



**Cerebra Research Unit Advisory Group Meeting
Minutes of Meeting: Thursday 11th March 2010**

Present: Chris Morris (Chair), Claire Lloyd, Camilla McHugh, Nigel and Ellen Tremlett-Williams, Debbie Cross, Sallie Parker, Kim Antonio, Helen Bear, Amy Francis, Lucy McCance, Ginny Humphries, Richard Tomlinson,.

- 1. Apologies: Stuart Logan, Katrina Wyatt, Sarah Dean, Kate Bratt-Farrar, Becky Hart, Tamsin Ford**
- 2. Introductions**
- 3. Matters arising not on agenda and actions from last meeting**
 - Consider alternating days & times of meetings so they alternate to allow more and different people to attend, i.e. weekday evening, Saturday morning.
 - South West focus might be more appropriate than Devon only to detect variation in services and broader population; also fits with the Cerebra regional rep Helen Bear remit.
 - Publicity ideas: school websites and newsletters.
 - Private as well as state schools
 - Primary Times – magazine to all parents with primary child. **Action CRU**
 - Item in school bag, postcard?
 - SENCO co-ordinator Alison Cann – recommended by Lucy McCance **Action CRU**
 - Children’s Centre’s
 - Portage would be good contact
 - Other parent support groups
- 4. Update on CRU staff and Family Involvement**
 - Family faculty currently 63 parents
 - Helen Bear offered to distribute information about CRU to schools, parents etc. that she meets. **Action CMc: Send Helen leaflets/posters**
- 5. Marketing**
 - What messages do we want to get across

- It may be more the way we come across that is important, ideas included being: welcoming and optimistic, jargon free, emphasise parents are free to dip in and out of working with us, no research experience required it's the parenting a child with special needs experience that is invaluable
- Ginny pointed out that this also applies to approaching clinicians as well as they may be apprehensive about getting involved in research.
- Presenting a case study of parent/child who has been involved, perhaps from osteopathy trial?

6. Annual Event

- Purpose – a celebration & fun day was favoured over a dry academic event.
- Parents may be keen to hear 'key note' speaker but children wouldn't sit through these so support would be required.
- Maybe crèche facilities could be offered, but it was recognised that this may be difficult to organise due to legal issues. Gaining support from teachers at special schools who are skilled, trusted and CRB checked might be one option
- Portage organises days out and will have experience in organisation.
- Collaboration with social services might be mutually beneficial.
- An space to go for 'time out' would be valued e.g. marquee with quiet area.
- Information stands that can be viewed at parent's leisure were suggested
- Crealy would be good but would need provision for children who cannot use facilities – good for siblings
- Location – needs to be central & easily accessible to potential participants.
- Helen Bear is also organising a summer event for her Cerebra region and would be keen to collaborate; this would be mutually beneficial.
- A working group will be recruited to help organise and advise on details,

Action: CMc to email all Advisory group parents initially for volunteers, possibly also family faculty, CM to discuss and plan with Helen Bear.

7. Website

- Should ask schools to link to our website **Action: CM/CMc email schools and request link**
- Forum needs to be fed (weekly) to keep active
 - It was suggested that parents don't have time to contribute
 - 'Mum's net' have bug following – what do they do?
 - Research is perhaps a difficult topic for a parent forum
- Web front page changes – parents will look at this once done & provide feedback

8. Mapping services in Devon & the SW

- Need to pass information back to statutory organisations that parents cannot easily access information, also discussed were
 - Is this a core research project- how do people access services? (RT)
 - This information should be out there already; do we need to replicate this? For instance DISCplus provide information about services – can we collaborate?

- RT asked whether we can turn this into a research project so we can go to statutory organisations and say 'this works better than that'. Consider an approach similar to Time in Hospital communication project where parents are interviewed about their experience seeking services & information about services.
- We could develop training package so that professionals are more aware of parents' experience of seeking services to create more empathy.

Action is work In progress CM/CRU

9. Question generation and Prioritisation Process

- **Ideas.**
 - *Pain management and communication of pain* (ET-W) was raised and generally felt to not be well understood by parents or professionals – could perhaps be summarised as a 'What's the Evidence' initially?
 - *Respite services* were also discussed, especially because legal changes may have reduced the number of official respite services available leading some parents to make private arrangements (N T-W)
 - Parents had mixed views and experience of the *direct payments* system
 - Kim may give us list of research topics by email.
- Add all new ideas to forum/Cerebra facebook page so that they get seen and we can find out how important the issues are to other parents, these can be fed into question prioritisation process **Action CRU**

10. Measuring the impact of involvement/partnership in the work of the CRU

- Share abstract for INVOLVE conference with advisory group, and request that any parents that would like to be part of the conference and help plan poster & presentation to make contact. **Action CM**
- Asked for volunteers to work with us on the ongoing evaluation of the partnership between the unit staff and parents, perhaps scope for another working group to concentrate on this aspect of our work. **Action CRU**

11. AOB

- Travel expenses forms. **CMc to look into childcare payment**
- Poor take up of a weekend for families with complex needs – portage DCC -E & N T-W trying to get more families interested.

The next meeting is Thursday 10th June; 10 a.m. to 12 noon

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