



Healthy Parent Carers project Working Group

Meeting 12

Monday 3 July 2017, South Cloisters, St. Luke's Campus

Family Faculty:

Annette, Bel, John, Julia, Kirsty, Mirtha

PenCRU: Chris, Gretchen, Silvia

Overview

- We are applying for funding to carry out a feasibility study to test whether the Healthy Parent Carers (HPC) programme can be delivered on a larger scale.
- Council for Disabled Children are keen to collaborate in the next stage of this programme.
- The feasibility study control group should receive the HPC guide.
- To make the programme worth doing, the benefits should last at least 3/6 month, but ideally more than 6 months.
- The programme should be held in school term time. Daytime and evening sessions should be offered to try to make it accessible to as many as possible.
- Participants should be given the option of completing the questionnaires either online or on paper.
- Remuneration for completing the questionnaires would not be an expectation, but would be an incentive.

What next?

- We will finalise the design of the feasibility study
- If you have any comments or come across any information or resources relevant to the programme, please email PenCRU@exeter.ac.uk

Review of the Healthy Parent Carers programme

- Chris started the meeting by giving the group a review of the Healthy Parent Carer (HPC) project to date. Overall, the programme received very positive feedback from participants of the first group.
- Now, we are applying for funding to carry out a study to see if the intervention is effective to improve the health and wellbeing of parent carers. The [feasibility study](#) would test whether the programme can be delivered on a larger scale. We also want to test whether it would be feasible to run a large study to test whether it is effective and cost-effective.

- Speaking from her experience facilitating the programme in the pilot study, Bel suggested that the facilitator manual should give guidance on how to address difficult situations arising during the sessions.

What's next for the Healthy Parent Carers programme?

- A professionals stakeholder meeting took place on 19 June 2017. The key outcome of this meeting was that the Council for Disabled Children are keen to collaborate in the next stage of the project as they have experience of delivering similar programmes and have facilitators who have the skills to deliver the HPC programme.
- Gretchen explained that once parents sign up to take part of the study, they will be asked to complete a questionnaire, three times throughout the duration of the study, asking them various questions about their health and wellbeing. Gretchen also explained that the feasibility study requires a control group. This means that when parent carers sign up to take part in the study, in addition to completing the questionnaires, they are either allocated to receive the intervention (HPC programme) or are allocated to the control group. The following options for control group intervention have been considered: no intervention, where parent carers are simply asked to complete the questionnaires; parent carers receive the HPC guide; a waiting list system whereby the control group receives the intervention after the first group have completed the programme. The Family Faculty disliked the “no intervention” option, and expressed concern over the “waiting list” option, acknowledging that it would be costly and that parent carers who sign up initially may lose interest if they do not receive the intervention immediately. The Family Faculty agreed that the “guide” option was preferable.
- One group member suggested that when the study is first advertised, it could simply ask for parents to take part in a study to improve parent carers’ health and wellbeing, and not mention the HPC programme to avoid participants feeling disappointed if they are allocated to the control group. However, Chris and Gretchen explained that participants must know about the different groups (intervention and control group) before they officially sign up to take part in the study.

How long should the benefits last for the programme to be worth doing?

- The group agreed that it is not easy to find a clear moment after the end of the HPC programme when its benefits start fading. Although parent carers may not be thinking about CLANGERS every day, they may still use it as a technique to get through a difficult time. CLANGERS are a way to build resilience, and not a one-day fix to improve health and wellbeing.
- Overall, the Family Faculty felt that the benefits should last at least 3/6 months after the end of the programme, but ideally will go beyond 6 months.
- As session facilitator, Bel thought that she would feel satisfied if she was able to make a parent carer happier for one day.

Group session logistics

- Gretchen explained that we hope to have sessions held across the South West.

- The programme could be held over 6-12 weeks, with one 2-4 hour session per week. The group agreed that scheduling sessions for school term time is ideal. Daytime and evening sessions can be offered.

Questionnaires

- The group agreed that participants should have the option of completing the questionnaires online or on paper. Some Family Faculty noted that it would be necessary to have the option of saving progress on each questionnaire, so that it would be possible to partly complete the questionnaire and then return to it at a later stage. Online questionnaires should be mobile and tablet compatible. Participants should be told how long it will take to complete the questionnaire, and a progression bar for the questionnaires would be helpful. Participants should be informed of how many questionnaires they will be asked to complete, how long each will take, and when they need to be completed by. This phrasing was deemed more acceptable than informing participants that they need to complete questionnaires for 1 hour.

Acknowledgement to encourage parents to complete the questionnaires

- The Family Faculty felt that remuneration for completing the questionnaires would not be an expectation, but is an incentive. Remuneration should not be mentioned when the study is first advertised, but mentioned before participants officially sign up to take part.
- It was suggested that the value of remuneration could be between £15 and £20. It was also suggested that participants could receive £10 on completion of the first set of questionnaires, £15 for the second, and £20 for the third. Another group member suggested participants receive a bonus after completing all three sets of questionnaires.