

Healthy Parent Carers Project - Meeting 8

8th July 2015 UEMS, St. Luke's

Family Faculty: Annette, John, Maureen, Maria, Ursula, Jen, Mirtha, Patty, Karen, Harriet, Ruth, Clare, Lyndon, Bel. **PenCRU:** Chris, Ola.

Overview

- We reflected on our experiences of using CLANGERS since the last meeting and agreed they are a good way of promoting health and wellbeing, and should be the basis of the intervention.
- We then discussed specific steps needed to take up new activities related to CLANGERS and agreed that understanding of the change process would be helpful to parent carers.
- Finally, we discussed how to deliver the HPCs programme and agreed that the best way to deliver it would be in groups, but that a booklet was required. The booklet could be also introduced to and given out at short workshops delivered to existing groups of parent carers.

What next?

- If you would like to share your experiences of being involved in the Healthy Parent Carers project and of using CLANGERS, please email a.borek@exeter.ac.uk.
- The meetings will resume in autumn to revise and finalise the Healthy Parent Carers booklet.
- If you have any comments or come across any information or resources relevant to the programme, please email PenCRU@exeter.ac.uk or a.borek@exeter.ac.uk.

Introduction

In the first part of this meeting we reflected on our experience of knowing about and using CLANGERS since the last meeting, and on the specific steps that need to be taken in order to use CLANGERS in practice.

In the second part of the meeting we discussed different ways to deliver the programme.

Discussion 1. Experiences of using CLANGERS

Which CLANGERS did you use or did you not use?

- Many people used all CLANGERS and found all of them relevant (although some proved more difficult – see below).
- Sometimes people took specific actions in order to do CLANGERS whereas at some other occasions just seeing some of the existing actions as CLANGERS had a positive effect.

What activities did you undertake specifically to do CLANGERS?

- Different activities might work for different people so it might be important and helpful to share everyone's ideas and experiences and try various things.

Examples of activities that were taken to do CLANGERS:

Connecting:

- with neighbours
- with family (being accepting and tolerant)
- with other parent carers at DPCV
- with a friend I used to work with
- smiled at people
- went for a coffee

Learning:

- learnt some more about photography
- about gardening
- what not to do, what works and what doesn't
- learnt mindfulness

Being Active:

- went for a walk
- did gardening

Noticing:

- smell of flowers
- plants in my garden more, the wildlife and garden life
- actively noticed things around me
- noticed weather

Giving:

- advice to my daughter about mindfulness
- supported my friends, neighbours and family
- a meal to my parents
- listened to a friend

Eating well:

- ate more vegetables this week
- had more fruit & veg daily
- consciously looked at my diet more

Resting / relaxing:

- practiced mindfulness
- went on a trip out as a family
- went on holiday

Sleep:

- had an occasional extra hour of sleep in the afternoon

How easy or difficult was to use CLANGERS?

- *Connecting* with family members might be particularly difficult for parent carers as they don't always feel understood and supported by the family. Another difficulty might be related to connecting with colleagues if parent carers don't work. It is important to acknowledge these difficulties and accept them but also focus on developing positive connecting elsewhere, e.g. with other parent carers (beneficial for peer support and shared understanding), and with people with shared interests (beneficial to meet non-parent-carers, to keep a personal life).
- *Sleep* was recognised as a very difficult aspect to improve because it can be affected by not only individual factors but also child-related factors. The focus should be on understanding these influences and finding out advice on sleep hygiene that relates either to improving child's sleep or to improving one's own sleep hygiene.
- It can be difficult to remember what all CLANGERS mean and might need a reminder, e.g. little card with CLANGERS explained.
- Some actions might require more work and fitting in within busy life, and can be difficult to do things when one is very tired.

Did CLANGERS have any effect on your health and wellbeing?

- There was a general agreement that using CLANGERS have had a positive effect and there was an agreement that they should be kept in the programme.

Is just knowing about CLANGERS beneficial or is taking specific actions necessary?

- Being aware of CLANGERS can lead to changing some behaviours (e.g. swapping unhealthy snacks for healthy ones, being more aware of one’s surrounding, using relaxation techniques). However, awareness alone is not sufficient to make as much impact as making specific plans to take action to do CLANGERS.
- It is important to *actively* think about CLANGERS rather than just *passively* know about them: thus one should look for what new actions they can take up to do CLANGERS rather than look back and interpret some of the past actions in terms of CLANGERS. This is how the change would come about.

Other comments:

- Although an assumption that everyone knows about what is healthy or not is common, people can still learn some new things that they were not aware of, e.g. about impact of white noise and screen light on sleep.
- The Health & Wellbeing Wheel was useful to assess one’s situation and would be useful to do it again to see one’s progress.
- Doing CLANGERS should form a part of a daily routine and help turning negatives into positives.

Discussion 2. What steps are needed to take up new behaviour? (see diagram below)

- Setting goals is important; the goals need to be SMART (specific, measurable, achievable, realistic, timely).
- Setting reminders or prompts to take action should be included as a separate step, e.g. reminders in the calendar, phone, signs, whiteboards etc.
- Reflect or Review steps should also include (a) identifying barriers and solutions, (b) reward and recognition (if the goal was achieved), and (c) acceptance (if the goal was not achieved).
- It could be useful to understand the process (the stepping stones) but it needs to be presented in a way that is not overwhelming, for example, by providing examples of specific small actions.
- People should be encouraged to set and achieve small goals first, and then making them bigger.
- Perhaps parent carers could do a brainstorming activity in a group to identify their own steps and their own activities.

Discussion 3. What are the best ways to deliver Healthy Parent Carers programme?

Booklet

<p>Benefits:</p> <ul style="list-style-type: none"> - easily accessible - could read it in your own time - can refer back to it - quick & cheap - easy to distribute - could reach more people - could provide links to further info & organisations - could be used by other existing groups independently 	<p>Challenges:</p> <ul style="list-style-type: none"> - it is easier to ‘cheat’ & fail - less accountability - have to be self-monitored - misinterpreted expectations - passive, not interactive - anonymous - lack of support - hard to track usage (might not be used) 	<p>What it should be like:</p> <ul style="list-style-type: none"> - handed over personally - including information (CLANGERS), evidence, examples, useful contacts & quotes from parent carers - including goals & monitoring of progress - engaging, interactive (with things to fill in) - visual (diagrams, pictures, colours) - concise & clear (easy to read)
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- Booklet is a good idea but with a stand-alone booklet there is a risk that it might not be used.
- It would be better if it was used together with a group-based programme or a workshop and comes with a bit more explanation.
- It should come from a credible sources, e.g. GPs, parent carer forums, support groups.
- It should be made clear that the booklet was developed together with the parent carers in the Family Faculty.
- It would be useful to include quotes from parent carers – **we will need volunteers to provide personal reflections about CLANGERS and their impact on health & wellbeing** (face-to-face or by phone or email; please email a.borek@exeter.ac.uk if you'd like to do that).

Group-based programme

Benefits:	Challenges:	What it should be like?
<ul style="list-style-type: none"> - provides better understanding - opportunity for connection, possible friendships, company - meeting like-minded people - interactive (discussion, sharing ideas, info) - opportunity for support & role models - time away from caring, taking time for yourself - provides more motivation, feedback& more personal accountability 	<ul style="list-style-type: none"> - accessibility, attendance, drop out - time-consuming - requires commitment - might feel pressure to succeed - more expensive (funding) - need to manage what group is for - need for a facilitator - recruitment - not reaching as many people - suitable time (term time only, day or evening?) 	<ul style="list-style-type: none"> - 8 to 10 group sessions - weekly or fortnightly in school hours - 8 to 20 people in the group (allowing for drop out) - delivered by trained parent carers & someone approachable, empathetic, understanding of PC issues - could include buddy up, peer support, Family Fun day etc.

- Group-based programme would be better than a booklet alone but a booklet could be given in addition to groups. Alternatively, a compromise could be to deliver a workshop, give out a booklet, and then deliver another workshop after some time.
- There were different views on who should the programme be delivered to – for example to primary carers only, to all parent carers, or to anyone (parent carers, grandparents, siblings). Also, perhaps separate groups for dads could be formed.
- Groups require facilitators – they could be parent carers but they might need training.
- It is important to make the programme sustainable in the long term. We discussed whether it would be possible to develop programme materials that wouldn't require professionals to deliver it or trained facilitators but instead they could be picked up by existing parent carer groups and used within them. In that case it would need to be made clear what the programme is (e.g. talking about CLANGERS) and what it isn't (e.g. peer support).

Other delivery strategies mentioned:

Phone app, emails (email support), closed Facebook group, webinars, short workshop (1 hr, half day or a day long).

Which organisations should we engage with?

Parent Carer Voice, DIAS (Devon Information, Advice & Support), Contact a Family, Cerebra, Face to Face, Down Syndrome support groups, North Devon Parent Carer Forum.

How do we want to take the project forward in autumn?

We will develop the booklet over the summer and in autumn we will resume the meetings to review and revise the booklet and plan a group-based programme. After that we might consider other delivery strategies.

Stepping stones to behaviour change

