

Supplementary Material

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

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Supplementary File 1: Additional Quotes for Identified barriers mapped to Behaviour Change Wheel - Theoretical Domain Framework

	TDF domain	TDF Construct	Theme	Quotes
Capability	Knowledge	Knowledge (about condition)	Lack of awareness and understanding	<p><i>'It's a bit of a battle with the school. Now that he's changed [school] trying to get them to actually understand more about the acquired brain injury.'</i> (Robert's Mother)</p> <p><i>'They've never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't necessarily specialists that they have all this to cope with on a daily basis.'</i> (Nurse-2)</p> <p><i>'We or they may not know at the outset, you as clinicians may not know at the outset what the impact of this is in long term. And so as they're going through the education process... you may hit a particular aspect of the curriculum or a cognitive step that you want them to take, and suddenly you find that they have lost that knowledge or they can't bridge that gap, or they've lost that function. But you and they don't know that until they reach that benchmark, milestone, challenge what, whatever it might be, so it's a really unpredictable kind of future for them with lots of unknowns. And for those people supporting them...things can suddenly happen out of the blue that you might have assumed were still there. And yet it's a loss that they have had somewhere.'</i> (EPS-1)</p> <p><i>'It's just really difficult to get a consistent kind of agreement and understanding between everybody. I find that's more difficult in secondary schools than primary schools, where they've usually got just one or two teachers. Yes, fatigue is a big one that comes up as a problem. I hear the word 'lazy' quite a lot.'</i> (AHPN-2)</p> <p><i>'It is a bit of an information overload when you're in a crisis situation though, because you don't want to accept that your child's got something really serious, it's a really difficult mental place that you're in. So there is a bit of an information overload because you're coming to terms with a lot of things.'</i> (Megan's Mother)</p>
		Procedural knowledge	Lack of knowledge regarding system navigation	<p><i>'That's you guys in specialist roles in a tertiary centre, you know, not knowing where to go. Then you've got community professionals struggling to also find that support and then we're expecting families who've got even less understanding to kind of be able to access, haven't we?'</i> (Nurse-2)</p> <p><i>'I mean they say then, oh go on and look at the local offer, and that's how you're left, go and have a look at the local offer, and you go on there and you're just bamboozled, and I think to myself, why don't they make it really simple, why don't they do a flow diagram saying, and pointing you to all the services... and make it all, because it's almost like they don't want you to find the services.'</i> (Megan's Mother)</p>
	Skills	Skill assessment	Lack of recognition or assessment of needs	<p><i>'I don't know if it's the [diagnosis] that's affected anything but I suppose his organisational skills sometimes don't come naturally to him and I don't know if that's in himself or it's a result of anything...I think there are some subtle things and you think, is that that or is that just how he would be anyway?'</i> (Oscar's Mother)</p> <p><i>'No one may know what the impact of this might be long-term, you don't find the problem until they reach the benchmark/milestone/challenge'</i> (EPS-1)</p> <p><i>'They've never had to deal with any of this before and I think there's a complete lack of understanding out there from other professionals that aren't necessarily specialists that they have all this to cope with on a daily basis.'</i> (Nurse-2)</p> <p><i>'the understanding perhaps within a school environment....understanding about what they need and the hidden disability of ABI with our more mobile children.'</i> (AHPN-7)</p> <p><i>'So it's about very much what the family and the child's goals are, isn't it, and about trying to establish what they are and then this assessment of need, isn't it? So like X was saying, it relies on them knowing what their needs</i></p>

			<p>are and then whether those needs are being met, whether they're unmet or even unrecognised, in that they don't actually even recognise that it's a need.' (AHPN-7)</p> <p>'I think as health professionals, we almost sometimes dismiss that sort of stuff, don't we, as like the cherry on the top of the cake because you're still alive. What are you moaning about? Get on with it, sort of thing... We almost don't even think of any of that extended stuff because we're so focused on okay, do whatever treatment we need to do, let's keep you alive, let's get you sorted, let's get you home.' (Nurse-1)</p> <p>'So for a child who has an injury in primary school, actually you might not see some of the impact in terms of the executive skills... till secondary school and then that's a whole bigger challenge that hits sort of a second wave of it.' (AHPN-7)</p> <p>'The impact can be subtly changing as they grow, or improving as they grow, or indeed deteriorating...' (EPS-3)</p>
	Ability/Skill development	Lack of ongoing rehabilitation access to address impairments	<p>'...so every day since I've had that I've struggled and my whole left side a lot weaker, my whole body's weaker in general but more my left side's weaker, so I will struggle with mobility and balance and stuff.' (Jack)</p> <p>'...we've both seen that Elijah struggles a bit with his memory and sometimes he struggles with trying to find the right words to say so he'll take a while to answer something to try and get the right word but, it's not major, but it is different to what it he was.' (Elijah's Mother)</p> <p>'Banter sometimes can be a bit tricky. The filter's not on and he says what he's thinking out loud, and sometimes that can be, oh my gosh, should he have said that? I mean, the people around him know but, in the future, not everyone's going to know that.' (Hamza's Mother)</p> <p>'Now, he can get a bit emotional about things and he does have some organisational...maybe he just needs to get into the habit of organising, but he can react in some - Just very, very subtle, just ticks a few little boxes, and you just need to understand him.' (Oscar's Mother)</p> <p>'Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things'(Megan's Mother)</p>
Memory, attention, and decision processes	Cognitive overload/tiredness	Impact of Fatigue	<p>'Fatigue is huge, and it plays a massive role' (Charlotte's Mother).</p> <p>'Much more tired, after school and stuff' (Elijah).</p> <p>'If you've got a child who's very, very fatigued and is really struggling, the parent's priority might be school and getting them to do the best at school and anything outside that might just seem too much to ask for, almost, because I think for a lot of families, the focus is on education and if a child is too tired to manage in school, then they're not even thinking about anything outside of that.' (Nurse-1)</p> <p>'Managing their fatigue - I don't know if anybody has, that's such an under researched area and actually for schools to manage children and for children themselves actually. I don't know what it's like in the primary sector, I would imagine difficult, but for children to learn how to pace themselves and to manage their fatigues extremely difficult in the school context because of the way that the day works.' (EPS-1)</p>

Opportunity	Social influences	Social support	Social isolation/Lack of CYP peer relationships	<p><i>'Not really, no, don't really have any really.... Yeah you can say I sit with them at lunchtime, but you can also say they're not my friends, just because I'm sitting with them doesn't mean I'm friends with them.'</i> (Megan)</p> <p><i>Amelia: 'Yeah, so I've been playing out with my friends.'</i></p> <p><i>Amelia's Mother: 'That one can be a bit tricky, can't it, because I don't like you to go too far, do I? ...Like yesterday when her friends wanted to go off like round the block, you know, that is more challenging obviously for Amelia and for me to let her do that.'</i></p> <p><i>'He's become a bit of a recluse, to be fair. He spends a lot of time indoors.'</i> (Barney's Mother)</p> <p><i>'But that, no contact with other children...there's no groups or social groups I can take her to where – she's in that in between stage, you know what I mean...there's just nothing there as far as I can see.'</i> (Megan's Mother)</p> <p><i>'Yeah, that junction thing, that one road that terrifies you.'</i> (Hamza)</p> <p><i>'I think it actually contributes to that isolation because she... needs meeting and taking to lessons, so...she's wobbly on her feet, she's already looking vulnerable and she's feeling like she's more singled out, so it's actually having that social impact on her as well.'</i> (EPS-4)</p> <p><i>'it's all about the socialisation, being able to integrate with his peers, particularly at school, and that being a challenge for many, many reasons. Mobility, emotions, you know, the physical side of things, endurance, all of those types of things, but that being – his biggest need and wish and desire is that socialisation.'</i> (AHPN-1)</p>
			Lack of peer support for parents/families	<p><i>'I think, if there's something for people with common experiences that give their tips, I don't know, or professionals that can advise, I think that would be useful'</i> (Oscar's Mother)</p> <p><i>'I suppose maybe speaking to people that actually understand what you're talking about rather than just, "well, you know, he looks fine". He is fine, but it is quite isolating and lonely really.'</i> (Robert's Mother)</p> <p><i>'I know a lot of parents that I see actually don't feel massively supported and they will seek their own sort of parental support, so they might just access support groups through Facebook, initially, if it's not well known to the charities or, like you guys were saying, actually charities are going under and it is harder and harder for parents to seek that kind of support.'</i> (AHPN-5)</p> <p><i>But it's kind of, perhaps it's asking too much for a hospital to be a social...but the hospital is the pinnacle of this isn't it, it's the only place that we've all, one thing we've got in common is the hospital.... there's lots of other women and children and whatever out there, that could do with the morale support and it's just a tremendous thing to get that support from somebody else going through the same thing.'</i> (Megan's Mother)</p> <p><i>'You know if the child in question has got siblings, you know, there's a lot of attention for that period of time, maybe on their sibling and then everything should be back to normal and it's not and there's still a lot of attention on that child. And actually...there's not an awful lot of support for the siblings of children with brain injuries, or you know cancer treatments, it's not there, and actually they've gone through a massive emotional turmoil as well. And then that can affect the relationship between the two siblings, or, however, many siblings there are.'</i> (EPS-2)</p>
	Environmental context and resources	Environmental stressors	Substantial parent care and advocacy role	<p><i>'We're in a very fortunate position because I didn't work before, although I would've liked to have gone back to work to be fair, but yeah, full-time carer and my husband...he's retired. So in that way we're really, really fortunate, because we don't leave her unattended....so we just like swap and we manage to work it that way....And then I thought about the personal payment, and I thought...how am I going to get somebody to do this, I can't just get anybody and it's so unpredictable.'</i> (Megan's Mother)</p>

			<p><i>'...it was such a battle' (Charlotte's Mother)</i></p> <p><i>'something I've pushed very hard for' (Amelia's Mother)</i></p> <p><i>'nothing happens at all unless as a parent you're finding you're way with it' (Megan's Mother)</i></p> <p><i>'I think in terms of brain injury I think there's no consistency of support, the consistency's not there...Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things' (Megan's Mother)</i></p> <p><i>'I think there's a complete lack of awareness of actually how much the parents have to do and how much they have to manage and how much, on that discharge, is actually handed over to them...All those little tasks that, in hospital, are just done and then they have to then start all that and build all that back up as normal at home, on top of having to manage the whole NHS, which is ridiculously complicated.'(Nurse-2)</i></p> <p><i>'I think the families and the young people I worry about more are perhaps those who can't express those things [needs and views] in the same way, or who perhaps don't have that support. And I think that's where, perhaps we need to be thinking about how we put that support in around them a little bit more kind of thoroughly, I suppose, so that there are, there does feel like there is perhaps big gaps?' (AHPN-7)</i></p>
		Lack of clear pathways/systems (health/social care/education)	<p><i>'Again, you've got to understand how systems work to know who to go to, which parents often don't.' (Nurse-1)</i></p> <p><i>'I think the downside was just education, from, as soon as she was poorly, you know, and when things started to decline, you know, mainstream it was such a battle...you know, I can take a step back and go, actually they're sort of batting her away, but the reason is because they are frightened because, you know, she's quite complex...I think in comparison to medical, education has been extremely hard, like I say, now she's got it but in one year she literally had three hours in a school with education, in a whole twelve months and it was just so frustrating.' (Charlotte's Mother)</i></p> <p><i>'I think the recognition that ABI is often long term/lifelong and that children are developing and that there's changing needs across developments and that transitions matter and that all of those other things matter, is just lost in commissioning.' (AHPN-7)</i></p> <p><i>'I think most challenges extend into education and other settings as well, because you think about that sudden change of needs of an ABI and the education system is not set up to deal with that. So you know, you've often got kids going back in where they can't get any EHCP [Education Health Care Plan]. They probably won't even meet the criteria for an EHCP in a lot of our counties now, but also they've missed the funding pots because it's not the start of term when they had their brain injury. They're trying to get them back into school to get them participating, to get them seeing friends, to get them doing all those things we want them to do but they can't because they've not got a TA [Teaching Assistant] or they've not got the support and they're having to just juggle things within education because the system is not fit for purpose when you've got that change in needs.' (AHPN-7)</i></p>
		Impact of Covid-19 pandemic	<p><i>'He'd only just sort of started with his whole time one-to-one when we went into lockdown, so he sort of fell even further behind.' (Robert's Mother)</i></p> <p><i>'Well, it started really before Covid hit. Physio stopped. Occupational therapy, he had one visit while he was still in hospital, and that never took place again, which was promised. Speech and language. It's almost as if [county] just washed their hands of him. There's no support there.' (Hamza's Mother)</i></p>

		Resources/material resources	Lack of resources (adaptation delays, lack of accessible activities, services and support, socio-economic factors)	<p><i>'Because he's struggling with buttons and his tie and laces and what have you, [specialist] did refer him to the OT [occupational therapy] around here. She did go into school and see him, but she said, because he's not physically disabled, if you like, and that's what they specialise in, so it was just sort of- She sent me some stuff through the post to try with him in regards to buttons and things, but I think it would be quite handy if he could see somebody, if it was still within the team sort of thing.... Because they [OT] sort of help with day-to-day stuff as well, don't they?'</i> (Robert's Mother)</p> <p><i>'She is interested in doing something but how do I, how do I do that.... what can I do for her and I don't know what I can do for her, I don't know where I can go to get help for her....I find it really difficult, really, really difficult, because there's no help with it at all, so [specialist nurse] has pointed me to the, you know, where I can get the information and I've gone on looking at the list of groups and trying to work out and I just give up in the end, because I just, I can't see anything that meets her needs.'</i> (Megan's Mother)</p> <p><i>'I think from my perspective, there is certainly a frustration around not being able to offer as much as one might like to. So we're very much based on episodes of care in the community...We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need...they perhaps won't put that referral through. So it is hard to – certainly, it is difficult.'</i> (AHPN-1)</p> <p><i>'I think in terms of brain injury I think there's no consistency of support, the consistency's not there...Everyone has helped within their speciality, but then you're discharged from that and there's lots of little things that happen all the time that you need advice on and you don't have it. You don't have any point of contact, you don't have one person who can help you with all these things.'</i> (Megan's Mother)</p> <p><i>Much as we all want to, I think it is an endless frustration that we think oh, it would be brilliant for an OT to get involved at that point and to be able to help out with X, Y and Z, but can we find an OT in the community that we can make a referral to or that the child meets their threshold to get involved? No, not really. Same with speech and language. I mean, we have endless challenges getting speech and language therapy involved to support our patients and you can see those gaps, can't you, so clearly.'</i> (AHPN-7)</p>
Motivation	Social/professional role & identity	Social identity	'New normal'	<p><i>'Get them back into a proper [football] team'</i> (Elijah's Mother)</p> <p><i>'I hate it when they're holding my arms when I'm walking, I was like so annoyed. I really just want them to stop doing that.'</i> (Megan's Mother)</p> <p><i>'Feels more singled out...she's more comfortable with students who knew her before and know this is not what she's really like....'it's a real barrier in her, she doesn't want to be seen as special, you know that's like how she phrases it''</i> (EPS-4)</p> <p><i>'Yes, there's something about being the same as your peers, isn't there, doing the same things, being the same, not standing out.'</i> (Nurse-1)</p> <p><i>"Yes, I think that's for children and parents. Everybody compares, don't they, to what natural development is and what children should be doing.'</i> (SCP-1)</p> <p><i>'I think there's a few things in primary [school] where it's a rite of passage to be able to go on a residential, but whether you feel like you can be, you know some of the things with brain injuries is it leaves you maybe having fits now and then, so could you go?'</i> (EPS-2)</p>

			<p><i>'So sometimes it's about that acceptance, it's about the adjustment to kind of changes in identity and other issues where we're thinking, but it would be brilliant if people just knew and knew how to help, cos they all want to help, but it's not always in keeping with what young person wants.'</i> (AHPN-7)</p> <p><i>'All those stages that we sort of take for granted can be major sort of hurdles and blocking points, unless there's either a prompt or actually some physical assistance and it's that sort of – I don't know what the sort of either naivety or vulnerability, that we take a lot of that for granted or accept it as normal development stages and that, to an ABI can be quite a challenge.'</i> (AHPN-4)</p>
	Professional role/boundaries	Professional roles and boundaries	<p><i>'We only advocate when we're open to them...and is it our role to advocate?'</i> (AHPN-4)</p> <p><i>'I was always getting criticised in my role for molly coddling families and doing everything for them but, like you say, some families need that and actually sometimes, or most of the time, they only need it for a couple of months, just while they're getting themselves back on their feet and to... You know, it's giving them that understanding and that perspective, that they won't know what's more important and what isn't because why would they?'</i> (Nurse-2)</p>
Beliefs about capabilities and consequences	Self-confidence	Lack of parental or CYP confidence	<p><i>'she's lost all her confidence completely now talking to other people. She's looking to me all the time....'</i> (Megan's Mother)</p> <p><i>'Parents have a hard time having confidence and letting teenagers get out'</i> (SCP-1)</p> <p><i>'Children are just not necessarily confident enough to access those higher cognitive demand type groups.'</i> (AHPN-5)</p>
	Perceived competence	Lack of insight	<p><i>'It's not the actual journey of knowing the direction that you're going to walk to and from, it's the actual crossings, being aware of whose right is where and being aware of give-ways, being aware of three-way junctions..'</i> (Hamza's Mother)</p>
	Beliefs	Safety concerns	<p><i>'The bike was more because he'd still got the [condition] and I think I was too scared to take the stabilisers off and let him go for it.'</i> (Robert's Mother)</p> <p><i>'So for many of ours, they feel that the seizures rule their lives, so it's about trying to change that mental attitude. You can do anything with seizures, absolutely anything...It's just a case of adjusting that mindset to say you can do this, we just need to take a few extra precautions.'</i> (Nurse-3)</p>
Goals	Goals (distal/proximal)	Lack of support to achieve longer-term goals	<p><i>'I think we're really good at thinking about the short-term aims and what our short-term goals are for these young people who've had ABI, but actually thinking long term, actually much more thinking about long term and how do we support these children long term because that's often what they are going to have to experience, is long term input for them.'</i> (AHPN-5)</p> <p><i>'We set the goal, we do it, we discharge and then we might reopen again if there is another need, but that very much relies on the families and/or the schools being able to communicate that to you and if they're not identifying that as a need.'</i> (AHPN-1)</p> <p><i>'She's got targets set, ...but it's all in fluffy educational language isn't it...well it's not happened...it's a complete waste of time'</i> (Megan's Mother)</p> <p><i>'I had a child that did have an EHCP...we were presented with his old EHCP to go through what his new one was and basically they just literally scored out everything they couldn't do, so the parents were presented with this document that literally had everything just crossed out....I don't know whether it was a legal thing...but I found</i></p>

				<i>that really poorly managed... Actually, we're better off starting again from scratch, rather than, actually let's rule out what they couldn't do. To me, it was almost criminal.'</i> (AHPN-4)
Emotion	Affect	CYP emotional impact	<p><i>'But I can't go swimming...because of my epilepsy...I'd drown really.'</i> (Megan)</p> <p><i>'I think quite a few of our children find frustration that they're not able to do the things that they were able to do before and want to do.'</i> (AHPN-6)</p> <p><i>'There's also an element of grief experienced by these children for what they've lost in terms of their capacity or their cognition or even time that they may have spent in hospital that they've lost socially.'</i> (EPS-1)</p> <p><i>'And there's therefore almost denial that she's not in the situation in the reality she's in'</i> (EPS-4)</p> <p><i>'The fear of what will happen because of the gag, the choking, and the gag reflex with my student. And that's why partly she doesn't eat anything in school. She really, really doesn't want to.'</i> (EPS-4)</p> <p><i>'A lot of them feel anxious because they perhaps weren't doing anything wrong, they were going about a normal activity and then something terrible happened to them or they feel anxiety for the future concerning their health. They feel personal anxiety about their families, their friends, all of that.'</i> (EPS-1)</p>	
		Parental emotional impact	<p><i>'It cuts quite deep when you're comparing, when you see what all her friends are doing now and that she can't do any of that.'</i> (Megan's Mother)</p> <p><i>'I think it was such a traumatic time in our lives, it was so awful, and I was at such a low ebb and it was all.....because you're dealing with your own trauma... and it's like you've got a bit of post-traumatic stress disorder, I think after, I bet a lot of parents feel like this...when they've had a child that's in hospital with a serious illness, you feel really traumatised afterwards'</i> (Megan's Mother)</p> <p><i>'I really wanted to put him in a bubble wrap suit, I won't lie'</i> (Fred's Mother)</p> <p><i>'They want to but then they're scared. They're worried about them going out'</i> (SCP-1)</p> <p><i>'Parents fully expect their child to be the same as they were pre-diagnosis and it's that shock as they go through months and years and they just want their child to be the same as they were before, but you know they're not going to be the same and it's adapting to the child's needs for now'</i> (EPS-5)</p> <p><i>'it's almost as if those parents then tend to not be able to have that time to grieve properly and deal with trauma, what they've been through, because all of a sudden their whole life has changed and I find that a lot of my families, there can be relationship breakdowns as well and quite often, it tends to be the mum within the family that feels that she needs to take all of this on and then that breaks down relationships. It's a really hard time for them. It's almost like the devastating effects once you're home because you are in that bubble in hospital.'</i> (SCP-1)</p>	
		Family impact	<p><i>'I think they've found it quite tough actually....They did [have support] at the beginning with a psychiatrist, she did a really valuable session with, well it ended up being me and the boys actually at that point and they found it really helpful and a lot came out of that about how they were feeling and how difficult they were finding things, which I hadn't appreciated at that point.'</i> (Megan's Mother)</p> <p><i>'It is about balance...there's some things like when we've been to cinema...we can all do that together, but it is things like swimming that I feel we are, we're limited on things like that....so I feel like sometimes the boys miss out. But it is about compromise.'</i> (Charlotte's Mother)</p>	

Additional facilitator quotes mapped to Behavioural Change Wheel - Theoretical Domain Framework				
	TDF domain	TDF Construct	Facilitator Theme	Quotes
Capability	Knowledge	Knowledge (about condition)	Increase knowledge and awareness about long-term impact of an ABI	'I think teacher education is really, really key at the start of all of this.' (EPS-1)
		Procedural knowledge		
	Skills	Skill assessment	Support and up-skill parents	'We would usually advise that there should be like an open package of care so that they can re-access services as they need it' (AHPN-6)
		Ability/Skill development	Integrated collaborative cross-sector family-centred care pathways	'He walks...with a splint on his left leg. He's getting, with physio, he's learning techniques to walk without his splint. He's not there yet, by no shadow of doubt he needs his splint to be able to walk.... But yeah, he's doing lots better.' (Barney's Mother)
Memory, attention, and decision processes	Cognitive overload/tiredness	Access to specialist assessment, review and rehabilitation support	'so it's called Grid.... she's got like her favourites on there, so topics;... so we're trying to build her up on words...we've built her up from two words to three words, to four words, to press the speaker, how to put that in the bin when she's finished talking, which she's doing amazing with that.' (Charlotte's Mother) 'Managing their fatigue - I don't know if anybody has, that's such an under researched area.' (EPS-1)	
Opportunity	Social influences	Social support	Support and up-skill parents Peer support for whole family	'I think parents forget all that, that actually that is a need for independence, isn't it? Then we fail to make those referrals to adult social care for a PA and all of those things that could help them be independent because we just carry on in this thing that parents will look after them and take them everywhere.' (Nurse-2)
	Environmental context and resources	Environmental stressors	Support and up-skill parents Access to specialist assessment, review and rehabilitation support	'Well, it's down to [hospital youth worker] that got him onto this [college course] through - because he knew somebody at [charity], got in contact with them' (Barney's Mother) 'We belong to the [charity]. They've been absolutely brilliant. Yeah, they've been really, really good, like really quite a good like source of help for me as well.' (Amelia's Mother)
		Resources/material resources	Integrated collaborative cross-sector family-centred care pathways	'I know we all would like ABI to be better recognised in all areas, but for families financially within benefit support, for it to be a part of the criteria.' (SCP-1)
Motivation	Social/professional role & identity	Social identity	CYP motivation/goals Access to specialist assessment, review and rehabilitation support Support and up-skill parents	'Some of it is working really closely with families to try and support increasing motivation and looking at motivation and what they get out of it. That's half of the challenge.' (AHPN-5) 'So we had a huge teams meeting with a lot of her multidisciplinary input into that, so everybody's goals and what they wanted for her in all areas obviously and that is reviewed regularly.' (Charlotte's Mother)

		Professional role/boundaries	Integrated collaborative cross-sector family-centred care pathways	<i>'So some of it, I think, is just awareness of when other professionals can get involved and just that collaborative working, so that people can access more therapy and more their lives, really.'</i> (AHPN-5)
Beliefs about capabilities and consequences	Self-confidence	Access to specialist assessment, review and rehabilitation support	Support and up-skill parents	<i>'we could be supporting these challenges with participation that we often see further down the line, we could be supporting that so much more effectively if there was just investment in that longer term perspective, but we often get kind of a huge investment in that acute sort of side, which is really needed but then it thins out, doesn't it?'</i> (AHPN-7)
	Perceived competence			
	Beliefs			
Goals	Goals (distal/proximal)	CYP motivation/goals	Access to specialist assessment, review and rehabilitation support	<i>Right, what are the things you like to do? (Charlotte's Mother) Charlotte selects activities she likes to do and presses 'speak' on communication aid) 'Story Book Train Crayons Teddy Doll Ball'</i> <i>'I want to do well in school... that was a goal that I set this year' (Robert)</i> <i>'Maybe because I just like doing sports, I just like being active; and my dream is to be in the [professional sports association] at the moment, so that's what I'm trying to work up to.'</i> (Fred)
Emotion	Affect – Whole family	Peer support for whole family	Bravery and resilience	<i>Is it so impossible for the hospital to provide something, something where you could give your consent and it could be an independent link up, or some kind of group or something, where people can, can just link up with each other ...but the hospital is the pinnacle of this isn't it, it's the....one thing we've got in common.... there's lots of other women and children and whatever out there, that could do with the morale support and it's just a tremendous thing to get that support from somebody else going through the same thing.'</i> (Megan's Mother) <i>'There is a need to be brave to do something new/ do a new activity/join a new group and that can require a lot of energy and resilience'. (SCP-2)</i> <i>'Having somewhere or somehow that we can support these parents better in terms of managing their shock and their trauma and their grief, so that they can advocate effectively and sort of identify the needs themselves, isn't it? So it's helping them, supporting them to support their child is another thing to add in.'</i> (AHP-7)