

**Notes of PenCRU Advisory Group Meeting**

**Thursday 27 June 2013**

**Present:** Tricia Stone, Julia Melluish, Mary Fredlund, Chris Morris, Claire Lloyd, Val Shilling, Astrid Janssens, Sarah Bailey, Anna Stimson

**Apologies:** Stuart Logan, Bel McDonald, Antonia East

Welcome and introductions

Matters arising and actions from last meeting:

* C&YP’s group – Camilla did meet with Zara Todd (VIPER) and a group of interested parents to discuss issues around setting up a group.
* Newsletter – Hard copy is still valued, in partnership with online version for web links etc. Will continue to be produced quarterly, with a larger version annually to coincide with the Annual Report. **Action: New FIC** to produce next issue in October.
* It was agreed it would be useful to be sent copies of the notes from the previous meeting with agendas for upcoming meetings in future.
* CM has not yet talked with Braham Norwich about a question generation concerning education issues, but is still interested in this possibility. **Action:** **CM**

Question Generation:

* The new system works but has not been marketed and we do not get a lot of questions at present. CM noted we are still not in a position to handle a large volume of questions and need to be wary of marketing too aggressively as we could promote unrealistic expectations.
* JM suggested establishing a link from Cerebra’s website to our question generation page which could be quickly removed if it generated too large a volume of traffic.
* TS asked if the process could be simplified to encourage questions from C&YP, CM said once a C&YP group was established this could be something they could look at.
* MF asked if we should be looking to give people the skills to answer questions for themselves? It was noted that this was similar to the ‘Finding the Evidence’ leaflets already -produced. It was noted that some journals which would be useful to consult are only available at cost or from University networks. It was also noted that academic language used can be off-putting.
* JM stated it would be interesting to display questions that have been asked by other people (anonymously), and it was noted that this can spark additional ideas and confirm to parents that their ideas aren’t off track or unsuitable, and can help understand why some questions don’t progress. VS agreed this was good for transparency. CM noted that giving examples can sometimes be unintentionally misleading. **Action: AS** to collate questions that have been submitted and SB to look at adding to website.
* MF suggested asking for research ideas/general opinions at the Family Fun Day. CL raised reservation that the fun day has historically been ‘work free’. **Action: AS** toprovide apassive opportunity for attendees to make suggestions (question ideas, general thoughts on PenCRU/today’s event, how we could help you be more involved with the unit) and provide post-it notes for comments, (already populated with a few from us as a starting point). – Note MF asked for this to be accessible, not in a corner.
* CM reported that the JLA Childhood Disability Research Priority Setting Partnership questionnaires had been sent out to lots of groups and were available online. To date there have been around 350 responses in the first 3 months. Responses have shown a 50/50 split between parents and professionals. The survey remains open until September.

Staff News

* The new Family Involvement Coordinator, Meghan McCrory, will be joining us on w/c 29 July.
* BM suggested at interview that it may be useful for Megan to take the Face2Face Welcome training, and it was agreed this would be a good idea. **Action: VS** to discuss with MM and BM.
* JM noted how a new Cerebra area representative has sent an email out introducing themselves and asking it anyone would like her to meet in person and suggested Megan do the same.
* It was noted that emails sent out to FF are addressed to ‘Dear All’ as routine and it would be nice if these could be personalised in future. **Action: SB/MM** to set up mail merge to populate names.
* It was also suggested inviting the FF to come along and meet Megan informally, either just parents at a coffee morning, or as it will soon be the school summer holidays, with children at George V playing fields for a bring your own picnic lunch. **Action: JM** offered todiscuss ideas with Meghan once she is settled in.

Funding Update

* Cerebra funding has been approved for the unit until 2019. It was agreed this is very positive news and should be publicised as much as possible. **Action: AS** to contact specialised publications such as Primary Times, DiscPlus etc.
* NIHR Fellowship application from CM has not been selected, so we will need to consider other funding opportunities for the ‘healthy parents’ idea. **Action: CM** to report feedback on the application when received.
* MF suggested liaising with Paul Dieppe and the Wellbeing Centre for possible collaboration and as an additional partner in future proposals on ‘healthy parents’. **Action: CM** to investigate.
* Proactive Primary Care – Initiated by Stuart Logan. An outline has been submitted led by Institute of Child Health, London, and is under review
* Implications for public health of theories of disability - An outline has been submitted led by Newcastle, and is under review.
* Kleine Levin Syndrome (KLS) evidence review as part of large programme grant – not selected.
* Peer support in Neo-natal Intensive Care Units (NICU) – will hear back in mid-July. CM suggested Wellbeing in Women could be approached for funding for the health of female parent/carers? VS noted they do not seem to have large resources available, but worth investigating. **Action: CM** to consider.
* Potential proposals: (i) Gastro tube feeding and regional differences in provision with Gill at City University, London.

(ii) Braham Norwich has suggested an idea around SEND provision, possibly involving Jane Raca and Mencap.

Building a Partnership

* Discussed how to increase level of parent involvement. Video conferencing with a number of other sites or option of web link-in from home suggested. Agreed a webinar does not work well for discussion type event and is better suited to information giving.
* MF suggested topic of ‘channelling anger effectively’. Perhaps half day on anger management and half day on empowering yourself to be more active in your child’s care.
* TS suggested joint BaP event with Braham Norwich’s group in the wake of changes to SEND provision.

Feedback on CDC Parent Workshop

* Good networking opportunity.
* Sound concept, but ideology a bit off target in suggesting parental failings in language, etc.
* Overall perhaps requires a little more development work before it is ready for full roll-out.

Future programme of work

* No additional detail to add at this stage.
* Top priorities remain involving families in research.

Family Fun Day

* JM raised concerns with the choice of Living Coasts: Not enough to do for full day, no open spaces/play areas, ‘Room With a View cramped for numbers expected.
* MF agreed these issues would be a concern and make it unsuitable for her son to attend.
* CM asked the level of commitment already made. . **Action: AS** to assess current situation and investigate options.

Conferences

* EACD<http://eacd2013.org/> The European Academy of Childhood Disability three day conference will be in Gateshead 10th-12th October 2013. The theme of the conference is From Basic Research to Policy*.* We will be collaborating on a workshop on Saturday morning on involving parents in research and would like parents to be involved. There may be other opportunities as other projects have submitted ideas that have yet to hear back.
* PenCLAHRC Involvement <http://clahrc-peninsula.nihr.ac.uk/ppi-conference.php> Organised and hosted by the PenCLAHRC Patient and Public Involvement Team. Midday 13 to Midday 15 November 2013, in Exeter. CM has proposed a workshop on involving young people with Gail from Newcastle and Zara Todd from VIPER. The Peer project has submitted an item.
* BACD South West <http://www.bacdis.org.uk/index.htm> British Academy of Childhood Disability (BACD) Regional Meeting 3 October, in Exeter.

Any Other Business

* We looked at the new website which was generally well received.