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Understanding the support needs of disabled children and their families in East Kent

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Contents

Executive summary

Title: Understanding the support needs of disabled children and their families in East Kent

Objective: Explore the support needs of parents and carers of children with physical disabilities (< 18 years) within a therapy service in the South East of England.

Method: Qualitative methods were used including focus groups and interviews with 9 parents/carers of children with a physical disability. Framework analysis approach was used to analyse the data.

Results:
Data was organised into the following themes.

- Parent and carer experiences of using services including direct experience of therapy services
- Education
- Organisation of services and access to information
- Impact of disability on family and carer life
- Experiences and views of personalised care.

Conclusions:
Parents and carers had varied experiences of therapy services. Parents and carers valued close relationships established over time when therapists had knowledge and understanding of their child and family situation. Families experienced most difficulty over the provision of equipment and poor liaison between different parts of the care system added to stress and frustration. Few parents and carers had knowledge or awareness of personal health budgets and were unsure about whether a personal budget would improve their access to or experience of therapy.

Practice implications:

What do parents/carers want from therapy services?

- A trusted relationship with a therapist who knows their child and family circumstances.
- Continuity of care for their child over the long term.
- Reassurance and regular feedback about their child's therapy in terms that recognise the child's strengths as well as limitations.
- Flexibility in how therapy is provided
- Planning for the longer term needs of the child especially in relation to equipment needs and at key transition points such as entering school.
- A therapist who will act as an advocate, helping the parent and carer navigate the wider care system to ensure that the best choices are made for their child in terms of

wheelchair provision, adaptations to the home, tertiary care, education and personal health budgets.

What does the system need to provide?

- Equipment system that delivers the 'right' equipment at the 'right' time.
- Enable therapist to identify, prescribe and obtain, the right equipment at the right time.

Service recommendations

- Sharing of the key findings with therapists to build on the many examples of 'good practice' identified in the report – these include: returning phone calls, sharing information, involving parents in decisions about their child's care, making therapy 'fun', and sensitivity to the other pressures and competing demands on the family.
- Identify families with complex needs and review caseloads - taking into account part time working and maternity leave to achieve better continuity of care.
- Involve families in determining how therapy services can maintain a relationship with families and meet their needs in the short and longer term.
- Explore the potential of therapist as advocate - helping parents and carers make informed choices about their child's care, that could include choices around the best use of personal budgets.

Recommendations for CCGS or service restructuring

- Personalisation may offer the opportunity to recreate a model of care based on relational and individualised case load for the small number of children with complex and long term needs.

- Packages of care could be built around the therapist as an advocate. Individual therapists are enabled to work in partnership with families on a longer-term basis and take on a flexible and adaptable care approach focused on the evolving needs of the child and the family.

- Where there are opportunities to create personalised budgets as part of the care model, consultation with parents would be needed to ensure that they include the most appropriate elements from the perspective of parents. Parents of children in this group have longstanding and detailed understanding of what would improve their experience of care and help them caring for their child.

- From our research, elements that might be useful for inclusion in a personalised care package are equipment choices. The consultation may also highlight therapies, which are not currently available to the NHS, but which parents may deem beneficial for their child.

- Parents could also be consulted on areas of care which in their experience may not be suitable for inclusion in personalised care budgets for example in areas where it may be difficult for a non-expert to make an informed choice and where there may be deemed 'risks' to their child's health and wellbeing.

Implications for further research

- Research that explores the relational boundaries of therapist carer relationships and the types of support that families expect and services can provide.
- Systematic review of current practice for families of children with complex needs. Does family Centred Care lead to a reduction in carer stress and improved outcomes?
- Greater understanding about the potential role of therapists as an advocate in the deployment of personal budgets and personalised care.
- Better understanding about how to engage therapists and involve parents and carers of children with complex needs in research about them.

Background

There are an estimated 40,000 children with complex physical health needs in England who require the involvement of a number of health and social care professionals and multiple services (Care Quality Commission 2014). These children are a heterogeneous group, inclusive of those with life-long or life limiting conditions; such as cerebral palsy, muscular dystrophy and acquired brain or spinal injuries following trauma. Many children have associated disabilities such as epilepsy or other learning, communication and behavioural difficulties; resulting in complex individual needs (Lewis & Lenehan 2012). With medical advances and better care, the numbers of children surviving childhood and living into adulthood are increasing - raising questions over the support needs of parents and carers (Gibson et al. 2009).

Caring for a child with complex needs has a personal cost for both the child and their family. Children with disabilities are likely to have poorer outcomes across a range of indicators compared to their non-disabled peers; including lower educational attainment, poorer access to health services and consequently poorer health (Lewis & Lenehan 2012). They also experience a more difficult transition to adulthood and adult services and are likely to find it difficult to find employment (Care Quality Commission 2014). Because of the additional burden of caring for a child with a disability; families may have one or both parents out of work and experience financial hardship (Contact a Family 2014). They are more at risk of family break up, while siblings may suffer from emotional and behavioural problems, for example due to interrupted sleep (Ziviani et al. 2014).

There are also psychological and physical consequences on the family. In adjusting to a child with a disability families are vulnerable to poor psychological health and experience higher levels of stress and anxiety compared to parents of non-disabled children (Raina et al 2005). Parents and carers also are at greater risk of musculoskeletal problems associated with lifting and the long term physical burden of supporting a child with a physical disability (Nicholson 1999). Despite these additional needs, families often have reduced access to services such as respite care or short breaks, due to lack of appropriate choices and environmental barriers (Robinson 2000).

Families caring for a child with a disability carry out a number of tasks which can be described in terms of caring 'work' that includes responsibility for managing the child's therapy and this results in the family having to adjust or adapt to how family life is organised and managed (Corbin & Strauss 1988). Therapists can play an important mediating role in how successfully families' adapt and adjust to their child's disability (King et al 2004). Adopting the principles of family centred practice therapists and families work in partnership making decisions about the child's care and consider carefully the aims and anticipated outcomes of therapy and the impact this is likely to have on family life (King & Chiarello 2014). Family centred models of care emphasise the role of the therapist as provider of information, focusing on good communication and developing close partnership working with families (Kruijsen-Terpstra 2016).

However, realising the 'ideal' type of family centred service, may be difficult to achieve and reality may fall short of expectations. Therapists may inadvertently place additional strain on families and have unrealistic ideas about what families can achieve (Gough 2008). What has been described as a 'it might help and won't hurt' when introducing new treatment modalities - can be at the expense of the child engaging in normal everyday activities (Gibson et al 2009). Failure to work in a family centred way is more likely where therapists have high caseloads and for other reasons fail to embrace a culture of partnership working with parents (Dodd 2009).

In the United Kingdom parents and carers of children with physical disabilities access a range of health and social care services that includes community rehabilitation services inclusive of physiotherapy, occupational therapy and speech and language therapy. Typically, in England, therapists are members of a multidisciplinary paediatrician led team delivering care in the child's local community (Seal 2013). Families in the South East of England also access medical and therapeutic care from specialist centres such as Great Ormond Street in London. Where mobility problems exist families will access the wheelchair services, and Local authority social services, when specialist equipment or adaptations to their home environment are required. Parents and carers must therefore navigate a complex landscape of provision, with differing eligibility and entitlement criteria –often cited by families as a significant cause of additional stress and anxiety (Contact a Family 2014).

The Care Act (2014) and The Children & Families Bill introduced in 2013 were intended to improve the integration of health, education and social care and to reform the care system – for parents and carers of children with disabilities the aim was to give them greater choice and control of their child's care. A key feature of these reforms has been the introduction of personal health care budgets for children with Education, Health & Care plans (Contact a Family 2014, DoH 2014). Personal health budgets have been available for some time within adult services and may provide a solution when there has been a failure to provide integrated services that meet individual needs (Read, Blackburn & Spencer 2012). The purpose of a personal health budget for parents and carers of disabled children is to enable families to develop an individualised package of care that meets their child's needs. However, take up by families has been slow to date and roll out amongst clinical commissioning groups has been patchy (Welch 2012).

We know little about parent and carers views of therapy services or the specific therapy support needs of parent and carers of children who have physical disability in England and the UK. In the light of policies designed to promote the uptake of personal health care budgets it is opportune to explore current perceptions amongst parents and carers of their views about being 'given more control' and greater choice over their child's therapy. Therapists require a greater understanding of the support needs of families in order to provide responsive and personalised services. The study explores whether therapy services in East Kent are meeting commissioning expectations including expanding choice and control for parents, delivering responsive and timely services; and resolving difficulties with the co-ordination of care.

At present little is known about what type of support families want from therapy or how they may decide to use personal budgets, as and when this option becomes available to them. Qualitative research focusing on the views of families can help to provide answers to these questions.

Methods

Aims of the current research

The current research aimed to examine the support needs of disabled children and their families in East Kent. The project was funded by East Kent Hospitals University Foundation Trust (EKHUFT) and findings were reported to the Trust to inform the planning of therapy services. Specific objectives were as follows:

1. To identify what support from therapy services families want and need;

2. To explore families' views regarding the three policy priorities (access and empowerment; responsive services and timely support; quality and capacity);

3. To explore how parents view the introduction of personal budgets and how they intend to exercise 'choice' when obtaining expert support for their child;

4. To examine potential transition points requiring a change in the nature or intensity of support provided by therapy services.

5. To scope potential of conducting a larger study.

Participants

We aimed to recruit parents and primary carers of children with physical disabilities (aged 18 years or younger), who access at least two paediatric therapy services (e.g. physiotherapy, occupational therapy, and speech and language therapy). Nine participants were recruited, all of whom were female and had children aged between 2 and 16 years. Participants accessed a range of services.

Procedure

Participants were recruited via therapy teams and local parent groups (see appendix) and the research team attended meetings with these groups to discuss the research. Parents/ carers meeting the study inclusion criteria were provided with an information sheet and expression of interest form together with a postage paid envelope. Twenty-one people returned the expression of interest forms and were contacted by the researcher to discuss the study. They were invited to attend a focus group or one-to-one interview and provided with a range of dates, times and venues. Fifteen people accepted the invitation; of these two attended a focus group, two attended face-to-face interviews and five were interviewed over the telephone. The remaining six people cancelled or did not attend. Participants were not required to give a reason for withdrawing. Informed consent was obtained prior to the focus group/ interviews.

A focus group / interview guide was developed to cover the following themes: getting the help you need when you need it (including questions around timely access to services and quality of the support provided); personalised care (which included views on the proposed introduction of personalised budgets and how this might affect care); managing transition (exploring periods of change in support needs and the responsiveness of therapy services). All focus groups and one-to-one interviews were recorded and transcribed verbatim. The focus group and face-to-face interviews lasted for around 1 hour, telephone interviews were typically shorter (30-45 minutes). All participants were fully debriefed at the end of the study and provided with a summary of the findings.

Data analysis

Interviews were entered into NVIVO and analysed using 'framework analysis' (Fern 2005, Bowling 2005, Pope et al 2008). This approach is particularly useful in applied research, in that it allows combining exploring pre-determined themes with more open and emerging categories. It involves five key stages: familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation.

Ethical approval

Ethics approval was obtained prior to the start of the study from the National Research Ethics Service (13/YH/0374) and R&D approval from EKHUFT.

Results

Parent and carer experiences of therapy

Parents and carers we interviewed had contrasting experiences of therapy. For some it was positive, for others less so, while others had a mixed experience.

Therapists personal attributes contributed to a positive outcome for parents and carers, comments such as 'she listened', 'she is always there' 'she always gets back to me' provide insight into how important the perceived 'responsiveness' of individual therapists was to overall parent and carer experience.

Therapists' ability to listen and respond extended to providing 'reassurance' to parents and carers about the child's progress. For example, one parent reports that between therapy blocks 'she's (the therapist) is happy to talk to me over the phone because a lot can happen in 6 weeks' or, in another instance receiving a written report in the child's school book 'every time' the therapist had seen her child at school was important.

Where there was a good relationship between parent and therapist, parents trusted the therapist's opinion seeing them as a valuable source of knowledge and information about their child's condition,

'I feel like I have learnt a lot from the therapist, they explain everything very, very well' (09).

Parents and carers valued 'timely' support and interventions that met the needs of the child, whether this was provision of equipment that assisted the child's independence as in this instance,

'By giving her a walker, by giving her the means to be able to have a bath such as bath seating and anything that will help her in the means of getting up and doing things' (05).

Or, when therapists had provided 'hands on' therapy.

'Today, she's shuffling on her bottom, she's standing on her feet, albeit with a lot of support, but she's standing and she's now starting to take steps by herself, also with a lot of support holding her up. But she wouldn't be at that point if she didn't have all the support that she's got up until now' (05).

The best experience of therapy was where it didn't 'feel a chore' but was described by the parent as part of the child's everyday play experiences.

'And I think the other thing I like about the therapists is it... it never feels like a chore. A lot of my friends or whatever would say, "Oh god..." you know, "is the physio really hard to do at home and is it hard work?" And I'm like, "Don't even really think about it. We just..." It's

part of his normal day and we don't sit and suddenly have to do physio and I think that's partly because of the way they put it across. It's very much play so for him it's fun' (08).

Parents valued therapists who were able to anticipate the needs of the child and contacted families before they needed to 'chase' for help. For example, planning for transition to school and predicting and planning equipment needs in instances where children has a deteriorating condition such as muscular dystrophy.

Therapists' ability to build a long term and trusting partnership with the family meant they had insight and knowledge of the family dynamics as well as a good understanding of the needs of the child. This included the ability to be 'intuitively' aware of parental concerns, which enabled therapists to respond quickly when a concern was raised 'I know she would fit him in' (08) - alleviating parent and carer stress associated with the concern.

'Her attitude is if you're feeling stressed about it and you think it's not right, let's... Let me see [name of child], just even if it's only a reassurance for you' (04).

'And they... you know, they're always talking to you about what their thoughts are and what they think he needs and what he's doing very well. Very encouraging all the time and I think all of that put together takes away any kind of stress that might be there from it' (08).

How quickly or the speed of response to a request from a parent was very important to parents and carers, as described below.

'Physio took a while to come in, OT I think they were quite quick to come in but we didn't notice that so much because we already had Physio at that point, but she's very very good, if I ask her to come out to the house and check on something for me she'll come out to the house and that's not a problem we can book that in within a week or so' (05).

'When we've asked them for something they've kind of got back to us. If they haven't been able to give us the answer straight away they've got back to us within sort of 24 hours' (07).

The ability to be able to contact a professional easily for information advice or reassurance was important and extended to other professionals the families came into contact with.

'The *really* good thing that came out of that because we got an immediate... obviously immediate diagnosis with the epilepsy nurse –[name of nurse], *absolutely* fabulous woman, she's great – I can ring them up and ask her anything and she can look as well and see what appointments [name of child] been booked in' (04).

In contrast, there were many instances where therapists and other professionals were less responsive and the service failed them in some respect. Dismissing a parent's or carer's concern as unfounded was not untypical and parents found this equally frustrating and distressing.

'The [name of therapy] therapist just seemed to think that I am still being an overprotective mother and that *she's fine'* (04).

Parents wanted to be involved in decisions about their child's therapy; parents felt excluded when a therapist didn't take account of their opinion or as described here ignored a 'mother's instinct' as to what was right for her child.

'So I think I terms speech and language therapy, although they have a means to do things and a way of doing things and giving you support, I think sometimes they need to look at what the child can and can't do and what the child wants.

Ok, have a bigger picture maybe, you think, or..

Yeah, or go by what the mother's instinct is' (05).

What was perceived as inflexibility, 'they are gonna do it their way ', resulted in parental frustration who wanted to be 'given the means' to be able to help her child.

'I don't feel they (SPAL) take my opinion on board. I feel like they have an outlook on something and they're gonna do it their way' (05).

Parents sometimes felt that they were 'expected to do a lot' and there were occasions when therapists didn't appear to understand the strain families were under. In this instance, managing the needs of a sick child.

'I'd had to try and keep him all clean, give him his medicines, get the house sorted, do the dinner and I had to do physio on him and get his, he's got like a Cough Assist machine, I had to be doing all this, massaging him and she came in and she told me that I had to do all these things in a day and I'm like…I just burst into tears when she went because I thought I can't cope with this. (03)

In certain instances, parents and carers recounted a sense of 'being on their own' with issues, being self-reliant and battling for everything. In some cases, parent's express low expectations of the service or did not believe therapists were there to help or support them.

'Right, do you know what? Nobody's helping me. I'll do it myself' (01).

In a situation where the child had a deteriorating condition there was frustration that there wasn't more 'forward planning' that things could be put in place and that services could be more proactive.

'Everything that we've got for [name of child] we've had to fight for and why should you do that because they know what's going to happen with their condition so why don't they have a plan of what we should be doing as time goes on, get ready for things' (03).

A recurring issue was therapists failing to 'return telephone calls', or parents finding out via a third party that a therapist or other professional involved in their child's care was 'going on

maternity leave' and then experiencing a 'gap' in therapy until an alternative therapist was found.

'You occasionally get a good one and then they get pregnant, don't they' (01).

The part time nature of therapist working patterns seemed to be an issue 'I think she is a part-timer so I don't know' (05).

When the service did respond, it was often seen as 'too slow' for some parents who felt that they had to 'chase' to get things done.

'What I feel with the services is it can be slow so if you don't get on that phone you get lost in the system and it's important with their condition the faster you can get treatment like physio, then you get the OTs in, you get the things you need then it's better for him' (03).

At the other end of the scale parents felt that the transition from nothing happening to everything happened 'at once' was like an avalanche it all happened at once' (01).

The language and way that therapists referred to their child was also an important issue for parents and carers, they wanted a child's strengths to be discussed as well as highlighting the things a child was unable to do

'It does not mean that when it's your child it feels ok for people to write really harsh reports without any positive wording in them' (06).

Parents and carers experience of 'a system of care'

When asked about their experience of therapy services, parents and carers spoke in terms of a 'system of care' in which different services (i.e., health, social care, education) combine. Even where a parent or carer reported a positive experience of 'therapy' they often recounted experiences about failures in other parts of the care system that had a lasting impact.

Failures in one part of the system, for example involving provision of equipment, at the time of diagnosis or in communication with their child's school were perceived as a general systemic failure. How elements of the system of care worked or didn't work together were a source of frustration, adding additional pressure at times of family stress as in this incident.

'…we were fired out a lot of letters all at once, needing to go to appointments, often several in the same week. It wasn't clear what the purpose of the appointment was or exactly what they were seeing us for and it didn't really explain, it would say 'come to X's clinic' but it didn't say what for or why

And often you'd be saying exactly the same things three times in one week and when you've got a very premature sick baby that's the last thing you want to be doing because it just felt like, don't these people speak to each other?' (06).

Parents depend on therapists communicating with one another to get the right type of support; however, there were incidences where parents and carers felt they were 'caught in the middle' of services eligibility criteria for specialist equipment. There appeared to be ample 'room for error' in these situations and parents had to complain to 'get anything done'.

'Yeah as the more I've complained I think they do talk to each other a bit more (the 2 OTs). If I've got an issue they will then talk to each other but it's like when I phone up for something in particular, I usually would ring [name of therapist] and she would say; "oh no I can't do that, you need to talk to[name of therapist] " which would be nice if we had a list of things that they do for us really, something that just…' (03).

Parents and carers discussed the practical difficulties of 'shared care' between local community services and the specialist centres that families' accessed in London. Although families valued the specialist input into their child's care, journeys to and from London were stressful and created an added pressure.

'You know, I mean you've got all that plus family life to cope with and they just think *oh, pack up to London* and that's fine' (01).

'She's not stressful itself it's more what is going on surrounding her such as obviously with regard to going up to London and having people pick and poke at her…' (05).

Although participants were not asked about the time their child was diagnosed, given the opportunity to talk about their child's care many chose to return to this moment and related how poorly this was handled by professionals involved. For many, despite the passage of time, this was a vivid moment, clearly recollected with the associated emotions and concern for their child's future.

In one instance the early intervention of physiotherapy was recalled as being particularly helpful and supportive 'she came very quickly' 'it was really helpful' and in instances when a diagnosis was uncertain a physiotherapist had assisted in providing practical support and reassurance while the family awaited the outcome of medical tests and reports.

Respondents reported mixed experiences with NHS services over time. Parents, particularly of older children, remembered the difficulties about receiving a comprehensive diagnosis of their child's condition. One of the issues highlighted was a reluctance in the service to conduct the appropriate tests with the urgency parents expected to identify the condition. The parents of child with neurological problems had to push for urgent appropriate scans:

'I pushed the consultant to get that EG done straight away, you know "Right, I want it... I want a cancellation. I'll come at any point at a drop of a hat." Which I did, that's how we got it. And then he said, "Oh well you won't get a diagnosis, a definite diagnosis, of epilepsy straight away. That just doesn't happen. It's a build-up over months and different sieges and bla, bla." He was totally wrong. He rang me up and said, "Oh, we've seen a gross abnormality, you'd better bring [name of child] in. We want to do an urgent MRI," so he was eating his words. He was kind of trying to just really shove me away because I was pushy

mother but actually it was right; she needed that EG quickly and then an MRI quickly to see and then it was like – wow, that's a can of worms!' (04).

With the limited number of respondents, it is difficult to determine whether this experience of the parent with a teenage child is still common or whether services, such a referral, tests, have improved a with improving assessment tools and diagnosis pathways.

Experiences with NHS services are individual and over a long history with any service, not everything will be perfect at all times. However, from the interviews conducted for this study, there is a link between poor experiences at crucial periods of the child's life or their illness history and the perception of health services generally. In the interviews, respondents were able to recall in explicitly detail about things what had gone wrong and clearly emotionally affected, even after a long time. A number of them were still angry about things that had gone wrong

'it just makes me so cross because if he'd had it from the word go it would have been fine but because it's only come here - down to late diagnosis which is nothing to do with me; you know, no medical practitioners actually picked up on it - it's now a struggle to get him the help that he is entitled to.*' (03)*

Some of the parents had formed a rather negative perception of health services, which in turn also coloured their approach in dealing with service providers. Some of the parents had turned into 'continuous fighters', expecting the worst outcome at all time.

An overriding theme in this is the way communication between health professionals and parents is managed. Parents of younger and older children highlighted the difficulties in being listened to when raising problems with their child's development by health professionals, and quite often being dismissed in their anxieties:

'I need her to be seen at the moment by GI consultant but that is getting there. Some of the things that I have said in the past haven't been kind of picked up on for a while and I think well, I've said that six months ago. (05)

'At [name of school] Primary School where they straight away said, "He's got major problems going on here." You know, "He's not reading. He's not writing. He's…" you know, "He's stumbling around," etc., etc. Now these are all things that I highlighted with my local doctors at Wye for years – absolutely years and years. You know; he's falling over, he didn't crawl. Nothing! Absolutely no help! (06)

Poor communication is not only a problem for parents, but can also be experienced by the older children themselves when they are deemed old enough to be part of the consultation and exchanges. For young people appropriate and reassuring communication about their condition is central to keeping motivation and positive outlook going in the context of the experience of disability. One of the parents of teenager highlighted the impact of 'off message' medical consultation:

'It would have been really nice for someone –not myself- to sit down with him and said: "This is happening" … He had all this medical stuff thrown at him with no explanation as to why and it was a lot for him to take on board. You know, he really withdrew inside himself. He was like, "That's it. I'm not going to school now thank you very much. I'm not going… I'm not going out at the weekend. I'm not going anywhere. I'll just sit here where I'm safe," you know. "I'll play on my X-Box and that's it.' *(01)*

Conversely, good communication helps to keep the parents in the loop of the development issues and can result in a parent feeling empowered and supported. The mother of young child with developmental problem has found that the multi-disciplinary approach taken in the care of her daughter has been exemplary:

'We've got access to this kind of hub of knowledge and I think so far I have – and I said this actually at our last team about the child meeting – that, you know, in large part where [name of child] is today is the large part of the interplay between all of these teams and, you know, really that's a great thing that we can sit and look at a very happy baby with her rough start in life is now crawling and active and mobile and so really I wouldn't want to rock that boat at all' (09).

Parent/carer experiences of specialist equipment provision.

Problems with equipment at some point or other were reported by most parents interviewed. The exception was one parent; whose child is comparatively young. The mother reported that she had not experienced any problem with equipment provision. She also works within the health system and may have a different relationship to the system.

Because of the complex arrangements surrounding eligibility criteria for equipment and provision of specialist equipment from different health, social and education services, parents and carers when discussing issues didn't always distinguish between services, it didn't matter who provided the equipment - what mattered was whether it met the child's needs and how responsive services were in getting the right equipment in place quickly for their child. The type of problems encountered included receiving appointments for wheelchair assessment, delays in ordering issuing and receiving equipment, and the issuing of inappropriate or incomplete equipment. In one instance the parent had 'told' therapist what was required but therapist had ordered the 'wrong thing'. Particularly tricky was the adaptation of housing to fit the needs of the growing child.

Assessment and receipt of equipment

Difficulties in getting appointments with wheelchair services were reported and, at times, resulted with a child using a wheelchair they had outgrown.

'But she outgrew her wheelchair several months ago, yeah, you just wait months and months for appointments basically' (07, mother).

'And the problem is by the time they measure her and order one and it takes another four months she's grown again. … And then she'd get in a chair and she's right on the limits of it so we know it's not going to last very long' (07 father).

'We did get a chair but it came in the house two three weeks within the time period of what she said' (05)

Having to wait for other types of equipment was also an issue. The parents of a 12-year-old experienced difficulties with the time delay between assessment for walking and standing equipment and its provision by health services.

"We basically had an assessment for various equipment such as walkers and standing frames…. It was a year, I think, to get a walker (07).

Parents reported that they had experience that the 'equipment bank' tended to look first for equipment already in use before ordering new equipment. This is potentially sensible approach to 'recycling' equipment no longer needed by others, but it can add several weeks to the provision of a piece of equipment for a child, who in the meantime has to do without.

' Yeah I think just anything kind of takes a little while for it to actually whirl round in their system and kind of come back because they have to look through the system where it's already been used so the used site or whatever it is that they have …. So I think they have to look on that for at least six to eight weeks and then they can request it new and then obviously from new it can take six to eight weeks again. So the bath took, I don't know a matter of sixteen weeks or something' (05).

While parents highlighted their experience of good collaboration with therapists on equipment in some instances, equipment needs were also an area where parents noted often a tension between "changes" in equipment needs and their timely and appropriate provision. Planned equipment when a child is having surgery – getting the equipment in place so it is ready for when the child comes out of hospital was a specific issue for some families.

Incomplete or inadequate equipment

The parent of one of the younger child was unable to use a paediatric wheelchair, because necessary accessories to the equipment, which need to be ordered separately, had not come. They were now in the situation of having a new wheelchair in their home, but had to keep using the old (now too small) wheelchair until the additional piece of equipment arrived. Moreover, this delay ran to several months.

I've got two paediatric chairs here because we've got one that she's currently using and then a second one that we're waiting for the equipment to come. The equipment hasn't yet come so we can't use the chair. But... So we can't get rid of the one that she's currently using because we can't use the new one!' (09).

But she outgrew her wheelchair several months ago, yeah, you just wait months and months for appointments basically. And the problem is by the time they measure her and order one and it takes another four months she's grown again' (07).

The resulting problems experienced could include extended periods of inadequate provision, resulting in extra burdens for parents and carers. Furthermore, developmental progress of the child may have been compromised when the equipment supposed to enable is not readily available.

Other parents had experience of receiving equipment that did not work for their children. For example, one parent recalled an instance when attempting to provide additional support with writing at school. The parent had purchased a voice activated writing programme privately; however, it was deemed disruptive in class and subsequently was not allowed. Instead, the child was issued with a tablet based writing aid, but was unable to use this piece of equipment for reading due to a lack appropriate contrast between letters and background.

'They gave him the little typing tablet thing which the screen is so dark and the letters are black. The screen is dark green – and when you type the letters they come in black. It's at an angle, [name of child] can't see it' (02).

Larger scale adaptations to the home

Maybe it is not surprising that timely adaptations to the physical environment of the home can involve lengthy and difficult processes. Participant seven (father) reported that the waiting list for a first contact for consideration for a disabled facilities grant was currently two years – in a situation where the need for changing the access to the home exists now. The solution provided in the meantime is a temporary ramp, which in turn took 18 months to be built.

Parents also highlighted 'missed opportunities' in adapting and future proofing the home as the child grows older and needs change, resulting in problems with care later on and requiring additional adaptations. Participant 3 related that she had increasing problems with bathing her son, who is now 15 years old. He was issued originally with a therapeutic bath, plus a wet-room floor to prevent spillage. While at the time the adaption was suitable for the circumstances, a number of years on, his needs have changed. The bath is no longer age appropriate and is detrimental to his dignity as a young person.

'Now he's an adult it's now he comes from my dining room across the hallway into his bathroom half naked, I can put a towel over him, it's not a problem but then his bathroom comes off of my lounge. Now who wants a bathroom off of their lounge but we had no choice but if they'd put the bedroom in and the bathroom at the back of it… ' (03).

'It's less movement for him, you're not going to hurt him then that way, it's much better … I needed these slings and I told them in advance and it still took ages to come and I had to borrow some from school in the end to get bigger ones, and that's disgusting, it really is, that's not fair. ' (03).

There were instances when participants seemed happier with equipment provision but not knowing what equipment would be readily available was the issue

'The biggest problem I see about the *whole* thing – I have to encapsulate – is you don't have the knowledge and then nobody tells you and you find out by accident.' (04)

The role of therapists in the provision of equipment

While in each specific case, there is an individual explanation for some of the problems experienced, for parents these problems constitute a systemic failure, rather simply as an isolated error of either professionals or the services. The system of equipment provision and adaptation is experienced as slow and cumbersome, and not always producing the appropriate results. There are also challenges with providing an adequately responsive service to accommodate the rapidly changing needs of children, who grow and might outgrow their equipment quite suddenly. Often parents need to plug the gap, either by managing the bridging period or supplying their own solutions.

For this reason, the support from therapists as back-up and advocates within the terrain of equipment provision was seen as central. Therapists were often seen as agents for providing workable interim solutions, but also as agents who could navigate the system on behalf of the clients and circumvent 'pitfalls', highlighting and anticipating future needs and signposting around the limitations of the equipment system itself.

'OT has come in and we've put certain things into her buggy before now to support her back so that she can sit upright and things like that so it's all very around [name of child], supportive with her and she is very, very supported by them' (03).

'Not really, I just feel that [name of child] has come a long way and without the support and without them people being there she wouldn't be in the position she's in now and I thank them for that.'(06).

Parents were particularly grateful when the therapists highlighted the need for planning ahead (often with equipment in mind) to make life easier for the child:

'OTs and physios are really important they would be on the top of my list …' (03)

Reactions to equipment problems

Delays were experienced due to the complex decision making process associated with some of the larger equipment purchases (such as wheelchair assessment) and the housing adaptation system. There was a degree of understanding about this and parents recognised that due process had to take place, given the extent of the costs involved in particular with regards to the housing adjustments.

However, parents expressed greater frustration over some of the inadequacy in decision making - categorised by some parents as being led by 'red tape' rather than by the need of the child. The way various types of equipment had to be applied for and procured. One example is the experience by participant nine about her daughter being unable to graduate to the second paediatric wheelchair (already provided) because other parts of the wheelchair equipment had not come through yet.

Parents expected and wished for greater collaboration between the therapists who know the child well and the equipment services that are responsible for providing wheelchairs and social services that provide housing and larger scale adaptations.

Parent/carer experiences of transition to school and education

The study included respondents, whose children covered the range of education pathways and school types. Hence we decided to cover the responses firstly from a school journey perspective, nursery care, primary school and secondary school. It has to be noted that the experiences of parents of older children will travers specific changes in the school education policy and provision over the last decade and hence may not reflect the current aspects of educational provision and assessment.

One of the parents has a child in nursery. She feels that her child is happy being at nursery. Much of the interactions between the nursery staff, the parents and the health services (through occupational therapy) seem to be brokered through the parent. This arrangement seems to be working well, with the therapists being part of the decision making process and helping to 'set' up the child in the nursery.

'There's no reason that [name of child] can't go to nursery so we all discussed it in her recent, you know, TAC meeting; *was everyone happy that [name of child] could go to nursery? Was it going to be safe for her? Yes, it was.* Then we began to talk about the equipment needed and there was sort of a bit of a silence really.' (09)

'And she, again, has been into the nursery happily and there's great interplay there where, you know, she'll come and assess [name of child] needs when we need, you know, when we require her to come in.' (09)

However, the family provides the necessary equipment in order to enable their child to participate in nursery life.

'I'm sort of currently choosing not to because I think we can adapt one of the seats that are there and so we're speaking to [name of therapist] to see if we can make necessary adaptations to the chairs already in the nursery but if it *was* needed and we did want [name of child] to go to the nursery and she had to have the chair it would be at my cost'(09).

The parent makes the point that ordinarily children are encouraged to attend nursery, not the least in preparation for primary mainstream school. In the case of special needs, the parents provide the necessary equipment to enable their child to participate in nursery:

‘I don’t see why children should be denied access to nursery, children with special needs, just because their parents can’t afford to buy the equipment’ (09).

Of course, nursery education is comparatively recent and it may be that in this case the nursery was not equipped to take a child with physical disability. However, it still leaves the question to what extent nursery provision is set up to include young children with disabilities.

Primary education

From a parental perspective, the provision in primary school can be more fraught. Participant six had particular difficulties with settling her child into the Reception year.

‘..at that time you didn’t have the kind of the EY em, you know the Early Years Foundation; I didn’t realise how behind she was and it came as a horrible, horrible shock to me … and sent me into a complete panic’ (06)

The difficulties were confounded by the lack of understanding on part of the school when her child was discharged from occupational therapy. The school interpreted the discharge letter as ‘closing of the case’ and did not feel further obligated to implement and work on the recommendations included in the discharge report.

‘Well, so the occupational therapist was saying that there are ongoing needs please do these strategies to help but just because it’s a discharge report because they don’t offer any more therapy, then the school takes that, ‘well they’re discharged so we don’t, we don’t need to do anything or there’s nothing to do’ (06).

For another parent, the lack of training of teaching assistants was of particular concern

‘They’re supposed to be trained to understand. They’re supposed to be trained to read through every child’s statement to go through with the teachers, you know… Each teacher is supposed to be aware of each child’s problems / strengths / weaknesses. They don’t do it! They don’t. They just go, “Oh he’s got a teaching assistant, she can get on with it. Oh, she can’t be bothered, he can get on with it.’ (02)

The parent clearly felt abandoned by the school in enabling her child’s participation in school life and experienced disinterest by his teachers in enabling his education.

Secondary schools

The same issue comes up in secondary school. Two parents reported that the barriers for full participation are now even higher, as the elements of ‘learning’ and the demands of the curriculum are taking increasing precedence and there is a lack of flexibility and skills in supporting the child

'But also, yeah, that TA, yes, he has a scribe for every extended piece of writing but the TA would quite often go, "You can do it. Go on." "No, I can't. I'm only..." and he will only let them know at the very last minute that I've gone as far as I can go. "No, you can do it. Go on. Go on, finish that bit off." "No, actually I can't." "You can do it! You can do it otherwise it has to go home with you!' (02).

Parents described significant problems with balancing the recommendations made by therapy services on how to manage the condition on a day to day basis, and the pace of school life. Items parents found difficult to deal with was the apparent disregard of fundamental recommendations about maintaining physical well-being:

'The first thing on his statement says *please monitor his fatigue levels*. You know, *don't let him get overtired.* You know, and he's carrying a great big, heavy bag and now he's got to carry this as well and they're wondering along with a cup of tea, you know, and I just…' (02).

'keeping children not tired and exhausted was to keep things contained; "Oh we can't do that because…" you know, "they have to keep up with everybody else." Well it's going to impact on their whole learning experience if they're too tired to learn, you know, so I'm sorry, that's not good enough' (0).

'it says on his statement that he's supposed to have help before and after PE, during changing, have a list of adapted… the curriculum is supposed to be adapted for his needs' (0).

The two parents also thought that their children found themselves marginalised within the school environment and sometimes even segregated and excluded:

'They've got a huge school with so many people who've got so many, you know, what we consider to be disabled children and we pigeon hole them, we keep them all together like this and therefore then they're easier to handle.' (0).

'they're shoved in a corner because they're all considered thick' (0).

"This child has got problems; you stick him with another child that's got problems just because." You know, [name of child] quite capable of going, "Yeah, child y all right but I don't want him as my best friend, thank you very much." [name of child] got friends who go to Kings and, you know, other schools around the area who he's known before going to these schools and as far as he's concerned, he's quite capable of deciding who his friends are thank you very much. *Don't try and tell me who my friends are,* you know.

he has a scribe for every extended piece of writing but the TA would quite often go, "You can do it. Go on." "No, I can't. I'm only..." and he will only let them know at the very last minute that I've gone as far as I can go. "No, you can do it. Go on. Go on, finish that bit off." "No, actually I can't." "You can do it! You can do it otherwise it has to go home with you!"

One of the parent took her daughter out of school because she felt nothing was offered to her

Yeah. Yeah so I pulled her out of it really rather than the school because I didn't think she was getting anything out of it and the teacher didn't want her there and I felt, you know, I felt… (01)

The parents clearly put the accountability on these poor experiences at the door of the secondary schools:

I think he's absolutely fine in a normal school but I think what they need to do in normal schools is up their game big time. They really do. (02)

In this context sympathetic intervention and continued advocacy was important to the parent and young person, because it was only external effective intermediary that could be drawn in to make the point about continued support.

'She's (therapist) been brilliant for [name of child] and whenever we have a meeting with her and the school all the others sit back, yes, take their notes' ().

It seems that both having clear recommendations in a statement and the continued support of therapists are an important for parents to continue to exert some leverage on secondary schools to ensure that the needs of their children are met appropriately. But it can be a frustrating to get these recommendations implemented and the continued advocacy of therapists in the school seems to be an important back up.

Even the small number of participants who commented extensively on the school experience demonstrates that there are continued problems with schools meeting the needs of children with physical disabilities adequately. As the child grows up and progresses in its school career, parental influence tends to diminish as the educational expectation is about increased independence and autonomy in managing school life Young people themselves are often not the best advocates about their problems and needs during the teenage years and find it hard to represent themselves effectively. This makes it harder for parents with disabled children to keep effective communication going with schools regarding their children who may find it difficult to make their voices heard.

In secondary schools in particular, this problem can be exacerbated because the educational goals attend to shift increasingly towards delivering a mainstream curriculum, and to standards and outcomes, all of which create tensions with the very specific adjustments and requirements for support and intervention for the children with special needs. Given these dilemmas, it seems that the therapy services have a particular role to play in advocating for the implementation and use of therapy recommendations in the secondary school context, in order to maximise the chances of the young person to have a successful school experience and career.

Parent/carer views on personal health care budgets

The question asked about personal budgets were for most parents a hypothetical one as they had little-to-no experience of personal health care budgets. In one case, one of the older teenagers had experience of direct payments. Her mother explained the difference having this had made:

'She is now 18 and she has been her PA since she was 16. Well I pay her. Do the direct payments thing? (01)

'Well I use direct payments in that I have this girl come in and she actually baths [name of child] a couple of times a week and once a month she takes her out for the day. In addition, I am in charge of my own transport budget now. They give me £5,000 a year to take [name of child] to and from school and whereas before when KCC were just paying me mileage, I used to be able to say to them, "Look, I can't take [name of child] into school tomorrow. Can you buy a taxi?" they would. Now it is up to me to get that taxi.' (01).

Overall, though there was uncertainty among the respondents, particularly those with younger children, on whether the personal budget applied to them, what they could buy with it and whether it improved their access to services:

'I don't know if it's only very profoundly disabled children who are entitled to that budget or quite how that works, and no one's ever suggested that I would be entitled to a budget.' (06)

It doesn't really apply to us because we don't get it but I do think it's a good idea for other people, yes, because they can use what carers they choose as opposed to, you know, being told!' (07).

It is the availability of services, which may be otherwise more difficult to access, or where there is delay, that these parents imagined may be of particular benefit.

'I'd rather just carry on with what we're doing. If it... if it... If basically the cost of the services I'm getting on the NHS would come in at less than the pot of cash that I would be given, then that in some ways is quite useful because it would allow in part for me to pay for some of the private services that I'm already buying' (09).

When parents considered personal budgets, they assumed a personal health care budget could be used to fund the health and therapy services, possibly facilitate quicker access to these services, or buy in additional services not available to them at present. Having additional choice in the type was highlighted as a distinct advantage

'You would hope then because you have more control that you would get those bits quicker. I would want to keep what I have but just hopefully like when it comes to equipment then it could be faster (03).

'There could be, as you say, hydrotherapy or it could be some other kind of therapy that he needs that I can't get or I have to wait longer for or something then, yes, it would be great to

be able to say, “Well actually that’s great, I’ll wait for that but I’m also going to do Fred around the corner and boompty-boom.’ (08)

‘if I had that budget and I was told I had a certain amount to spend and then this is how much this costs, this is how much that costs, I would definitely some sensory integration therapy and I would really value the opportunity to do that so as a parent you know that would be my comment.’ (06).

Like participant six, other parents were also aware that potential additional choice in itself is not enough, but that level of funding needs to be equivalent to what is already available.

‘So I think before I would be kind of... if I was given the option to choose whether that would be something I’d like to sort of sign up to or not, I’d want to know on a quantified basis what’s the value of the services that I’m receiving’ (09).

‘if I was given the option to choose whether that would be something I’d like to sort of sign up to or not, I’d want to know on a quantified basis what’s the value of the services that I’m receiving …. If I had the pot of cash … to control it myself, my first question would be does my pot of cash allow me to have the exact same service I’ve got now?’ (09)

Maybe it depends how much everything costs as well and if you’ve got enough in your budget to pay for those things that are important.’ (03).

What emerges from these quotes is that parents currently not using personal budgets view the programme as a fund to assist the access of health services, in particular therapy services. This leads parents to consider the trade-off between the current level of services received and the opportunity of self-funding may offer in increased flexibility and choice of services that can be bought in. In turn this prompted some of the parents to reflect what is most important to their child in terms of current provision and the choices they perceive they would have to make if the current system of accessing was converted into a cash payment:

‘Given a choice, if I only had a budget to choose one or the other I suppose I would probably have to choose the sort of Down’s syndrome specific approach because it would be slightly absurd not to. However, I would be very loathed to lose the kind of communication speech and language therapy that we have with the NHS because I think both together in parallel is a very holistic and a very, from my perspective, complete approach to language and they’re not contradictory’ (09).

While none of the parents had actively considered personal budgets, this perception in the ‘either or’ categories of personal budget may well be an explanation on why parents do not have opted for personal budgets or informed themselves about it more and it may not see it as a particularly attractive options. Parents identified the risks and uncertainties that came with self-management.

‘So the thing is if you’re given a certain amount of money, then I can see that dwindling quite fast with the amount of attention … needs in the areas that she needs.’ (05).

'let's say for the sake of argument that every single parent wanted physiotherapy and there weren't enough physiotherapists to do that, and there was no extra money, is that saying that then some other budget would be cut like OT or Speech and Language, would it have to be cut, so it doesn't feel very thought through at all' (06).

While personal choice is of value, parents were also aware that with the current process of accessing services there is a degree of certainty and reliability to (eventual) access to these services, which in their current circumstances outweighs the potential of personal budgets. The majority of parents quoted above comparatively young children, and the support and therapeutic interventions they require are maybe still more manageable than in the future.

The additional complexity of having to organise for example a taxi service to school for your teenager on a regular basis, for many parents with younger children may not be an acute or difficult. This points again to the developmental and age dimension in how disability influences everyday life. Personal budgets in these circumstances are not seen as an easy option, not just simply about the risks, but also as yet another demand on parents to manage their child's condition.

'Because otherwise you could be sitting with a large pot of cash without really knowing what it is your child is supposed to need. Whereas from my perspective because I had Sally telling me, "This is what your child is likely to need," she then made the necessary referrals, we then got the people involved.' (09)

'You know, I'm busy enough already. If I've then got to arrange for her physiotherapy and her occupational therapy and so on, you know, I am... '(01)

Personal budgets for the parents in our study were not a simplistic choice of having it or not. There was a lack of clear understanding of what having it means and the potential was interpreted as a substitute for current ways of accessing the service. Parents were aware of the advantages of the personal budgets and could see how it might benefit their children by providing more personalised and timely health provision. However, they were also aware of potential pitfall in the form of under provision due to the costs of services, the additional managerial burden of decision making associated with having the budget. Interestingly, some parents highlighted the potential impact on the system of provision if therapy services by choice were introduced.

Discussion

This study explored the therapy support needs of disabled children and their families in East Kent. The aim was to identify what support families want and need and their experience of therapy. Following the introduction of a personal health care budget and the entitlement of families to this support, the study explored parents' views about the opportunity to exercise greater 'choice' and 'control' over their child's care.

Relationships and the importance of two-way communication.

For parents and carers establishing a trusting relationship with a therapist who knows the family well was important - parents and carers valued therapists who worked with the whole family, not just the child, and understood the many pressures of family life. Personal attributes that were important to families included a willingness on the part of the therapist to be flexible and responsive; for example, calling at home and arranging to see a child at short notice. Willingness to work outside of a 'narrow job description' and deal with families on a personal basis is an important element identified in the literature on support for families of children with disabilities (Canary 2008).

The importance of two-way communication between health professionals and parents is also widely acknowledged in the literature and was highlighted by parents and carers in the current study. Supportive communication provided the basis for ongoing discussion and feedback about the child's progress that was so important to parents and carers. Regular and ongoing communications that included what has been described as 'comforting messages' from therapists served to reduce parental anxiety and stress (Burleson 2009). Others have confirmed the importance of trust as the basis for the delivery of effective therapy, arguing that families are more likely to respond positively to interventions and follow the advice of the therapist with whom they have formed a strong relationship (King & Chiarello 2014).

Conversely lack of understanding and appreciation of the other pressures on families, where parents are expected to be responsible for interventions but may be limited in their ability to make informed decisions or access the information and resources needed to take on the role, is an issue for therapists (Dodd et al. 2009; Kruijsen-Terpstra et al. 2016). There were instances in the study where therapists failed to recognize parents and carers' limitations, expecting them to take on caring responsibilities without support. Parents in the study saw the therapist as the expert and wanted them to take the lead, but also felt that therapists should recognize parental needs too (e.g., emotional and practical training). Just coping with the day-to-day stresses and strains of bringing up a family meant that placing additional burdens, associated with following a programme of therapy, may not be realistic and in some instances was the 'last straw'.

Analysis from the study suggests the need for therapists to understand that there may be different perspectives on what families regarded as being 'best for their child'. With limited robust evidence of the effectiveness of therapy interventions it is perhaps important to acknowledge that no one opinion is necessarily right in all circumstances (Whittingham et al

2011, Gibson et al 2009, Novak 2013). What families required was a flexible approach where therapists are able to adapt to changing situations and possibly the changing needs of the family and recognize the wants and needs of the child as they develop (Kruijsen-Terpstra et al 2014). There were several examples of the impact of poor communication on the part of therapists and other health professionals involved in children's care. Failure to listen to parents or acknowledge parental concerns, not returning telephone calls or responding to messages were all examples of where communication could be improved.

Continuity of care

Continuity of care and the establishment of a long-term relationship with key services and individuals was an important theme. The therapy workforce is made up largely of young women, hence absences and gaps due to maternity leave were an issue for some parents who had experienced several alterations in who provided therapy for their child. This suggests the need for better forward planning around maternity leave with adequate cover to ensure that families did not experience a gap in service, particularly at a critical time of transition. Similar findings about the importance of continuity of care to carers are reflected in other areas of health care for example, maternity services and carers of adults with long-term chronic conditions (Haggerty et al. 2003; Gallagher et al. 2013).

Provision of equipment and other services

There are well recognized difficulties with the provision of specialist equipment that led to stress and strain on families and some pronounced service 'gaps'(Beresford et al 2001; NewLife 2007; Health 2010). One of the major areas of difficulty highlighted by this cross section of parents has been around quite limited aspects of health provision more generally, which despite attempts to improve access, appear from our findings to remain problematic. These include pervasive issues with obtaining appropriate equipment at the right time, with coordination around larger scale adaptations to home; but also with access to specialised therapies and therapeutic services- for example, hydrotherapy and sensory integration therapy. The experiences of the parents we consulted is that these are specifically difficult to obtain.

Personalised care

The study has also provided insight into the views of parents and carers about personal health budgets, at a time when personalisation more generally is seen as providing a solution to poor coordination and integration of services for those with long term care needs (Chaplin 2015). There is some evidence that the introduction of direct payments, a precursor to personal health budgets, for carers of disabled children is a welcome initiative enabling parents and carers 'to take control' and reduced the need for contact with different service providers - regarded as one of the most stressful aspects of caring for a disabled child (Blyth & Gardner 2007).

Review of the impact of personal health budgets in other aspects of health care, report mostly positive outcomes but identify difficulties with the 'process' and the concept of personalisation which has some inherent contradictions in terms of equitable access to

health care (Hatton et al. 2013; Williams & Dickinson 2015). Our findings confirm a lack of awareness of entitlement amongst carers - only one parent had experience of using direct payments and few had any knowledge or awareness of their entitlement to a personal health budget (Davidson et al. 2013; Alakeson 2013; Department of Health 2012).

Uptake across Clinical Commissioning Groups (CCGs) has been slow ( ). It has been suggested that the success of personal budgets will depend on individuals being in a position to 'argue their case' and therapists may be well placed to help families. The continued involvement of a therapist, who knows the child and has specialist knowledge remains therefore an important dimension of care valued by parents and carers (Kruijsen-Terpstra et al. 2016; Dhillon et al. 2010).

Options for personal budgets to be used to obtain equipment, an area identified as particularly frustrating for parents, may increase if budgets are allowed to be used in this way. However, the cost of devolving these choices to parents and the need for additional support to enable parents and carers to make informed decisions needs further clarification. Parents in our study were wary and concerned about taking on this additional responsibility. For some parents this might be the right option; for many other parents though the responsibility of managing a personal health care budget was thought to create as many problems and dilemmas as it potentially solves (Hayles et al. 2015). There remains concern about how personalisation will work in practice and the impact of personalisation on a wider consensus about equity and entitlement within the NHS (Williams & Dickinson 2015).

There are important messages for commissioners and service providers arising from the current study. Ironically, at a time when there are demands to rationalise therapy services and close scrutiny of clinical contact data may result in therapy services being unable to deliver the personalised, flexible and responsive services that parents and carers value. Little work has been undertaken to establish workforce demand or the likely costs of providing care of this type. NHS costs have focused largely on counting clinical activity focused on the child– which fails to take account of the informal elements of support that therapists provide, delivered through the many small interventions that parents and carers identified as so important to them.

Issues arise because it is unclear who is the direct recipient or beneficiary of the service involved. A service that acknowledges and addresses the support needs of parents and carers, and the child as the beneficiary, may increases demands on already overstretched services. Commissioners may need to explore costs that have the potential to deliver longer-term cost savings, extending possibly to other parts of the health care system- for example, mental health services, which may pick up the costs of carers psychological health.

Engaging parents and carers in research about them

A number of parents who initially expressed interest in taking part in the study failed to follow up. We can only speculate about the demands on their time and practical issues that may have made it difficult to take part in the interviews. We did provide individual and

telephone interviews as options for those who may have found it difficult to attend the focus group format. From this study, it would seem that parents of children with physical disabilities are a less easily defined group and may not access organized support networks. We accessed the parent support network but found that few parents and carers who met our inclusion criteria were involved. For larger scale proposal development alternative strategies of recruiting parents and carers will need to be developed and current thinking is that internet forums may provide a good starting point for engagement. We also feel that we need to explore further how to engage therapist in research as gatekeepers in the light of the known benefits of engagement in research (Hanney et al. 2013).

We also need to reconsider our strategy for eliciting view which focused on asking parents about transition points, parent did not naturally provide a chronological account of their experiences and asking them to follow a trajectory was difficult – parents had plenty to say but focused on issues that were most current and often emotionally charged – a free flowing style of interview suited our purposes better in terms of approach to interviewing parents and carers. That is not to say that our original intention to explore transition points was not worthwhile, as taken as a whole the accounts provided insight into developmental and care transition pints that children and families experienced (Gibson et al. 2009).

Conclusion

Previous research has confirmed the importance of support to parent and carers of children with complex disabilities. The study highlights the important role therapists' can play in supporting parents and carers of children in the context of a wider 'care experience', covering health, social care and education services. We found that parents and carers do not easily differentiate between services and differential professional responsibilities. This is important as there are many therapy specialties involved in a child's care and lack of coordination between, for example therapists employed by wheelchair services, social services and health services in some instances created long term barriers and a 'ripple' effect on future relationships.

The type of support that families can access either via professional of informal networks is important to the child's progress and health outcomes and may influence the wellbeing of the family. Although there is acknowledgement that other factors, aside from the type of professional support plays a role, there is consensus that *how* formal support is provided is crucial to family outcomes and assessment by parents (Canary 2008). Despite recent policy initiative designed to address limitations in care and support, the study found that the life story of living with disability and bringing up a child with physical disability is still one of service gaps, lack of professional engagements at crucial times, silo thinking in services, and gaps in provision that parents have to fill, identified over a decade ago (Sloper 1999). It is disappointing that the families we interviewed identified similar issues.

The study also highlighted the many examples of good practice within therapy services and important recommendations arise for therapies around the need to preserve flexible working models of care for this needy population of children and their families. We also identified

aspects of everyday care that therapists can actively build and develop to sustain trusted relationships with parents and carers. The potential of greater personalization of care provides possibilities for therapists to assume an important mediating role as advocate, supporting and guiding parents and carers in decisions affecting their child's care, while ensuring parents and carers receive appropriate support.

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Acknowledgements

The researchers extend their thanks to all the parents and carers in East Kent who gave generously of their time as participants in the study.

Appendices

1. Application form EKHUFT IPGS 2012-13

EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST

RESEARCH & DEVELOPMENT (R&D) DEPARTMENT

INTERNAL PROJECT GRANT SCHEME (PGS) AWARD 2012

The submission deadline is Friday 19th October 2012

Successful applications will be notified by Monday 3'd December 2012

EKHUFT R&D Department is committed to bringing doctors, nurses, midwives, allied health professionals, biomedical scientists and staff from Higher Education Institutions (HEIs) together to improve human health through excellence in research.

The National Institute of Health Research (NIHR) allocates Research Capability Funding (RCF) to research-active NHS organisations in proportion to the total amount of other NIHR income received, and also on the number of NIHR Senior Investigators associated with the organisation. RCF helps those organisations to act flexibly and strategically to maintain research capacity and capability.

The Trust seeks to use RCF in building and strengthening research capacity in those areas that are of strategic importance to the Trust, and where the outcomes of IPGS supported work lead to substantial and sustainable growth of research through acquisition of external funding from major grant awarding bodies, principally NIHR (e.g. Research for Patient Benefit, RfPB). This is most likely to be achieved through collaboration within the Trust, the local NHS (e.g. Primary Care) and HEIS (e.g. University of Kent, Canterbury Christchurch University, University of Greenwich).

The internal project grant scheme (PGS) is the main vehicle by which the Trust will distribute RCF in the 2012-13 financial year. Up to £55,000 funding is available, and this may be allocated to one or more projects.

In addition, unallocated monies from the Cardiovascular Research Grant Award are available for projects specifically addressing an area relevant to cardiovascular disease. Up to £25,000 may be allocated to one or more projects. If an individual application exceeds this sum the project may be jointly funded by CV Research Grants Award and IPGS.

Please read the following carefully as it contains important information about eligibility and review criteria. If you have any questions, or if you would like assistance identifying additional collaborators or resources to enrich your research proposal, please contact the R&D Department on 01304 222561/01304 222691/01304 222550.

Criteria

a) The research project proposed for IPGS funding:

- Will address an important research question in an area that impacts on human health.
- Will utilize any one of the spectrum of research methodologies relevant to health research.
- Should demonstrate clear intent to build upon work funded through 'PGS by the applicant(s) seeking substantial long-term funding from NIHR or other major grant awarding body (e.g. MRC, Welcome Trust, British Heart Foundation, CRUK etc.)
- Should align to the Trust's strategic objectives
- May include collaborative research conducted by a team of researchers with appointments in different Trust departments.

'd • May include collaborative research with HEIs, local NHS, commercial or other 3-sector organizations provided that an EKHUFT employee leads the project proposed.

- May be partly or wholly funded by IPGS.
- Must commence within 6 months of date of award offer letter.

b) The research project proposed for CV Research Grant Award funding:

- Will address an important research question in an area that impacts on human cardiovascular disease.
- Will utilize any one of the spectrum of research methodologies relevant to health research.
- Should demonstrate clear intent to build upon work funded through CV Research Grant Award Funding by the applicant(s) seeking substantial long-term funding from external grant awarding bodies (e.g. NIHR, MRC, Wellcome Trust, British Heart Foundation, CRUK etc.) • Should align to the Trust's strategic objectives
- May include collaborative research conducted by a team of researchers with appointments in different Trust departments.
- May include collaborative research with HEIs, local NHS, or other 3-sector organizations (but not commercial organizations) provided that an EKHUFT employee leads the project prqposed.
- May be partly or wholly funded by CV Research Grant Award.
- Must not involve any element of animal research.
- Must commence within 6 months of date of award offer letter.

c) Priority will be given to projects (either may apply; relevant to both funding streams):

- In areas that are novel to applicants, in particular those requiring generation of pilot data prior to external funding applications.
- Where the applicant(s) does not have an established track record in research, and has sought collaboration or assistance from experienced researchers in developing their proposal.

Terms of reference and scoring systems to be used by the panel of reviewers who will decide on successful applications are available on request from R&D Department or via SharePoint.

Applicant Eligibility

- Any individual who holds a substantive employment contract with the Trust.
- Academic staff from .HEls may apply providing a Trust employee is leading the project proposed.
- Applications from solely experienced/senior researchers will be accepted only if the proposed project supports the development of new collaborations with academic staff from an HEI or within the Trust, or the area of research proposed is in a field of study that is wholly novel to the (co-)applicant(s).
- Applicants should have a good history of compliance with EKHUFT Research Governance and no ongoing research misconduct investigation.

Funding provided

May include (not an exhaustive list):

- Researcher salaries (e.g. research nurse, other research staff)
- Costs of consumables and capital equipment appropriate to the research project • Cost of usage of NHS equipment & other resources e.g. laboratory investigations, CT scanning, clinic space.
- Conference presentations & publication costs (not more than 10% of total sum requested)
- Part-funding of a project that exceeds the funds available through 'PGS would e considered. Written evidence of firm commitment to funding remainder of proposal is required with this application.

If you wish to discuss your proposed research area in advance of submission of an application, please contact Dr Andrew DiBiase, Deputy Director of Research and Development (Andrew[r].DiBiase@ekht.nhs Ilk) who will be chairing the \PGS awards panel.

EAST KENT HOSPITALS UNIVERSITY NHS FOUNDATION TRUST

RESEARCH & DEVELOPMENT (R&D) DEPARTMENT

This application form for 2012-13 'PGS must be completed in full

This form must be completed electronically. **Please do not exceed requested word limits**. Those applications that do so **will not be accepted** and will be returned to applicants.

The completed application form should be sent by e-mail to: charlotteroberts2@nhs.net or Sandra.tapsell@ekht.nhs.uk. In addition one signed application should be returned to:

Department,
spital,
ey Road,

The
Buckland Hospital,
Coombe Valley Road,
Dover,
CT17 OHB

. Details of Principal Applicant (Trust employee)

Name:	Dr Eve Hutton
Address:	East Kent Hospitals University Foundation Trust First Floor Offices Buckland Hospital Coombe Valley Road Dover Kent
Post code:	CT17 OHD

Telephone:	(01303)228826	Facsimile:	

E-mail address: eve.hutton@nhs.net

Have you applied for or received approval for an academic post? Yes C] No☒ .

If yes, when does I did it commence?

Details of co-applicants if an

Name: Annette King

Address: Centre for Health Services Studies University of Kent, Canterbury, Kent, CT2 7NF

Present Appointment: Kent Academic Lead for the NIHR ROS-SE

Email address: A.M.King-9@kent.ac.ukSignature:

Date: 15-10-2012

Name: Dr Kate Hamilton-West

Address: Centre for Health Services Studies University of Kent, Canterbury, Kent, CT2 7 NF

Present Appointment: Research Fellow and Quantitative Research Advisor (Health Psychology Lead) for the NIHR RDS-SE.

Email address:k.e.hamilton-west@kent.ac.uk

Signature:

Date: 16/10/12

Name: Sarah Hotham

Address: Centre for Health Services Studies University of Kent, Canterbury, Kent, CT2 7NF

Present Appointment: Research Associate Email address: s.hotham@kent.ac.uk

ture:

12/10/12

address: s.hotham@

Signature:

Date:

Declaration:

I declare that the information provided by me in connection with this application is true and complete in every particular.

Signature: Date: 18/10/12

2. Curriculum Vitae

(To be completed by applicant and co-applicants. Alternatively a maximum TWO page CV may be attached that must detail the information requested below.)

Surname: Hutton	Forename: Eve
Work Address Floor 1 Child Health Offices Buckland Hospital Coombe Valley Rd Dover Kent	
Telephone No: 01304 222528	Fax No:
E-mail address: Eve.hutton@nhs.net	
Qualifications: Diploma Occupational Therapy, University Hospital Wales, Cardiff 1988 MA Health Studies, University of Kent, 1996 PhD Social Policy & Administration, University of Kent, 2000	
Present appointments: Head Paediatric Occupational Therapist EKHUFT Senior Lecturer Canterbury Christ Church Universit	Date Started: 27.05.2008 0.9wte 27.052008 0.2wte
Previous appointments (including dates): Senior Lecturer Canterbury Christ Church University 2000 - 2008 (1.0wte) Project Manager PAMs Education & Training Project 1999 - 2000 South Thames Training Research Fellowship 1996-1999 Senior Paediatric Occupational Therapist 1992 -1996 Senior Occupational Therapist 1989-1992 occu ational Thera ist 1988 - 1989	
Research Experience (max 500 words): Principle Investigator, Posture & Mobility Group Research Award (2008) £ 5,000 Funding awarded to carry out a pilot project exploring the views of teachers and teaching assistants who care for children with physical disabilities in mainstream schools. Principle investigator, TDA Research & Development Award (2007-2009) £18,000 Funding awarded to develop and pilot research informed teaching resources for mainstream schools designed to promote the motor and sensory skills of young children. Principle investigator, Kent County Council — Standards Fund (2010) £7 ,000 Award to further develop research informed teaching resources for primary schools in order to link with Healthy Schools objectives. Principle investigator, East Kent Hospitals University Foundation Trust (2010) £21 ,000 Award to develop an outcome measure to assess parents and teachers knowledge, understanding and confidence when using postural care interventions with children. Chief Investigator, National Institute of Health Research (2011) 240,000 Award to explore educational program designed to support teachers and parents who care for children with postural care needs at home and school.	

Clinical Research Training (e.g. GCP, Research Governance Workshop, including dates) I have completed Good Clinical Practice (GCP) training with the NIHR Clinical Research Network (2012).

Publications (max 5)

Hutton E (2008) Back to school —piloting an occupational therapy service in mainstream schools in the UK . Reflective Practice. 9 (4) 461-472

Hutton E, (2009) Occupational Therapy in mainstream primary schools: an evaluation of a pilot project. British Journal of Occupational Therapy. British Journal of Occupational Therapy 72 (7) 308313.

Brown T, Mu K, Peyton CGI Rodger S, Stagitti K, Hutton E, Casey J Watson C, Swee Hong C, Huang Y, Wu C (2009) Occupational therapy students' attitudes towards individuals with disabilities: A comparison between Australia, Taiwan, the UK and the US. Research in Developmental Disabilities (30) 1541-1555.

Hutton E, Coxon K (2011) Posture for learning': meeting the postural care needs of children with physical disabilities in mainstream primary schools in England — a research into practice exploratory study. Disability and Rehabilitation.
http://informahealthcare.com/doi/abs/10.3109/09638288.20dO.54483

Hutton, E.t Hamilton-West, K. E. (2012). Development of a reliable, valid measure to assess parents' and teachers' understanding of postural care for children with physical disabilities. EKHUT Internal Grant Report.

Signed: 	Dated: 18/10/12

2. Curriculum Vitae

(To be completed by applicant and co-applicants. Alternatively a maximum TWO page CV may be attached that must detail the information requested below.)

Surname: Hamilton-West	Forename: Kate
Work Address: Centre for Health Services Studies University of Kent Canterbury Kent, CT2 "INF	
Telephone No: 01227 823872	Fax No: 01227 827868
E-mail address: k.e.hamilton-west@kent.ac.uk	

Qualifications:

Associate Fellow of the British Psychological Society (AFBPsS), BPS, 2011

Registered Health Psychologist, Health Professions Council, 2009

Postgraduate Certificate in Higher Education (PGCHE), University of Kent, 2007

Accredited Supervisor for Health Psychologists in Training, British Psychological Society, 2005

Chartered Psychologist (C.Psychol), British Psychological Society, 2004

Ph.D. Health Psychology, University of Kent, 2003

BSc. Psychology, with First Class Honours, University of York, 1997

Present appointments:	Date Started:
Research Fellow and Quantitative Research Advisor (Health Psychology Lead) for the NIHR RDS-SE.	May 2011 (part time)
Health Psychologist, KCA (Clinical Lead for Pilot Diabetes Psychology Service)	June 2012 (part time)

Previous appointments (including dates):

Lecturer in Health Psychology, School of Psychology, University of Kent, Sept 2003 to August 2011

Researcher, Department of Health CORE Grant, PSSRU, University of Kent, Jan 2003 to sept 2003

Doctoral Researcher, ESRC Studentship, School of Psychology, University of Kent, Dec 1999 to Dec 2002

Medical Education and Training Officer, South Thames Deanery and City & Hackney NHS Trust, May 1998 to Nov 1999

Research Associate in Clinical Psychology, School of Health Policy and Practice, University of East Anglia, Sept 1997 to April 1998

Research Experience (max 500 words):

I have extensive research experience and a strong track record of research funding, having held several grants as principle investigator or co-investigator. I am currently co-investigator on an NIHR RfPB grant focusing on enhancing knowledge, understanding and confidence in providing postural care for children with physical disabilities. This is a multidisciplinary project in collaboration with colleagues at the University of Kent, Canterbury Christ Church University and East Kent Hospitals University Foundation Trust. I have published in peer reviewed journals, supervised several MSc and PhD projects, directed a BPS-accredited MSc programme and taught research methods to psychology undergraduates. I am also a quantitative research advisor for the RDS-SE and a BPSaccredited supervisor for trainee health psychologists. I have published a health psychology textbook which includes a chapter focusing on research methods.

Clinical Research Training (e.g. GCP, Research Governance Workshop, including dates)

I received training in research methods and statistics both as an undergraduate (BSc Psychology 1997) and postgraduate student (PhD Health Psychology, 2003). My psychology training also covered research ethics including informed consent (Chartered Psychologist 2004; HPC Registered Health Psychologist, 2009). I served as a member of the research ethics committee for the School of Psychology (2007-8). I have completed Good Clinical Practice (GCP) training with the NIHR Clinical Research Network (2012).

Publications (max 5)

- Hotham, S. , Sharma, D. & Hamilton-West, K.E. (2012). Restrained eaters preserve top-down attentional control in the presence of food. Appetite, 58(3), 1160-3.
- Hamilton-West, K,E. (2011). Psychobiological Processes in Health and Illness. London: Sage Publications Ltd.
- Hamilton-West, K.E. (2010). Managing the impact of ankylosing spondylitis on the patient and society. International Journal of Clinical Rheumatology, 5 (5).
- Hamilton-West, K.E. and Milne, A.J. (2010). Help-seeking in relation to signs of dementia: A pilot study to evaluate the utility of the common-sense model of illness representations. Psychology, Health and Medicine, 15 (5). pp. 540-549.
- Hamilton-West, K.E. and Mallia, C. (2010). Smoking-related attitudes and perceptions among young adults in Malta and the UK. Psychology Health and Medicine, 15. pp. 347-356.

Signed:	Dated: 16/10/12

Surname: King	Forename: Annette
Work Address: Centre for Health Services Studies University of Kent Canterbury Kent, CT2 7NF	
Telephone No: 01227 823672	Fax No: 01227 827868
E-mail address: a.m.king-9@kent.ac.uk	
Qualifications: Master of Business Administration, Kent, 2010 Postgrad Diploma, Health and Social Care Management, de Montfort, 2006 B Sc (Hons.) Sociology and Political Economy, City, 1989	
Present appointments: Academic Team Lead Kent RDS SE	Date Started: October 2008
Previous appointments (including dates): Research Applications and Development Manager, CHSS, 2007-2008 Programme Research Manager, EKHUFT, 2004-2007 Senior Research Officer, Strategy Unit, Cabinet Office, 2002-2004 Research Fellow, London School of Hygiene and Tropical Medicine, 1998-2002 Research Fellow, University of East London, 1990-1997	

Research Experience (max 500 words):

As the Academic Lead for the RDS SE in Kent and member of staff in the Centre for Health Services Studies, I manage the team of RDS research advisors in Kent. Prior to that I worked with academic colleagues to develop and prepare academic research applications for external funding. I also continue to work on research projects in the role of co-investigator and specialise in qualitative research methods. Projects I am working on tend to be mixed methods. My methodological background is qualitative research methods and evaluation methodologies.

I have a particular interest in health management and organizational issues in the NHS, and have worked in cross-national research in informal care. Cun•ent and recent work includes a pilot study to test the use of concordance therapy in diabetes in primary care, research into hospice services (commissioned projects and also supported by RNB), research on information giving and long-term support in stroke, and into GP and practice nurse training. I am currently involved in a NIHR RfPB project which evaluates a training programme for parents and teachers who care for children with postural care needs.

I have worked in a variety of research settings: I started out working on a cross-national study on the experience of informal caring in Eastern and Western Germany and the UK at the University of East London. The study used a biographical interpretative methodology approach and resulted in 'Cultures of Care' (2000, Routledge). At the London School of Hygiene and Tropical Medicine, I was involved in two studies on health services integration and hospital mergers.

As senior research officer in government, I was a staff member of the Chief Social Researcher's Office in the Strategy Unit of the Cabinet Office. I worked on a review of the cross government departmental review on ' government pilots' and contributed to various research methods initiatives.

I gained NHS research and research management experience as Research Programme Manager in EK_HUFT between 2004-2007, in Health Care of Older People. I worked on a variety of projects, including stroke research and on health resource group research. The post has been invaluable in understanding the context of clinical research in the NHS.

Clinical Research Training (e.g. GCP, Research Governance Workshop, including dates)

I received training in research methods and statistics as an undergraduate and have taken numerous additional courses in specialised methods training. Most recent courses include a 3.5 day course in clinical statistics (UCL, 2011) and a I day course in computer software for 'Framework analysis' 2012. I have completed Good Clinical Practice (GCP) training with the NIHR Clinical Research Network (2012).

Publications (max 5)

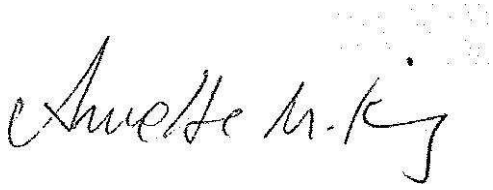
with Jenkins, L., Brigden, C. (2012) Evaluation of the 'Life after Stroke' service in East Kent, final draft Report to the Stroke Association, CHSS

with Holdsworth, L (2011). 'l Preferences for end of life: views of hospice patients, family carers and community nurse specialists", International Journal of Palliative Nursing, 17, 5, pp. 251-256.

with Katona, C. et al. (2010) Improving Concordance in Older People with Type-2 Diabetes (ICOPE-D) — Final report to RfPB;

Fulop, N., Protopsaltis, G. , King, A, G., Allen, P. , Hutchings, A, Normand, C. (2005) Changing organisations: a study of the context and processes of mergers of health care providers in England, Social Science and Medicine, 60, 1, p. 119-130.

Lewis, J., King, A and Davies, P. (2004) 'How do we know (and why) something works?' in Government Chief Social Researcher's Office, The Magenta Book, Guidance Notes on Policy Evaluation, www. olic hub.gov.uk London.

Signed: 	Dated: 16 October 2012

Surname: Hotham	Forename: Sarah
Work Address: Centre for Health Services Studies University of Kent Canterbury Kent, CT2 7NF	
Telephone No: 01227 827759	Fax No: 01227 827868
E-mail address: S. Hotham@kent.ac.uk	
Qualifications: BPS Stage 1 Health Psychology (2010) Associated Teacher Accreditation Program (ATAP) (2010) MSc Research Methods in Psychology (2008) BSc (Hons) Psychology (2007)	
Present appointments: Research Associate at Centre for Health Services Studies, University of Kent	Date Started: October 2011 (part time)

Previous appointments (including dates):

June 2007- Current: Research Assistant — Dr Joachim Stoeber, School of Psychology, University of Kent

September 2008-December 2008 : Research Assistant- Pfizer, Sandwich, Kent

January 2009- March 2013: PhD Researcher (funded by School of Psychology- University of Kent)

January 2009-2012: Associate Lecturer- School of Psychology, University of Kent

Research Experience (max 500 words):

During my MSc and PhD training I have been engaged in independent psychological research. This involves the designing of psychology experiments, recruitment of participants, data collection and analysis of results using SPSS. My involvement in all these elements has been extensive and an integral part of my PhD work. I am currently a Research

Associate on an NIHR RfPB grant focusing on enhancing knowledge, understanding and confidence in providing postural care for children with physical disabilities. This is a multidisciplinary project in collaboration with colleagues at the University of Kent, Canterbury Christ Church University and East Kent Hospitals University Foundation Trust. I have published in peer reviewed journals and taught research methods to psychology undergraduates. During my various research positions I have gained extensive experience of both quantitative and qualitative analysis of data.

Clinical Research Training (e.g. GCP, Research Governance Workshop, including dates)

I received training in research methods and statistics both as an undergraduate (BSc Psychology 2007) and postgraduate student (PhD in Cognitive/Health Psychology, to be completed March, 2013). I have completed Good Clinical Practice (GCP) training with the NIHR Clinical Research Network (2011).

Publications (max 5)

- Hotham, S,, Sharma, D. & Hamilton-West, K.E. (2012). Restrained eaters preserve topdown attentional control in the presence of food. Appetite, 58(3), 1160-3.
- Hutton, E., Hamilton-West, K. E. (2012). Development of a reliable, valid measure to assess parents' and teachers' understanding of postural care for children with physical disabilities. EKHUT Internal Grant Report.
- Stoeber, J. , Uphill, M. A., & Hotham, S. (2009). Predicting race performance in triathlon: The role of perfectionism, achievement goals, and goal setting. Journal of Sport & Exercise Psychology, 31, 211-245.

Signed: Dated:

3. Funding stream being applied for

Internal project grant scheme (maximum funding £55,000)	x

4. Project Details

a. Title of project (max 20 words)

Understanding the support needs of disabled children and their families in East Kent

b. Lay summary of project (max 250 words)

'Aiming High for Disabled Children' (Department for Education, 2007) highlights three priority areas for improving services for disabled children: access and empowerment; responsive services and timely support; and improving quality and capacity. At the heart of this report is an emphasis on understanding what type of support disabled children and their families want and need and determining how and when this support can best be provided. The current government is to introduce a Children & Families Bilt in 2013; this will reform Special Educational Needs assessments and introduce personal budgets for children with Education, Health and Care plans.

The proposed research aims to focus on the support needs of families to ensure therapy services in East Kent can prepare for these changes and respond to needs identified. We plan to conduct focus group interviews with parents of disabled children to identify whether there are key transition points (requiring a change in the nature or intensity of support provided). In the focus groups, families will also be asked to comment on the policy priorities: access and empowerment; responsive services and timely support; quality and capacity — considering how these can best be achieved. This research will provide valuable information to inform planning and commissioning of therapy services. We have built in plans to disseminate the findings to relevant stakeholders. If this application is successful, we also plan to apply for funding from NIHR to examine how the NHS might improve delivery of therapy services for disabled children and their families.

c. Objective(s) of project (e.g. hypothesis under investigation, max 500 words)

The research project has four main objectives:

1. To identify key transition points requiring a change in the nature or intensity of support provided by therapy services to disabled children and their families.

2. To identify what support from therapy services families want and need at these key transition points

3. To explore families' views regarding the three policy priorities (access and empowerment; responsive services and timely support; quality and capacity) and how these priorities can be achieved in relation to the transition points identified.

4. To explore how parents view the introduction of personal budgets and how they intend to exercise 'choice' when obtaining expert support for their child.

No hypotheses have been formulated, due to the exploratory nature of the research. This research will help to formulate hypotheses for a larger study for which external funding will be sought (NIHR grant).

d. Background to project (e.g. review of relevant literature, max 500 words)

It is recognised that 'although medical care, support and auxiliary services are important aspects of helping individuals reach their maximum potential, successful management of chronic disease or disability requires considerable individual and family effort' (Falvo, 2005, p19). Individuals and their families must understand how to carry out daily care activities and integrate regimens into daily routines; they must also understand preventative health care measures to retain function and prevent further disability and health problems (Falvo, 2004). Successful management of chronic disease or disability also necessitates psychological adjustment, the ultimate goal of which is acceptance of the condition and its limitations, along with realistic appraisal and implementation of strengths (Falvo, 2005). The process of adjustment however is varied and individuals may go through stages of denial, hopelessness, anger and mourning before reaching this goal; some individuals may never reach acceptance (Falvo, 2005).

For children with congenital disabilities and their families, the process of adjustment coincides with the process of parent-infant attachment and bonding; if parents are not effectively supported during this critical period, disorders of parenting may result, with implications for the child's developing personality and his or her ability to form an independent identity (Falvo, 2005). It is recognised that children with disabilities are likely to have poorer outcomes across a range of indicators compared to their non-disabled peers, including lower educational attainment, poorer access to health services and consequently poorer health, more difficult transitions to adulthood and poorer employment outcomes

(Department for Education, 2007). Families of disabled children are also more likely to have one parent or both parents out of work and more likely to experience family break up, while siblings may be more likely to suffer from emotional and behavioural problems, for example due to sleep deprivation (Department for Education, 2007).

In order improve outcomes for disabled children and their families; the current government has proposed a new Children & Families Bill which is expected to be introduced in 2013. One element of the Bill will be the introduction of personal budgets for children with Education,
Health and Care plans. The reforms are intended to 'put parents in charge' and to give them 'real choice and control of care, instead of councils and health services dictating how they get support' (www.education.gov.uk). In the light of this therapy services will require a greater understanding of the needs of families in order to provide responsive services particularly at key transition points.

At present little is known about what type of support families want from therapy services or how they may decide to use their child's personal budget when choosing expert support. Qualitative research focusing on the views of families can help to provide answers to these questions.

e. Explanation of how objectives will be achieved (e.g. research methods, subject selection & sample size calculation, data collection & analysis, statistical considerations etc.; max
1500 words)

This section should include a full description of research activities to be undertaken and by whom; what contribution the activity makes to the achievement of objectives and justification for costs.

The research team have prior experience of conducting qualitative research to explore the support needs of those caring for children with disabilities and using this qualitative data to inform the development of interventions (supported by internal and external research funding). For example, Hutton and colleagues conducted qualitative research to explore the views of parents and teachers providing postural care in the school/ home environment (Hutton, 2008; Hutton & Cox, 2008). This research identified a need for further information and training. As a result, Hutton et al (2009) developed an information booklet for parents and teachers — the A-Z of postural care. In 2011, the research team were successful in securing funding from NIHR to develop and evaluate a training programme based on the AZ. This external funding was preceded by an internal ('PGS) grant which enabled the researchers to develop and validate an outcome measure to be used in the evaluation of the training programme. At each step in this process, research findings have been reported to funders and stakeholders — the research has also resulted in several peer-reviewed publications and further publications are planned for 2012/13.

We intend to take a similar approach to the investigation of support needs of disabled children and their families. The scope of this research is broader than that of the previous research (described above) in that we intend to investigate all support needs identified by families, rather than needs relating specifically to postural care. Since this topic has not been extensively researched we feel that it is appropriate to begin with focus group interviews. Focus groups constitute a useful setting for exploring viewpoints and issues based on shared experiences (Fern 2001, Bowling 2005). In the case of this study, the focus groups will build on the collective experience of having children with disabilities going through various stages of childhood and managing changing needs in relation to the disability. The topics to be explored in the investigation are lead by the policy priorities highlighted in 'Aiming High for Disabled Children' (Department for Education, 2007) -

specifically: access and empowerment; responsive services and timely support; and improving quality and capacity. The anticipated changes in provision of services following the introduction of the Children & Families Bill in 2013 provide the context for this research.

A topic guide will be developed by the research team in collaboration with the steering group.

We have made provision for up to six focus groups, each of 1.5 h duration. These will comprise parents/carers of disabled children aged between 2 and 13 years, receiving therapy services in East Kent. From previous experience, we will keep focus group size limited to no more than 10 participants in order to be able to explore topics in some depth. Hence an overall sample of no more than 60 participants is envisaged (6 focus group x 10 participants). We intend to organise the groups according to the age of the children. For example, two focus groups could convened of parents/carers of younger, pre-school children, from 2/3 onwards; the other four could be for parents/carers of primary school age children (5-9) and for older children (up to age 13) respectively. However, we will work with the steering group to develop the most appropriate groupings in order to capture shared experiences of key transition points.

The focus group discussions will be recorded and transcribed verbatim. The approach to analysis will be 'Framework analysis' (Fern 2001, Lewis 2004, Pope et al, 2008). This method is particularly useful in applied research, in that it allows combining exploring predetermined themes with more open and emerging categories from the focus group data.

The activities to be undertaken are as follows:

<u>Set up — months 1-3</u>

1. Set up a steering group to oversee the project development: this will include relevant stakeholders (e.g. parents of disabled children, occupational therapists working with disabled children and families)

EH will take the lead, with support from the other team members

2. Literature review focusing on support needs of disabled children and their families

KHW and SH will take the lead, with support from the other team members

3. Development of focus group methodology (e.g. number of participants, inclusion/exclusion criteria, interview questions)

AK will take the lead, with support from the other team members. The methodology will be discussed and agreed with the steering group to ensure that it is acceptable to all stakeholders.

4. IRAS application for the focus groups

SH will take the lead, with support from the other team members. The steering group will be asked to comment on draft materials (e.g. information sheets and consent forms) to ensure that these are easily understood and use appropriate language (avoiding technical jargon/ medical terminology).

5. R&D approval and good clinical practice compliance

Following ethical approval, the team will apply for R&D approval from East Kent Hospitals Trust [all team members have current valid research passports and OH/CRB clearance]. A site file will be developed in line with good clinical practice guidelines. SH will take the lead, with support from the other team members.

<u>Data collection and analysis: Month 4-7</u>

6. Conduct the focus group interviews and analyse the data

Focus group interviews will be conducted by SH and AK in accordance with the methodology approved by the research ethics committee. SH and AK will analyse the data to identify in order to:

1. identify key transition points requiring a change in the nature or intensity of therapy support provided to disabled children and their families [Objective 1]
2. identify what support families want and need at these key transition points [Objective 2].
3. explore families' views regarding the three policy priorities: access and empowerment; responsive services and timely support; quality and capacity [Objective 3].

4. explore how parents view the introduction of personal budgets and how they intend to exercise 'choice' when obtaining expert support for their child [Objective 4].

Report writing and feedback: Month 8

8. Project Report to EKHUFT

The findings will be written up and a report submitted to EKHUFT.
KHW will take the lead with support from the other team members.

Activities to be conducted beyond the funded period

9. Wider dissemination of findings

The findings will be written up and submitted to Disability and Rehabilitation. We also intend to submit an abstract to the Posture & Mobility Annual Conference. Other relevant conferences and journals will be considered and discussed by the steering group (for example, any journals with a relevant 'themed call'). Preparation of papers and conference presentations will be an agenda point for all steering group meetings — this will ensure that steady progress is made towards these end points over the course of the project.

Publications and conference presentations will be developed jointly by the research team — this is the approach we have used in the past and we now have a 'well-honed writing team'.

10. Submission of funding application to NIHR to further examine how the NHS might improve delivery of services for disabled children and their families.

Preparation of an application for further funding will be an agenda point for all steering group meetings- this will ensure that steady progress is made towards this end point over the course of the project.

As above, this will be a collaborative effort by the research team, who between them have considerable experience of designing and conducting applied health research. For the preparation of the NIHR application we will draw in the methods support offered through the Research Design Service.

Justification of costs

The co-applicants are not employed in HEFCE-funded positions, but have fixed-term employment contracts directly linked to research grants. It would not be possible

therefore to conduct this research without the IPGS funds. However, we will be able to work on an

NIHR grant application beyond the period of the 'PGS grant. We are hopeful therefore that the small grant requested will act as 'seed-funding' for a larger external grant. The team have been successful in securing NIHR funding (and other external grants) in the past. Our current NIHR grant followed directly from a previous IPGS-funded study (please see section e above).

The costs are calculated on the basis of the time needed to conduct the research (8 months) and the percentage FTE of each team member (as below). SH will be responsible for the dayto-day management of the research and therefore has a larger FTE than the other team members.

Sarah Hotham (60% FTE) Kate
Hamilton-West (10% FTE)
Annette King (10% FTE)

We believe that the planned research will also provide a valuable contribution to capacitybuilding in EKHFT. We intend to invite therapists to join the steering group — therapists will have the opportunity to develop research skills through their involvement in the project.

f. Collaboration & consultation (max 500 words)

This section should detail evidence of academic and financial support from sources external to EKHUFT. Written evidence of such support may be requested. Where consultation (e.g. with patient groups) has taken place about the project, this should be detailed here.

The project team currently holds an NIHR grant focusing on postural care for children with physical disabilities. The steering group for this project includes academics, therapists and parents of children with disabilities; development of further research projects is an agenda item for the steering group meetings. The idea of identifying key transition points in order to provide appropriate and timely support was developed in these meetings; parents noted that key transition points (requiring a change in the nature or intensity of support provided) are likely to include for example, the point at which a child is no longer able to use a pushchair and starts to use a wheelchair for the first time. Another key transition point parents noted is the point at which the child becomes too heavy for the parent to lift, making it difficult to get in and out of the car. Speech therapists have identified the transition to using a communication aid as an important one. Therapists also reflected that the way services are organised may not best support the needs of families at key transition points — for example, starting school is a point at which children and families experience considerable change — at this point the family also transitions from pre-school to school therapy services. The steering group members felt that this change might add an additional strain at a point when families already have much to adjust to. We feel that these concerns warrant further investigation and research.

g. Anticipated started date of project:	h. Anticipated duration:
1/8/2013 (the current NIHR grant ends 31/7/2013)	8 months

i. Monitoring of project progress (max 500 words)

This section should detail the milestones the applicant(s) will use to demonstrate progress against achievement of objectives. In the first year of the project, milestones for completion by 6 and 12 months should be detailed. Thereafter, milestones at not less than yearly intervals should be provided, The R&D Department will require reports on milestones to judge whether funding should continue. Any potential risks to successful project completion and measures taken to mitigate these risks should be outlined.

A steering group will be set up to oversee the project's development and ensure that progress is made in according to project milestones. These are described in greater detail in section f (above).

By month six we will have completed the literature review, developed the focus group methodology, submitted the IRAS application, obtained R&D approvals and started to recruit to and run the focus groups. By month 8 we will have completed the focus groups, analysed the data and produced a report for EKHUFT. After the funded period (and within 12 months) we intend to prepare a paper for publication in Disability and Rehabilitation, submit an abstract to the Posture and Mobility Annual Conference, and submit an application for NIHR funding. [NB — although the set-up period may seem quite short, we have excellent links with relevant stakeholder groups and all team members already have research passports and CRB clearance, so we should not need a long set-up period].

j. Ethical review.

Will project require review by a research ethics committee?
Yes If not, please explain reasons why:

k. References

Bowling A (2005) Research methods in health 2nd ed. Milton Keynes OUP
Falvo D (2004) Effective patient education: A guide to increased compliance London Jones & Bartlett
Falvo D (2005) Medical and psychosocial aspects of chronic illness and disability London Jones & Bartlett
Fern E (2001) Advanced focus group research. Sage Thousand Oaks
Hutton E (2008) Postural management for children with physical disabilities in mainstream primary schools — a pilot study of the views of teachers and teaching assistants. Posture & Mobility Group.
http://www.fastuk.org/research/projview.php?id=1571
Hutton E Coxon K (2008) Involving parents as service users in an interprofessional research project. Journal of Interprofessional Care 22(6) 661-663
Hutton E Poole C Godden S Mortimore J Jensen J Ariss T (2009) A-Z of postural care. http:/./www.ekhuft_.nhs.uk home-age/patients-and-public/a-z-of-patient winfortnaiion/a-c/
Lewis A et al (2004) The reality of research with children and young people London Sage
Pope C et al (2008) Analysing qualitative data BMJ 320 (7227) 114-116

l. Dissemination of results (max 250 words)

Please indicate how you intend to make others aware of the outcomes of your research.

Findings will be reported to EKHUFT and to the steering group. The applicants will also present findings within their organisations (e.g. at internal seminar series). We also intend to present the findings at the Posture and Mobility Annual Conference. Other relevant conferences and journals will be considered and discussed by the steering group (for example, any journals with a relevant 'themed call').

m. Any further information relevant to this application (max 500 words)

If not clearly specified elsewhere in this application, please indicate below how the proposed project fulfils the project & applicant eligibility criteria laid down on pages 1 & 2. Particular attention should be paid to how the applicant intends to use the outputs from this project to seek external (e.g. NIHR) funding.

As noted above we are hopeful that the small grant requested will act as 'seed-funding' for a larger NIHR grant. The team currently holds an NIHR RfPB grant (ending 31/7/13) — this grant followed directly from a previous IPGS-funded study (please see section e above). We successfully delivered on the previous IPGS grant and provided a full and timely report to EKHUFT. We have presented the findings of the previous study at academic conferences and we are in the process of submitting a paper for publication.

n. Suggested external reviewers

Not all applications will be subjected to external peer review. The opinion of one of more external reviewer will be sought if, in the opinion of the IPGS panel, there is insufficient expertise within the panel to judge the scientific merit or some other aspect of the application. Please ensure that you have contacted external reviewers prior to application submission and ensured their willingness to act in this capacity.

Reviewer 1.

Name: Dr Terry Pountney

Institution: Chailey Heritage Clinical Services

Address: Beggars Wood Road, North Chailey, Nr Lewes

Telephone Number: 01825 722112

Fax number: 01825 721063 e-mail address:

terry.pountney@nhs.net

Reviewer 2.

Name: Professor Annemarie Ruston

Institution: Centre for Health and Social Care Research, Canterbury Christ Church University

Address: Rowan Williams Court, 30 Pembroke Court, Chatham Maritime] Kent ME4 4UF

Telephone Number: 01634 894 472

Fax number: 01634 894494 e-mail address:
annmarie.ruston@canterbu .ac.uk

5. Budget

Please supply sufficient justification and details for all budget items (e.g. necessity for items and itemised proposed expenditure). The scheme will not fund food or drinks unless they are for use with study participants (e.g. focus group participants; special dietary requirements for subjects).

You will require input from the Finance Department to complete this section.

Item	Justification for item (e.g. Statistician to assist with data analysis - 4 hours @ £xmour=)	Amount (£)
Staff costs		
(Co-) applicant(s) time	Annette King and Kate Hamilton-West each at 0.1 fte	£9,313
Other research staff time	Researcher Co-Investigator Sarah Hotham at 0.6 fte	£21781
Statistician/data anal sis time		
Other	Helen Wooldridge - Transcri tion- 3 da s	£501
Research Costs		
Investigations (e.g. lab, radiological		
Capital equi ment		
Use of facilities e. . clinics ace/time		
Patient Expenses (e.g. travel)	Travel for participants (mileage, public transport, parking permits) @ £8-00 per artici ant: 60 x £8	£480
Other	Refreshments for focus groups @ per focus group (6x £10) £10-00 Childcare for participants with children younger	£400
Administrative Costs		
Telephone calls		
Photocopyin Iprintin	Postage and printing expenses	£300
Stationery (envelo es/paper)		
E-mail/Internet		
Software		
Postage		
Publication costs (not to exceed £1000 or 5% of total grant requested, whichever is the higher amount; intended journal to be s ecified		
Other		

Travel Expenses (the Trust will fund must no attendance at a single conference/meeting/congress; these expenses exceed £1000 or 5% of total grant applicant requested, whichever is the higher amount; and conferences to intend to submit should be specified which if at all possible, with itemised estimates of costs)		
Airfares		
Car Expenses (not including normal daily travel to workplace)	Travel for researcher to attend focus groups: 6 journeys @ 30 mites average @45 pence per mile Project related travel	£81 £150
Accommodation		
Other (include registration fees here)		
TOTAL		£33,066

6. Supervisors (if any) certification

I have thoroughly assessed and endorse this protocol and I am prepared to supervise this project and advise on the expenditure of the funds allocated.

Signature: _____ Date: _____

Name: _____

_____

Please obtain the following authorizations:

7. Head of Department

I confirm that I have read this application and am willing to accommodate this project and administer these funds: (E-mail confirmation to R&D Department is acceptabte)

Signature: H Weymouth ..... Position: Head of R&T

Name in block capitals: H WEYMOUTH Date: ..1.1a1Q.7.l.a

8. R&D Finance Manager

I confirm that the applicant involved the Finance Department in the costing of this project proposal: (E-mail confirmation to R&D Department is acceptable)

Signature: ..... J Douglas ..... Position: R&D .... .

Capitals: V DOUGLAS Date: 18/10/2012

Name in block capitals: . *

2 - REC Ethics Favourable review letter

Health Research Authority

National Research Ethics Service

NRES Committee Yorkshire & The Humber - Sheffield
HRA NRES Centre Manchester
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7832 Facsimile: 0161 625 7299

21 November 2013

Dr Eve Hutton
Head Paediatric Occupational Therapist
East Kent Hospitals University Trust
Floor 1, Child Health Offices
Buckland Hospital
Coombe Valley Road
Dover
Kent
CT17 0HB

Dear Dr Hutton

Study title:	**Understanding the support needs of disabled children and their families in East Kent**
REC reference:	**13/YH/0374**
Protocol number:	**N/A**
IRAS project ID:	**133831**

Thank you for your email of 15 November 2013, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Helen Penistone, nrescommittee.yorkandhumber-sheffield@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

The Committee specified the following additional condition:

- The Committee noted that the address for this Committee had been added to the Participant Information Sheet as a contact for concerns. Please remove this.
- Please replace this with an independent contact for complaints, such as the local PALS office.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list

of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter from Dr Eve Hutton		28 October 2013
REC application - 133831/518764/1/904		28 October 2013
Protocol	1	17 September 2013
Investigator CV - Dr Eve Hutton		
Letter of invitation to participant	Support Group v1	16 October 2013
Interview Schedules/Topic Guides	1	10 September 2013
Advertisement	1	17 October 2013
Other: Letter from funder from Mr Andrew Dibiase		
Evidence of insurance or indemnity		17 July 2013
Evidence of insurance or indemnity		17 July 2013
Evidence of insurance or indemnity		26 July 2013
Evidence of insurance or indemnity		26 July 2013
Response to Request for Further Information	from Dr Eve Hutton	15 November 2013
Participant Consent Form	2	13 November 2013
Participant Information Sheet	2	13 November 2013
Letter of invitation to participant	2	13 November 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/YH/0374	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

On behalf of
Professor Basil Sharrack
Chair

Email: nrescommittee.yorkandhumber-sheffield@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Nicole Palmer
University of Kent

Dr Art Ationu
East Kent Hospitals University Foundation Trust

3 - Participant Information v3

University of Kent

East Kent Hospitals University NHS
NHS Foundation Trust

Introduction

We would like to invite you to take part in a focus group to discuss your experience as a parent of a child with a physical disability. Please read the following information carefully as it gives you the details of this research, why we would like you to take part, and what you will be asked to do if you agree to take part.

Why is this study being carried out?

This focus group is being carried out to discuss the support needs of children with a disability and identify key points in a child's development that require a change in the nature or intensity of support provided by therapy services.

Why have I been invited?

We are inviting you to take part as you live in East Kent and care for a child with a physical disability or a neurodisability between the ages of 1-19 years.

What are you asking me to do?

We are asking you to agree to participate in a focus group discussion;

1. You will be invited to take part in a 90 minute focus group.

2. At the focus group we will ask you a number of discussion questions to encourage your views and opinions about the support needs children with a disability.

What will the focus group involve?

The focus group will involve the researchers gaining your opinions and views on a number of topics. For example, as part of the focus group you will be asked to discuss key transition points (i.e., points requiring a change in the nature or intensity of support) in children's needs. We will also ask you to comment on what support from local therapy teams was received at these key points. Finally, we would also like to gather your views on government policy for disabled children and the idea of personalised care budgets. The focus group will be an informal gathering and an open forum to discuss these topics. The focus groups will be recorded so transcriptions of the discussions can take place at a later date. All recordings are confidential and will not be shared with anyone outside of the research team.

How long will I be involved in the focus group?

The focus group is 90 minutes.

How long is the study?

You will only need to attend one 90 minute session as part of the study.

What are the possible benefits of taking part?

As a result of taking part in the focus group the information you provide will inform therapy services about the type of support families would like to receive.

What are the possible disadvantages of taking part?

You may find the focus group too time consuming.

Will taking part affect the usual treatment my child receives from therapists and/or those who take of my child at school?

No. Taking part or declining to take part in the study, will not affect the usual care your child receives.

Who is organising and funding this study?

The study is funded by East Kent Hospitals University Foundation Trust. Researchers from University of Kent will carry out the study with support from your local care provider.

Who has reviewed this study?

The Research Ethics Committee York and Humber- Sheffield has reviewed this study and gave permission for this leaflet to be distributed to parents/carers of a child under the care of therapy services in this area.

If you want to participate, please return the tear-off slip at the bottom of the invitation letter. If we do not hear from you, we will send you one reminder letter.

What happens to the information I give?

All information collected from the focus groups will remain strictly confidential. No interview transcripts will contain personal identifiable information and only broad trends will be reported. If quotes from individuals are used when reporting the data these will be identified by a generic participant number and not by your name. However, due to the unique nature of some situations it may be possible for you to identify yourself from these direct quotes despite efforts by the research team to anonymise data.

The transcripts will be securely stored for as long as is required by the Data Protection Act and then they will be destroyed. We have no access to your medical records. Only the local therapy team have access to your child's medical records.

If during the course of the focus group concerns are raised around the safeguarding of children, the researcher will report these concerns to the Chief Investigator Dr Eve Hutton, who in turn may report these concerns to the Kent Safeguarding Children's Board. http://www.kscb.org.uk/.

Government guidance defines safeguarding of children as:

- Protecting children from maltreatment;
- Preventing impairment of children's health or development; and
- Ensuring that children are growing up in circumstances consistent with the provision of safe and effective care

If an incident is reported to the Kent Safeguarding Children's Board the individual concerned will be informed by the Chief Investigator – Dr Eve Hutton- that a report has been made to the Board.

Will I get to know the results of the study?

A summary of results will be sent to you after the study has finished.

Do I have to take part?

It is entirely your choice to take part. You will be required to give an individual participant number so that the information you provide will be anonymous. This will mean that even if you agree to take part now, you can still withdraw at any stage, without giving a reason.

What do I do now?

If you are interested in taking part please return the expression of interest reply slip, including your preferred way of contact, to a member of the research team. Alternatively, if you do not wish to make a decision now, the form can be returned in the pre-paid envelope provided. If you agree to take part, you will be contacted by the researcher to answer any questions and to arrange an appointment at the (insert local centre here).

Insurance Policy

In the unlikely event that something goes wrong during the focus group, the University of Kent provides indemnity insurance policies that cover harm to volunteers arising from the negligence of their employees.

What happens if something goes wrong?

If you have any complaints about the conduct of this research, you should contact the Chief Investigator Dr Eve Hutton on 01233 898915.

Child Health Management Offices, First floor, Buckland Hospital, Coombe Valley Road, Dover, Kent. CT17 0HD

Your normal NHS channels of complaint are open to you if you are unhappy about the clinical care you receive. Your details of your local Patient Experience Team are:

Patient Experience Team
First Floor, Trust Offices
Kent and Canterbury Hospital
Ethelbert Road, Canterbury
Kent, CT1 3NG

Thank you for your interest in our study

For all queries regarding this research, please do not hesitate to contact:

Researcher: Dr Sarah Hotham
Email: S.Hotham@kent.ac.uk
Phone: 01227 827759

Research Supervisor: Dr Kate Hamilton-West
Email: K.E.Hamilton-West@kent.ac.uk
Phone: 01227 82387

4 - Invitation letter

Dear Parent/Carer,

I am writing to invite you to take part in a research study that aims to identify the support needs of families in East Kent. You have been sent this invitation because you care for a disabled child.

The research is interested in gathering the opinions of parents on a number of topics. These include how the support needs of disabled children may change at key points and what support can therapy services provide at these key points.

The study is funded by the East Kent Hospitals NHS University Foundation Trust and the study will conducted by researchers at the University of Kent. The study has received approval from the NHS Research Ethics committee (13/YH/0374). For more information about the study please see the enclosed information sheet.

If you decide to take part this would involve:

- Attending a focus group that will last 90 minutes. The focus group will include approximately 5 other parents/carers of disabled children.

It is entirely up to you whether to take part, but your input is very valuable to us and will help identify key points when extra support may be needed, and the type of support you would like to receive from therapy services at these points. If you decide you do not want to take part, the support you receive from your therapy team will not be affected.

If you would like to take part in the study, please fill in the attached contact slip or email Dr Sarah Hotham at S.Hotham@kent.ac.uk. We will then come back to you with more information about the study.

If you would like more information before you make a decision about whether or not to take part please contact the local therapy team leader, Dr Eve Hutton the Chief Investigator of the study (eve.hutton@nhs.net / 01304222528) who will be happy to answer any questions you have.

Yours sincerely

Eve Hutton

Please complete and return this form in the envelope provided only if you would like to be contacted to participate in the focus group.

Name: …….

Telephone: ……

Address: ……

……....

Email: …….

Age of child……

The best times and days of the week for me to attend the focus group are:

……

……

5 - Invitation letter (NHS)

January 30th 2014

Dear Parent,

I am writing to invite you to take part in a research study that aims to identify the support needs of families in East Kent. You have been sent this invitation because your child's therapy service has identified you as a parent/carer of a disabled child. Your details have not been shared with anybody outside the service

The research is interested in gathering the opinions of parents on a number of topics. These include how the support needs of disabled children may change at key points and what support can therapy services provide at these key points.

The study is funded by the East Kent Hospitals NHS University Foundation Trust and the study will conducted by researchers at the University of Kent. The study has received approval from the NHS Research Ethics committee (13/YH/0374). For more information about the study please see the enclosed information sheet.

If you decide to take part this would involve:

- Attending a focus group that will last 90 minutes. The focus group will include approximately 5 other parents/carers of disabled children.

It is entirely up to you whether to take part, but your input is very valuable to us and will help identify key points when extra support may be needed, and the type of support you would like to receive from therapy services at these points. If you decide you do not want to take part, the support you receive from your therapy team will not be affected.

If you would like to take part in the study, please fill in the attached contact slip or email Sarah Hotham at S.Hotham@kent.ac.uk. We will then come back to you with more information about the study.

If you would like more information before you make a decision about whether or not to take part please contact the local therapy team leader, Dr Eve Hutton the chief investigator of the study (eve.hutton@nhs.net / 01304222528) who will be happy to answer any questions you have.

Yours sincerely
Eve Hutton
Head Occupational Therapist (Children, Young People & Families)
Carousel Child Health Department, Buckland Hospital, Coombe Valley Road, Dover, Kent. CT17 0HD

Please complete and return this form in the SAE provided only if you would like to be contacted to participate in the focus group.

Name: …….

Telephone: ……

Address: ……

……....

Email: …….

Age of your child……

The best times and days of the week for me to attend the focus group are:

……

……

6 - Focus group questions

Focus group Topic Guide: To be used for focus groups with parents

The focus group topic guide will be in three parts:

- part one will explore key periods of change
- part two will ask participants to reflect from their own experience on three aspects of service delivery (Aiming High White paper, 2007) :
    - access to services
    - timely support of services
    - the quality of the support.
- part three will explore viewpoints of personal care and personal budgets.

Part One:

The discussion will explore the experiences with rehabilitative services (Physiotherapy/Occupational Therapy/ Speech and Language) at key transition points in care needs. - The focus will be on the care provided by these services.

As a stimulus for discussion a time line (6 monthly up to age of 2, then yearly) and participants will be invited to mark down individually, where they remember key points were when the care needs of the child changed substantially.

The discussion will focus on key common points and explore the circumstances and experiences at those points in relation to rehabilitative services.

Areas covered in the discussion to include:

- **how did the care needs changed**
- **how did parents notice this**
    - **the reasons for this:**
    - **internal (child development -** change in height/weight of child, progression of disability,
    - **external (change in circumstances, for example family)** developmental progression of sibling, schooling
- **what was the impact (child, family, parent)**
- **what therapy services were in place**
- **how did therapy services respond**
- **any gaps**
- **examples of good practice**
- **other support that would have been useful at the time**

Part Two: This part of the focus group will be about getting the help you need when you need it.

This part will focus on the experience families have had in relation to the three policy priorities set out in the Aiming High for Disabled Children paper, 2007. The ambition of this policy was to improve services for disabled children across three key areas: access to services; timely support of services; and the quality of the support.

The discussion will focus on these policy priorities and your experience of these priorities.

Areas covered in the discussion to include:

- **An example/s of when support was received promptly and/or effectively**
    - **what support did parents need**
    - **what support was provided**
    - **how frequently did parents receive this type of support**
    - **why was this support needed/requested**
    - **why were parents pleased with the support you received**

- **An example/s when support was not received promptly or effectively**
    - **what support did parents require but not receive**
    - **why was the support needed/requested**
    - **what elements of the support were not met**
    - **reasons for this failure to meet support needs**
    - **what could have been done differently**

Part three: This part will focus on personalised care budgets
The discussion will focus on your views of personalised care and what you would do if provided with a personalised budget for the future care of your child.
Areas covered in the discussion to include:

- explanation of personalised care (of which personal budgets are a feature)

- **how would personalised care affect the current level and quality of support parents/children receive**
- **what elements of support would parents use a personalised care budget to cover**
- **what elements of in support would parents not use a personalise care budget to cover**
- **what elements of support would parents expect to remain the same**
- **views on whether future support be easier or harder to receive if personalised care budgets were implemented**
- **would personalised care have affected areas highlighted in part one**
- **would support have been improved**
- **would there have been fewer gaps**

(Keep a tally on a flip chart indicating number of parents who think it will be more or less likely ask parents to explain/expand).

7 - Consent form

CONSENT FORM

Understanding support needs of disabled children and their families

I have read and understood the participant information sheet for the above study. I have had the chance to ask any questions and I understand that I am free to withdraw from the study at any time, without giving a reason. In addition, I am aware that confidentiality and anonymity will be maintained at all times.

I consent to:

(Please tick all five boxes to indicate consent)

I confirm that I have read and understand the information sheet dated (Version 2: 13/11/2013) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
I give permission for interviews and focus groups to be recorded and the use of anonymous direct quotes. Due to the unique nature of some situations it may be possible for you to identify yourself from these direct quotes despite efforts by the research team to anonymise data.	☐
I understand that the research data collected during the study may be looked at by other individuals from the research team, the sponsor, regulatory authorities or the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	☐

I agree to take part in the above study. ☐

_____	_____	_____
(Participant Name)	(Date)	(Signature)

_____	_____	_____
(Researcher Name)	(Date)	(Signature)

One copy of the consent form is for you to keep and the other to be given back to the researcher.

PROTOCOL

Understanding the support needs of disabled children and their families in East Kent.

REC Ref: **13/YH/0374**

Co-sponsors: University of Kent & East Kent Hospitals University Foundation Trust

CI: Dr Eve Hutton

Co-Investigators: Dr Kate Hamilton-West, Annette King, Sarah Hotham

Research Protocol

Understanding support needs of disabled children and their families.

Overview and Aims:

The proposed research aims to focus on the support needs of families to ensure therapy services in East Kent can prepare for these changes and respond to needs identified. We plan to conduct focus group interviews with parents of disabled children to explore the experience of transition points in the care needs of the child and to identify whether there are key transition points (requiring a change in the nature or intensity of support provided). In the focus groups, families will also be asked to reflect and comment on their experiences of on priorities in new policies for disabled children: priorities: access and empowerment; responsive services and timely support; quality and capacity. It will also seek the views of parents on personal care budgets a major policy development in the next few years, which will inform service delivery. The research project will provide valuable insights into the perceptions and experiences of parents who have physically disabled children and will contribute to improved planning and commissioning of therapy services.

The research project has four main objectives:

1. From the perspective of parents, to explore and identify key transition points requiring a change in the nature or intensity of support provided by therapy services to disabled children and their families.

2. To identify what support from therapy services families want and need at these key transition points

3. To explore families' views regarding the three policy priorities (access and empowerment; responsive services and timely support; quality and capacity) and how these priorities can be achieved in relation to the transition points identified.

4. To explore how parents view the idea of personal care budgets and how they would exercise 'choice' when obtaining expert support for their child.

Design:

The design of the research is divided into three phases:

Phase One: Set up and development of materials

Phase One of the research focuses on two areas: First obtaining ethical and R&D approval and second, on the development of a topic guide for the focus group. The project steering group will be set up in Phase One and will include representatives from therapy services and parents

who care for a disabled child. The topic guide and questions to be asked in the focus groups will be developed in conjunction with and steering group drawing on their expertise.
Links with local parent support groups will also be made to inform them about the work we will be undertaking and discuss opportunities to meet with parents in their group to discuss participating in the research.

Phase Two: Data Collection

This phase of the research will include six focus groups with parents of children with a physical disability or a neurodisability (i.e., Aspergers, Autism). Focus groups are a useful setting for exploring viewpoints and issues based on shared experiences (Fern 2001, Bowling 2005). In the case of this study, the focus groups can build on the collective experience of caring for a child with physical disabilities during childhood and adolescence.

Organisation of focus groups: In total six focus groups will be convened for carers/parents. The aim is to recruit 6 participants for each of these focus groups (36 participants in total). Focus groups will be formed according to the age (i.e., pre-school, primary, secondary) and disability of the child (i.e., physical and neurodisability), resulting in six separate groups to which parents will be assigned. Each focus group will be scheduled to last 2 hours each. It is envisaged that the focus groups will be held at NHS therapy/child centres in East Kent (e.g., the M.A.S.H (Multi Agency Specialist Hub) in Ashford or the Children's centre at Kent Canterbury Hospital) on a selection of dates between November – February, 2014.

A qualitative researcher will be responsible for collecting and analysing the data from the focus groups. This researcher will be supervised by a Chartered Health Psychologist and will keep regular contact with the Steering Group.

The focus group discussions will be recorded and transcribed verbatim.

Phase Three: Analysis and Report

This phase will include the analysis of qualitative data, writing of reports and journal articles and the dissemination of the findings at relevant conferences and to relevant stakeholders.

Data analysis: The approach to analysis will be 'Framework analysis' (Fern 2005, Bowling 2005, Pope et al 2008). Analysis involves five key stages: familiarization; identifying; a thematic framework; indexing; charting; mapping and interpretation. 'Framework' is particularly useful in applied research, in that it allows combining exploring pre-determined themes with more open and emerging categories from the focus group data. The overall thematic framework will allow differences and commonalities between informant groups to emerge and links the analysis to the quantitative study.

The data will be fed into a qualitative data analysis software NVIVO –, which includes the data analysis facility to 'Framework analysis' approach.

Participants

Participants will be recruited via two avenues:

1) Parent support groups

The researcher will approach co-ordinators of local parent support groups either by phone, letter or email to provide some preliminary information about the study and to ask if a member of the research team could attend a scheduled group meeting to present the research project to parents.

At the group meeting the researcher will present a short introduction to the study and outline what would be involved if parents chose to participate. The researcher will answer questions that arise and distribute information sheets and expression of interest forms. Parents who wish to take part will be asked to return the expression of interest form to the researcher, either at the meeting or via post. Postage paid envelopes will be provided for this purpose.

In addition the research project will be advertised via posters placed in local Multi Agency Specialist Hubs (M.A.S.H) in Ashford and Swale. We will also place posters in locations where parent support groups meet. Posters will supply a brief description of the study and details of who to contact should parents like to take part. Interested parents will then be sent an information sheet and expression of interest form by the researcher.

2) NHS therapy teams

Parents of children with physical and neurodisabilities who meet the study inclusion criteria will be identified by EKHUFT therapy teams (Occupational therapy, physiotherapy and speech and language therapy). These details will be provided to either the CI (Dr Eve Hutton who is based at EKHUFT) or an administrator at EKHUFT who will send the identified parents information about the study together with expression of interest forms. Parents will be asked to return the expression of interest forms to the researchers using a reply paid envelope provided. The researchers will not have access to any medical records.

The NHS recruitment route will also be followed to invite parents of children receiving therapy services from Kent Community NHS Trust.

Up to six focus groups will take place across East Kent. We aim to recruit 6 participants for each of these focus groups. Therefore, we aim to recruit 36 participants in total.

Potential participants will be identified according to the following criteria:

a) Parent or carer of a child aged between 1 and 19 years with a long-term (i.e., over 12 months as defined by the Disability Act) physical disability or neurodisability receiving either occupational therapy/physiotherapy/speech and language therapy.

Procedure

Information sheets and expression of interest letters with a reply slip for the participant to return will be provided to all interested participants via the two avenues described above. Participants who have indicated a willingness to participate will be followed up by the researcher and provided a confirmation of the date, time and location of the specific focus

group relevant to them (i.e., based on the age of their child and the particular disability). Participants who confirm their attendance at the relevant focus group will be called two days before to remind them and answer any preliminary questions.

The focus group sessions will follow guide specifically developed for this project. The guide is included as an appendix to this protocol. The guide includes three parts that will explore parents' experiences with rehabilitate services at key transition points, thoughts about the help they receive, and viewpoints on personalised care.

At the focus group meeting, information about the study will be given by the researcher and any outstanding questions will be discussed. Consent forms will then be signed. Once consent forms have been completed and any questions answered, the focus group will begin.
A qualitative researcher will be responsible for collecting and analysing the data from the focus groups. This researcher will be supervised by a Chartered Health Psychologist and will keep regular contact with the Steering Group.

The focus groups will last 2 hours in total- 1.5 hours focus group and 30 minutes to complete consent form and ask questions if required. The focus groups will be held on a selection of dates November– February, 2014.

Measures:
This is a qualitative study, and the outcome will be the themes identified through the analysis of the focus group discussions.

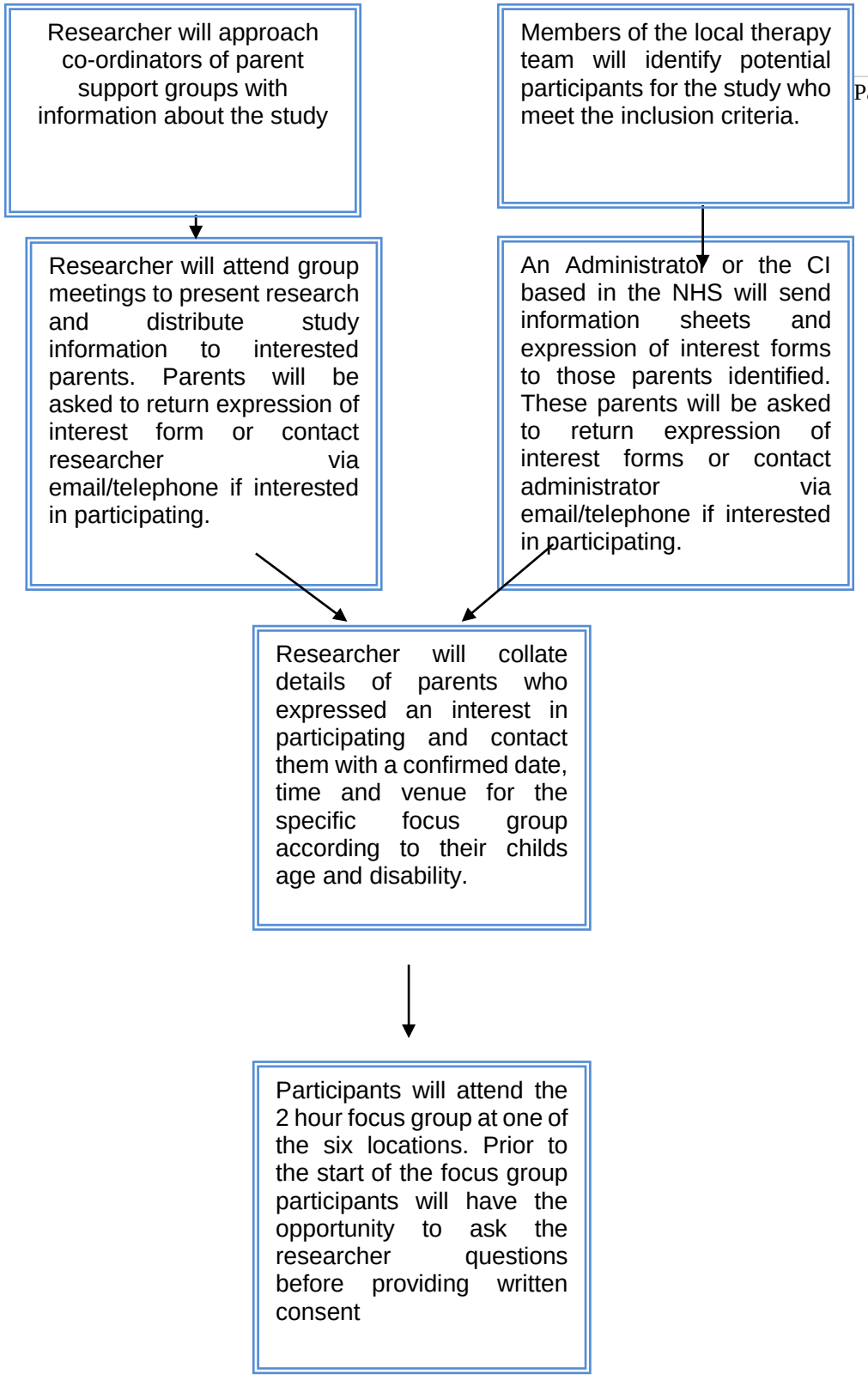
Inter-subjectivity will be ensured through the role the research team members will take in the analysis of the focus group data. All researchers will develop and agree an initial thematic framework for the analysis on initial reading of the transcripts. The framework will be applied to the trnascript by the main researcher and cross-checked by one of the team members.

Statistical Analysis:

This is a qualitative exploratory study; there will be no statistical analysis.

Flow chart for the recruitment of participants:

Figure 1: Study Procedure



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- **what was the impact (child, family, parent)**
- **what therapy services were in place**
- **how did therapy services respond**
- **any gaps**
- **examples of good practice**
- **other support that would have been useful at the time**

Part Two: This part of the focus group will be about getting the help you need when you need it.

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    - **why were parents pleased with the support you received**

- **An example/s when support was not received promptly or effectively**

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