

# Parent-to-parent support – what are the benefits and costs?

This research summary was written by PenCRU and members of the study advisory group

## Key Findings

- We evaluated the one-to-one befriending service offered to parents of disabled children by Face2Face (F2F) in Devon and Cornwall
- Parents', befrienders' and professionals' views and experiences of peer support were generally positive but it can be hard to measure the impact of peer support
- We found that there were important impacts for the parents who supported others, as well as those receiving support. In particular this group benefitted from the training and ongoing mutual support
- We think it is important that people think carefully about whom peer support is likely to have an impact on when they design evaluations; who you include will affect how the service is valued in terms of costs and benefits

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

### Background

Parents and carers of disabled children are at risk of physical and mental health problems. Parents often seek support from their peer group; emotional and practical support given by people who share similar experiences.

There are many different types of peer support groups and services; some informally organised, others with a formal structure.

We conducted an evaluation of one specific peer support service; the one-to-one befriending service offered to parents of disabled children by Face2Face (F2F) in Devon and Cornwall. This evaluation is intended to provide information

that will help decision making by different groups of people including those who might use, refer to or fund this type of service.

### What did we do?

#### Study Advisory Group

We set up an Advisory Group made up of parents of disabled children, members of Face2Face and representatives from local and national charities, Local Authorities, and a GP.

The Advisory Group helped us with every stage of the research. Some of the group helped us to analyse our findings and they also helped to write this summary.

We did three pieces of work: a systematic review, a qualitative study and a costing study.

**Systematic review:** Bringing together the findings of lots of different studies to find out what is already known about peer support for parents of disabled children.

We looked at over 5,000 references and filtered out the ones which didn't meet the selection

criteria decided by the advisory group. 17 papers were included in the review.

Ten studies had interviewed parents about their experiences of support (qualitative methods); 8 had tried to measure the effect of support using questionnaires (quantitative methods). One of the studies did both things.

## What did we find?

### What did the interview studies find?

We found four main themes:

- *A shared sense of social identity* was the most common theme and included a sense of belonging, support and empowerment, reduced feelings of isolation, loneliness and guilt. Parents/carers felt that people not in a similar situation could not understand their experience.
- Also important were *Learning from the experience of others*; *Personal growth* (including increased confidence and feeling more in control) and *Supporting others* (including the benefits of helping someone else)
- Four papers also identified some situations when peer support did not work (such as a bad match between the parents).

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

#### *Psychological health:*

Some studies reported benefits of peer support relating to anxiety, concern, and confidence and coping, however, the findings were inconsistent.

#### *Family function:*

One study reported evidence of improvement on a measure of acceptance and family adjustment to disability, but four others reported little or no change.

#### *The experience of parents receiving support:*

Only one of four studies 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:*

There was weak evidence from one study that parents receiving peer support increase their use of community services, but did not decrease use of medical service.

### **Key implication**

More research is needed to find out whether there are differences between how people feel about peer support and what can actually be measured. It may be that these differences are caused by variation in the design of the studies.

**Qualitative study:** To explore peoples' views and experiences of peer support in general and the Face2Face service in particular.

We interviewed 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.

## What did we find?

All of the groups thought highly of parent-to-parent support and thought that well run services could be a positive experience for both the parent receiving and the parent giving support.

### **How and why does peer support work?**

Parent-to-parent support was thought to work because of the shared experience between matched parents of disabled children, providing an environment for parents to speak freely without judgement, learning from the experience of others and support and encouragement.

However, not everyone wants or feels able to engage in peer support and the timing of when peer support is offered can be critical.

### **What outcomes are achieved and for whom?**

#### *Impact for parents receiving support*

- Feeling more emotionally stable and accepting of situation
- Increased confidence and feeling better able to cope with everyday life
- A sense of reduced isolation; just knowing other parents were out there helped

### **Impact for parents giving support**

- Feeling good that you have been able to help someone else
- Increased confidence and feelings of self-worth
- Benefits of having taken part in the training and the friendships made there
- The ongoing support that befrienders give to each other
- Risk of emotional burden, time commitment and concerns about doing a good job

Some of the things people talked about also led us to think that parent-to-parent support might have a broader impact than just on the people involved in the service. Some examples include:

- Parents representing other parents as committee members
- Joining and organising parent organisations
- Undertaking advocacy work

### **Elements of a 'good' parent to parent support service**

Participants in the study, particularly in the professional group, were concerned to know that the service was properly structured and managed. This is because they were concerned for the wellbeing of the parents giving and receiving support.

Important features of the service discussed by all of the groups included:

- Proper training, support and supervision for befrienders
- Confidentiality and flexibility around visits for parents
- Rules and boundaries around the befriending relationship
- Systems in place to deal with issues around safeguarding children and concerns for the physical and mental health of parents

### **Key Implication**

As well as parents receiving support, evaluation of these services should include parents that offer support and should also think about impact

for the broader community of parents of disabled children.

**Costing study:** investigating what is needed to provide the service in terms of time, resources and money.

- The main expected resources in providing the service were befrienders' time, and the time and cost of the service co-ordinators and managers.
- Befriender training was also anticipated to be a significant cost. As the service is offered at home it also results in travel costs and related expenses.

We collected two types of information:

**Direct service costs and overheads** such as wages, training, telephone, IT, postage etc.

To get this information, the services in Devon and Cornwall provided us with their financial accounts for a 12 month period.

**Indirect service costs** such as befriender's time.

To get this information, befrienders recorded how much time they spent doing things for Face2Face such as travelling and doing admin as well as the time they spend supporting families, over a 3 month period.

We compared this information with the number of families who received peer support over the 12 month period.

### **What did we find in the costing study?**

The services in Devon and Cornwall had different models for providing peer support:

- An individual co-ordinator model which has approximately 20 befrienders, provides one-to-one support which is also provided by the mentor co-ordinator, has no office premises, and is supervised by an area manager
- A multiple co-ordinator model which has approximately 63 befrienders, provides one-to-one and group support which is not

provided by the three mentor co-ordinators, has an office base and an area manager

It was more expensive to provide the multiple co-ordinator model, but this does not take account of the benefits that people may have obtained from the service.

Befriending activities varied considerably between befrienders, with large proportions of time spent in mutual support activities.

The qualitative study and the amount of time befrienders spend in mutual support suggest that their outcomes should be considered, which impacts on any calculation of cost per person benefitting from the service.

### Key implication

When considering the cost of a service such as Face2Face, evaluators should carefully consider who the potential beneficiaries are, as this will affect the perceived value for money.

Readers who would like more detail about the specific costs of service provision are encouraged to contact the authors for the full report ([pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk))

### What are the strengths and limitations of the study?

- We worked closely with the Study Advisory Group throughout the project. This helped us design research that is relevant and useful to families and people that work with them.
- A strength of the study is that we have been able to talk to people using the service, people

delivering the service and relevant professionals.

- A limitation of the study is that we were not able to talk to people who had withdrawn from the service or had a bad experience. This means our findings may be biased.
- Doing the costing study and the qualitative study alongside each other has helped us get a better understanding of the service in terms of the costs and benefits.

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

The study was reviewed and approved by the Peninsula College of Medicine and Dentistry Research Ethics Committee.

We will publish the findings of the study in academic journals. Before the journals accept the papers for publication they will ask independent experts to look at them and decide whether the research has been done properly and whether it is important enough to publish.

### What's next?

We will make the full report of the study available to a broad range of people through our website and the websites of other charitable organisations such as Cerebra and the Mentoring and Befriending Foundation.

### Where can I read more?

This is a very brief summary of the research. **If you would like a copy of the full report, please contact: [pencru@exeter.ac.uk](mailto:pencru@exeter.ac.uk)**

The team that carried out the research are: Val Shilling, Annie Hawton, Sarah Bailey and Chris Morris with support from the Study Advisory Group.

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