education and social care/charity professionals (including members of study steering group) and one young person PPI representative.

Ten themes emerged regarding possible solutions for the identified issues which were mapped to the COM-B/TDF (Table 2). Within these themes the priorities for intervention were identified as ongoing monitoring of CYP needs and goal setting; a single point of contact; support for parents; and communication and coordination between sectors. These findings were used to inform the theoretical modelling of the intervention.

B: Theoretical Modelling

Formulate Guiding Principles

Using the previously synthesised findings and the findings from the co-design workshop, we developed guiding principles which detail the key issues to be addressed, the design objective and distinctive features of the intervention that are key to success (Table 3).

Table 2: Workshop findings mapped to COM-B/TDF

	TDF domain	TDF Construct	Theme	Workshop participant comments
Capability	**Knowledge/** **Skills**	Knowledge (about condition) Procedural knowledge Skills/skills development Ability/Competence	Education/Training	**Parent-directed** • Individualised approach – options – online, face-to-face, one-to-one, groups • Themed educational sessions on aspects of ABI impact, 'how to' guides e.g., Education Health Care Plan (EHCP), where to go for help, looking after yourself, what to expect, what could happen • Understand triggers for seeking help and how with different options – website, charities, nurse specialist/case manager, clinic • Impairment related management strategies e.g., fatigue **School-directed** • Teacher education re: ABI and impact for return to school and ongoing education e.g., fatigue, cognitive impairments • Peer training e.g., 'ABI Ambassadors' in schools, school to school support • Link schools to sources of training and support e.g., charities, local authority and community health training teams • 'Friends don't understand' - CYP peer awareness sessions **Professional-directed** • Professional education days • Educate primary care – so GP's know where to go for help
Opportunity	**Social influences**	Social support	Peer support opportunities (whole family)	**Whole family** • Family fun/support days • Social opportunities for CYP and siblings – shared activities **Parent-directed** • Parent support groups (options - local, online, face-to-face, individual, group, therapeutic) **Professional-directed** • Peer support/networks (health/education/social care/charity)
	Environmental context and resources	Resources/material resources	Digital resources	**Support parents/professionals with advocacy** • Regional 'hub' – website – co-develop with parents • Information for parents, professionals, schools • Information/signposting to sources of support e.g., charities, local authority services, SENCOs etc. • Idea sharing – e.g., accessible activities – families able to add to • Videos/quotes from other parents • Educational sections – see education/training theme • Timing of accessing information –need to be able to access when need it, even years after

			Practical resources	• Financial support – e.g., help with benefits • Support with return to school (e.g., case manager) • Point of contact and know who can help e.g., specialist nurse/case manager/SENCO/charities • 1:1 support to access activities (for CYP) e.g., support worker • 'Disability passport' – individualised working document – needs and strategies
			Clinical service provision	• Routine check-ups for CYP and parent – 4/8 weeks, 3/6/9/12 months with team (prevent getting lost) • Re-access options - need ways back in when need it • Goal setting – reviews and encouragement
			School support	**Return to school pathway** • Need for a plan -it's complex and need to reduce delays • Multi-disciplinary team meetings to share information and signpost to support • Special Educational Needs Team involvement/Special Educational Needs Register (SEN-K code) • 'Reasonable adjustments' e.g., phased return/small groups, reduced timetable • Support with EHCP process (see **Communication**) • Importance of time with friends – restoring friendships • CYP voiced wanting to be 'treated as equal' **Transitions** • MDT meetings - importance of communication and early planning including SEN Team
		Person x environment interaction	Communication strategies	• Social media – educational links/signposting to charities/accessible activities • Central point of access/contact – Case manager/key worker role • Website – easy to find information – all in one place • Multi-agency meetings involving parents regarding return to school and transitions • Signposting – professional responsibility to signpost/safety net parents/resources for professionals
Motivation	**Beliefs about capabilities**	Self-confidence	Confidence building (CYP)	• Recognition of needs and that going back to school is hard • Strategies to support – CYP know plan, small groups, phased • Support from parents, siblings, school staff, peers
	Goals	Goal/target setting	Goal setting	• Independence is important (CYP) • Sports and activities – restrictions because of diagnosis but need to 'focus on what can do' (CYP) • Need help to set goals and encouragement to follow them (CYP)
	Emotion	Affect	Emotional support	• Individualised approach – options important (1:1, peers, online, informal groups) • Access to counselling – flexible timing e.g., in hospital, may not be ready until years after • Post Traumatic Stress Disorder support • Targeted support for different family members • CYP Support – emotional strategies – how to cope (CYP) • Sibling support – flexible timing • Family support worker (charity provided)

Mapping intervention objectives and features to BCW

Using the BCW, we mapped the intervention objectives to the nine intervention functions. We identified the corresponding intervention functions that are likely to be effective in addressing the identified barriers and achieving the intervention objectives. Three intervention functions, ‘education’, ‘training’ and ‘enablement’ were identified that could address multiple barriers (Supplementary File 3).

The next step was to consider which of the seven BCW policy options would support the delivery of the identified intervention functions (32). We identified three policy options appropriate for supporting the delivery of the selected intervention functions - ‘communication/marketing’ (using print, electronic, telephonic or broadcast media), ‘guidelines’ (creating documents that recommend or mandate practice) and ‘service provision’ (delivering a service) (Supplementary File 3).

Stage 3 – Identify content and implementation options

A. Behaviour change techniques

The next step was to identify which ‘behaviour change techniques’ (BCT) are most appropriate for the intervention objectives and functions, and which mode of delivery was best suited. Using the BCT taxonomy (v1) we identified BCTs required for each intervention objective and function, ensuring these also correlated with the COM-B/TDF domains that were originally identified as important to target (32). The guiding principles combined with the behavioural analysis enabled a detailed intervention plan to be added to the guiding principles table (Table 3).

Table 3: Guiding Principles/Intervention Planning Table

	Key issues identified in mixed methods study	Design objectives	Key features of intervention to achieve objective	Mechanisms	
				Behaviour Change Technique Taxonomy (v1)	BCW Intervention functions
1	CYP-ABI experience severely restricted participation as a result of multiple interacting barriers	To identify and address participation restrictions of CYP-ABI and their families	Routine needs assessments	Social support (practical)	Enablement
			Identification of unmet needs	Problem solving	
			Goal setting/coaching (CYP/Parents)	Goal setting (behaviour)	
			Action Planning	Action planning	
			Liaison with MDT/Team around child	Social support (practical)	
			Referrals/signposting	Social support (practical)	
			Support parents	Social support (practical & emotional)	
2	Parents and those supporting CYP-ABI lack of awareness and understanding of impact of ABI which leads to under-recognition of needs	To increase understanding about impact of ABI of those supporting CYP-ABI increase recognition of needs	Support parents to develop health literacy	Instruction on how to perform the behaviour	Training
			Support parents to understand impact of ABI and recognise needs	Information about health consequences	Education
				Information about social and environmental consequences	
			Provide education re: impact of ABI to those supporting CYP and family e.g. school staff	Information about health consequences	
				Information about social and environmental consequences	
3	CYP-ABI and their families experience reduced HRQoL/wellbeing which impacts family functioning	To support family wellbeing	Offer needs-based emotional and practical support	Social support (practical & emotional)	Enablement
			Signpost to sources of support/groups etc	Social support (practical)	
			Liaise with MDT/Team around child	Social support (practical)	
4	Parents have a substantial care and advocacy role and experience difficulty navigating systems	To support parents to navigate systems/services effectively	Upskill parents in system navigation	Instruction on how to perform the behaviour (impart skills)	Training
			Support and empower parents	Social support (practical)	Enablement
			Signposting to resources	Social support (practical)	
			Advocacy as needed	Social support (practical)	
			Point of contact for families	Problem solving	
5	Parents and professionals experience difficulty with coordinating and communicating across sectors	Facilitate cross-sector collaboration/ communication	Liaison/point of contact between services across sectors	Social support (practical)	Enablement

B. Mode of delivery

Deciding on the mode of intervention delivery was important. Considering the workshop findings, participants wanted a range of options, including face-to-face as individuals or in group settings, and 'distance' meetings via telephone or virtual meeting platforms. As the target population have differing needs and reside across a large geographical region, covering five counties, a range of intervention delivery modes were needed. For example, education and training for a school could be delivered virtually or in a group face-to-face. It will be important to assess the acceptability, practicality and affordability of intervention delivery within feasibility testing to ensure it is effective for families living across the region (34).

C. Logic Model

Following the systematic and detailed BCW intervention design process enabled the key objectives and active ingredients for the intervention to be identified leading to the production of a logic model that included a description of the core components, necessary resources, mechanisms of change and identification of short- and long-term impacts and outcomes for the intervention (Table 4). The TIDieR Checklist informed the description of the intervention (41).

<table>
<tr><th colspan="5">Table 4: ABI-Participate (ABI-P) Intervention Logic Model</th></tr>
<tr><td colspan="5">Aim: To support CYP-ABI and families identify and address participation and wellbeing needs</td></tr>
<tr><td>Rationale for intervention</td><td colspan="3">The Problem:
- Reduced participation and wellbeing of CYP-ABI and families
- Lack of support for parents
- Lack of understanding and awareness of long-term needs
- Participation essential for supporting health and wellbeing
- Multiple needs and barriers identified preventing participation and wellbeing, hindering rehabilitation and recovery in the long-term</td><td rowspan="6">Moderating and contextual factors
- Clinical commissioning guidelines and criteria (acute and community – county specific)
- Education Act
- Education Health Care Plan
- Family support/social network
- Charity provision e.g. CBIT Family Support Worker
- Consultant/rehab clinics
- Nurse specialists
- Community therapy services
- SENCOs
- Local Authority support services
- Cross-sector engagement with intervention
- NICE Guidelines – Childhood cancer, major trauma, CND
- NHSE Service Specification for Paediatric Neurorehabilitation</td></tr>
<tr><td>Resources</td><td colspan="3">Resources required and context for intervention delivery:
- Skilled health/social care professional knowledgeable in ABI trained in intervention components
- Patients identified at discharge home or ABI clinic review (3-6 months+ post injury)
- Screening tool/Needs assessment proforma
- Experienced MDT supporting ABI-P and providing rehabilitation
- Effective cross-sector MDT communication/collaboration (health, education, social care, 3rd sector)
- Effective collaboration with charity partners
- Engaged CYP and family</td></tr>
<tr><td>Intervention</td><td colspan="3">Core intervention components and mechanisms:
- Appointment arranged with CYP/family and mode (F2F/virtual)
- Needs assessment and goal setting completed with CYP/family
- Gather info on rehab input to date/referrals made/liaise with MDT
- Tailored action plan made re: identified individualised needs/goals, level of support required
- Liaison with CYP's school/college etc.
- Support parental needs (e.g. health literacy, advocacy, signposting, referrals, system navigation, emotional and psychological support)
- Support participation goals through coaching CYP/parent
- Referrals/signposting as required (e.g. psychology, therapies)
- Liaise with MDT/Team around Child to ensure needs met
- Withdrawal as needs met/goals achieved
- Routine reviews (6 months, 1 year, 2 years post injury)
- Reassessment of needs ahead of key educational transitions (+/- at routine clinic reviews)
- CYP/family able to re-access support as required (point of contact re: emerging needs)
- Coordinate transition to adult services</td></tr>
<tr><td rowspan="2">Outcomes</td><td>Individual outcomes</td><td>Organisational outcomes</td><td>System outcomes</td></tr>
<tr><td>- Parent (or older CYP) reports increased self-efficacy in managing and supporting CYPs needs
- Increased participation and wellbeing
- Decreased parental distress and family functioning impact
- CYP/family satisfaction</td><td>- CYP access education with appropriate support for learning
- Schools feel supported
- Effective cross-sector communication/ collaboration between services</td><td>- Reduced absence from school
- Reduction in healthcare visits
- LT impact on CYP's education and contribution to society
- Parental health and wellbeing
- Parent able to return to work</td></tr>
</table>

The 'ABI Participate' (ABI-P) intervention aims to support CYP-ABI and their families identify and address participation and wellbeing needs. Needs assessments and individualised goal setting and action planning would be completed with CYP and families. This includes supporting participation goals through coaching CYP and parents, and ensuring referrals for additional therapy or support are made when needs are identified, such as to psychology. Families and professionals wanted a single point of contact and signposting to sources of information and support. 'ABI-Participate' also includes information sharing, referral and team meeting coordination, liaison with CYP's school/college and supporting parental practical and emotional needs. The intervention would continue until needs were met or goals achieved, with a single point of contact in the long-term should families or those working with a CYP-ABI need advice or support. Other features included reassessment of needs at routine reviews in a follow-up clinic, ahead of key educational stage transitions or as new needs emerge. Coordination of transition to adult services would also be provided. The intervention would help to improve understanding and awareness of long-term needs. It would increase support for parents and CYP to improve their participation and wellbeing by identifying and addressing needs of the whole family. It would help families and health, education, social care and charity professionals working with CYP-ABI and their families to overcome barriers by helping to coordinate cross-sector communication and collaboration. The intervention needs to be situated within and supported by a multi-disciplinary neuro-rehabilitation service. The multi-disciplinary team would need capacity to support the assessment of needs and provide targeted rehabilitation interventions, when needs are identified, such as neuro-cognitive interventions or higher-level physical skills training required for return to sport.

Discussion

This paper has described how we used a theory-, evidence- and person-based approach to develop a complex intervention aimed at improving participation in CYP-ABI and their families. As recommended by the MRC guidance, underpinning the development of complex interventions with theory and evidence is essential to ensure interventions are evidence informed and grounded in a theoretical understanding of behaviour change (26, 28). The addition of the PBA ensured an in-depth understanding of the life experiences of the population and stakeholders, their needs and views on acceptable solutions (35). As the PBA focuses specifically on the development of complex behavioural interventions, it was well suited to be combined with the theory and evidence approach in this work (42).

The intervention we have developed is founded on the biopsychosocial model of the ICF and multidisciplinary teamwork. It is family-centred, tailored to individual needs and contexts and follows a rehabilitation process of assessment, goal setting, intervention delivery, monitoring and review (19). It includes elements of existing case management, coordinator, or patient navigator interventions. It also includes a therapeutic element of goal-oriented coaching. Both of which have been used in other health populations, including adults with TBI and CYP with neuro-disabilities (43, 44). The World Health Organisation recommends the implementation of integrated care models and patient navigator roles to help patients navigate the complex systems and facilitate integration of care (45). As found in this study, there is an increasing acknowledgement of the need for care to be coordinated to support those living with long-term conditions and their family caregivers due to the complexity of coordinating care, ensuring needs are met and undue stress prevented (43, 45).

Gagnon et al (46) identified six key supportive roles that family members of adult TBI survivors undertake – researcher, advocate, case manager, coach, activities of daily living supporter and emotional supporter. They concluded that family members require ongoing counselling, support and education about system navigation, accessing community programs and workplace rights to prevent burnout. Gardiner et al (44) explored patient navigation within children with neuro-disabilities. Their scoping review found a diversity of terminology and descriptions used for navigation-type models for children with neuro-disabilities. However, each was characterised by four central domains: *facilitate* – integration/coordination of resources, supports and services, *provide* – information, advice and education, *intended outcomes* – improved health, behaviour and capacity and reduced patient and family distress, and *guiding principles* – client-directed, family-centred and collaborative. These findings align with the findings of our study and proposed 'ABI-Participate' intervention.

An additional element identified in our study, and by Gagnon and colleagues' (46), was coaching and supporting CYP and families in identifying and achieving participation goals. Palisano et al (47) proposed a conceptual framework for optimal participation of children with physical disabilities that considers the dynamic interaction of determinants (child, family, and environment) and dimensions (physical, social, and self-engagement) of participation. Their recommendation that interventions need to be goal-oriented, family-centred, collaborative, strengths-based and ecological also align with our findings.

Health coaching is defined as *'a goal-oriented, client-centred partnership that is health-focused and occurs through a process of client-enlightenment and empowerment.' p24 (48)*. Coaching can help patients and families identify and achieve their goals and has been shown to be effective in positively influencing health status, health behaviours and costs (49). There is increasing evidence supporting coaching in promoting parental self-management and empowerment, addressing parental health literacy and advocacy skills, and CYP participation in parents of CYP with chronic disabilities (49, 50). With evidence of substantial caregiver burden, increased emotions and stressors, mental health problems and the impact of socioeconomic status on outcomes for CYP-ABI and their families, coaching and enablement interventions are vital (17, 51-53). Ogourtsova et al's (49) systematic review found heterogeneity within the interventions with some being CYP-directed, some parent-directed and some mixed. They recommended further research exploring the outcomes of the different modes of delivery and the effectiveness of these on CYP and parental outcomes, recognising that these are linked with CYP outcomes improving when parent-related outcomes improve. Novak et al's (50) systematic review of interventions for preventing and treating children with cerebral palsy found evidence of effectiveness in several interventions relevant for CYP-ABI. There was strong evidence of effectiveness for goal-directed training on gross motor and hand function skills and parent interventions that enhance parenting skills (Stepping Stones Triple P) and enhance parent's ability and flexibility to use their parenting skills in stressful situations (Acceptance and Commitment Therapy). They also found weak positive effectiveness for coaching and the CO-OP (Cognitive Orientation to Occupational Performance) intervention on motor outcomes, selfcare and parent outcomes, however further research is recommended to further explore this.

The technological advances enabling the widespread use of virtual meeting platforms for health consultations during the COVID-19 pandemic, have made telehealth delivery of some components of 'ABI-Participate' possible (54, 55). Not only are most patients and families now familiar with these platforms, but workshop participants suggested them as plausible modes of delivery. This enables specialist rehabilitation in a tertiary setting to be made accessible to people at a long geographical distance and also offers an opportunity to upskill and support local providers with education and training delivered virtually. This delivery mode is being used in Rohrer-Baumgartner et al's 'Child in Context' study (24). A future feasibility study should include exploration of both its acceptability and use and the impact of digital exclusion.

Strengths and Limitations

The strengths and limitations of the scoping review, survey and qualitative study are reported elsewhere (13, 16, 37). Involving CYP, parents and stakeholders from across health, education, social care and charity sectors at every stage of this research is a strength, ensuring their views and needs remained at the centre of the process and the intervention. To our knowledge, this is the first intervention development study within the CYP-ABI literature to have used a theory, evidence and person-based approach. This novel paper demonstrates the value of combining these approaches to develop a complex intervention for addressing participation needs in CYP-ABI and their families. By following the PBA and BCW process, a detailed and rigorous approach was employed to understand needs, identify barriers and facilitators, and design the intervention (including the active ingredients/mechanisms). The mixed methods design enabled us to define the problem further, understand the local context and, using theory, provide a detailed description of the barriers and facilitators to participation. The addition of the co-design workshop with stakeholders to prioritise and generate solutions was invaluable in ensuring the most pertinent targets were selected. The theoretical modelling process enabled us to clearly articulate the key objectives and features of the intervention by using guiding principles. The behavioural analysis systematically documented the process of selecting the active ingredients and functions of the intervention and the policy options for implementing it. Finally, the logic model presented an overview of the intervention, the resources, core components and mechanisms as well as the contextual factors that must be considered and the outcomes that could be measured to assess effectiveness.

This study was conducted in one region within the UK and therefore findings may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home. Whilst every attempt was made to ensure diverse representation at every stage, this did not occur within the workshop, partly due to some participants being unable to attend on the day, but also due to self-selection in who agreed to attend. However, the needs, barriers and facilitators reported align with those reported internationally and many of the themes from the qualitative study, which did include more diverse representation, were repeated, and affirmed at the workshop. We plan to include further stakeholder and PPI consultation within feasibility testing.

Future directions

There is evidence of effectiveness for the different components of our intervention, but research is needed to test the feasibility of the intervention in our target population and context, and to investigate its acceptability, deliverability and effectiveness. Within this, identification of standardised outcome measures and methods of determining whether needs are met, is required to measure effectiveness. Further consideration also needs to be given to the overall care pathway for CYP-ABI in which this intervention would be situated following hospital discharge. Given the barriers reported and lack of access to rehabilitation, this intervention would not be adequate in isolation, and other elements need to be developed and delivered alongside this intervention. For example, specialist neuro-rehabilitation and review clinics, particularly for those CYP whose needs cannot be met within primary care, mental health or community therapy services (e.g., cognitive, neuropsychological or higher-level motor therapy needs that do not meet referral criteria). For 'ABI-Participate' to be effective, there needs to be appropriate specialist service provision and referral pathways for CYP with these needs. The mapping of regional service provision demonstrated that these do not exist, except for a very limited regional ABI medical follow-up clinic and neuropsychology service, with long waiting lists, further delaying access to support.

Conclusions

This research has provided an in-depth understanding of the participation and wellbeing needs of CYP-ABI and their families. In addition, the barriers and facilitators they and stakeholders face in one region accessing support and rehabilitation have been identified. We have developed the 'ABI-Participate' intervention with CYP-ABI, their parents and professionals from across health, education, social care and third sectors with the aim of addressing the unmet needs and barriers of this population. Further research is now required to test the feasibility of the intervention and to develop the care pathway to support its effective implementation.

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Competing interests

RK received PhD studentship funding from NIHR Applied Research Collaboration-East Midlands, University of Nottingham and Health Education England. JM receives funding from NIHR (UK) and NIH (US). KR receives funding from NIHR HTA grant funding (15/130/11), NIHR Programme Grant funding, NIHR HealthTech Research Centres, EPSRC Rehabilitation Technologies Network, NIHR School of Primary Care Research, MS Society. JM is a Data Monitoring Committee member - del Nido versus St. Thomas' blood cardioplegia in the young (DESTINY) trial: a multi-centre randomised controlled trial in children undergoing cardiac surgery (funded British Heart Foundation). RK is a Topic Advisor (Children and Young People) NICE Guideline Committee - Rehabilitation for Chronic Neurological Disorders. KR was an unpaid advisor to NHS England in the development of a toolkit for NHS professionals to support return to work after stroke. KR was a member of the NIHR HTA Clinical Evaluation and Trials panel between 2017-2021, JM is current member of the NIHR RfPB East Midlands panel. JK, JW, EB and VL have no competing interests to disclose.

Data statement

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

Author contributions

RK conducted the workshop and the primary data analysis and wrote the manuscript.

KR, JM, EB and VL, assisted with the workshop in facilitating the groups and contributed to writing the manuscript.

KR, JM, JK, JW supervised the research, assisted with the data analysis, framework mapping and contributed to writing the manuscript.

All authors assisted with the intervention development.

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Captions for Figures

Figure 1: Intervention development process and methods employed.

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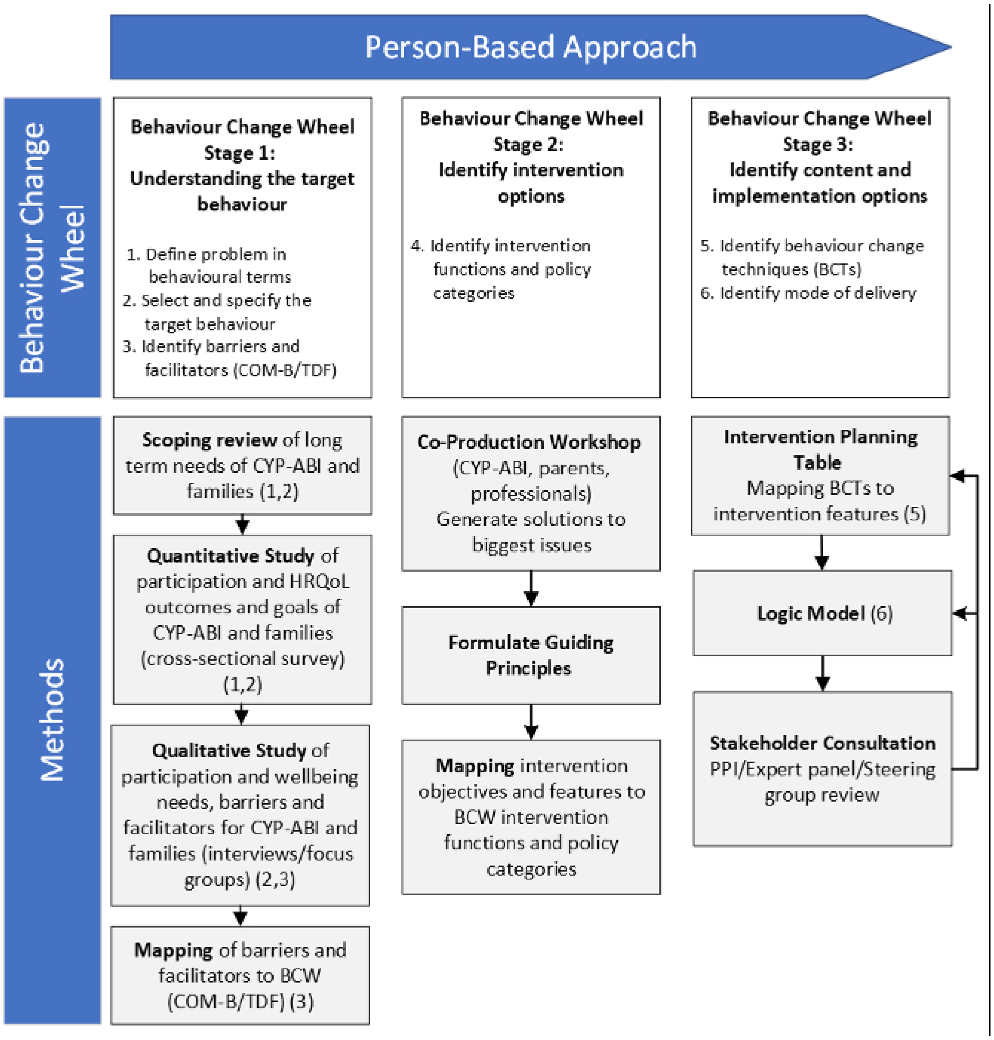

Figure 1: Intervention development process and methods employed.

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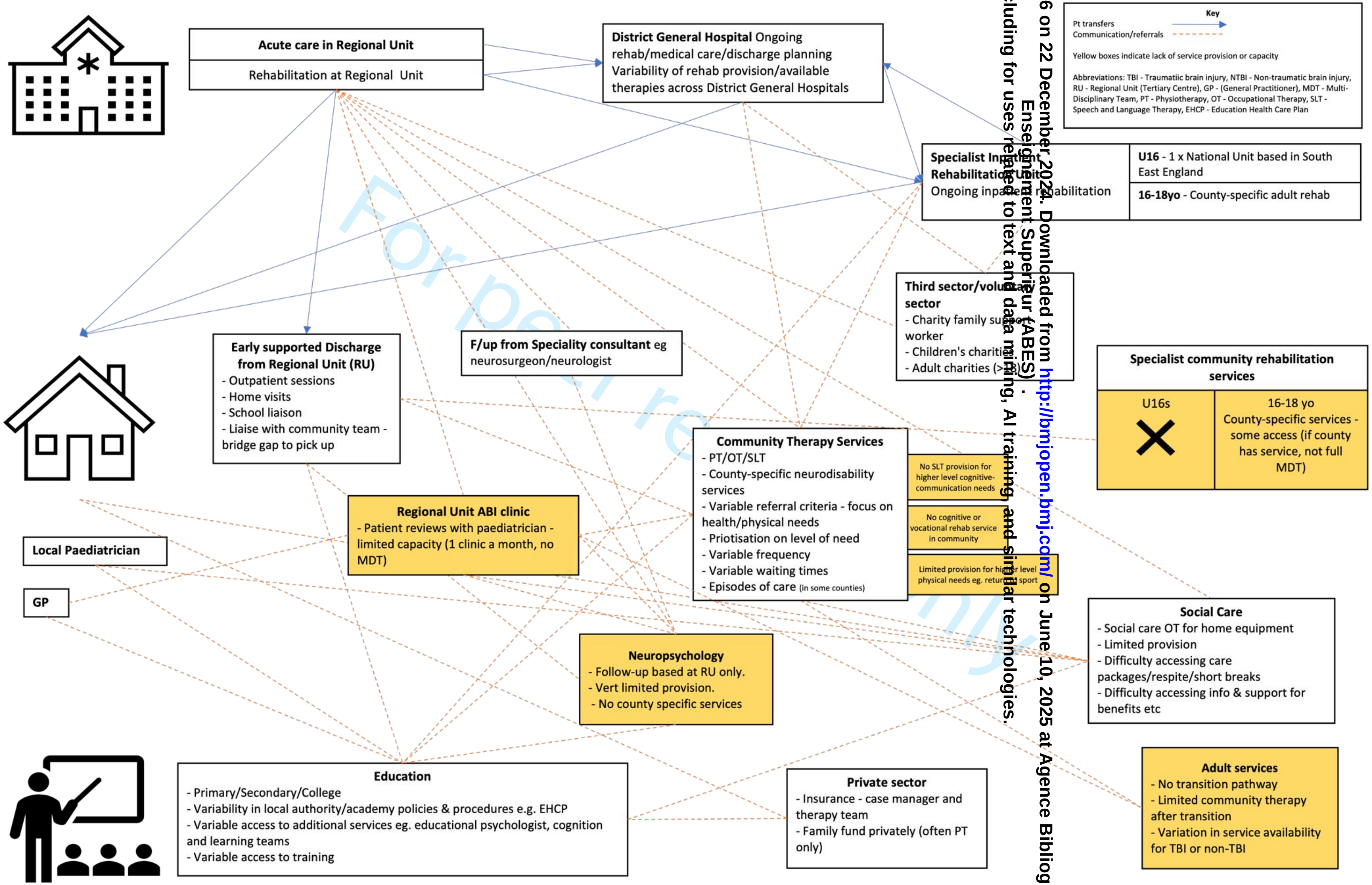
Key
Pt transfers
Communication/referrals
Yellow boxes indicate lack of service provision or capacity
Abbreviations: TBI - Traumatiic brain injury, NTBI - Non-traumatic brain injury, RU - Regional Unit (Tertiary Centre), GP - (General Practitioner), MDT - Multi-Disciplinary Team, PT - Physiotherapy, OT - Occupational Therapy, SLT - Speech and Language Therapy, EHCP - Education Health Care Plan
Acute care in Regional Unit
Rehabilitation at Regional Unit
District General Hospital Ongoing rehab/medical care/discharge planning
Variability of rehab provision/available therapies across District General Hospitals
Specialist Inpatient Rehabilitation Unit
Ongoing inpatient rehabilitation
U16 - 1 x National Unit based in South East England
16-18yo - County-specific adult rehab
Third sector/voluntary sector
- Charity family support worker
- Children's charities
- Adult charities (>18)
Early supported Discharge from Regional Unit (RU)
- Outpatient sessions
- Home visits
- School liaison
- Liaise with community team - bridge gap to pick up
F/up from Speciality consultant eg neurosurgeon/neurologist
Specialist community rehabilitation services
U16s
✕
16-18 yo
County-specific services - some access (if county has service, not full MDT)
Community Therapy Services
- PT/OT/SLT
- County-specific neurodisability services
- Variable referral criteria - focus on health/physical needs
- Priotisation on level of need
- Variable frequency
- Variable waiting times
- Episodes of care (in some counties)
No SLT provision for higher level cognitive-communication needs
No cognitive or vocational rehab service in community
Limited provision for higher level physical needs eg. return to sport
Regional Unit ABI clinic
- Patient reviews with paediatrician - limited capacity (1 clinic a month, no MDT)
Local Paediatrician
GP
Neuropsychology
- Follow-up based at RU only.
- Vert limited provision.
- No county specific services
Social Care
- Social care OT for home equipment
- Limited provision
- Difficulty accessing care packages/respite/short breaks
- Difficulty accessing info & support for benefits etc
Adult services
- No transition pathway
- Limited community therapy after transition
- Variation in service availability for TBI or non-TBI
Education
- Primary/Secondary/College
- Variability in local authority/academy policies & procedures e.g. EHCP
- Variable access to additional services eg. educational psychologist, cognition and learning teams
- Variable access to training
Private sector
- Insurance - case manager and therapy team
- Family fund privately (often PT only)

COM-B Behavioural Diagnosis				
Define the problem	CYP-ABI and their families experience restrictions in participation in activities at home, school and in the community due to multiple barriers, which impacts on their wellbeing.			
Target behaviour	Increasing participation of CYP-ABI and their families in activities at home, school and in the community.			
Barriers and facilitators				
COM-B/TDF Domain		TDF Construct	Barrier/Facilitator	Theme
Capability	Knowledge	Knowledge (about a condition)	Barrier	Lack of awareness and understanding
			Facilitator	Education and training for families and professionals
		Procedural knowledge	Barrier	Lack of knowledge regarding system navigation
			Facilitator	Support and upskill parents
	Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs
			Facilitator	Access to specialist assessment and review
		Ability/skill development	Barrier	Lack of ongoing rehabilitation access to address impairments
			Facilitator	Access to specialist rehabilitation support
	Memory, attention, and decision processes	Cognitive overload/ tiredness	Barrier	Impact of fatigue
			Facilitator	Education and training regarding managing fatigue
				Support with learning
Opportunity	Social influences	Social support	Barriers	Social isolation/lack of CYP peer relationships
				Lack of peer support for parents/families
			Facilitator	Peer support for whole family
	Environmental context and resources	Environmental stressors	Barriers	Substantial parent care and advocacy role
				Lack of clear pathways/systems (health/social care/education)
				Impact of Covid-19 pandemic
			Facilitators	Point of contact/support for parents
				Care pathway/policies
		Resources/ material resources	Barrier	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)
			Facilitator	Information resources
Motivation	Social/ professional role & identity	Social identity	Barrier	'New normal'
			Facilitator	CYP motivation
		Professional role/ boundaries	Barrier	Professional roles and boundaries
			Facilitator	Collaborative cross-sector working
	Beliefs about capabilities and consequences	Self-confidence/ perceived competence	Barriers	Lack of parental or CYP confidence
				Lack of insight
				Safety concerns
			Facilitator	Access to rehabilitation support
	Goals	Goals (distal/proximal)	Barrier	Lack of support to achieve longer-term goals
			Facilitator	CYP motivation/goals
	Emotion	Affect	Barriers	CYP, parental and family emotional impact
			Facilitators	Resilience/bravery
				Support for families

Commented [KR1]: Are these from the qualitative data analyses

Commented [RK2R2]: Yes - the expanded version from the table of the full barriers and facilitators in the quals paper

Identification of BCW intervention types

COM-B		TDF	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental Restructuring	Modelling	Enablement
Capability	Physical capability	Skills					▨ *				▨ *
	Psychological Capability	Knowledge	▨ *				▨ *				▨ *
		Skills	▨				▨				▨ *
		Memory, Attention, Decision-Making processes	▨ *				▨ *				▨ *
Opportunity	Physical opportunity	Environmental Context & Resources					▨ *	▨	▨		▨ *
	Social opportunity	Social Influences						▨	▨	▨ *	▨ *
Motivation	Automatic motivation	Social/professional role & identity		▨	▨	▨	▨ *		▨	▨	▨ *
		Emotion		▨	▨	▨	▨		▨	▨	▨ *
	Reflective motivation	Beliefs about capability and consequences	▨ *	▨	▨	▨				▨	
		Goals	▨ *	▨ *	▨ *	▨				▨	*
		Social/professional role & identity	▨ *	▨	▨	▨				▨	*

Shaded squares are BCW suggested links. * indicates links relevant to key objectives of intervention

Identification of BCW Policy Options

	Communication/ marketing	Guidelines	Fiscal measures	Regulation	Legislation	Environmental/ social planning	Service provision
Education	▨ *	▨ *		▨	▨		▨ *
Persuasion	▨	▨		▨	▨		▨
Incentivisation	▨	▨	▨	▨	▨		▨
Coercion	▨	▨	▨	▨	▨		▨
Training		▨ *	▨	▨	▨		▨ *
Restriction		▨		▨	▨		
Environmental restructuring		▨	▨	▨	▨	▨	
Modelling	▨						▨ *
Enablement		▨ *	▨	▨	▨	▨	▨ *

Shaded squares are BCW suggested links. * indicates links relevant to key objectives of intervention

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Enabling participation in community-dwelling children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development

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Enabling participation in community-dwelling children and young people with acquired brain injuries and their families – a theory-, evidence- and person-based approach to intervention development

Rachel Keetley [1,3]
PhD Student – Centre for Rehabilitation and Ageing Research / Clinical Specialist Children's Physiotherapist

Joseph C Manning [2,3]
Professor of Nursing and Child Health / Charge Nurse Paediatric Critical Care Outreach Team

Jade Kettlewell [4, 5]
Senior Research Fellow and NIHR SPCR Post-Doctoral Fellow

Jane Williams [3]
Consultant Paediatrician – Neuro-disability

Emily Bennett [3]
Consultant Neuropsychologist

Victoria Lyon
Patient and Public Involvement Representative

Kathryn Radford [1, 5]
Professor of Rehabilitation Research

[1] Centre for Rehabilitation and Ageing Research, School of Medicine, University of Nottingham, [2] School of Healthcare, University of Leicester, [3] Nottingham Children's Hospital, Nottingham University Hospitals NHS Trust, [4] School for Primary Care Research, University of Nottingham, [5] NIHR Nottingham Biomedical Research Centre.

Corresponding author: Rachel Keetley
Centre for Rehabilitation and Ageing Research
School of Medicine
University of Nottingham
Nottingham
rachel.keetley1@nhs.net

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Abstract

Objective: To co-design and develop an intervention to promote participation and well-being in Children and Young People (CYP) with Acquired Brain Injury (ABI) and family caregivers.

Design: A complex intervention development study including a scoping review, mixed methods study, co-design workshop and theoretical modelling.

Setting: Community dwelling participants in one geographical region of the UK

Participants: CYP with ABI (5 - 18 years) and their parents, health, education, social care and voluntary/third sector practitioners

Results: The intervention development process using a theory driven and evidence informed approach, combining the Behaviour Change Wheel and the Person-Based Approach is described. Findings from the scoping review and mixed methods study were analysed and synthesised using the framework method and the International Classification of Functioning, Health and Disability (ICF) and the Behaviour Change Wheel. Evidence of identified participation needs, barriers and facilitators was presented at the co-design workshop. The findings demonstrate the significant long-term impact of an ABI on CYP participation and both CYP and parent wellbeing with significant unmet family needs. Barriers and facilitators were identified, with key barriers being lack of knowledge and understanding, lack of parental and family support, and a need for cross-sector collaboration and communication. Stakeholders identified potential solutions and intervention ingredients, such as the need for education for families and schools regarding long-term impact of ABI, and longer-term practical and emotional support for families. Findings from the workshop were analysed using the framework method and synthesised with previous findings using the Behaviour Change Wheel. Theoretical modelling enabled guiding principles to be identified and an intervention logic model to be produced. 'ABI-Participate' is a novel, multi-faceted intervention, developed with CYP with ABI, their parents and professionals from across health, education, social care and charity sectors. Using a case coordination model, ABI-

Participate aims to address the unmet needs and barriers of this population and includes needs assessment, goal setting, action planning, health coaching, practical and emotional support for families and multi-agency liaison and collaboration, adopting an individualised needs-based approach.

Conclusion: A systematic process using a theory-, evidence- and person-based approach resulted in a novel, co-designed, multi-faceted intervention, grounded in an in-depth understanding of CYP with ABI participation needs, barriers and facilitators. Further development and refinement of the individual elements of ABI-Participate and the care pathway to support its implementation is now required prior to feasibility testing.

Strengths and limitations of this study:

- Involving CYP, parents and stakeholders from across health, education, social care and voluntary/third sectors at every stage of this research ensured their views and needs remained at the centre of the process and the intervention.
- Use of a theory, evidence and person-based approach ensured a detailed and rigorous intervention development process and a theoretically and contextually informed complex intervention.
- The findings from this study may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home.
- Feasibility and effectiveness testing is now required.

Keywords: Children and young people, Acquired Brain Injury, Participation, Wellbeing, Intervention

Background

Sustaining an ABI as a CYP as a result of trauma or non-traumatic causes (e.g. infection, stroke, tumour) can lead to an array of physical, cognitive, emotional and behavioural sequelae [1]. These sequelae can impact on wellbeing and participation in activities at home, school and the community [1, 2]. Outcomes within this population are heterogeneous with a range of influential factors such as injury severity, location, age at injury, premorbid abilities and personal, socioeconomic and environmental factors (e.g. family functioning) [2, 3]. Many CYP under the age of 18 experience persistent or life-long effects, which impact on physical and psychological development, quality of life, educational achievement and social inclusion. These continue to emerge months or years after the event as developmental, education and social demands increase [4-7].

The ICF defines participation as involvement in life situations, which enhances wellbeing. It is both a fundamental right and essential part of child development [8, 9]. Research has shown that participation is associated with improved quality of life, social competence, educational success, future life outcomes, and overall well-being of CYP with and without disabilities[10-12]. CYP with ABI and their families have reported experiencing participation restrictions, negatively impacting on their wellbeing, with extensive unmet and unrecognised needs found to persist up to 12 years post injury [1, 13-16]. The impact of a CYP sustaining an ABI on the family is well documented. Sudden change in roles, routines and lifestyle for families affected by ABI intensifies stress for the entire family, impacting family functioning and well-being [17]. Participation restrictions for a CYP with ABI lead to loss of social interaction, isolation and marginalisation, impacting participation and well-being for the whole family unit [18, 19]. Additionally, sudden health literacy needs, increased caregiver burden, parental stress and financial hardship can impact the mental and emotional health of the whole family, including siblings [2, 20, 21]. Rehabilitation interventions must consider the entire family's needs, recognising the interconnectedness of family members' and that addressing parental needs may improve CYP outcomes [16, 21].

Rehabilitation following an ABI aims to enable individuals to achieve optimal levels of participation by reducing the impact of difficulties and maximising wellbeing, activities of daily living, functional ability, and social integration [22, 23]. However, international variability in paediatric rehabilitation provision and follow-up leads to uncertainty regarding long-term CYP with ABI outcomes and the best way to provide long-term support [7, 24]. Identifying and addressing individual family psychosocial and systemic issues is essential to ensure rehabilitation interventions can be effective [4]. The literature recommends family-centred rehabilitation care models, collaborative multi-system interventions, and long-term regular follow-up [25-29]. However, it remains unclear what components should be included and how these should be delivered to meet the needs of CYP with ABI and their families and optimise CYP with ABI participation and wellbeing.

Rehabilitation interventions are typically complex with multiple needs and factors to be addressed [28]. Complexity is defined by the number of interacting components, a range of possible outcomes, the need to tailor the intervention to different contexts, and dependency on the behaviours of those delivering and receiving the intervention [30, 31]. This complexity makes complex interventions difficult to implement. Factors likely to affect implementation need to be understood and addressed during intervention development. When developing interventions that aim to result in a behaviour change (e.g., increasing parental confidence to support their CYP with ABI), we need to understand the target behaviour, its influences, the context for delivery, as well as identify the mechanisms of change and resources required [32].

The Medical Research Council’s framework for developing and evaluating complex interventions recommends the use of theory and evidence when designing an intervention [30]. Drawing on existing theories, such as the Behaviour Change Wheel, can help identify important and relevant factors and inform the content and delivery of an intervention [33, 34]. Evidence from previous research can help define the problem, understand context, and identify target behaviours. Uncertainties or gaps in the literature can be addressed using primary data collection, such as quantitative surveys to assess outcomes or qualitative interviews and focus groups to gain deeper understanding of needs, barriers and facilitators [32]. Engagement with stakeholders through primary data collection is essential to ensure population needs and context are understood and guide intervention design and implementation into real-world practice [35].

We describe the intervention development process for the ‘ABI-Participate’ intervention using an integrated theory-, evidence- and person-based approach [32]. This approach ensured a pragmatic, systematic, rigorous intervention development process was adhered to. The process necessitates stakeholder engagement and an in-depth understanding of behaviour, its barriers and facilitators, and how implementation of an intervention could change behaviour [34, 35]. The aim was to co-design and develop an intervention to promote participation and well-being in community dwelling CYP with ABI (all causes and severities) and family caregivers.

Theoretical frameworks

We integrated the Behaviour Change Wheel and Person-Based Approach in our intervention development process. The Behaviour Change Wheel was selected as the most appropriate theory for developing our intervention for CYP with ABI as it provides a systematic process using theory and evidence to develop interventions [36]. It incorporates the COM-B model of behaviour which aids description of how *capability, opportunity* and *motivation* influence *behaviour*, and the Theoretical Domains Framework which subdivides the COM-B components to aid greater understanding of barriers and facilitators at individual, organisational and community levels [36, 37]. Once these have been identified, the Behaviour Change Wheel leads developers through a process identifying the components required for the intervention. It aids identification of *‘intervention functions’* to target the behaviour and barriers and ‘*policies’* to support intervention delivery. This leads to the selection of *‘behaviour change techniques’*, specific strategies designed to change behaviour which are the active, observable, replicable and irreducible ingredient of an intervention – i.e., the proposed mechanism of change [36] (Table 1).

Table 1: Behaviour Change Wheel (BCW) components and definitions [36]

COM-B Components *(for any behaviour to occur there must be capability, opportunity and motivation to do it)*		**TDF Domains** *(integrative framework synthesising key theoretical constructs)*	**BCW Intervention Functions** *(broad categories of means by which an intervention can change behaviour)*	**BCW Policy Options** *(types of decisions made by authorities that help to support and enact the interventions)*	**Behaviour Change Technique (BCT) Taxonomy Groups** **(16 groups containing 93 BCTs)** *(active component of an intervention designed to change behaviour)*
Capability	Psychological	- Knowledge - Skills - Memory, attention, and decision processes - Behavioural regulation	- Education - Persuasion - Incentivisation - Coercion - Training - Enablement - Modelling - Environmental Restructuring - Restrictions	- Guidelines - Environmental/Social planning - Communication/Marketing - Legislation - Service Provision - Regulation - Fiscal Measures	Goals and planning Feedback and monitoring Social support Shaping knowledge Natural consequences Comparison of behaviour Associations Repetition and substitution Comparison of outcomes Reward and threat Regulation Antecedents Identity Scheduled consequences Self-belief Covert learning
	Physical	- Skills			
Opportunity	Social	- Social influences			
	Physical	- Environmental context and resources			
Motivation	Reflective	- Social/professional role & identity - Beliefs about capabilities - Optimism - Beliefs about consequences - Intentions - Goals			
	Automatic	- Social/professional role & identity - Optimism - Reinforcement - Emotion			

The Person Based Approach, designed for the development of health-related behaviour change interventions, integrates well with the Behaviour Change Wheel and provides a process for combining stakeholder co-production with mixed-methods research [38]. It ensures that the views of individuals who will interact with the intervention (i.e. key stakeholders such as CYP, parents, health, education, social care and charity practitioners) are included throughout, increasing the likelihood of the intervention being successfully implemented in real-world practice. Guiding principles are formulated, describing the key intervention design objectives which can be mapped to Behaviour Change Wheel intervention functions and behaviour change techniques. This theoretical modelling process facilitated the development of a logic model to describe the intervention, planned mechanisms of change, resources required and impact on outcomes [39].

Methods and Results

Using the GUIDED framework for reporting intervention development, here we describe the methods and results for each stage of the intervention development process following the process as depicted in Figure 1 [40].

INSERT FIGURE 1

Patient and Public Involvement

CYP with ABI, their parents and stakeholders representing health, education, social care and voluntary/third sectors were involved throughout the study. Four families were involved in identifying the research question and design of the study. One young adult with ABI has assisted with the data analysis and synthesis and dissemination, including being a co-author on this paper. Findings from each stage were disseminated to study participants during the co-design workshop. The findings and recommendations will be disseminated further via the production of a lay summary video.

Stage 1 – Understanding the target behaviour

To understand the target behaviour, the problem needs to be defined, target behaviour selected and specified, and barriers and enablers identified. A scoping review of the literature and primary mixed methods research was conducted to address this aim.

A. Synthesis of relevant literature – Scoping Review

We conducted a scoping review to identify relevant literature regarding the needs of CYP with ABI and their families, and whether needs were met, unmet or unrecognised. The methods and findings of this are reported elsewhere [13]. Four themes were found regarding needs related to CYP's impairments, parent and family support, return to school and long-term after-care. Needs were mapped onto the ICF, with a substantial proportion of needs relating to participation and contextual factors. Key findings were the impact on parents and family and the lack of communication, collaboration and long-term follow-up. A lack of awareness and understanding underpinned all reported needs and led to many needs being unrecognised. Recommendations within the majority of the articles reviewed included the need for specialist follow-up and integrated care pathways that are CYP and family centred. However, there were gaps in the literature. The voices of CYP are limited, there is a lack of focus on personal factors such as psychological and emotional needs for the CYP and families, a lack of focus on community participation, including recreation and leisure activities, and a lack of data regarding outcomes and needs within a UK National Health Service context. These findings led to the development of a mixed methods research study.

B. Mixed methods research study

An exploratory sequential mixed-methods study was designed to explore the long-term participation and wellbeing needs of CYP with ABI (5-18 years) and their families, one to four years after injury, in one geographical region in the UK.

The study consisted of a quantitative cross-sectional survey which explored participation and wellbeing outcomes and goals of CYP with ABI and their parents. Qualitative interviews and focus groups were conducted with CYP with ABI, parents and stakeholders to explore needs, local context, and barriers and facilitators in more depth. We began recruitment in March 2021 with all surveys, interviews and focus groups completed by November 2022. Ethical approval was gained from the UK Health Research Authority, East Midlands-Nottingham 2 Research Ethics committee (REC-20/EM/0258). Informed consent/assent was gained from all participants via survey completion and written consent forms. The methods and findings from each of these studies are summarised below and reported more fully elsewhere [16, 41].

Quantitative Study

Survey results demonstrated the significant long-term impact of an ABI on CYP participation and both CYP and parent wellbeing; 72% of CYP had severely restricted participation, 67% had reduced Health-Related Quality of Life (HRQoL) [16]. Around half (53%) of parents reported reduced HRQoL and family functioning and 37% of parents screened positive for anxiety/depression. Relationships were found between CYP and parental outcomes. Higher CYP participation and HRQoL was related to higher parental HRQoL and family functioning. Higher levels of parental anxiety/depression were related to lower CYP participation and parental HRQoL and family functioning. CYP and parents reported goals that mapped to the activity and participation domains of the ICF, demonstrating the importance of these activities to their wellbeing.

Qualitative Study

The qualitative study involved CYP with ABI and their parents who had participated in the survey and health, education, social care and voluntary/third sector stakeholders. Significant unmet participation needs were found, impacting CYP with ABI and family wellbeing [41]. Barriers and facilitators, mapped to the Behaviour Change Wheel, spanned *'capability, 'opportunity' and 'motivation'*. The greatest barriers aligned to the Theoretical Domains

Framework domains of knowledge, skills, social influences, environmental context and resources, social identity and emotion. Identified facilitators included increasing awareness and understanding, supporting parents, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways.

C. Mapping of current service provision

Current service provision and pathways were mapped out of the information provided by stakeholders and members of the research team and study steering group who work within the clinical service (Supplementary file 1). The mapping demonstrated the complexity of communication and referral routes from acute to community health services, and between health, education and social care providers. Additionally, the lack of provision or capacity of long-term specialist support services and collaborative care pathways was clear.

D. Synthesis of findings

Following the Person Based Approach and Behaviour Change Wheel intervention development process, the findings of the literature review and mixed-methods research were collated and synthesised using the Framework Method of analysis to map the findings and themes to the ICF, COM-B and Theoretical Domains Framework [42, 43]. This enabled us to define the problem in behavioural terms, identify the target behaviour and identify and specify barriers and facilitators (Supplementary File 2). This also allowed us to consider what needs to change and at what level. Specifying the barriers provided clarity regarding those that were individual factors (CYP/family), external organisational level (health/education systems) and community level (society) factors. Although there were individual factors with every CYP with ABI and family experiencing unique circumstances, there were many commonalities and a multitude of external factors that impacted on families in similar ways. Four key issues were identified and used to inform the design of the intervention:

1. Reduced CYP with ABI and family participation and wellbeing - support needed to enable participation and improve wellbeing by addressing unmet needs.
2. Lack of practical, psychological and emotional support for parents - support needed for parents to enable them to navigate systems and processes and support their CYP.
3. Lack of understanding and awareness - training and education needed for those who support CYP with ABI across health, education, social care, voluntary/third and community sectors.
4. Lack of cross-sector collaboration – a need to improve communication and collaboration between sectors and access to support in the years after ABI.

A multi-faceted intervention was required to target key issues that are common across the CYP with ABI population whilst also providing individually tailored support to meet the specific needs of CYP and their families.

Stage 2 – Identify intervention options

The next stage in the Behaviour Change Wheel process was to link the 'behavioural diagnosis' (Supplementary File 2) with intervention functions likely to be effective and policy categories that can aid implementation [36].

As we had identified a large number of barriers and facilitators, there was a need to prioritise which were to be targeted. We therefore consulted CYP, parents and stakeholders on this and asked for their help in generating potential solutions.

A. Co-Design Workshop

An experience-based co-design workshop with multiple stakeholders (CYP, parents and health, education and voluntary/third sector practitioners) was held in person in July 2023. The aim was to co-design and develop an intervention to promote participation and wellbeing in CYP with ABI and family caregivers. The objectives were to present and confirm the key issues identified, discuss priorities and generate possible solutions and identify local context-specific barriers/enablers to intervention delivery [39]. The data collected informed the guiding principles and theoretical modelling of the intervention. Ethical approval was gained in May 2023 from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS 234-0323).

Procedure:

Participants were recruited from those who participated in the interview and focus group study with an invitation to attend the workshop sent by email. Additionally, members of the research team, study steering group (healthcare professionals from the acute neurorehabilitation team) and a Patient and Public Involvement representative were present at the workshop to assist with facilitating groups and contribute.

All participants provided written consent/assent prior to the workshop, with parents consenting for CYP under 16 years alongside their CYP's assent. An external facilitator (AH) ran the workshop on the day, to allow the research team to listen and document discussions. The four main issues identified from the previous research, and the aims of the workshop were conveyed to the participants by the researcher (RK). Three break-out groups discussed solutions focused on the main issues, each group was facilitated by a member of the research team and study steering group (KR, JM, DC, MD). Parents and professionals were divided between two groups, one focusing on parental support and the other on cross-sector collaboration/pathway. A separate group for the CYP was supported by a facilitator, patient and public involvement representative (VL) and play specialist (AP). A range of resources were provided to each group – paper, post-it notes, pens and Lego. The 'draw, write, tell' technique was used within the CYP group with the facilitators ensuring CYP's artwork or verbal contributions were well described in written form [44]. The groups reconvened and each fed back to the whole group, where potential solutions were discussed.

The workshop findings were collated and analysed by RK using content analysis to code and categorise the data to the COM-B/Theoretical Domains Framework using the framework method of analysis [42, 43]. The findings and themes were discussed with the research team and study steering group to ensure rigour by reviewing and triangulating the findings, validate the coding and reduce potential biases.

Findings

In total, 17 participants attended the workshop including four CYP aged 6-17, four parents (mothers), eight health, education, social care and voluntary/third sector practitioners (including members of study steering group) and one young person PPI representative.

Ten themes emerged regarding possible solutions for the identified issues which were mapped to the COM-B/Theoretical Domains Framework (Table 2). Within these themes the priorities for intervention were identified as ongoing monitoring of CYP needs and goal setting, a single point of contact and support for parents and communication and coordination between sectors. These findings were used to inform the theoretical modelling of the intervention.

B: Theoretical Modelling

Formulate Guiding Principles

Using the previously synthesised findings and the findings from the co-design workshop, we developed guiding principles. These detail the key issues to be addressed, and the intervention design objectives and distinctive features that are key to successfully addressing these (Table 3).

Table 2: Workshop findings mapped to COM-B/Theoretical Domains Framework (TDF)				
	TDF domain	**TDF Construct**	**Theme**	**Workshop participant comments**
Capability	**Knowledge/** **Skills**	Knowledge (about condition) Procedural knowledge Skills/skills development Ability/Competence	Education/Training	**Parent-directed** • Individualised approach – options – online, face-to-face, one-to-one, groups • Themed educational sessions on aspects of ABI impact, 'how to' guides e.g., Education Health Care Plan, where to go for help, looking after yourself, what to expect, what could happen • Understand triggers for seeking help and how with different options – website, charities, nurse specialist/case manager, clinic • Impairment related management strategies e.g. fatigue **School-directed** • Teacher education re: ABI and impact for return to school and ongoing education e.g., fatigue, cognitive impairments • Peer training e.g., 'ABI Ambassadors' in schools, school to school support • Link schools to sources of training and support e.g. charities, local authority and community health training teams • 'Friends don't understand' - CYP peer awareness sessions **Professional-directed** • Professional education days • Educate primary care – so GP's know where to go for help
Opportunity	**Social influences**	Social support	Peer support opportunities (whole family)	**Whole family** • Family fun/support days • Social opportunities for CYP and siblings – shared activities **Parent-directed** • Parent support groups (options - local, online, face-to-face, individual, group, therapeutic) **Professional-directed** • Peer support/networks (health/education/social care/charity)

	Environmental context and resources	Resources/material resources	Digital resources	**Support parents/professionals with advocacy** Regional ‘hub’ – website – co-develop with parents Information for parents, professionals, schools Information/signposting to sources of support e.g., charities, local authority services, SENCOs etc. Idea sharing – e.g., accessible activities – families able to add to Videos/quotes from other parents Educational sections – see education/training theme Timing of accessing information –need to be able to access when need it, even years after
			Practical resources	Financial support – e.g., help with benefits Support with return to school (e.g., case manager) Point of contact and know who can help e.g., specialist nurse/case manager/charities 1:1 support to access activities (for CYP) e.g., support worker ‘Disability passport’ – individualised working document – needs and strategies
			Clinical service provision	Routine check-ups for CYP and parent – 4/8 weeks, 3/6/9/12 months with team (prevent getting lost) Re-access options - need ways back in when need it Goal setting – reviews and encouragement
			School support	**Return to school pathway** Need for a plan -it’s complex and need to reduce delays Multi-disciplinary team meetings to share information and signpost to support Special Educational Needs (SEN) Team involvement/Special Educational Needs Register ‘Reasonable adjustments’ e.g., phased return, small groups, reduced timetable Support with Education Health Care Plan process (see **Communication**) Importance of time with friends – restoring friendships CYP voiced wanting to be ‘treated as equal’ **Transitions**

				MDT meetings - importance of communication and early planning including SEN Team
		Person x environment interaction	Communication strategies	Social media – educational links/signposting to charities/accessible activities Central point of access/contact – Case manager/key worker role Website – easy to find information – all in one place Multi-agency meetings involving parents regarding return to school and transitions Signposting – professional responsibility to signpost/safety net parents/resources for professionals
Motivation	**Beliefs about capabilities**	Self-confidence	Confidence building (CYP)	Recognition of needs and that going back to school is hard Strategies to support – CYP know plan, small groups, phased Support from parents, siblings, school staff, peers
	Goals	Goal/target setting	Goal setting	Independence is important (CYP) Sports and activities – restrictions because of diagnosis but need to ‘focus on what can do’ (CYP) Need help to set goals and encouragement to follow them (CYP)
	Emotion	Affect	Emotional support	Individualised approach – options important (1:1, peers, online, informal groups) Access to counselling – flexible timing e.g., in hospital, may not be ready until years after Post Traumatic Stress Disorder support Targeted support for different family members CYP Support – emotional strategies – how to cope (CYP) Sibling support – flexible timing Family support worker (charity provided)

Mapping intervention design objectives and features to Behaviour Change Wheel

Using the Behaviour Change Wheel, we mapped the intervention design objectives to the nine intervention functions. We identified the corresponding intervention functions that are likely to be effective in addressing the identified barriers and achieving the intervention objectives. Three intervention functions, ‘education’, ‘training’ and ‘enablement’ were identified that could address multiple barriers (Supplementary File 3).

The next step was to consider which of the seven Behaviour Change Wheel policy options would support the delivery of the identified intervention functions [36]. We identified three policy options that would be appropriate for supporting the delivery of the selected intervention functions - ‘communication/marketing’ (using print, electronic, telephonic or broadcast media), ‘guidelines’ (creating documents that recommend or mandate practice) and ‘service provision’ (delivering a service) (Supplementary File 3).

Stage 3 – Identify content and implementation options

A. Behaviour change techniques

The next step was to identify which ‘behaviour change techniques’ are most appropriate for the intervention objectives and functions, and which mode of delivery was best suited. Using the Behaviour Change Technique taxonomy (v1) we identified Behaviour Change Techniques required for each intervention objective and function, ensuring these also correlated with the COM-B/Theoretical Domains Framework domains that were originally identified as important to target [36]. The guiding principles combined with the identification of behaviour change techniques and intervention components enabled a detailed intervention plan to be added to the guiding principles table (Table 3).

Table 3: Guiding Principles/Intervention Planning Table

	Key issues identified in mixed methods study	**Intervention design objectives**	**Key features of intervention to achieve objective**	**Mechanisms**	
				Behaviour Change Technique Taxonomy (v1)	**Behaviour Change Wheel Intervention functions**
1	CYP-ABI experience severely restricted participation as a result of multiple interacting barriers	To identify and address participation restrictions of CYP-ABI and their families	Routine needs assessments	Social support (practical)	Enablement
			Identification of unmet needs	Problem solving	
			Goal setting/coaching (CYP/Parents)	Goal setting (behaviour)	
			Action Planning	Action planning	
			Multi-disciplinary Team (MDT) liaison/ Team around child meeting	Social support (practical)	
			Referrals/signposting	Social support (practical)	
			Support parents	Social support (practical & emotional)	
2	Parents and those supporting CYP-ABI lack of awareness and understanding of impact of ABI which leads to under-recognition of needs	To increase understanding about impact of ABI of those supporting CYP-ABI to increase recognition of needs	Support parents to develop health literacy	Instruction on how to perform the behaviour	Training
			Support parents to understand impact of ABI and recognise needs	Information about health consequences Information about social and environmental consequences	Education
			Provide education re: impact of ABI to those supporting CYP and family e.g. school staff	Information about health consequences Information about social and environmental consequences	
3	CYP-ABI and their families experience reduced HRQoL/wellbeing which impacts family functioning	To support family wellbeing	Offer needs-based emotional and practical support	Social support (practical & emotional)	Enablement
			Signpost to sources of support/groups etc	Social support (practical)	
			MDT liaison/Team around child	Social support (practical)	
4	Parents have a substantial care and advocacy role and experience difficulty navigating systems	To support parents to navigate systems/ services effectively	Upskill parents in system navigation	Instruction on how to perform the behaviour (impart skills)	Training
			Support and empower parents	Social support (practical)	Enablement
			Signposting to resources	Social support (practical)	
			Advocacy as needed	Social support (practical)	
			Point of contact for families	Problem solving	
5	Parents and professionals experience difficulty with coordinating and communicating across sectors	Facilitate cross-sector collaboration/ communication	Liaison/point of contact between services across sectors	Social support (practical)	Enablement

B. Mode of delivery

Deciding on the mode of intervention delivery was important. Considering the workshop findings, participants wanted a range of options, including face-to-face as individuals or in group settings, and 'distance' meetings via telephone or virtual meeting platforms. As the target population have differing needs and reside across a large geographical region, covering five counties, a range of intervention delivery modes were needed. For example, education and training for a school could be delivered virtually or in a group face-to-face. It will be important to assess the acceptability, practicality and affordability of intervention delivery within feasibility testing to ensure it is effective for families living across the region [38].

C. Logic Model

Following the systematic and detailed Behaviour Change Wheel intervention design process enabled the key objectives and active ingredients for the intervention to be identified leading to the production of a logic model that included a description of the core components, necessary resources, mechanisms of change and identification of short- and long-term impacts and outcomes for the intervention (Figure 2). This was developed iteratively, through review with the research team, study steering group and patient and public representative, and refinements made. The TIDieR Checklist informed the description of the intervention [45].

INSERT FIGURE 2

The ‘ABI Participate’ intervention aims to support CYP with ABI and their families to identify and address participation and wellbeing needs. Using a case coordination model, needs assessments and individualised goal setting and action planning would be completed with CYP and families, considering development stage and family context [46-48]. This includes supporting participation goals through coaching CYP and parents and ensuring referrals for additional therapy or support are made where necessary. Families and professionals wanted a single point of contact and signposting to sources of information and support. ‘ABI-Participate’ also includes information sharing and team meeting coordination, liaison with CYP’s school/college and supporting parental practical, emotional, and psychological needs. The intervention would continue until needs were met or goals achieved, with a single point of contact in the long-term, should families or those working with a CYP with ABI need advice or support. Other features included reassessment of needs at routine reviews in a follow-up clinic, ahead of key educational stage transitions or as new needs emerge. Coordination of transition to adult services would also be provided. The intervention would help to improve understanding and awareness of long-term needs. It would increase support for parents and CYP to improve their participation and wellbeing by identifying and addressing needs of the whole family. It would help families and health, education, social care and voluntary/third sector practitioners working with CYP with ABI and their families to overcome barriers by helping to coordinate cross-sector communication and collaboration. The intervention needs to be situated within and supported by a multi-disciplinary neuro-rehabilitation service. The multi-disciplinary team would need capacity to support the assessment of needs and provide targeted rehabilitation interventions, when needs are identified, such as neuro-cognitive interventions or higher-level physical skills training required for return to sport.

Discussion

This paper has described how we used a theory-, evidence- and person-based approach to develop a complex intervention aimed at improving participation in CYP with ABI and their families. As recommended by the Medical Research Council's guidance, underpinning the development of complex interventions with theory and evidence is essential to ensure interventions are evidence informed and grounded in a theoretical understanding of behaviour change [30, 32]. The addition of the Person-Based Approach ensured an in-depth understanding of the life experiences of the population and stakeholders, their needs and views on acceptable solutions [39]. As this approach focuses specifically on the development of complex behavioural interventions, it was well suited to be combined with the theory and evidence approach in this work [49].

The intervention we have developed is founded on the biopsychosocial model of the ICF and multidisciplinary teamwork. It is multi-faceted, family-centred, and tailored to developmental stage, individual needs and contexts, It follows a rehabilitation process, involving assessment, goal setting, intervention delivery, monitoring and review [23]. Based on a case coordination model, ABI-Participate also includes a therapeutic element of goal-oriented coaching, which aims to identify and address the participation needs of the whole family. As found in this study, and recommended by the World Health Organisation, there is an increasing acknowledgement of the need for care to be coordinated to support those living with long-term conditions and their family caregivers due to the complexity of coordinating care, ensuring needs are met and undue stress prevented [21, 48, 50-52].

Gagnon et al [47] identified six key supportive roles that family members of adult traumatic brain injury survivors undertake – researcher, advocate, case manager, coach, activities of daily living supporter and emotional supporter. They concluded that family members require ongoing counselling, support and education about system navigation, accessing community programs and workplace rights to prevent burnout. A scoping review by Gardiner et al [53] found a diversity of terminology and descriptions used for navigation-type models for children with neuro-disabilities. However, each was characterised by four central domains: *facilitate* – integration/coordination of resources, supports and services, *provide* – information, advice and education, *intended outcomes* – improved health, behaviour and capacity and reduced patient and family distress, and *guiding principles* – client-directed, family-centred and collaborative. These findings align with the findings of our study and are incorporated into the proposed 'ABI-Participate' intervention.

An additional element identified in our study, and by Gagnon and colleagues [47], was coaching and supporting CYP and families in identifying and achieving participation goals. Palisano et al [54] proposed a conceptual framework for optimal participation of children with physical disabilities that considers the dynamic interaction of determinants (child, family, and environment) and dimensions (physical, social, and self-engagement) of participation. Their recommendation that interventions need to be goal-oriented, family-centred, collaborative, strengths-based and ecological also align with our findings. ABI-Participate could be used flexibly and at different time points, recognising that needs differ at different developmental stages and points of transition (i.e. more intensive support needed during educational transitions, particularly into secondary school and transition to adult services and or employment).

Health coaching is defined as *'a goal-oriented, client-centred partnership that is health-focused and occurs through a process of client-enlightenment and empowerment.' p24* [55]. Coaching can help patients and families identify and achieve their goals and has been shown to be effective in positively influencing health status, health behaviours and costs [21]. There is increasing evidence supporting coaching in promoting parental self-management and empowerment, addressing parental health literacy and advocacy skills, and CYP participation in parents of CYP with chronic disabilities [21, 56]. Ogourtsova et al's (21) systematic review of health coaching for parents of children with developmental disabilities found heterogeneity within the interventions with some being CYP-directed, some parent-directed and some mixed. They recommended further research exploring the outcomes of the different modes of delivery and the effectiveness of these on CYP and parental outcomes, recognising that these are linked with CYP outcomes improving when parent-related outcomes improve.

Existing interventions could be integrated with ABI-Participate. For example, goal-directed interventions (e.g. PREP - Pathways and Resources for Engagement and Participation), coaching interventions (e.g. CO-OP - Cognitive Orientation to Occupational Performance), parent interventions (e.g. Stepping Stones Triple P), or psychological interventions (e.g. Acceptance and Commitment Therapy [56-58]. However further research is recommended to further explore the acceptability and effectiveness of integrating them in this intervention.

The technological advances enabling the widespread use of virtual meeting platforms for health consultations during the COVID-19 pandemic, have made telehealth delivery of some components of 'ABI-Participate' possible [59, 60]. Not only are most patients and families now familiar with these platforms, but workshop participants suggested them as plausible modes of delivery. This enables specialist rehabilitation in tertiary settings to be made accessible to people living at long geographical distances and also offers an opportunity to upskill and support local providers with education and training delivered virtually. This delivery mode is in use in Rohrer-Baumgartner et al's 'Child in Context' study [28]. A future feasibility study should include exploration of both its acceptability and utility, as well as how to deliver this to those without access to the internet.

Strengths and Limitations

The strengths and limitations of the scoping review, survey and qualitative study are reported elsewhere [13, 16, 41]. Involving CYP, parents and stakeholders from across health, education, social care and voluntary/third sectors at every stage of this research is a strength, ensuring their views and needs remained at the centre of the process and the intervention. To our knowledge, this is the first intervention development study within the CYP with ABI literature to have used a theory, evidence and person-based approach. This novel paper demonstrates the value of combining these approaches to develop a complex intervention for addressing participation needs in CYP with ABI and their families. By following the Person Based Approach and Behaviour Change Wheel process, a detailed and rigorous approach was employed to understand needs, identify barriers and facilitators, and design the intervention (including the active ingredients/mechanisms). The mixed methods design enabled us to define the problem further, understand the local context and, using theory, provide a detailed description of the barriers and facilitators to participation. The addition of the co-design workshop with stakeholders to prioritise and generate solutions was invaluable in ensuring the most pertinent targets were selected. The theoretical modelling process and use of guiding principles enabled us to clearly and systematically articulate and document the process of identifying the key objectives, features and functions of the intervention, and selection of the policy options for implementing it. Finally, the logic model presented an overview of the intervention, the resources, core components and mechanisms as well as the contextual factors that must be considered and the outcomes that could be measured to assess effectiveness.

This study was conducted in one region within the UK and therefore findings may not generalisable, however, understanding the specific needs within the region are important in planning services and delivering care close to home. Whilst every attempt was made to ensure diverse representation at every stage, this did not occur within the workshop, partly due to some participants being unable to attend on the day. However, the reported needs, barriers and facilitators align with those reported internationally and many of the themes from the qualitative study, which had more diverse representation, were repeated, and affirmed at the workshop. This intervention has been developed iteratively, with CYP, parents and stakeholders. Further stakeholder and patient and public representative consultation and expert consensus development workshops are now required to refine, specify and confirm intervention components prior to feasibility testing.

Future directions

There is evidence of effectiveness for the different components of our intervention, but research is needed to test the feasibility of the intervention in our target population and context, and to investigate its acceptability, deliverability and effectiveness. Within this, identification of standardised outcome measures and methods of determining whether needs are met, is required to measure effectiveness. Further consideration also needs to be given to the overall care pathway for CYP with ABI in which this intervention would be situated following hospital discharge. Given the barriers reported and lack of access to rehabilitation, other elements need to be developed and delivered alongside this intervention. For example, specialist rehabilitation and review clinics, particularly for those CYP whose needs cannot be met within primary care, mental health or community therapy services (e.g., cognitive, neuropsychological or higher-level motor therapy needs that do not meet referral criteria). For ‘ABI-Participate’ to be effective, there need to be referral pathways for CYP with these needs. The mapping of regional service provision demonstrated that these do not exist, except for a very limited regional ABI medical follow-up clinic and neuropsychology service, with long waiting lists, further delaying access to support.

Conclusions

This research has provided an in-depth understanding of the participation and wellbeing needs of CYP with ABI and their families. The findings demonstrate the significant long-term impact of an ABI on CYP participation and both CYP and parent wellbeing with significant unmet family needs. Barriers and facilitators families and stakeholders face in accessing support and rehabilitation are identified. Key barriers identified were a lack of knowledge and understanding of the impact of ABI across every level of society, lack of parental and family support, and a need for cross-sector collaboration and communication. Providing parental support, long-term access to specialist assessment and rehabilitation, peer support and integrated collaborative pathways were identified as facilitators.

We have iteratively developed a novel, multifaceted intervention the ‘ABI-Participate’ intervention with CYP with ABI, their parents and stakeholders from across health, education, social care and voluntary/third sectors with the aim of addressing the unmet needs and barriers of this population. Adopting a case coordination model and an individualised needs-based approach, ABI-Participate includes needs assessment, goal setting, action planning, health coaching, practical and emotional support for families and multi-agency liaison and collaboration. Further refinement of the components of ABI-Participate and development of the care pathway to support its implementation are now required prior to feasibility testing.

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Competing interests

RK received PhD studentship funding from NIHR Applied Research Collaboration-East Midlands, University of Nottingham and Health Education England. JM receives funding from NIHR (UK) and NIH (US). KR receives funding from NIHR HTA grant funding (15/130/11), NIHR Programme Grant funding, NIHR HealthTech Research Centres, EPSRC Rehabilitation Technologies Network, NIHR School of Primary Care Research, MS Society. JM is a Data Monitoring Committee member - del Nido versus St. Thomas’ blood cardioplegia in the young (DESTINY) trial: a multi-centre randomised controlled trial in children undergoing cardiac surgery (funded British Heart Foundation). RK is a Topic Advisor (Children and Young People) NICE Guideline Committee - Rehabilitation for Chronic Neurological Disorders. KR was an unpaid advisor to NHS England in the development of a toolkit for NHS professionals to support return to work after stroke. KR was a member of the NIHR HTA Clinical Evaluation and Trials panel between 2017-2021, JM is current member of the NIHR RfPB East Midlands panel. JK, JW, EB, and VL have no competing interests to disclose.

Data statement

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

Authors' contributions

RK conducted the scoping review, mixed methods study and workshop, the primary data analysis, wrote the manuscript and is guarantor. KR, JM, EB, VL assisted with the workshop in facilitating the groups, assisted with the data analysis and contributed to writing the manuscript. KR, JM, JK, JW supervised the research, assisted with the data analysis, framework mapping and contributed to writing the manuscript. All authors assisted with the intervention development.

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Captions for Figures

Figure 1: Intervention development process and methods employed.

Figure 2: ABI-Participate Logic Model

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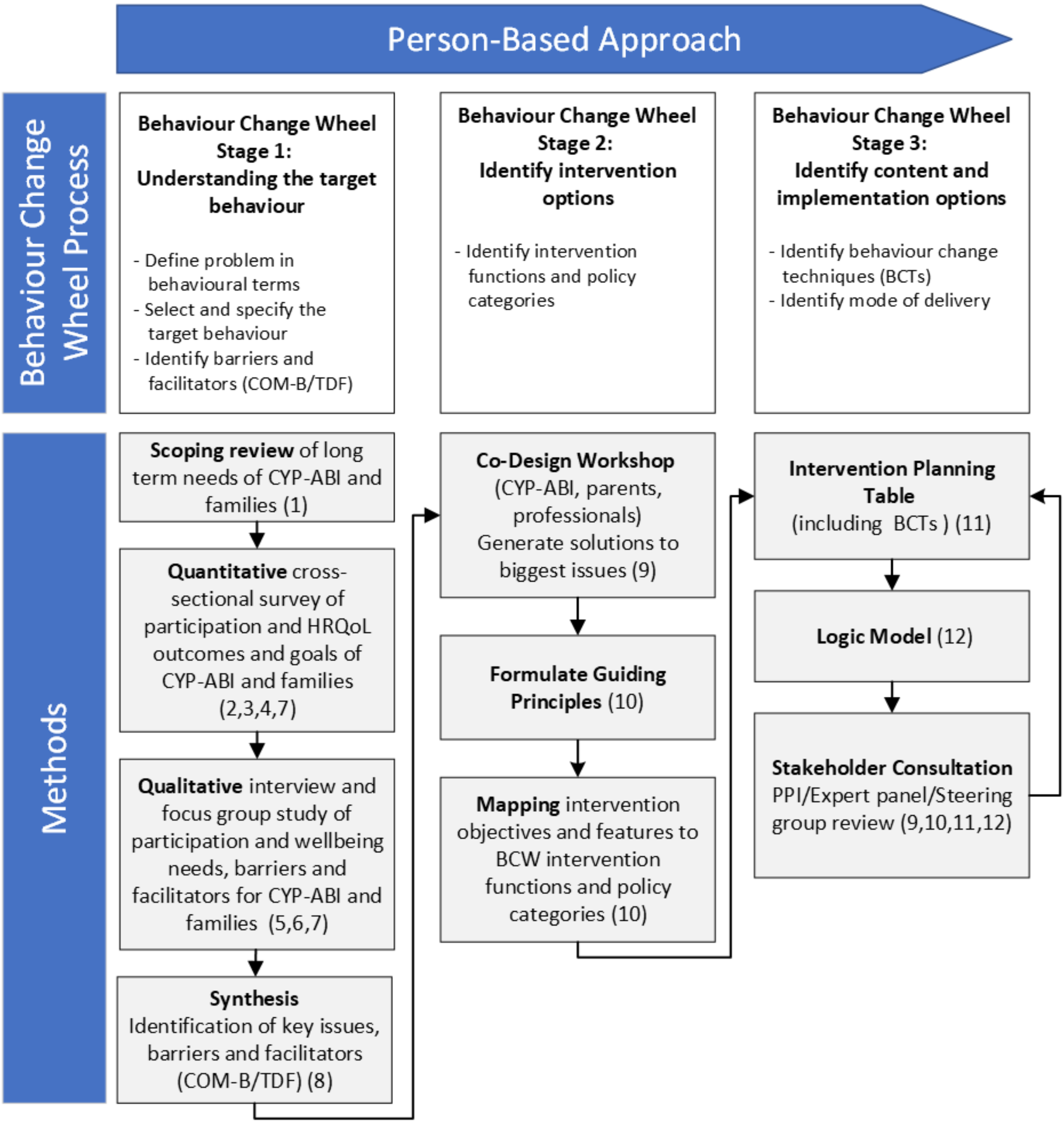
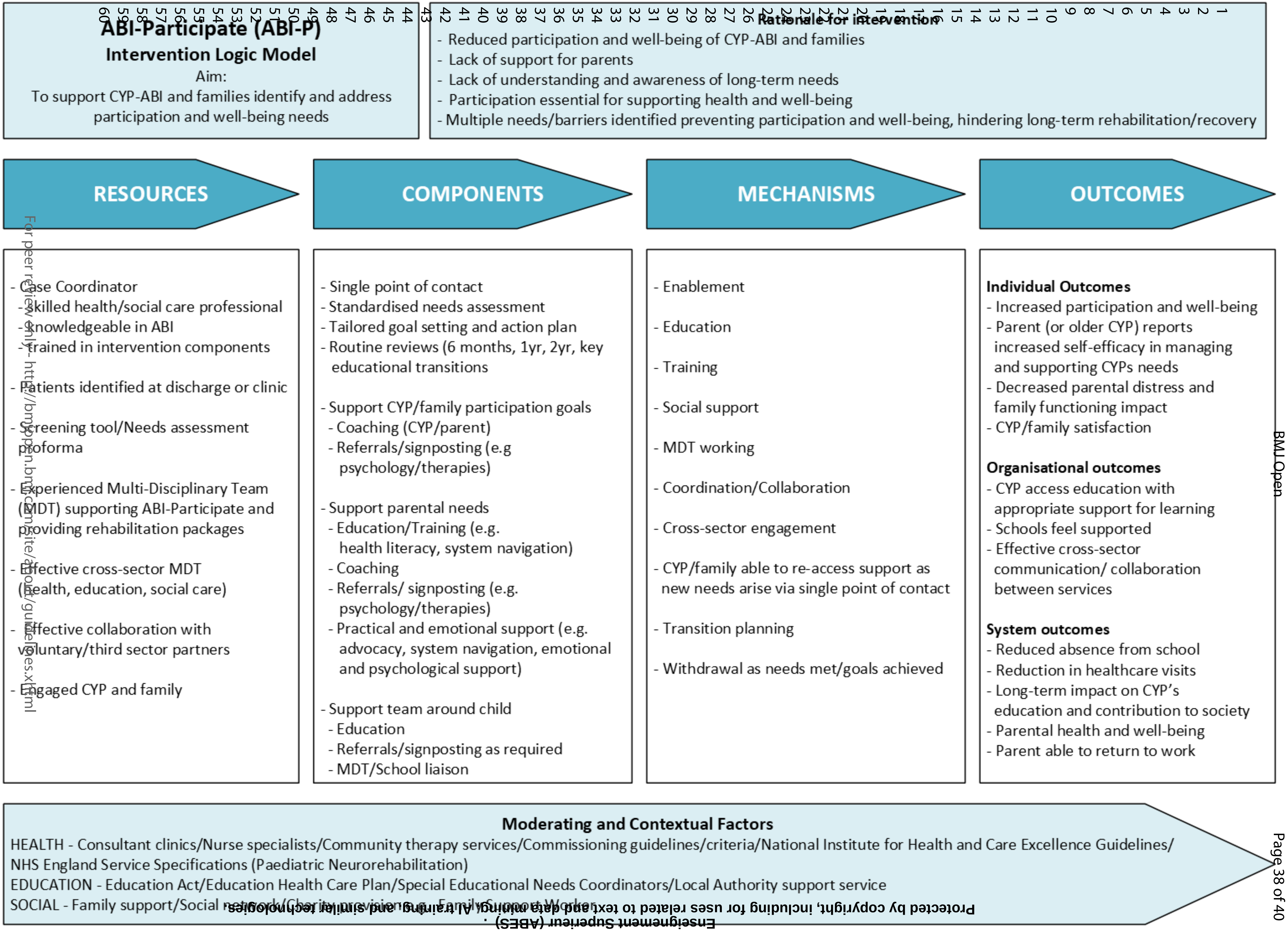

Person-Based Approach
Behaviour Change Wheel Process
Behaviour Change Wheel Stage 1: Understanding the target behaviour
- Define problem in behavioural terms
- Select and specify the target behaviour
- Identify barriers and facilitators (COM-B/TDF)
Behaviour Change Wheel Stage 2: Identify intervention options
- Identify intervention functions and policy categories
Behaviour Change Wheel Stage 3: Identify content and implementation options
- Identify behaviour change techniques (BCTs)
- Identify mode of delivery
Methods
Scoping review of long term needs of CYP-ABI and families (1)
Quantitative cross-sectional survey of participation and HRQoL outcomes and goals of CYP-ABI and families (2,3,4,7)
Qualitative interview and focus group study of participation and wellbeing needs, barriers and facilitators for CYP-ABI and families (5,6,7)
Synthesis Identification of key issues, barriers and facilitators (COM-B/TDF) (8)
Co-Design Workshop (CYP-ABI, parents, professionals) Generate solutions to biggest issues (9)
Formulate Guiding Principles (10)
Mapping intervention objectives and features to BCW intervention functions and policy categories (10)
Intervention Planning Table (including BCTs) (11)
Logic Model (12)
Stakeholder Consultation PPI/Expert panel/Steering group review (9,10,11,12)



ABI-Participate (ABI-P)

Intervention Logic Model

Aim:
To support CYP-ABI and families identify and address participation and well-being needs

Rationale for intervention

- Reduced participation and well-being of CYP-ABI and families
- Lack of support for parents
- Lack of understanding and awareness of long-term needs
- Participation essential for supporting health and well-being
- Multiple needs/barriers identified preventing participation and well-being, hindering long-term rehabilitation/recovery

RESOURCES

- Case Coordinator
  - skilled health/social care professional
  - knowledgeable in ABI
  - trained in intervention components
- Patients identified at discharge or clinic
- Screening tool/Needs assessment proforma
- Experienced Multi-Disciplinary Team (MDT) supporting ABI-Participate and providing rehabilitation packages
- Effective cross-sector MDT (health, education, social care)
- Effective collaboration with voluntary/third sector partners
- Engaged CYP and family

COMPONENTS

- Single point of contact
- Standardised needs assessment
- Tailored goal setting and action plan
- Routine reviews (6 months, 1yr, 2yr, key educational transitions

- Support CYP/family participation goals
  - Coaching (CYP/parent)
  - Referrals/signposting (e.g psychology/therapies)

- Support parental needs
  - Education/Training (e.g. health literacy, system navigation)
  - Coaching
  - Referrals/ signposting (e.g. psychology/therapies)
  - Practical and emotional support (e.g. advocacy, system navigation, emotional and psychological support)

- Support team around child
  - Education
  - Referrals/signposting as required
  - MDT/School liaison

MECHANISMS

- Enablement
- Education
- Training
- Social support
- MDT working
- Coordination/Collaboration
- Cross-sector engagement
- CYP/family able to re-access support as new needs arise via single point of contact
- Transition planning
- Withdrawal as needs met/goals achieved

OUTCOMES

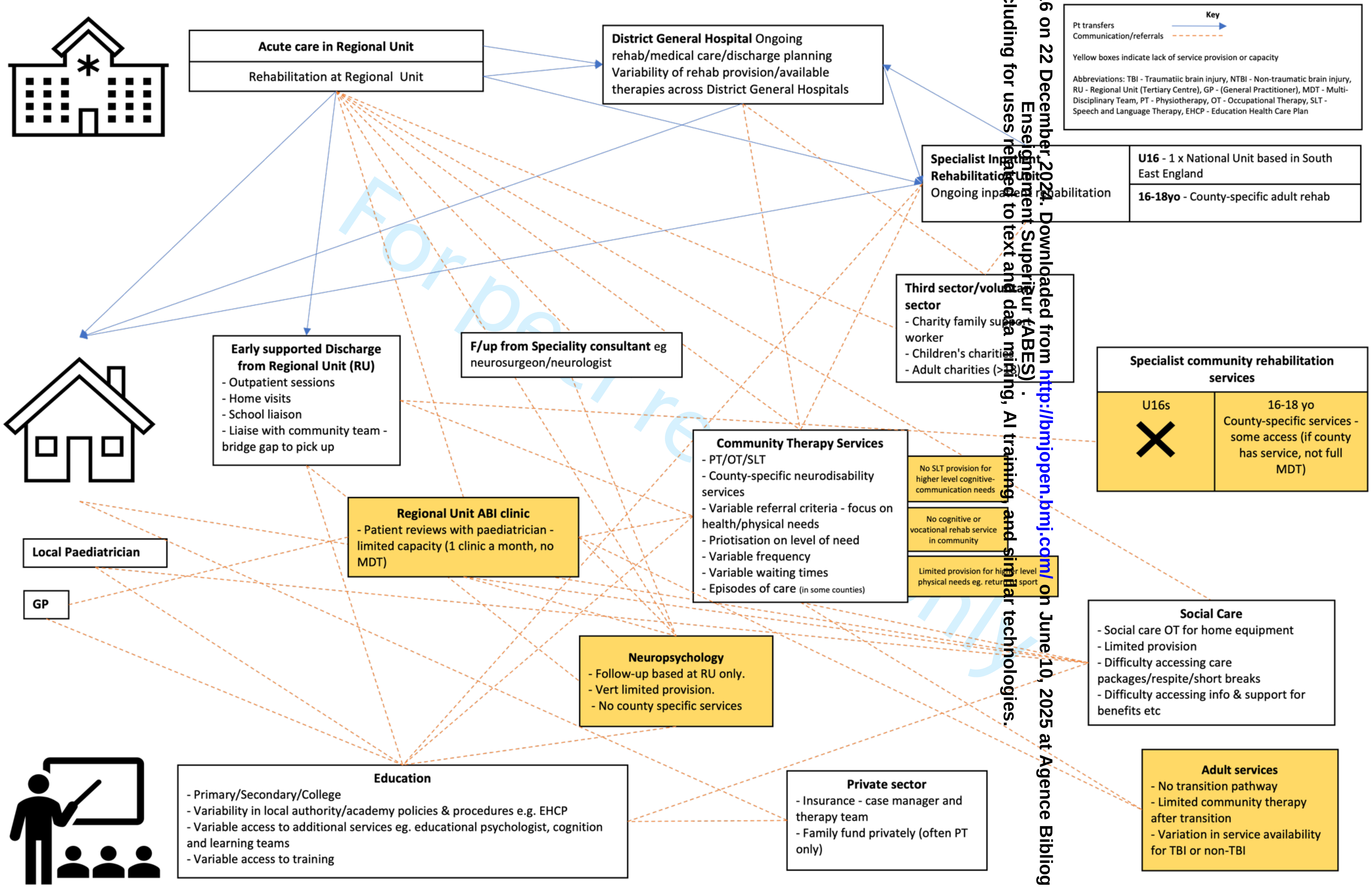
Individual Outcomes
- Increased participation and well-being
- Parent (or older CYP) reports increased self-efficacy in managing and supporting CYPs needs
- Decreased parental distress and family functioning impact
- CYP/family satisfaction

Organisational outcomes
- CYP access education with appropriate support for learning
- Schools feel supported
- Effective cross-sector communication/ collaboration between services

System outcomes
- Reduced absence from school
- Reduction in healthcare visits
- Long-term impact on CYP's education and contribution to society
- Parental health and well-being
- Parent able to return to work

Moderating and Contextual Factors

HEALTH - Consultant clinics/Nurse specialists/Community therapy services/Commissioning guidelines/criteria/National Institute for Health and Care Excellence Guidelines/ NHS England Service Specifications (Paediatric Neurorehabilitation)
EDUCATION - Education Act/Education Health Care Plan/Special Educational Needs Coordinators/Local Authority support service
SOCIAL - Family support/Social network/Charity provision e.g. Family Support Worker



Key
Pt transfers
Communication/referrals

Yellow boxes indicate lack of service provision or capacity

Abbreviations: TBI - Traumatiic brain injury, NTBI - Non-traumatic brain injury, RU - Regional Unit (Tertiary Centre), GP - (General Practitioner), MDT - Multi-Disciplinary Team, PT - Physiotherapy, OT - Occupational Therapy, SLT - Speech and Language Therapy, EHCP - Education Health Care Plan

Acute care in Regional Unit

Rehabilitation at Regional Unit

District General Hospital Ongoing rehab/medical care/discharge planning
Variability of rehab provision/available therapies across District General Hospitals

Specialist Inpatient Rehabilitation Unit
Ongoing inpatient rehabilitation

U16 - 1 x National Unit based in South East England

16-18yo - County-specific adult rehab

Third sector/voluntary sector
- Charity family support worker
- Children's charities
- Adult charities (>18)

Early supported Discharge from Regional Unit (RU)
- Outpatient sessions
- Home visits
- School liaison
- Liaise with community team - bridge gap to pick up

F/up from Speciality consultant eg neurosurgeon/neurologist

Specialist community rehabilitation services

U16s	16-18 yo
✕	County-specific services - some access (if county has service, not full MDT)

Community Therapy Services
- PT/OT/SLT
- County-specific neurodisability services
- Variable referral criteria - focus on health/physical needs
- Priotisation on level of need
- Variable frequency
- Variable waiting times
- Episodes of care (in some counties)

No SLT provision for higher level cognitive-communication needs

No cognitive or vocational rehab service in community

Limited provision for higher level physical needs eg. return to sport

Regional Unit ABI clinic
- Patient reviews with paediatrician - limited capacity (1 clinic a month, no MDT)

Local Paediatrician

GP

Social Care
- Social care OT for home equipment
- Limited provision
- Difficulty accessing care packages/respite/short breaks
- Difficulty accessing info & support for benefits etc

Neuropsychology
- Follow-up based at RU only.
- Vert limited provision.
- No county specific services

Adult services
- No transition pathway
- Limited community therapy after transition
- Variation in service availability for TBI or non-TBI

Education
- Primary/Secondary/College
- Variability in local authority/academy policies & procedures e.g. EHCP
- Variable access to additional services eg. educational psychologist, cognition and learning teams
- Variable access to training

Private sector
- Insurance - case manager and therapy team
- Family fund privately (often PT only)

COM-B Behavioural Diagnosis

Define the problem	CYP-ABI and their families experience restrictions in participation in activities at home, school and in the community due to multiple barriers, which impacts on their wellbeing.
Target behaviour	Increasing participation of CYP-ABI and their families in activities at home, school and in the community.

Barriers and facilitators

COM-B/TDF Domain		TDF Construct	Barrier/Facilitator	Theme
Capability	Knowledge	Knowledge (about a condition)	Barrier	Lack of awareness and understanding
			Facilitator	Education and training for families and professionals
		Procedural knowledge	Barrier	Lack of knowledge regarding system navigation
			Facilitator	Support and upskill parents
	Skills	Skill assessment	Barrier	Lack of recognition or assessment of needs
			Facilitator	Access to specialist assessment and review
		Ability/skill development	Barrier	Lack of ongoing rehabilitation access to address impairments
			Facilitator	Access to specialist rehabilitation support
	Memory, attention, and decision processes	Cognitive overload/ tiredness	Barrier	Impact of fatigue
			Facilitator	Education and training regarding managing fatigue
				Support with learning
Opportunity	Social influences	Social support	Barriers	Social isolation/lack of CYP peer relationships
				Lack of peer support for parents/families
			Facilitator	Peer support for whole family
	Environmental context and resources	Environmental stressors	Barriers	Substantial parent care and advocacy role
				Lack of clear pathways/systems (health/social care/education)
				Impact of Covid-19 pandemic
			Facilitators	Point of contact/support for parents
				Care pathway/policies
		Resources/ material resources	Barrier	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)
			Facilitator	Information resources
Motivation	Social/ professional role & identity	Social identity	Barrier	'New normal'
			Facilitator	CYP motivation
		Professional role/ boundaries	Barrier	Professional roles and boundaries
			Facilitator	Collaborative cross-sector working
	Beliefs about capabilities and consequences	Self-confidence/ perceived competence	Barriers	Lack of parental or CYP confidence
				Lack of insight
				Safety concerns
			Facilitator	Access to rehabilitation support
	Goals	Goals (distal/proximal)	Barrier	Lack of support to achieve longer-term goals
			Facilitator	CYP motivation/goals
	Emotion	Affect	Barriers	CYP, parental and family emotional impact
			Facilitators	Resilience/bravery
				Support for families

Identification of BCW intervention types

COM-B		TDF	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental Restructuring	Modelling	Enablement
Capability	Physical capability	Skills					▨ *				▨ *
	Psychological Capability	Knowledge	▨ *				▨ *				▨ *
		Skills	▨				▨				▨ *
		Memory, Attention, Decision-Making processes	▨ *				▨ *				▨ *
Opportunity	Physical opportunity	Environmental Context & Resources					▨ *	▨	▨		▨ *
	Social opportunity	Social Influences						▨	▨	▨ *	▨ *
Motivation	Automatic motivation	Social/professional role & identity		▨	▨	▨	▨ *		▨	▨	▨ *
		Emotion		▨	▨	▨	▨		▨	▨	▨ *
	Reflective motivation	Beliefs about capability and consequences	▨ *	▨	▨	▨				▨	
		Goals	▨ *	▨ *	▨ *	▨				▨	*
		Social/professional role & identity	▨ *	▨	▨	▨				▨	*

Shaded squares are BCW suggested links. * indicates links relevant to key objectives of intervention

Identification of BCW Policy Options

	Communication/ marketing	Guidelines	Fiscal measures	Regulation	Legislation	Environmental/ social planning	Service provision
Education	▨ *	▨ *		▨	▨		▨ *
Persuasion	▨	▨		▨	▨		▨
Incentivisation	▨	▨	▨	▨	▨		▨
Coercion	▨	▨	▨	▨	▨		▨
Training		▨ *	▨	▨	▨		▨ *
Restriction		▨		▨	▨		
Environmental restructuring		▨	▨	▨	▨	▨	
Modelling	▨						▨ *
Enablement		▨ *	▨	▨	▨	▨	▨ *

Shaded squares are BCW suggested links. * indicates links relevant to key objectives of intervention