



**Cerebra Research Unit Advisory Group Meeting  
Minutes of Meeting: Thursday June 10<sup>th</sup>, 2010**

- 1. Introductions: Chris Morris (Chair), Kim Antonio (parent), Becky Hart (parent), Helen Bear (Cerebra), Val Shilling and Camilla McHugh.**
- 2. Apologies: Lucy McCance, DebbieCross, Donna Beswick, Ruth Marchant, Lee Jones, Katrina Wyatt, Ginny Humphries, Richard Tomlinson, Tamsin Ford.**
- 3. Matters arising not on agenda and actions from last meeting**
  - Publicity ideas: a piece was published in the Primary Times. We have had several new parents join the family faculty since the article, one that stated they were contacting us in response to the Primary Times piece.
  - It was suggested at the last meeting that SENCOs might provide a good contact with parents. VS will follow this up with Lucy McCance who suggested it originally.
  - A number of new research questions were raised at the last meeting. These have only just been posted on the forum to see if other parents have any comments on whether they should be taken further.
  - The CRU has put the idea of having a Facebook page and Twitter account on hold, exposure to this media is available via the Cerebra Facebook page.
  - The issue of payments for childcare was raised at the last meeting and CMCh confirmed that childcare payments can be claimed with a receipt.

**4. Update on CRU staff**

- Val started on June 1
- Claire Lloyd had a baby boy, Alfie
- There is a new Head of Research & Education at Cerebra – Tracey Elliot, replacing Kate Bratt-Frarr

**5. Family Involvement**

-80 families are now on our family faculty database. Although the group is growing, it was noted that this is a small proportion of parent & carers in the region.

-CMc asked whether we should invite the entire family faculty to be part of all meetings, e.g. advisory group meetings and working groups, even if they hadn't registered their interest in that

group. It was decided that it was a good idea to ask everyone. Also, if it was a follow up meeting, to include a brief summary paragraph to bring people up to speed with the discussion so far and enable them to decide whether they want to join in.

-It was also suggested that the email title should be Cerebra Research Unit, with one or two words describing the topic, to enable parents to decide from the title whether it was likely to be of interest to them.

-We currently have little information about the families in our faculty and the group discussed sending out a details sheet to gather some key information about the families. A draft version of the details sheet was discussed and a number of suggestions made regarding the phrasing of questions. In particular, while everyone thought it was important that we ask whether children might be interested in becoming involved, we should explain why we are asking about including children and what it is we would be asking children to do. The parents present were happy to provide such information and the details sheet will be sent out in the next week. **CMc&VS**

- Val has made contact with the local organisers for face2face and parent carers' voice and hopes to start going to local meetings soon to meet families. The group suggested several other avenues to meet new families:

- Dame Hannah Rogers School Trust (chair Bronwyn Hewitt) has opened a new centre called Hannah's at Seale-Hayne. We will put this in the next newsletter and arrange a team visit. It may be possible to hold some advisory group meetings there.

Friends and family of special children, Plymouth – Kate O'Shaunessy

Scope – Andrew Mullins

Face2face Cornwall – Jane Armstrong

Petals Community Group – Erzebet Gordan. Chris has had contact with Erzebet who wanted to do some research on conductive education

Possibly speak to Donkey Sanctuaries and riding for the disabled schools to just leave a few of our leaflets in reception areas.

Calvert Trust activity holidays

## **6. Professional networking/mapping**

-Chris explained that the mapping project aimed to create a database of services (public/private and charitable) that people use. This information could be used for research and also to guide families.

-Long term this data base could be used to develop future research on how services are delivered and how efficiently they are delivered, using family reported outcome measures.

-Chris has been in contact with the 3 region leads for service provision at the integrated child and youth services but they are not in a position to help at the moment.

-The Council for Disabled Children (Christine Lenehan and Kate Martin) is keen to be supportive, particularly of the social inclusion project.

## **7. Annual event**

The annual event will be held at Paignton Zoo on September the 18<sup>th</sup>.

Discussed possibility that we may have to cap numbers and limit to immediate family

We discussed having a couple of speakers at the event however the group felt that perhaps this would just be too difficult with the children present as well. Parents who would be interested in the talks might not feel able to attend because their children would get bored etc. It was decided that a quick 'welcome' over coffee at the start of the morning would be the best solution but that families should be given the opportunity to get together at a fixed time and place for lunch, if they wanted to. There is also the option of a private bird show in the afternoon which would draw families together again before the end of the day.

It was felt that the talks would be of interest to parents and that they should be arranged as a separate event. Possibly look into holding the event at Hannah's at Seale-Hayne.

## **8. Website and Forum**

The forum is at a standstill and Kim and Becky explained that time really is a barrier for parents and that if they are going to look at a forum, they would tend to stick to one or two favourites.

As well as research posts we might consider posting other things of interest, such as the new centre at Seale-Hayne to try and gain some momentum.

Helen suggested that perhaps rather than just asking other sites to link to our forum, we could consider approaching Mumsnet to see if our forum could be incorporated into their section for disabled children. This would give us a broader audience and perhaps the nappy campaign could be a foot in the door for this.

We discussed the use of photos of children on the website. Both parents felt that they would be willing for their children's photos to be used and that real photos make a website more personal and appealing.

We could create a bank of photos that families would be happy for us to use.

Becky suggested we email the family faculty before the event in September to see if we could take photos on that day for use on the website and presentations.

We intended to discuss setting up a working group to look at the website/forum. This was not discussed at the meeting but will be added to the family details sheet and posted on the website/forum?

## **9. Unit programme of work**

We discussed the question prioritisation process and in particular, whether the group felt that it would be appropriate to consider some research specific groups (e.g. ASD), following a James Lind Alliance protocol to prioritise research.

HB was concerned that this approach could be seen as excluding people but Chris explained that there would continue to be generic questions that affect all of our family faculty, but some that are specific to certain conditions. Kim wondered whether or not this would actually be possible in terms of the number of families we currently have in the family faculty. It was agreed that the first step is to gather the family information and see just who makes up our family faculty.

## **10. Measuring the impact of involvement in the work of the CRU**

The unit has been given a 25 minute slot at the Involve conference in November (16<sup>th</sup> -18<sup>th</sup>) Chris is keen that the workshop be given by both the researchers and the parents. Both Kim and Becky would be interested to come however this needs to be organised closer to the time.

It is important that we begin to evaluate the impact that the families are having on the work of the CRU. We need to establish a working group to discuss how best to go about this.

The next meeting will be in September, date & time to be confirmed

N.B. we hope to hold this meeting either; mid week, early evening or on a Saturday morning following further consultation with families.