



**Cerebra Research Unit Advisory Group Meeting
Minutes of Meeting: Thursday 23rd September 2010**

Present: Chris Morris (Chair), Kim Antonio, Amy Francis, Becky Hart, Ginny Humphries, Richard Tomlinson, Stuart Logan, Val Shilling, Jess Oliver and Camilla McHugh

1. Introductions

2. Apologies: Helen Bear, Mike Hurley, Katrina Lucas, Sallie Parker, Sarah Watts

3. Matters arising not on agenda and actions from last meeting

- SENCOs: Val and Chris met with Alison McCann and Kevin Jones from the County Autism team who were interested in the unit and keen to be kept informed
- Reimbursement for childcare while parents attend meeting can be made if with receipt
- A family faculty details sheet has been sent out to all families. Information is filtering in.
- Chris and Val went to visit to Dame Hannah Rogers at Seale Hayne. Action: VS/CMc will continue working through the other suggested contacts from the last meeting
- Professional networking/mapping, finding way round services – we have had two meetings with DISCPlus
- Working group for the website has not had much interest – only 3 parents. Kim's son Josh (aged 13) is keen to be involved. The general feeling from parents present was that people don't tend to use the website because of a lack of time and concerns around committing to forums. This needs further consideration but website will remain updated at present.
- Ginny suggested that to increase the use of the website we could send email out links to new items on the site. Stuart would like to use the site to gain parents opinions on protocols and applications – emailed links may be a way to increase the number of hits these get.
- **Action: make contact with Josh and the parents who have expressed an interest to discuss design of website**
- **Action: Links to the British Academy of Childhood Disability Strategic Research Group**
<http://www.bacdis.org.uk/> and <http://www.bacdis.org.uk/research/>

4. Update on CRU staff - No changes

5. Professional networking

- Chris and Val met with Jude Odell, the inclusion team manager in Plymouth. From this, Chris has attending the Aiming High Strategic Group meeting in Plymouth and made contacts there including Jane Taylor at Plymouth Parent Partnership. The Plymouth staff are enthusiastic and appear open to collaborating. Either Chris or Val will attend future meetings to maintain and develop these contacts.

6. Annual Event

- Chris showed photographs of Zoo which was deemed to have been a great day out for everyone and a success. To be repeated again next year.

7. Question Prioritisation

- Process for managing and prioritising questions (Paper 1) was discussed
- Chris explained the process that a query would go through from being suggested which involves several key stages of clarification.
- There are currently 39 topics on the flowchart, far more than we have the capacity for and the group agreed that prioritisation was essential and that many topics would have to be shelved.
- **Action: VS full spread sheet of topics raised to be sent to group for information, no specific action required by group**
- Examples of type of issue raised
- Kim pointed to the importance of the social inclusion project which has the potential to impact on so many other factors – including a number of the seemingly very specific topics raised by different families.
- **Action: Link to SPARCLE project information <http://research.ncl.ac.uk/sparcle/>**

8. Building a Partnership Event

- Draft programme for event (Paper 2) was discussed and the general consensus was that the appeal of the event was good. Again, concerns around commitment and time may be reflected in the low numbers registered
- Chris asks if any parent volunteers for Wendy who would like to tell story
- Marketing
 - **Action: send flyer to Ginny directly**
 - **Action: email families again at the last minute and to send another postal invitation.**
 - **Ginny suggested Main stream schools with special units particularly St Lukes, Brunell Center (Sue Cambell) Action: CMc contact regards BaP and to foster links**

9. Communications

- Letters work better than email for some families so it is worth sending correspondence by post as well.
- It is fine to make lots of contact and send things more than once if they are important
- School magazines may be a good place to ‘advertise’ our work **Action: contact schools that we have established relationships with to discuss piece in school magazine**

10. Family Faculty Details Questionnaire

- All families have been sent a Family Details questionnaire either by post or email if not postal address is available
- So far, we have received 40 questionnaires back from the 91 families on our database. This is a great response. Non-respondents will continue to be kept informed of the unit’s activities.
- The parents of 31 young people have suggested that their children would be interested in being involved in the work of the research unit
- The families also provided information on things such as diagnosis (e.g. around half of the young people have a diagnosis of C.P.) and what school they attend (e.g. around a third attend mainstream school only)

- We also gathered information on how parents found out about the unit which will help us with planning future events and recruitment efforts.
- The parents present felt that it was fine to resend the questionnaires to those that had not replied. Sometimes this 'pestering' is important – parents may not respond initially because it caught them at a bad time, not because they don't want to give the information.
- **Action: CMC/VS to resend**

11. NHS Outcome Framework (outcomes for disabled Children)

- NHS Outcome Framework requires the use of outcome measures for specific conditions and treatments.
- Currently, the instruments being used measure different things and it is not clear what outcomes will be used for disabled children.
- What outcomes should be measured and how for disabled children? **Action: CM to prepare an outline grant application to the NIHR HSR programme call.**
- Considerations raised by the group were the dual measurement of clinical health benefit and experience; the potential for the family to be the unit not necessarily always the child; challenges of making the research fit the child and family within the constraints of good methodology – e.g. making research accessible to children with different communication needs; the lack of existing research on methodological issues in research with these young people.
- Several members of the group were happy to be part of the application (AF/GH/RT)

12. AOB

- BBC slot
- We reported back to the BBC:
Feedback from the advisory group was that it was important to use the slot but important that the content isn't dictated by the BBC. Public attitudes towards disability are a major problem for children's & families' social inclusion but are typically encountered unexpectedly, which is part of the problem! We also discussed issues faced by children with less visible disability such as autism – although this may also be difficult to represent visually. Therefore the issues were unlikely to meet the visual needs of TV. Pragmatic ideas for the slot that may be possible to present for a TV audience included some of the structural barriers to inclusion e.g. lack of accessible toilets & changing facilities for disabled children in public spaces that mean that a parent sometimes returns to their vehicle to change a nappy, or negotiating roads and narrow pavements with wheelchairs. It might be possible to mock up situations giving the young person's point of view. Whizzkidz (a mobility wheelchair charity) has Ambassadors who might be interested in taking part.
Action: Advisory group to think about situations that could be filmed and whether they or anyone else would be interested in being involved. Important to consider whether the story is something that can be filmed. Greg's email stated "It needs to be something we can actually see in action to back up the testimony from the parents etc."