



Healthy Parent Carer Project meeting

27/1/2015 St Lukes Campus

Family Faculty: Bel, Mirtha, Tricia, Ursula, Jeanette, Annette, John, Jane, (Start and end sections of of the meeting only – Mary)

PenCRU: Chris, Katharine, Anna

Other University of Exeter: Mark, Ola

Apologies (FF): Clare, Lynn, Julia, Kirstin

Introduction:

The healthy parent carer topic was first considered in 2012 following discussions initially around weight issues, and then also various other lifestyle and physical and mental health challenges specifically related to the unique circumstances of parents caring for a disabled child.

We reviewed the diagram created from discussions at a previous meeting that brings together some of the issues and barriers influencing parent carer health (diagram is in notes from 3 April 2014 [Healthy Parents Project meeting](#)). This made it clear that mental health and emotional well-being were considered as important as physical changes in weight, fitness etc.

Funding applications:

The first funding application had adopted a 'whole-system' approach to parent carer health, and this was considered not have sufficient merit to peer reviewers.

Further work led towards an intervention to promote positive mental health, building on evidence and guidance regarding diet and exercise. This application to the Medical Research Council (MRC) in September 2014 was not recommended for funding. The proposal was scored 6/10 with feedback that there was not enough focus:

- Not novel
- No clear goal for results of the invention
- Issues with long term feasibility
- It could promote further inequality amongst parent carers depending on individuals' ability to physically engage with the programme.

PenCRU will continue working on this topic and are recruiting a researcher for one year from April 2015 to focus specifically on this project.

What next?

- Everyone present agreed the intervention should be based around group activities, rather than be a programme to follow individually. The importance of a shared, common experience was considered important, and there was discussion around the idea of 'champions' to encourage participation.
- There was discussion about the possibility of an online element to the intervention allowing parent carers to interact with each other at time to suit them and without the need to travel. This appealed to some and not others.
- It was recognised a meeting could exclude some carers who lived in more isolated locations or home-schooled their children, but to encompass as many parents as possible it was considered best to run groups during the school day and endeavour to hold groups in different localities.
- Consensus was that a weekly meeting (with it made clear to attendees missing a session because of other caring commitments was fine) gave the best level of continuity and allowed parents to 'get into a habit' of taking time to do something for themselves.
- 8-10 in a group was considered the right size to allow people to feel comfortable sharing personal experiences and make real connections with each other, as larger groups could be impersonal. Several groups could run at once, and ideally in different locations if the demand was there.
- Mark reported that there are tentative studies that suggest the more social groups people engage with, the greater their resilience to handle challenges and changes. It was accepted that social isolation results in lower resilience. This would suggest basing our intervention solely around setting up a parent carer group is only an incremental part of improving health. A healthy parent carers group could however build self-esteem, self-efficacy and confidence; and foster the idea of taking time for yourself, alongside introducing ideas for activities which would allow attendees to then continue to pursue the activities that particularly interested them in other existing groups in their local communities (that were not limited to parent carers). We could give some level of sign-posting/support in helping them into these groups.
- It was suggested that a hand book could be created (similar to a secondary school pupil diary) which would give tips on stress management, confidence building etc., weekly targets, healthy eating tips, alongside lists of contacts for clubs, groups, classes etc. in the local area (if possible that have been scoped out to be flexible/suitable to fit in with caring commitments).

- A range of different activities for the group to try were suggested including:

Singing
Walking
Drama
Crafting

These 'fun' activities would take up part of the sessions alongside directed training aimed at building the key skills (problem solving, resilience etc.), possibly using and adapting elements from Face2Face training.

- It was recognised that employing skilled facilitators to introduce the activities would be prohibitively expensive and it was suggested choosing activities that utilised the expertise already within the group.
- Mark noted it was important to define the outcomes we want to achieve through the intervention and work on devising the content of the group activities should be done with these in mind. Key goals were considered to be in building:
 - Self-efficacy
 - Self-esteem
 - Resilience
 - Empowerment
- It was queried how we could measure the effectiveness of the intervention. It was suggested that stress levels can be measured by recording cortisol levels. Questionnaires are available to measure self-reported wellbeing, self-efficacy, etc.
- An appealing and engaging name for the intervention was discussed. The idea of a mnemonic around the word 'CARE' was mooted:

'Caring about resilience and esteem'

Connected, collective, caring
 Acknowledged, assertive, aware, acceptance
 Respected, resilience
 Empowered

The 'c' of care(r/ing) could be claiming and then the others being a list of things where 'a' could be 'autonomy'

Next – a number of those present at the meeting agreed to participate in trialing elements of a possible intervention to help refine the proposal. Although it was acknowledged that this group have some level of cohesion already from their involvement with PenCRU, it is likely any new parent carer groups may well contain people who have met elsewhere at support groups, special schools etc. too. However any new group will need to contain elements to build the group identity.

We hope the researcher to lead this work will begin in April, and we can test some of the ideas within the Family Faculty in the school summer term, and then with some parents from 'outside' the Family Faculty in the autumn term.