

Research Summary

Parent-to-parent support – does it help?

Findings from an interview study

This summary was written by PenCRU and reviewed by members of the family faculty

Key findings

- We interviewed parents and befrienders who had contact with a one-to-one befriending service and a group of professionals about their views and experiences of peer support.
- Key to the success of peer support was a feeling of shared experience between parents and befrienders.
- We identified a number of positive outcomes for parents: reduced isolation, emotional stability and personal growth; and for befrienders: training, mutual support, personal growth and self-worth and feeling that they were helping others.
- Potential negative impacts on befrienders included emotional burden, worrying about their performance and the time commitment required.
- We identified several aspects of how the service is organised and delivered that may be necessary to help establish the sense of shared identity that is so important to the success of peer support.

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 study 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. Parents often seek support from other parents and the health service in the UK actively encourages peer support.

In this research study we wanted to gain an in-depth understanding of people's views and experiences of a particular one-to-one befriending service offered by Face2Face.

What did we do?

This type of research is called a qualitative study. Qualitative research is used to explore and understand people's beliefs, experiences or behaviours. It asks questions about how and why. Researchers use methods like focus groups and interviews.

Study Advisory Group

We set up an Advisory Group made up of three parents, four befrienders and the local coordinator from Face2Face, 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 the interview guides that we used. They also helped us with the analysis and to write this summary.

Who did we talk to?

We spoke to 12 parents who had support through Face2Face, 23 parents who had offered support to others (befrienders) and 10 people working in health, social care or education.

We spoke to people in one-to-one interviews or as part of a focus group.

We asked them about their views and experiences of peer support in general and the Face2Face befriending service in particular.

The interviews and focus groups were recorded and typed up. This was to enable us to read the text and identify important patterns.

What did we find?

What did people think were the outcomes of peer support?

Participants talked about a number of outcomes. Some of these were for parents receiving support, some were for the befrienders.

Outcomes were dependent on a feeling of 'shared experience' between the befriender and the parent; that they could understand each other's situation through having had similar experiences themselves.

Unless you've got a disabled child, you don't get it [...] You can't understand someone unless you walk in their shoes. (a parent in this study)

Shared experience was important to help parents:

- Learn from the experience of other parents
- Speak freely, feel safe and not judged
- Receive support and encouragement

Key outcomes for parents receiving support:

- Reduced isolation
- Emotional stability and personal growth, particularly increased confidence and coping

Key outcomes for parents providing support:

- Positive experiences of training and mutual support amongst befrienders
- Personal growth and self-worth, including confidence
- Feeling that they had helped someone else

Both groups appeared to benefit from expanding their social network.

Befrienders sometimes experienced less positive outcomes such as emotional burden, worrying about their performance and time commitment.

What did people think was important about how the service is organised and run?

In particular, we were interesting in what was necessary to help build the sense of shared experience between parent and befriender, as this was seen as so important to success.

Organisational aspects and processes

- Flexible, confidential, one-to-one at home service
- Training and safeguarding

- Formal supervision and support
- Rules and boundaries around the relationship

Putting the right people together

- Ensuring that befrienders are ready and suitable to befriend
- Careful matching of families: for some it was important to match by diagnosis, for others matching parents who would get on

Parents as potential users of peer support

- The timing of when support is offered, needed and accessed (or not) is important but difficult to predict
- One-to-one peer support may not be right for people for a number of reasons such as not feeling able to share their emotions

Future research should investigate how these different factors might influence the befriending relationship and outcomes for parents and befrienders.

Limitations of our research

We were not able to interview any people who had declined or withdrawn from the service.

This means the people we spoke to may have had a positive bias towards peer support, although they did identify potential concerns and negative outcomes.

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

The qualitative study is published in a journal called *Child: Care Health & Development*.

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

What happened next?

We have written a report that brings together the qualitative study that we have done, with a costing study that looks at what is needed to provide peer and a systematic review drawing together other people's research.

We have made the plain language summaries widely available through our own website and those of other organisations such as Cerebra, the Council for Disabled Children and the Mentoring and Befriending Foundation.

We have also talked about this research at conferences to groups of professionals who work with families of disabled children and who might refer them to services.

We hope that this research will help parents, professionals that might refer to peer support services or people who might commission these services make informed decisions about peer support.

**The full version of the study is published in the journal *Child: Care Health & Development*.
If you would like a copy of this, the systematic review or the full study report please contact us at pencru@exeter.ac.uk**

The team that carried out the qualitative study are: Val Shilling, Chris Morris, Sarah Bailey and Stuart Logan with support from the Study Advisory Group. The research team are all part of the PenCRU and/or the NIHR Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC) at the University of Exeter Medical School. This research is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula (PenCLAHRC), and the charity Cerebra. The views expressed in this paper are those of the authors and not necessarily those of the NHS, the NIHR, the Department of Health, or Cerebra.