



PenCRU
Childhood Disability Research



Peer Support Project Stakeholders Meeting Thursday 12th July 2012

Overview:

At the midpoint of the project, the meeting gave us an opportunity to review what we have achieved over the last 12 months as well as to address some specific questions we wanted to bring to the group.

We began with an update on the three different parts of the study and also our plans to run the study in Cornwall, before moving onto a group discussion of some issues that we needed advice on.

Systematic review:

The systematic review aims to bring together the findings of lots of different studies to identify what is already known about peer support for parents of children with long-term conditions. The review is now written and ready to send off to the British Medical Journal.

We found that there were two different types of study. Those that had talked to people about their experiences of peer support, and those that had tried to measure things, like anxiety or stress before and after parents had some kind of support, and compare the results with a group of parents who didn't get support – called the control group.

What we found was that the studies that had interviewed people about their experience all reported a perceived benefit of parent support such as a sense of shared social identity, learning from others experiences, personal growth and supporting others. However, the studies that had tried to measure this benefit in some way, by using questionnaires of stress or anxiety or things like that, didn't always show a difference between people that had support and those that did not.

We now want to write a much briefer, more accessible summary of the paper that we can put on our website and the Cerebra website and also make more widely available perhaps through the mentoring and befriending foundation so that other families and groups can read about what we found.

We would like members of the stakeholder group to be involved in writing this summary but we also discussed whether we should open the invitation up to other members of the family faculty. The group thought that this would be a good idea to have fresh eyes on the project. Bel and Mary are going to read the review paper over the summer and have a think about how we might go about writing the summary with parents. We discussed getting together in the autumn, perhaps in an event similar to the Building a Partnership events.

Costing study:

The costing study will report on what is needed to provide the service both in terms of monetary costs and resources such as the time given by volunteers.

Over the last three months, the befrienders and coordinator in Devon have been recording the amount of time they spend doing different things for Face2Face. This includes time spent travelling or attending support meetings and many other categories as well as time spent befriending their parent. This will give us a good picture of how much time it takes to provide the service and how that time is being spent.

We have had a fantastic response from the befrienders in Devon. 15/20 befrienders and the coordinator have completed the work sampling forms. We had 100% of the questionnaires returned for April and May and I expect the same for June.

Annie and Bel will now be working together to gather the other relevant information such as the annual expenditure and information about the number of families being befriended and the amount of befriending they receive.

Qualitative research:

In this part of the project we are trying to understand more about the experience of parent-to-parent support by interviewing befrienders and supported parents.

We have finished all of the parent and befriender interviews in Devon. We interviewed 11 befrienders. This is less than the number of befrienders that filled out the work sampling forms because we felt it was not appropriate to interview the befrienders who are part of the stakeholder group because they have been so involved in the design of the project.

We did not have such a good response from parents, perhaps not surprisingly. 29 families had contact with the service in the timeframe we specified for the project. They were all sent invitation packs, followed by a reminder after two weeks. We had six responses and all of these parents have been interviewed.

Over the summer, we are also going to interview a small group of relevant health and social care professionals.

Cornwall:

We will be running the study in Cornwall from the 1st September to the 30th November. We have begun recruitment of befrienders for the study and it seems response in Cornwall will be just as high as it has been in Devon. We will wait until after the summer holidays to contact the parents who have had support.

Group discussion:

1. Contacting hard to reach parents – a new approach to recruitment

We have been approaching parents via a letter sent by Bel, the Face2Face coordinator. We wondered whether some parents were uncomfortable with the direct approach from Face2Face and whether we might get a response from one or two more parents if we advertised in DISCPlus.

The group felt that letters can easily get overlooked and might not be the best approach but we decided it was not appropriate for Bel or the befrienders to make a personal invitation to parents.

Although none of us could see any objection to putting an advertisement in DISCPlus, we weren't convinced that we would attract any more eligible parents – as all those eligible under the current study guidelines have been contacted. We would also need to think very careful about how we worded the advert and we would need to get approval from the ethics committee before we placed an advert. At the moment, we haven't decided whether we want to try this approach.

2. Gathering qualitative data from befrienders in Cornwall

We proposed running focus groups with befrienders in Cornwall rather than doing individual interviews. This is partly for practical reasons but will also enable us to test out some of the ideas coming out of the analysis of the interviews in Devon. The group thought that it was reasonable to change the study in this way and we will ask for approval for this change from the ethics committee.

We discussed how people might say different things in a group than they might on their own and the importance of agreeing ground rules around confidentiality. We felt that as the groups of befrienders know each other well and openly discuss their families with each other that focus groups would work well. We also decided that we would give group members the option to feedback on the transcript of the discussion.

3. Interviews with professionals – selecting people to invite

So far I have arranged two interviews with key professionals in Integrated Children's Services. I am also going to try and interview a paediatrician, a GP and a parent support advisor. As we are only able to interview a handful of professionals we have had to be pragmatic about what we can achieve and "cherry pick" individuals from a range of professions. Other suggestions from the group that I will follow up include keyworkers and parent liaison officers within schools.