



Healthy Parent Carers Project - Meeting 6

06/05/2015 South Cloisters

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Overview

- We agreed that the Healthy Parent Carers programme will aim to improve parent carers' health and wellbeing by increasing their empowerment and confidence to become healthier.
- The programme will encourage making changes in both psychological health (emotions and feelings) and physical health (diet and physical activity) but participants will be able to identify the changes that they want to make rather than being told what to do.
- The programme should give some opportunities to offload negative experiences and emotions and share experiences (particularly challenges related to battling services) but it will focus on individual changes rather than trying to change the system directly.
- The measure of success will be improvements in positive outcomes (perceived health and wellbeing) rather than reduction of negative outcomes (depression, anxiety).

What next?

- The next two meetings to design the programme will be held in June and July.
- If you have any comments or come across any information or resources relevant to the programme, please contact Ola by email (a.borek@exeter.ac.uk) or phone (1392 726041).

Introduction

A lot of work has already been done to identify what health and wellbeing issues parent carers face, and how their health could be improved. Notes from the previous meetings are available on the project website, which we have also up-dated with information about the project's background and a summary of the relevant work that has already been done

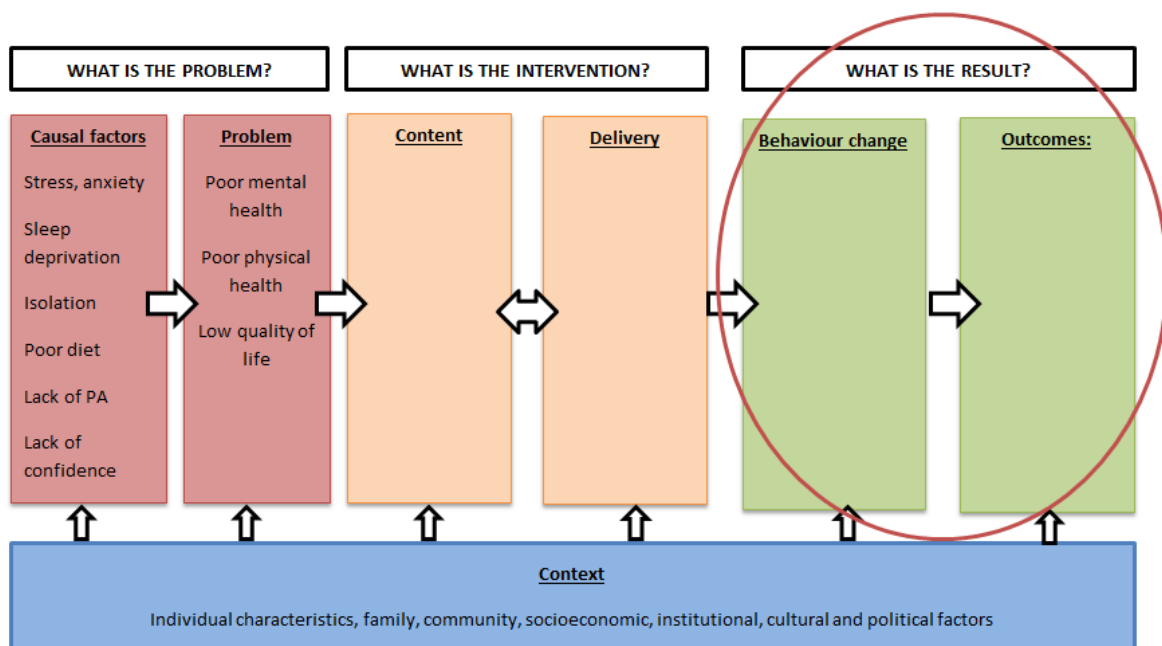
http://www.pencru.org/projectsmeetings/researchprojects/title_369410_en.php.

Over the next few months we will be putting all these ideas together to design a trial of the Healthy Parent Carers programme. In order to do that, we need to be clear about the following issues:

- (1) What is the problem that the programme will be addressing?
- (2) What should the content of the programme be and how should it be delivered?
- (3) What should the aims and results of this programme be?

The first question has been already addressed in the previous meetings and literature reviews. Briefly, we found that the health of parent carers is affected by many individual factors (e.g. stress, lack of sleep, isolation, lack of exercise, poor diet) and contextual factors (e.g. lack of support and care, having to 'fight' to access services, negative attitudes of others). This means that parent carers may face specific barriers that make it difficult to improve and maintain their health, compared to others in the general adult population, and they receive very little, if any, support in this area.

In this meeting, we focused on trying to identify what the intended results of the Healthy Parent Carers programme might be. In other words, we discussed what being 'healthy' would involve and what changes parent carers could possibly make to improve their health and wellbeing.



Discussion 1: What does 'health' mean to you?

Firstly, we discussed what it means to each of us to be and feel 'healthy' or 'unhealthy'. All these identified components are listed in Table 1 below. We then asked parent carers to choose which of these issues are most important. The priorities that were identified related to both psychological health (feeling happy, energised, positive, calm) and to physical health (being physically active and well, eating healthily). Here are the main points brought up in this discussion:

- Things that contribute to our feeling of being healthy or unhealthy relate to both psychological and physical health, and it is impossible and not right to separate the mental from physical health. All these aspects are interrelated and influence each other. They can also lead to a downward spiral of negative mental and physical health.
- Motivation to stay healthy is part of feeling healthy.
- 'Wellbeing' can be understood as part of being healthy but the term suggests more psychological or mental health than physical health.
- A sense of wellbeing is personal and different to every person but strategies to reach it are common and could be shared in the group and supported in the programme.

- The programme should focus on showing parent carers that it is important to take care of themselves, and that their better health will also benefit their children and families.
- A prescriptive approach ('telling' parent carers what they should or shouldn't do) should be avoided as it can contribute to the feelings of frustration, lack of control and understanding rather than empowerment and self-esteem. The input should be mainly from the parent carers.
- There were suggestions that perhaps the programme name should be changed to better reflect the fact that it targets both physical and psychological health, e.g. '*Health and Wellbeing of parent carers – empowering your choices*', '*Empowering parent carers to stay healthy*'.
- Programme outcomes could include: self-esteem, confidence, self-worth, self-skills / self-efficacy, self-evaluation, feeling good. Programme participants could be asked to rate their perceptions of health, e.g. 'how do you feel about your life?', 'how do you feel at the moment about your physical / psychological health?', 'how do you feel about your future?' etc. The programme should focus on measuring a positive effect (an improved sense of wellbeing) rather than an absence of a negative state (e.g. depression or anxiety).

Discussion 2: What changes would make you feel healthier?

In the second part of the meeting, we discussed the idea of 'circles of influence'. It illustrates how our health and wellbeing is influenced by factors that are relating to individuals, support groups, family, friends, community, and society (see Figure 1 below). In this discussion we asked you to think of what changes in each of these circles could improve your health and wellbeing. We also asked to focus particularly on what personal changes would make you healthier and how a support group could improve your health (the two inner circles). Your responses are in Figure 2 at the end. Here are the main points discussed:

- Things that could make you feel healthier related to both psychological health (e.g. taking time for yourself, keeping calm) and physical health (e.g. being more active, eating healthily), which reflects our earlier discussion that it is necessary to focus on both mental and physical health.
- It is important to identify and acknowledge all the issues that affect the health of parent carers, such as the 'fighting' for services, injustice and lack of recognition. However, a health programme can only focus on and attempt to influence changes that are possible within the individuals and support groups (the two inner circles). These personal changes might then lead to changes in the wider circles of influence (families, friends, communities, society), for example, by empowering individuals, strengthening shared social identity and peer support.
- A group could empower parent carers' by understanding each other's feelings and sharing common identity and experiences (which might also then lead to changes in the system).

Other points and issues discussed:

- The programme should not overlook the fact that parent carers' health is negatively influenced by the system, and it should recognise it and offer a possibility to offload these negative feelings and to validate them. Perhaps the programme can have an impact on the system in the future by making parent carers feel more empowered and energised, and by creating a shared identity.
- There are also other things that affect parent carers' health but can't be changed, such as child's sleep problems or problematic behaviours.

- However, we need to be clear that the Healthy Parent Carers programme can only focus on the individual changes and not changing the system (for this other strategies could be used, such as campaigning).
- The programme needs to find a niche rather than recreating what already exists, e.g. providing peer support such as Face2Face, skills in navigating the system such as Council for Disabled Children Expert Parent programme, or other organisations such as Parent Carer Forums.
- One of the issues is how to make a programme feasible in the long term, and this could be possibly addressed by finding an organisation that we could work in partnership with.
- Chris mentioned the concept of CLANGERS from Dr Phil Hammond's book 'Staying Alive', which we could use in the programme (could be discussed in more detail at the next meeting). These are evidence-based behaviours that are associated with health and wellbeing. The CLANGERS advice is currently too simplistic or not realistic for many parent carers, but could be modified.

CLANGERS (from 'Staying Alive', chapter 2):

Connect - With the people around you. With family, friends, colleagues, neighbours, strangers, pets, plants and place. Scientific research consistently points to strong relationships as a key to longer life.

Learn – Try something new. Rediscover an old interest. Sign up for that course. Learning new things will make you more confident as well as being fun. Exercising your brain as important as exercising your body.

(Be) Active – Discover a physical activity you enjoy and that suits your level of mobility and fitness. Moderate activity – don't overdo it without guidance from your doctor.

Notice - Filling up your brain with your senses leaves less space for anxiety and depression. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you

Give back - Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you. Again, research has proved this point – helping others leads to stronger mental health and mood.

Eat Well – Connect with local food producers, learn how to grow, prepare and cook food, notice the different sights, smells, textures and tastes of the ingredients and give back a meal to your friends and family.

Relax – To sleep well, you may need to housekeep your brain, write down any task for the follow day so you don't forget them and then just rest and reflect on the day you've had, reliving and re-savouring the good memories and feeling grateful.

Sleep – Essential for mental and physical health. The brain is very active during the sleep, clearing out all the clutter from the previous day.

What next?

- We are planning two more meetings before summer holidays. The second meeting will be in June focusing on the intervention content and delivery. The third meeting will be in July to review the design of the programme and to plan the 'trial' sessions in autumn.

- If you have any comments and ideas about the programme (or any aspect of it) at any time between the meetings please contact Ola by email (a.borek@exeter.ac.uk) or phone (01392 726041). We appreciate all your involvement and input in this project.

Output from the discussions

Table 1. What 'healthy' and 'unhealthy' mean to you?

Area of health	Aspects of feeling healthy	Aspects of feeling unhealthy
Diet	Eating healthy and good food Balanced diet Healthy snacks Eating at normal time	Eating junk and fast food Not eating Eating too much Eating at off times
Physical activity	Exercising Fitness / feeling fit / being fit Feeling physically well	Not exercising Unable to do physical activity / no time Not enjoying physical activity
Mental health	Feeling happy Having a sense of wellbeing Feeling energised / having energy Zest for life / vitality Wanting to do things / taking part in things Self-esteem Confidence Feeling empowered Good self-image Knowing I've done the best I can for what my aim is Having a life of my own, separate from my disabled child Feeling stress free Feeling calm A little time off / having 'me' time Being able to switch off and concentrate on other things Not feeling guilty for doing sth for me Positivity / being positive Looking forward to the future Feeling positive about the long term Having dreams and ambitions Feeling content Having a sense of peace within	Feeling unhappy / unhappiness Feeling / being depressed Wanting life to be over / morbid thoughts Feeling of misery Feeling lethargic Feeling down Feeling grief Feeling frustrated Emotionally drained Not able to stop worrying Having negative thoughts Stress Distress Feeling anxious Feeling anger Low self-esteem Isolation Being in a downward spiral Not enough 'me' time Feeling not able to cope Feeling not able to develop and follow a life plan Feeling unable to make decisions 'freely'

	Understanding of life Having resources to draw on	Feeling like having no choice
Relationships	Family life / happy family Time spent with a partner	No spare time Not enough family / partner time Can't connect with friends Lack of social interaction
Physical health	Pain free / having no joint pain Not overweight / keeping weight down	Feeling pain Having restricted movement Being physically ill Being overweight Feeling exhausted / tired Lack of physical energy and resources
Sleep	Getting enough / a lot of sleep	Lack of sleep
Other	Children feeling confident	Children not coping

Figure 1. Influences on health.

