Appendix i: Systematic review protocol

Project title:

What are the benefits and costs of providing peer support to parents of disabled children?

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What are the benefits and costs of providing peer support to parents of disabled children?

1. Background and research question

Existing research

It is broadly acknowledged that parents of disabled children are at increased risk of relationship problems, stress, depression and lack of sleep (Contact a Family www.cafamily.org.uk). Family relationships may suffer through exhaustion and stress and parents report feeling isolated, lonely and unsupported (Davies and Hall 2005).

Many of these problems are related to lack of awareness of appropriate services and financial benefits and lack of access to appropriate supportive networks. Some parents seek emotional support and advice from other parents in similar situations, i.e. finding a peer group. This may be accomplished through informal coffee mornings organised by schools and organisations such as Parent Carer Voice. More structured peer support programmes such as those offered by Face2Face seek to provide peer support to parents who are in greater need of support and advice and whose health and wellbeing may be affected. With substantial cuts in social services planned these pressure and difficulties for families of disabled children are likely to become worse. However, the provision of peer support has the potential to mitigate some of these problems and have a significant positive impact on later outcomes. If shown to be effective, such programmes have the potential to avoid families reaching crisis point, improve quality of life and by the same argument, reduce the need for immediate and future service use thus reducing the cost to health and social services.

Preliminary searches conducted in the preparation of the priority briefing for this project did not find any existing systematic reviews of peer support for parents of disabled children delivered on an individualised, flexible and informal basis. Four studies of peer support delivered by matched, trained supporting parents were found; a qualitative studies in parents of children with congenital upper limb deficiency (Kerr and McIntosh 2000), one mixed methods study in parents of children with chronic lung disease requiring technology assistance (Nicholas and Keilty 2007), one study of parents of children with cerebral palsy (Palit and Chatterjee 2006) and a comparative trial of parents with children in a neonatal intensive care unit (Lindsay, Roman et al. 1993) All the papers report positive benefits as a result of parent-to-parent support initiatives. In the comparative trial, measures of maternal mood states, maternal-infant relationships and home environment were significantly better in the group of parents who received parent-to-parent support compared with those who did not (Lindsay, Roman et al. 1993) Benefits reported in other studies include the provision of much needed emotional, social and practical support (Kerr and McIntosh 2000), reduced feelings of isolation, increased knowledge and an important sense of feeling understood (Nicholas and Keilty 2007) and improvement in parental mental health (Palit and Chatterjee 2006).

Reported challenges in implementing this type of peer support include scheduling difficulties and personality incompatibility. Semi-structured telephone interviews of 24 parents of children with special needs conducted by Ainbinder and colleagues highlight the importance of appropriate matching with supporting parents and the need for such programmes to exist as an adjunct to advice provided by health care professionals (Ainbinder, Blanchard et al. 1998).

Another mechanism for providing peer support might be via online or virtual communities. Initial searches did not return any systematic reviews or studies of peer support delivered by parents in this context.

Peer support programmes have the potential to offer a relatively low cost intervention for families experiencing physical, financial and/or emotional strain. Initial searches suggest a small and disparate literature supporting the anecdotal evidence of the benefits of peer support in this context. However as yet there is no systematic review of the effectiveness and cost effectiveness of peer support for parents of disabled children and therefore no clear guidance for those responsible for commissioning services.

Purpose and objectives

The aim is to review studies that evaluate peer support interventions delivered in any setting for parents of disabled children and specifically to explore the reported costs and benefits of such interventions.

If feasible we will explore quantitative evidence on the effectiveness and cost effectiveness of relevant interventions and map the components which are shared or different between interventions. We will review qualitative research to explore the experience of peer support from the perspective of both parties i.e. the persons receiving *and* giving support, to identify factors that contribute to the success or potential problems, of a peer support intervention. We will bring these components together with a narrative synthesis.

This review will inform the design of a programme evaluation of the peer support offered by the Exeter and East and Mid Devon division of Face2Face, a charitable, national network of trained parent volunteers who support parents of disabled children.

The interventions

Peer support programmes. A working definition of peer support could be “the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population” (Dennis [2003], p329) Or more simply, emotional and practical support given by people who have had similar experiences themselves. We will limit this review to peer support between parents or caregivers and exclude the body of literature relating to peers as people with the same condition.

2. Methods

Search strategy

Scoping searches, contact with experts and parents, identification and exploration of key papers etc etc will be used to refine the search strategy. See appendix 1 for search strategy.

The detailed search will be undertaken in the following electronic bibliographic databases: MEDLINE, MEDLINE In-process, EMBASE, PsycINFO, CINAHL, The Cochrane Library, Social Science Citation Index and Health Management Information Consortium (HMIC).

As an audit trail the detailed search strategies will be kept and recorded. The search results will be kept in EndNote X4 reference management software. The dates of searches will be recorded to enable updating as required and the cut off date for all searches will be specified.

The search process will be an iterative one (for instance if particular interventions are identified as being particularly relevant), further web-based or database searches may be carried out and the audit trail will reflect this. We have identified several key papers. Search results will be interrogated to ensure that these papers are identified.

We will also conduct hand searching of key journals (as indicated by the included papers) , citation searches of key authors, reference lists of key papers, references on key websites such as Contact a Family (www.cafamily.org.uk) and the Mentoring and Befriending Foundation (www.mandbf.org).

Study selection criteria and procedures

Types of study to be included

Studies will only be included if they describe the effects of parent to parent peer support and report data on one or more of the outcome measures. In the first iteration, we will not restrict by study design.

Criteria	Specification	Notes
Population	Parents and caregivers of disabled, chronically or seriously ill children and young people	• This includes primary caregivers and guardians. • Caregivers of children and young people with mental health/psychiatric conditions will be included • Studies of support offered to bereaved parents will be excluded. • Studies of caregivers to babies in neonatal intensive care will be excluded. • Studies of caregivers to children receiving treatment for cancer will be excluded.
Interventions	Peer support specifically: • one to one face to face • informal support groups • support groups affiliated to charities or organisations	• Internet support forums/groups will be excluded • telephone support will be excluded
Comparators	Studies may compare support with no support or compare one type of support with another. Qualitative studies that do not include a comparison group will not be excluded.	
Outcomes	• Psychological health of parents (including but not solely stress, coping, quality of life, self-efficacy,	Studies that report (quantitatively or qualitatively) on at least one of

	depression, anxiety) or positive adjustment • Experience of the person offering or receiving peer support (including but not solely changes in own confidence, knowledge, moving on to or back into employment, a sense of belonging/friendship/being part of something) • Economic implications of peer support programmes • Family function including relationships with partners and children and satisfaction as a parent • Accessing services and information; increased knowledge and expertise • Relationships with health professionals • Long term impact of peer support	the outcomes will be included
Setting	Any setting including: • home, school or hospital	
Study design	Any study design will be considered	Editorials, opinions, letters, reports published as meeting abstracts only will be excluded
Date	No date restrictions	
Language	No language restrictions	
Exclusion criteria	• Studies relating to patient-to-patient peer support rather than support offered to a parent or caregiver • Studies relating to peer support between carers of adult patients such as spouses with dementia • Studies relating to caregivers of babies in NICU or caregivers of children receiving treatment for cancer • Studies relating to internet support forums/groups or telephone support • Studies relating to interventions offered by professionals or interventions which are "training packages" given to parents rather than support • Studies which do not adequately describe the intervention[1]	

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[1] The 'content' of the intervention will not be possible to describe as the conversations are individualised and private and do not necessarily follow a formal predefined structure. Adequate description of the 'context' of the intervention will be sufficient including description of both parties, level of training of the person offering support, extent of support being offered in terms of time and availability, description of the purpose of the intervention e.g. emotional support, information and practical support etc. Efforts will be made to contact the authors of relevant studies for further clarification if the description is not sufficient before the study is excluded.

Study selection

The abstracts and titles of the references retrieved by the electronic searchers will be screened for relevance by two reviewers using the pre-specified inclusion/exclusion criteria. Discrepancies will be resolved by discussion. Full paper copies of potentially relevant studies will be obtained. Using the same methods, the retrieved articles will be assessed for inclusion. Discrepancies will be resolved by discussion, with a third reviewer if necessary. We will exclude duplicate papers. A PRISMA-style flowchart will be produced detailing the study selection process and the reason for exclusion of each full-text paper reported.

3. Quality assessment strategy

The quality of individual studies will be assessed by one reviewer (VS), checked by a second reviewer and any disagreement will be resolved by discussion involving a third reviewer if necessary.

We will use appropriate quality assessment criteria depending on the design of the included studies using the general principles published by the NHS Centre for Reviews and Dissemination and the Cochrane Collaboration.

4. Data extraction and synthesis

Quantitative data will be extracted by one reviewer (VS) into a piloted, standardised data extraction form. This will be checked by another reviewer. Discrepancies will be resolved by discussion with the involvement of a third reviewer if necessary. Data will be tabulated and will include details of the intervention type and content, the setting and the provider, sample characteristics of the included population and the type of outcomes measured. Where papers provide insufficient details of the intervention e.g. what is delivered and by whom, we will contact authors to obtain unpublished details, if they are unavailable in the published literature.

For qualitative studies, we will extract details of the methods of each study along with quotes, themes and concepts pertinent to our research questions. This process will be conducted by two reviewers independently. Any discrepancies will be resolved through discussion. A structured summary will be produced for each paper and the extracted data will be tabulated allowing comparison between studies.

We will bring together the qualitative and quantitative data in a narrative synthesis (Popay, Roberts et al, 2006). The exact choice of methods will be developed through the synthesis process and reasons for our choices recorded and reported.

5. Service Users/public involvement

This research question was developed from an idea suggested by parents who are part of the Cerebra Research Unit family faculty. The question was developed for prioritisation through PenCLAHRC with the involvement of two members of the Face2Face organisation (LJ and BM) who will continue to work with us on the systematic review and the larger research project. LJ and BM will play an integral role in: defining peer support to develop clear inclusion/exclusion criteria for the interventions, defining and prioritising outcomes, ensuring that the review is readable and relevant, dissemination of findings.

References

Ainbinder, J. G., L. W. Blanchard, et al. (1998). "A qualitative study of Parent to Parent support for parents of children with special needs. Consortium to evaluate Parent to Parent." J Pediatr Psychol 23(2): 99-109.

Davies, S. and D. Hall (2005). ""Contact A Family": professionals and parents in partnership." Arch Dis Child 90(10): 1053-1057.

Dennis, C. L. (2003). "Peer support within a health care context: a concept analysis." Int J Nurs Stud 40(3): 321-332.

Kerr, S. M. and J. B. McIntosh (2000). "Coping when a child has a disability: exploring the impact of parent-to-parent support." Child Care Health Dev 26(4): 309-322.

Lindsay, J. K., L. Roman, et al. (1993). "Creative caring in the NICU: parent-to-parent support." Neonatal Netw 12(4): 37-44.

Nicholas, D. B. and K. Keilty (2007). "An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance." Soc Work Health Care 44(3): 245-259.

Palit, A. and A. K. Chatterjee (2006). "Parent-to-parent counseling - a gateway for developing positive mental health for the parents of children that have cerebral palsy with multiple disabilities." Int J Rehabil Res 29(4): 281-288.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. and Britten, N. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. Final report, Institute of Health Research, Lancaster: ESRC Methods Programme.

Appendix 1: search strategy medline

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1948 to Present>

Search Strategy:

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1 exp Peer Group/ (11204)

2 exp Self-Help Groups/ (7974)

3 parent-to-parent.ti,ab. (195)

4 (support* adj network*).ti,ab. (1521)

5 (peer adj support).ti,ab. (1064)

6 (peer adj support).ti. (254)

7 1 or 2 or 3 or 4 or 5 or 6 (21002)

8 exp Parents/ (59345)

9 exp Mothers/ (21083)

10 exp Fathers/ (5212)

11 (support* adj5 (parent* or mother* or mum* or father* or dad*)).ti,ab. (7863)

12 8 or 9 or 10 or 11 (64425)

13 7 and 12 (1767)

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