



## Healthy Parents Project meeting

16/01/2014 Veysey Building

### Overview:

Parent health and wellbeing has been raised by members of the family faculty as an important area for research.

This was the first meeting to talk about some of the aspects of health and wellbeing that are important to parents and to begin to think about how we might do a piece of research in this area.

Chris introduced the topic of health and wellbeing and explained how we structure a research question in PICO format. PICO is a term used to describe four things you need to think about when asking a question that can be researched.

What **Population** are you interested in? This describes the group you are interested in, e.g. parents of disabled children

What **Intervention** do you want to find out about? This is the treatment or service you want to find out about, for the specified population.

What is the **Control (or comparator)**? This is what you want to compare the intervention or treatment with, for example, you may want to compare a new treatment with usual care.

What **Outcome** are you interested in? This is what you hope to happen or achieve as a result of the intervention e.g. reduced anxiety

We already know the population (parents of disabled children); the purpose of this meeting was to talk about the outcome and intervention part of any potential research question.

### Working in pairs:

The group worked in pairs to discuss several topics. The first question we discussed was:

**What aspects of your health and wellbeing are most important to you and other parent carers?**

This corresponds to the 'outcome' part of a research question.

We asked everyone to jot down all of the ideas that they had as they were going along and then try to prioritise, writing the 'top three' on individual post-its.

This proved to be very difficult because many of the aspects of health and wellbeing that were identified were closely linked, and it was sometimes hard for people to see them as distinct from each other. For example, depression could be linked with over-eating and loss of self-esteem. The relationship between different aspects of health and wellbeing is something we will consider closely as the ideas for the research develop.

The group came up with lots of suggestions. To simplify, Meghan and Morwenna sorted through the suggestions to see if any were similar and found that they grouped together into the following themes: depression, anxiety, physical health, weight, relationships, self-image, and sleep. Everything from the post-it notes is recorded in the table below.

Topic one: what aspects of health and wellbeing are most important to you?

Theme	Specific topic	Additional notes
Depression	Depression (3)	Linked to alcohol/drug abuse, over-eating, anti-depressants, run down, more susceptible to colds and flu etc, self-esteem (loss of), loss of career, loss of pride in appearance, relationships with spouse and family
Anxiety	Anxiety (2) Be prepared Stress Fear	stability Relief of stress Not wanting to feel fear
Physical	Strength (2) Weight (2)	Strength to carry out caring role, body stress (bad backs and knees from lifting) Lack of healthy eating/grab food quickly/comfort eat. No motivation or time to exercise
Relationships	Impact on personal relationships Impact on siblings and grandparents Communication	Feeling the need to apologise for their behaviour Ability to break down into easier terms
Self-image	Long-term plans Hope Self-worth Control	A sense of progression for self Lack of and desire for

	Resilience	Ongoing happiness level (graph drawn showing happiness level below 'normal' – same fluctuations but lower baseline)
Sleep		Fatigue and exhaustion  Relationship of anxiety with lack of sleep
Other		Desire for the opportunity for downtime/exercise etc

The second question that we worked on in pairs was:

**Thinking about the aspects of health and wellbeing we've discussed, what things have a positive influence on your health and wellbeing?**

This topic and the next correspond to the 'intervention' part of a research question.

Again, Meghan and Morwenna grouped the suggestions together into themes. The themes were:

Health needs (such as health checks, counselling and stress interventions); physical exercise; peer support; outside/community activities (such as studying or getting back to work); services and respite

Topic 2: what things have a positive influence on your health and wellbeing?

Theme	Specific topic	Additional notes
Peer support	Family/child/partner/peer  Participation/involvement Research/parent carer forums  Mentoring (2)	Meeting other parents of disabled children can reduce isolation    Speak to someone who has been through it before  Mentor/advocate in the community
Health needs	Health checks  Counselling  Stress interventions	   How to recognise need and access interventions
Respite (4)	Short breaks  Me time  Time together as a couple	
Services	SPOC  Shared responsibility for care and vision	Initially brings services together

	Support network	Respect for the parent as and intelligent individual who knows a lot
Physical exercise (3)		Enable access to exercise Special needs parents physical activity group
Outside activities	Studying Getting back to work	But requires flexibility

The third topic was:

**Thinking about the aspects of health and wellbeing we've discussed, what things have a negative influence on your health and wellbeing?**

Themes under this topic were: isolation; time (or lack of); feelings (such as stress and anxiety); other peoples' reactions and views; fear of the future and factors relating to 'the system' (such as feeling anger and resentment and having to fight the system, feeling like a 'project manager' for my child)

Task 3: what things have a negative influence on your health and well being?

Theme	Specific topic	Additional notes
Systems (problems)	Anger and resentment for the systems  Fight  Having to act as a 'project manager' for my disabled child	Fight the health systems regarding medication, diagnosis, treatments, products, equipment  Fight social services regarding respite, equipment, adaptations, transport, keyworker
Feelings	Stress  Anxiety	Triggers sensory issues
Isolation (3)		Feeling alone No support network Not knowing where to turn Relentlessness Stuck in the now and fear of future No point in moving forward if the future looks bleak
Views of others	Others peoples' reactions/ perspectives to/on our families	

Time	No downtime	
Fear of the future		<p>Being stuck in the now or a negative view of the future</p> <p>How long?</p> <p>Fear the future</p> <p>Own health – who would care for my children</p>

### Group discussion

A number of very important points were raised in the group discussion at the end of the meeting.

- Everyone was well aware of public health recommendations but felt that these didn't always fit with their life and caring commitments.
  - For example, although aware that they should eat healthily, many parents have to eat at irregular times and don't have the opportunity to eat healthily.
  - Similarly, many parents would like the opportunity to take exercise but may not be able to make time and crèches at gyms are not always able to take their children.
  - These generalised public health messages can add to a sense of failure – parents are aware of what they 'should' be doing and this can make them feel worse; there is a lack of provision to enable them to engage in health activities.
- All of the aspects of health and wellbeing highlighted on the post-its can be interrelated and feed into the other. This was likened to a downward spiral however it was noted that the spiral could go upwards again if the cycle was broken.
- Guilt was a very important and recurring theme throughout the discussion. The group talked about how they knew they should take exercise, make time for themselves etc but felt guilty about taking resources (financial or their time) away from their children.
  - An interesting discussion was whether or not this feeling of guilt was the same for dads as for mums or between the primary carer and other carers.
  - Support networks can be online
- Isolation was raised as something that has a negative effect on health and wellbeing however the group raised that isolation isn't necessarily resolved by having people around; you can feel isolated when you are surrounded by people. Equally, online support networks can reduce feelings of isolation without ever being in the same place.
- The pressure of time and responsibility was a key theme. The children come first so fitting in regular commitments to activities was difficult and the group described a tendency to put their own wellbeing at the bottom of the pile ('my stuff' is not a priority) this was thought to be habit forming and may be something to look at in the research.

- We discussed counselling, mindfulness, CBT, massage, reflexology as possible beneficial interventions, but the group were 'mindful' that one intervention may not suit everyone.
- Virtual services that could be accessed from the home, at anti-social hours, may enable parents to access interventions that would otherwise be unavailable to them.

### **What happens next?**

From our discussions there seemed to be two broad directions that we will look into in more depth before our next meeting.

1. Parent carers are well aware of the general public health messages but there are specific barriers for parents of disabled children that prevent them from doing some of these things such as taking regular exercise and healthy eating. Could public health interventions be tailored to suit parents of disabled children/avoid these barriers?
2. There are a range of interventions to promote psychological health; we discussed a few such as mindfulness. Is there potential for these interventions to have a positive effect on the psychological health of parent carers?

Morwenna has begun to do some searches of the published research literature to identify what research has already been done on these topics. She is doing two broad searches one looking at psychological impact for parent carers and one looking at physical health. In both searches we will be looking for any research into specific interventions to help with these things. **We will summarise what we find for discussion with you in the next meeting.**

Following suggestions from the group, Val has arranged to speak with Christina who is involved in the Health Checks being offered by Devon Carers. Val is also going to meet Jacinta from Health Promotion Devon's Community Development Team. Their work focuses on empowering communities to bring about the changes which will improve their health, wellbeing and quality of life. <http://www.healthpromotiondevon.nhs.uk/community-development>