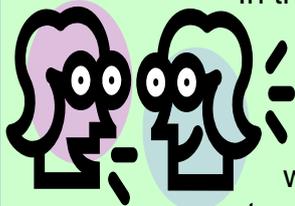


## New Research Project gets started Improving communication with children with disabilities when they have to stay in hospital



In the last newsletter we told you about our study to develop a training package for health professionals to help improve communication with children when they have to spend time in hospital. To help us do this, we are interviewing children with disabilities and their parents/carers about a recent stay on children's wards in either Exeter or Barnstaple hospital. We are asking about the things that were good and not so good, and any suggestions they would make to improve children's experience of being on the ward.

We now have the go ahead from the local ethics committee to proceed with the study and have started advertising the study on the wards. We are seeking to interview around 20 children and their parents/carers soon after they have been discharged. Families will contact us directly if they would like to hear more about the study. This is a really exciting project as children and their families will have an opportunity to change the practice of health professionals who care for them when they have to stay in hospital. If you would like any more information about the project, please contact Vanessa Edwards on 01392 722978 or [Vanessa.edwards@pms.ac.uk](mailto:Vanessa.edwards@pms.ac.uk) <http://tinyurl.com/y87hs73>



## NEW Cerebra in the SW & Cerebra Research Unit are planning a Family Event for later this year

Your chance to have your say!

At our recent Advisory group meeting in March we discussed holding a Cerebra Research Unit Annual Event for families. It transpires that Helen Bear, who is the regional officer for Cerebra in the South West, is planning an event too, so we are going to collaborate. The parents on our advisory group favoured a celebration and fun day rather than a 'dry' academic event.

We would love to hear your ideas and suggestions to help make this a fantastic family fun day out.

If you are interested in becoming part of a 'working group' to help make this event a success then please get in touch.



## Upcoming meetings

[Advisory Group: Thursday 10th June, 10.00am to 12 noon](#)

[Social Inclusion working group May 11th, 1pm to 3pm](#)

[Nappy service working group May, watch website for details](#)

*Please let us know if you would like to join any of these groups. See website for updates.*

## INVOLVE Conference

INVOLVE is a national advisory group that supports and promotes active public involvement in NHS, public health and social care research. INVOLVE believe that involving members of the public leads to research that is: more relevant to people's needs and concerns, more reliable, and more likely to be used. For more details see [www.invo.org.uk](http://www.invo.org.uk)

INVOLVE are holding their seventh annual conference on 16-17 November in Nottingham. The conference is an opportunity to hear about the impact of involvement on research and to share and gather ideas. Chris has offered the organisers a presentation about how we involve families of disabled children in all the activities of the Cerebra Research Unit. If we are selected we would really love to have one or two representatives of our family faculty to present with us. Please contact us if this interests you.

## Mapping services for children with disabilities & special health needs in Devon

We have been trying to understand how services for children with disabilities and special health needs are organised in Devon. We have found that it's not easy to navigate a county with varying boundaries and organisations providing services; and to make matters more tricky, there appears to be ongoing reorganisation!

When we discussed the topic recently at our advisory group, we heard how several parents at the meeting shared this frustration, and remarked that if the professionals find it hard to navigate then think how it is for the families!



We will be seeking to collaborate with DISCPlus and all the professional and voluntary groups in Devon to better understand the provision of, and equality of access to, services in the county. However we are also keen to hear from families about personal experiences of finding and accessing the services your child and your family need. Please write on the online forum or email us to share your experiences on finding and accessing services and support.

## Lycra study

Since the last newsletter we have continued to develop a research protocol to explore the effectiveness of Lycra sleeve/glove orthoses (splints) to improve handling ability of children with hemiplegia. This is now at an advanced stage and we will be submitting an application for funding to the NHS Research for Patient Benefit Programme towards the end of May.

Lycra orthoses are proving popular with many therapists and families; however there is little evidence that they improve functioning and some concerns that children do not like wearing the garments. The existing research about Lycra orthoses is undermined by the fact that the garments have varied in the amount of body they cover, and also that children had different sorts of impairments. We are seeking to overcome this problem by focusing only on arm and hand function in children with spastic hemiplegia.



Several families are in contact with us about the study and one father came to an earlier meeting and his contribution helped shape what we are doing. If the topic of this research interests you then get in contact with us.

## Advisory Group

We have an advisory group that meets every few months. The advisory group provides advice about various activities that we are involved in and is crucial to the success of our work. If you would like more information about



what would be involved the please get in touch. At our meeting in March seven parents came along, one parent told us afterwards:

*"I must say what a pleasure it was to be at the advisory group meeting today, I really was made to feel welcome and enjoyed taking part, I shall look forward too getting to know everyone better and becoming more involved in the work..."*

*(reprinted with permission)*

We are very keen to encourage more parents and carers to join us. For our autumn meeting we hope to hold it either on a Saturday morning or early one evening so that families unable to attend during office hours have an opportunity to get involved. If you have a preference for a time that suits you then please let us know.

## Did you know?

In March many of the staff in the Child Health Group at Peninsula Medical School participated in training from Triangle. Triangle are a national organisation who specialise in consultancy and advocacy work with children [www.triangle.org.uk](http://www.triangle.org.uk) Ruth from Triangle provided us with a day's training that helped us think through important issues to consider when communicating and consulting with children with special needs. This was a really helpful event and we learned a great deal. We hope to work closely with Triangle in the future.

## RESEARCH TO PROMOTE SOCIAL INCLUSION

We continue to pursue planning for a research programme to promote the social inclusion of disabled children. The topic of 'why some areas of Devon were more inclusive than other areas for children with special or additional needs' was prioritised by a group of parents who worked with Claire before she went on maternity leave. Therefore we have been enthusiastically looking at ways we can take this research forward. This work is evolving as we meet various stakeholders and hear different perspectives. Everyone we have talked to appears to sign up to the principle of social inclusion, but it is quite tricky to pin people down as to what social inclusion really means for disabled children, and how to make sure it happens.

Currently we are thinking of two separate projects that fit this theme. First, we convened a meeting for a group of people from diverse academic and consultancy backgrounds but all with interests in disability. At the meeting we discussed ideas for a research proposal to measure social inclusion of children; and also to review ways of measuring the related concepts of stigma felt by children and families, and public attitudes towards disability. We came away from the meeting feeling we were a good team to take the ideas forward, and identified some clear objectives. We will keep you posted as the ideas become more substantive. As always we are keen for members of our family faculty to get involved.

You may have seen a research report published last year by Contact a Family which found negative attitudes towards disability coupled with a lack of services to be the main barriers preventing families with disabled children from leading ordinary lives; for more details go to <http://tiny.cc/5hrbd>. Changing the way people think is incredibly challenging, but there is some cause for optimism if we reflect on the progress made against racism and sexism in society over the past decades (I know, to be realistic, progress isn't quick!).

Second, another of our ideas is for a community-led project locally in Devon that might be eligible for, and for which we could mount a collaborative bid with interested families and community groups to seek funding from the Lottery or other charitable agencies. This work could have a number of objectives, and being a local initiative might identify objectives related to accessing services and identifying barriers to inclusive activities. We are building a network of links with various people and organisations in Devon as part of our mapping project. A collaboration that engages our family faculty with members of the health and social care network, and local voluntary organisations, would be a strong team to bring about real changes to improve the health and wellbeing of children.

One example of what we thought was good practice is the Inclusion Service run by Sarah Mumford at South Devon PCT. The service operates in several ways to enable children with special needs to become involved in mainstream activities with other children. We are keen to hear about any similar services around Devon and elsewhere and also about families' experiences of finding and using services that promote inclusion.

### Academic meetings

Chris led a workshop about the Cerebra Research Unit for health professionals at the conference for Devon Children's Centres. You can see the slides from the presentation and some of the other presentations at <http://tiny.cc/ea696>

Chris will be presenting the first phase of our research to improve communication with disabled children when they have to spend time in hospital at the European Academy of Childhood Disability in late May.

### Look out for us in the media...

The Exeter Express & Echo came to see us about an article for their carer's page.



Chris may be interviewed on Radio Devon in their lunchtime health slot on 4 May.



### Nappy Services

One of the issues raised during our launch events last summer was the frustration parents felt when dealing with the nappy services provided in Devon. We are continuing to gather information about this service and there is a working group meeting in May to move this forward. If you have information that may be helpful; please get in touch.

## Get chatting on the forum!



It is very easy to join; and it is a great place to talk to other families about issues and events that are important to YOU. Have a look at the website for more information.

## Staff News

### Exciting news:



Claire has had her baby, she had a boy called Alfie Christopher on Friday 19th March. Mother and baby are doing well.

We look forward to welcoming Val Shilling when she starts in June.

Camilla is embarking on the challenge of running the London marathon on April 25th raising money for "[Childlife](#)", Childlife was established as a way for four lesser known charities, working with children throughout the UK, to come together and fundraise collectively.

## Join our Family Faculty!

We are always keen to hear from parents and carers who would like to be part of our Family Faculty. Membership of the Family Faculty does not commit you to anything, but will mean that you are kept informed about the work that we are doing and will be offered the opportunity to get involved in reviewing information leaflets about specific studies or for general CRU publicity, sitting on trial steering committees for specific studies, work with us to design studies, assist with disseminating the results of studies, or any other aspect of the work that we are doing that you have an interest in. We will ask for your email address, phone number and postal address and will send you regular updates. If you are interested in becoming a member of the Family Faculty then please let us know.



## We have moved! our new address is:



**Cerebra Research Unit,  
Peninsula Medical School,  
Veysey Building,  
Salmon Pool Lane,  
Exeter, EX2 4SG**

## Contact the Team

Website: [www.pcmd.ac.uk/cerebra](http://www.pcmd.ac.uk/cerebra)

Phone: 01392 722968/2901

Email: [cerebrereserchunit@pms.ac.uk](mailto:cerebrereserchunit@pms.ac.uk)

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Chris



Claire



Camilla



Katrina



Stuart



Hannah



Family faculty

