

Research Summary

Parent-to-parent support – does it help?

This research summary was written by PenCRU and members of the PenCRU Family Faculty

Key findings

- We looked at all studies of peer support for parents of children with chronic disabling conditions.
- When parents have been asked about their experiences of peer support, they felt that it had been beneficial in various ways.
- However, when studies have tried to measure the effect of peer support with questionnaires, they have not consistently found benefits.
- Further research is needed to understand why these findings vary.

Who carried out this research and why?

The idea to carry out research about peer support for parents of disabled children came from one of the parents in the PenCRU Family Faculty.

The review was led by the team at Peninsula Cerebra Research Unit (PenCRU) a childhood disability research unit at the University of Exeter Medical School.

The research was supported by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for the South West Peninsula – known as PenCLAHRC.

Background

Peer support is emotional and practical support given by people who share similar experiences. It has been shown that peer support can help

people with specific conditions such as cancer or in issues such as breastfeeding.

Parents and carers of disabled children are at risk of chronic health problems. Many parents use different types of peer support but no one has reviewed the evidence of the effectiveness of organised peer support for this group.

What did we do?

This type of research is called a systematic review. Systematic reviews bring together the results of all studies addressing a particular research question. They provide a comprehensive and impartial summary of research evidence.

Study Advisory Group

We set up an Advisory Group made up of three parents, four befrienders and the local coordinator from Face2Face (a one-to-one befriending service

for parents of disabled children), representatives from relevant charities (Scope, Cerebra, Contact a Family, A Brighter Tomorrow, Council for Disabled Children), a local GP and two representatives from Devon County Council.

The Advisory Group helped to develop the research question and set the criteria to decide which studies we should include or exclude. They also helped to write this summary.

Searching for evidence

We searched online libraries for all the research papers which have been written about parents and carers of children with disabilities supporting other parents and carers. We also looked at key websites for the same information. We looked at over 5,000 references and filtered out the ones which didn't meet the selection criteria decided by the advisory group.

Bringing the evidence together

Some studies had interviewed parents about their experiences of support (qualitative methods); other studies had tried to measure the effect of support using questionnaires (quantitative methods).

We grouped the reports according to what type of information was reported in the study and then all the information about parent to parent support in each group was brought together, or 'synthesised'. We then looked for similarities and differences in the findings within and between the groups of studies.

This enabled us to consider to what extent evidence from research can answer the question 'what are the benefits and costs of parent to parent support?'

What did we find?

What types of study were included?

- 17 papers were included in the review.
- Some papers looked at peer support for parents of children with mixed conditions and others looked at peer support for parents of

children with specific conditions such as dyslexia, limb deficiency or diabetes.

- 10 studies had interviewed parents alone or in focus groups about their experiences of support; 7 studies had measured the effect of support using questionnaires; and one study had done both.

What did the interview studies find?

We found four main themes across the interview studies:

Shared social identity was the most common theme.

- Parents/carers thought people not in a similar situation couldn't understand their experience.
- The shared social identity included a sense of belonging, support and empowerment, reduced feelings of isolation, loneliness and guilt.
- Parents felt better able to cope when supported by other parents with similar experiences.

Learning from the experience of others:

- Parents felt supported by being able to share useful, practical information and being able to learn from the experiences of others.

Personal growth:

- Several studies described how parents gained strength and were empowered through peer support.
- This enabled them to develop new skills and to feel motivated and confident parents.
- Parents described feeling more in control and less isolated or guilty.
- This in turn had a positive impact on their child.

Supporting others:

- Parents reported a sense that peer support was a two way process and felt that giving support was as important as receiving it.

- Giving support and sharing experiences validated their expertise as parents.
- Mentoring others enabled parents to see how far they had come in their own journey.

Four papers also identified some situations when peer support did not work, although no harmful effects were reported:

- Some parents found it difficult to give personal information to a stranger.
- Some were frightened of comparisons between their child and others.
- Parents who felt pressured by a professional to attend a group or those who felt the support they received did not match the level they expected or hoped for were less satisfied.
- For some parents, a lack of time to meet other parents can get in the way of successful peer support.

What did studies that measured the effect of support using questionnaires find?

Psychological health:

- Eight studies measured the effect of peer support on parents' psychological health.
- Some studies reported benefits of peer support relating to anxiety, concern, confidence and coping.
- However, the findings were inconsistent. Some studies measuring anxiety, concern, confidence, coping and other aspects of psychological health did not report strong evidence for the benefit of peer support.
- In some studies, peer support appeared to be more beneficial to those with high stress and anxiety, poor maternal health or lower coping skills; but we would need more research to be more certain that this is true.

Family function:

- Five studies measured the effect of peer support on family function.
- One study reported evidence of improvement on a measure of acceptance and family adjustment to disability, but four studies

showed little or no change on a different questionnaire measuring the impact of their child's condition on family life.

The experience of parents receiving support:

- Five questionnaire studies measured the experience of parents receiving support.
- One study found that 89% of parents receiving peer support had found the support helpful.
- Four studies looked at how much social support parents felt they had.
- Only one found that parents who had peer support as part of a study felt that they had more sources of social support than parents who had not received peer support.

Accessing services and information:

- Only one study measured the impact of peer support on accessing services and information.
- There was weak evidence that parents receiving peer support increase their use of community services, but no drop in Emergency Department or acute care visits or calls to specialists was reported.

Is there evidence of the effectiveness of peer support for parents of disabled children?

- The interview studies found that parents perceive benefits from peer support across different types of support and medical conditions.
- Findings from the questionnaire studies however did not find evidence to support these benefits; although the general trend favoured peer support, few studies reported strong evidence of a measurable effect.
- Overall it was not possible to fully answer the research question. We felt that the studies included were of acceptable quality but it is possible that the way we selected studies may have meant that some potentially valuable information was not included.
- None of the studies looked at cost-effectiveness and very few studies interviewed parents who had had a negative experience of support.

- It is common for people who are actively engaged in a support service and who have a positive view of it to be most likely to take part in the studies.

Who reviewed our research to make sure it was done well?

The systematic review is published in a journal called *Developmental Medicine and Childhood Neurology*.

Before the journal accepted the review to be published it asked two independent experts to look at the paper and decide whether it had been properly done and whether it was important enough to publish.

What's next?

This review shows a need to look more closely at peer support services and the methods used to study them. Better designed studies are necessary to help people make informed decisions about peer support.

In particular, we thought the following things should be researched more thoroughly:

- Are appropriate questionnaires used, are they sensitive to detecting relevant important health changes?
- When is the right time to measure the effect of support – for example how do we know when a parent has had 'enough' support to have an effect?
- What are the differences between the effects of one-to-one support and group support, and how important is it to match support by diagnosis in these different types of support?
- What is the impact of other types of support that parents might access at the same time of the study? Is it right or necessary to prevent parents from seeking other types of support while they are taking part in a study?
- Is it appropriate to ask parents to wait for support so that studies can compare them with parents getting support (this is called a control group)?

The full version of the systematic review is published in the journal *Developmental Medicine and Child Neurology*. If you would like a copy please contact us at pen cru@exeter.ac.uk

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