

### Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies

#### What did we find?

- Parents of children with chronic disabling conditions felt **better able to cope** when supported by other parents with similar experiences
- Parents who shared experiences with other parents said they felt **less lonely** and had **reduced feelings of guilt**
- Parents felt supported when they were able to share useful practical information and were **able to learn from the experience of others**
- Several studies described how parents **gained strength** and were **empowered** through peer support
- Parents felt that peer support was a two way process and **giving support was as important as receiving it.**
- For some parents a **lack of time** got in the way of successful peer support



#### Why did we do this review?

Peer support is emotional and practical support given by people who share similar circumstances and experiences.

Parents and carers of disabled children are at risk of chronic health problems and many use peer support to help them. We wanted to find out how effective organised peer support is for parents of disabled children.

The idea to carry out this research came from a parent working with the Peninsula Cerebra Research Unit, a childhood disability research group at the University of Exeter Medical School. We worked with parent advisors and the befriending service Face2Face.

#### How did we do this review?

The research was a systematic review. This brings together all existing research on a particular question. We searched online databases and websites for all the research papers which have been written about parents and carers of children with disabilities supporting other parents and carers.

We found 17 relevant studies. Some studied peer support for parents of children with specific conditions such as dyslexia or diabetes and others covered a combination of conditions. 10 of the studies had interviewed parents alone or in focus groups about their experiences of support, 7 studies had used questionnaires to measure the effect of the support and one study had done both.

## Quality of the research and cautionary notes

Studies where interviews were carried out found that parents believe they benefit from peer support across different types of support and medical conditions. Findings from the studies using questionnaires however, did not find strong evidence to support these benefits.

It was not possible to fully answer the research question with the papers we found. Although the studies found were of reasonable quality, the way we selected them might mean that some valuable information was not included.

No studies looked at whether the services were good value for money and very few interviewed parents who had had a poor experience of support.

## What next?

Better designed studies are needed to look more closely at peer support services to see how well they work. We do not know whether the questionnaires used were good enough to measure the services or when is the best time to assess the support. New studies could investigate how long it takes before parents feel the benefit of peer support. We also do not know the difference in benefit between a one to one support service and group support, or whether the diagnosis of the child makes a difference to how well the support works. New studies could try to answer these questions.



## Contact details and further information about the published paper:

The PenCLAHRC EST is part of Evidence Synthesis and Modelling for Health Improvement (ESMI), at the University of Exeter Medical School. Further information about this research is available on the University of Exeter Medical School website: <http://medicine.exeter.ac.uk/esmi/workstreams/>

The full version of the systematic review of these findings is published in the Journal of Developmental Medicine and Child Neurology You can access the paper here:

<http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12091/abstract>

If you would like copies, please email the evidence synthesis team on:

[evidsynthteam@exeter.ac.uk](mailto:evidsynthteam@exeter.ac.uk)

**This work was carried out in collaboration with the Peninsula Cerebra Research Unit (PenCRU). Some of the text is taken from the PenCRU research summary [www.pencru.org/projectsmeetings/plain language summaries/](http://www.pencru.org/projectsmeetings/plain%20language%20summaries/)**



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