 

Notes from the

Children and Young People in research Steering group meeting

**Tuesday, May 14th 2013**

1. **Attendees:** Carole MaKay (honorary grandmother), Helen Hobbs (parent), Amy Ley (Ellen Tinkham school), Claire Lloyd (PenCRU researcher), Alena Benson (parent), Robin Tay (CAMHS), Sarah Bailey (PenCRU researcher), Camilla McHugh (PenCRU FIC), Zara Todd\*(ALLFIE).

\*Zara attended the meeting via Facetime

**Apologies:** Antonia East, Kirsty Paine, Julia Melluish, Lynn Pashby, Christina Anderson, Bel MacDonald and Michelle Woodgates

1. **Feedback from last year’s meeting**

CMc gave a bit of background to the project so far and explained the previous ‘working group’ meeting and what has happened since. CMc explained that due to time and resources the project has taken a while to get going. We have been building up a network and learning from the experience of other organisations that already have experience of this type of work.

1. **Update**

• *Systematic review* – SB gave an update and on the work she is doing for the review ‘Involving disabled children and young people as partners in research’

• *Funding* –CMc updated the group that we applied and were successful in securing a small amount of money from the Catalyst fund from the university to help get the project started. It is likely that we will need to apply for further funding in the future

• *Staffing –* CMc explained that she will be leaving PenCRU and the new Family Involvement Coordinator (FIC) will pick up the work when they are appointed. It was proposed that the group here today might be interested in becoming members of a core steering group to guide the development of the Children’s group.

• *Collaboration with local and national organisations* – CMc recapped on what we have learnt so far from outside organisations and similar work that has taken place, namely the VIPER project.

1. **Discussion**

**Recruitment** – we used, with kind permission from VIPER, a flyer they had used to recruit young people in London, this helped the conversation get started.

* There was a general discussion about the age range to recruit and the benefit of possibly focusing on secondary school aged children for now, this could be expanded in future if the group decided it would be of benefit. There was discussion that in terms of the group dynamic ages 11-21 would be better and could be split into groups by the facilitator if needed.
* The group considered how many young people would be part of the group. ZT suggested that it is a good idea to recruit more people than we hope to have at meetings; in her experience at least 4 people per meeting will not be able to attend. AL has between 8-10 young people at Young Ambassadors meetings at ET School. The group decided that we would aim to recruit 12 young people.
* The group discussed the need to be careful with the wording on the flyer as many of the C&YP we are hoping to recruit would not consider themselves ‘disabled’; the group agreed on using the term ‘additional needs’. Children and young people with any kind of disabilities should be able to join the group. It is important to make that clear on the flyer – not just wheelchair users.
* It was suggested that we might want to have a clear idea about what we want the group to look like before we recruit so that we can immediately decide whether someone is eligible or not, and give any ineligible applicants a reason why they are not suitable.
* It was also agreed that it would be very important to have on the front page of the flyer the name and contact details of the person running the project so all queries can be addressed.
* Having two versions of the flyer, one with and one without symbols would make it more accessible to all C&YP.
* Make it clear that transport and Personal Assistance (PA) expenses will be covered and be able to signpost to these services if required.
* Make it clear on the flyer that joining the group involves attending meetings. This can be done in person or via Facetime or Skype. It was suggested that those joining the meeting remotely could have a ‘helper’ present in the meeting.
* Mention ‘other rewards’ to joining instead of mentioning voucher.
* In terms of where to recruit, it was agreed to spread it as far as possible and using our network of contacts. The places we discussed were mainstream and special schools, SENCO’s, DiscPlus, local Parent Forums and support groups, C&YP groups we know about, possibly GP/paediatricians, Child Development Centres and asking the Family Faculty if they would spread to their networks. It will be particularly important to make sure that we try to recruit children who attend mainstream schools as they are often not included in projects like this. Some mainstream schools (e.g. St Luke’s in Exeter and Honiton CC) have specialist units within them.

**Action**: It would be helpful if the group could find out about local PA/enabler provision, ZT mentioned a friend who is setting up an agency in Devon.

**Selection –** again we used the application form used by VIPER to aid our discussion.

* It was discussed that the application form should be made simple so it does not become a challenge to complete. The group felt that it was important to offer support to complete it and spell out in more detail alternative ways the form could be completed such as telephone, face to face assistance, helper, or video submission.
* It was also agreed that there should be a section on the form to identify whether someone had completed the form on the young person’s behalf and if so who had completed the form i.e. parent or helper and make it clear that it must be completed in the young persons’ own words/voice.
* The group discussed and decided that it was important that participants should be interested in research and that there are various ways to ask questions to tell whether they may be interested in research. For example, they may not directly say that they are ‘interested in research’ but might see it more as an ‘interest in changing things’.
* Some applicants may only be looking for a social experience/opportunity
* An issue was raised with questions such as ‘what other activities have you been involved in’ – not all may have been involved in other things and this may put them off. This could be rephrased to be ‘are you or have you been’ involved in other activities
* We also discussed that it was important to have a clear criteria for the applicants and for the group reviewing any of the applications
* The group agreed that a parent information leaflet should go out with the application pack, making it clear of parental commitment and role. An access requirements form would also be sent.
* The group also discussed that rather than have an ‘interview’ it might be good to hold a ‘getting to know you’ meeting with selected participants. The idea being to meet each other, the facilitator and other staff and to give them a general sense of what’s involved and decide if they would still like to join the group. This would also give the PenCRU team a chance to see if applicants were suitable too. We would run a parallel meeting with the parents to give them more information about the project and their potential commitment and role to their child or young person being involved.

**Other points raised…**

* At start of C&YP meeting give background – why we are meeting, what is your voice, why is it important that your voice is heard.
* An ‘about me’ form could be completed by each member, including staff, and circulated to the C&YP group before the first meeting. This could be to supply the group with information they would like the group to know about them i.e ‘I use a communicator’, ‘I need time to respond to questions’ etc.
* A medical emergency form needs to be completed to be held in confidence with staff members.
* In terms of communication with the group when it is set up; the group agreed that emails don’t tend to be very effective and that we would need to look at things like a closed Facebook page and text messages.
* The timings of meetings for young people were discussed; evenings were considered inconvenient because families are busy and the young people may be tired. School holidays or weekends might work best. It will be important to provide snacks!

CMc explained that there will be a pause while the new FIC is recruited and settled. The group will meet again, date to be confirmed, to discuss the next steps, with possible drafts of recruitment flyer, application forms, parent info sheet, access needs form and medical emergency form.