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## Peer Support Study Stakeholder Group Meeting

## 11th July, 2013

The main objective of the meeting was to discuss the findings of the costing study and the qualitative work. We had some excellent group discussion which has given us plenty to take on board as we get into the final stages of preparing the report and journal articles.

We also discussed:

### Measuring the impact of peer support

Measuring the impact of peer support will be an essential part of any future study. We began a discussion about what might be measured and how we might measure it by looking first at examples of what previous studies had done. In the systematic review we found that most studies had measured the impact of peer support on aspects of parent psychological health, such as anxiety, depression, coping, confidence and empowerment. Some had also looked at family function and accessing services and information. Typically, these things were measured before and after a period of peer support using questionnaires.

We looked at some examples of the sorts of questionnaire that have been used in previous studies. Some of the considerations we discussed included:

* Initial reaction to the ‘look’ of the questionnaires was not positive; they looked long and hard work
* Parents may associate completing questionnaires with formal assessment such as DLA forms and may have concerns about what will happen to their responses
* Some questionnaires are emotionally very challenging and it may be difficult for parents to complete them

The group also discussed what would be the appropriate things to measure and the challenges of assessing things that *don’t* happen as a result of peer support. For example, in the qualitative interviews and focus groups participants sometimes described the benefits of support in terms of marriages that didn’t break up, or children that didn’t go into care, family crises that were avoided.

The qualitative work also helped us to understand that peer support has the potential to impact on the broader community of parents of disabled children not just those that are directly accessing the service – how we would go about measuring these changes is another point for consideration.

In this meeting we simply wanted to open the conversation about measurement and gauge the group’s reaction to how other people have gone about it. What and how would be measured in future research projects will require more work.

### Respondent validation

Respondent validation is one way of increasing the credibility of qualitative research. Essentially, it means checking back with the research participants that the interpretations and conclusions we have come to are consistent with the messages they wanted to convey in their interviews and focus groups. It enables participants to challenge anything they disagree with and is thought to offer some validity to the process of analysis – i.e. it should counter any argument that the researcher had too much influence over what findings are reported. Respondent validation is not always used and there are some challenges, notably:

* Whether it is fair to contact our participants for feedback given that they have already given considerable time to the research and have busy lives
* How to produce a summary of the findings that is sufficiently detailed that participants can comment meaningfully but not so detailed that the task is burdensome
* We also need to give careful thought as to how any feedback we receive influences our interpretations, particularly as it is likely that only a selection of participants will respond

We decided that it was appropriate to offer participants the opportunity to feedback on the results but that it was important they did not feel obliged to do so. As all research participants indicated that they would like to receive a summary of the study for their own information, we thought it would be feasible to combine the two things; people who wanted to comment would then have the opportunity to do so whilst those who simply wanted a summary of the findings would also be satisfied.

### Conferences and publications

In the autumn we will be attending the European Academy of Childhood Disability in Gateshead where we have been invited to give two poster presentations; one about the findings of the study and one about how the stakeholder group was involved in the design and running of the study.

We have also been invited to give oral presentations at the British Academy of Childhood Disability locality meeting on the 3rd October and the PenCLAHRC (Peninsula Collaboration for Leadership in Applied Health Research and Care) Patient and Public Involvement conference on the 13-15th November. Both meetings are in Exeter. The focus of both talks will be how we (the stakeholder group and the research team) have worked together to design and deliver this piece of work and I hope that a member of the stakeholder group will co-present with me.

Over the summer months we will push ahead with writing up the report and preparing papers for academic publication. In the autumn, we will ask for your help in preparing summaries of the findings that we can use to spread the word about the study to a wider audience than might usually have time or access to journals.