The purpose of this briefing paper is to aid Stakeholders in prioritising topics to be taken further by PenCLAHRC as the basis for a specific evaluation or implementation research project. This paper was compiled in 2-3 days.

What are the benefits and costs of providing peer support to parents of children with autism spectrum disorders and ADHD?

Question ID: 1

Question type: Intervention

Question: What are the benefits and costs of providing peer support to parents of children with autism spectrum disorder and ADHD?

Population: Families with a child diagnosed with autism spectrum disorder or ADHD

Intervention: Peer support provided by the F2F charitable network of trained parent befrienders.

An exploratory evaluation of the F2F service in this population would be important in determining whether a full scale evaluation is appropriate. It is anticipated that the exploratory evaluation would consist of four elements:

1)   To work in partnership with parents involved with F2F in Devon and with the F2F National Network Manager to develop the study design and outcomes that are appropriate and acceptable to F2F and families using the service.

2)   A systematic review of the existing literature on providing peer support to parents of children with a disability, and also more broadly to carers in other contexts, in order to clarify the theoretical underpinning of peer support interventions and develop the evaluation protocol.

3)   To conduct a pilot evaluation of Devon F2F to assess:

•   Frequency of attendance and the amount of support provided by the befriender

•   Resources used to deliver the programme and associated public sector and charitable costs of providing support, e.g. the salary of the co-ordinator, training the befrienders and any expenses incurred

•   Evaluate non-monetary costs such as voluntary time

•   To assess how peer support works, and its impact in terms of outcomes, through qualitative research

•   To identify questionnaire based instruments to measure the identified outcomes that may include, psychological wellbeing, self-efficacy, coping, stigma and stress.

4)   Information gained from the pilot evaluation would be used to develop a protocol for a larger scale more definitive evaluation of the effectiveness and

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cost-effectiveness of providing peer support to parents of children with disability.

Control: The pilot evaluation will not require a control group. Additionally, we consider interviewing parents in crisis before support is provided to be unacceptable from an ethical perspective. The acceptability of asking parents in crisis to complete questionnaires will be explored as part of the pilot evaluation.

Outcome: The outcomes of this research will be distilling and understanding how and why peer support works, the likely benefits, resources expended and costing. However, a number of benefits of peer support have already been reported by parents. These include:

1) improved knowledge of, and ability to access, appropriate services and benefits

2) Improved partnerships between parents and professionals

3) Improved personal coping strategies

4) Improved family functioning, and ability of the gamily to cope and move forward

5) Improved personal quality of life, with consequent benefit for the child and siblings

6) Improved mental health through reduction in stress levels for parents

7) Improved access to informal supportive networks

8) We will investigate the appropriateness of utilising exiting measures such as the Parent Stress Index and the Parent Self-Efficacy Scale to compliment the qualitative element of this study.

Face2Face

Face2Face is an example of an established method of providing peer support to parents of disabled children. The Face2Face network was established in 1998. It is a charitable, national network of trained parent volunteer befrienders who emotionally support parents of children diagnosed with a disability. It forms part of Scope's Response service, which provide advice and information to disabled people across the country. All F2F befrienders are parents of a child with a disability. Many befrienders have used the service and move on to befriending as a form of self actualisation. Befrienders visit at home or another convenient location. The support is informal and flexible and designed to meet individual need. Support is offered to parents of children with any type of disability or special need. However, the single biggest group supported by F2F is families with a child diagnosed with an autistic spectrum disorder. Support may consist of one visit or be sustained over several months. On average parents seek support for 3-6 months and the average level of support is approximately one hour a week. Every befriender receives 40 hours of training delivered over a 10 week period by British Association of Counselling & Psychotherapy (BACP) registered counsellors and ongoing group support whilst befriending. Each F2F scheme is run by a professional co-ordinator (who is often a parent of a disabled child

themselves) who has links to professionals and other relevant organisations in the area. Parents are able to self refer but many are referred by health and social care professionals.

F2F currently has over 85 schemes around the country, with over 800 volunteers, covering approximately 25% of the country. It is primarily funded by service level agreements with Social Services and PCTs. Each scheme forms part of the national F2F network which co-ordinates the service and supports new schemes to develop. The aims of F2F are to provide emotional support that helps parents understand their emotional journey in response to their child's disability to increase participation and reduce barriers to inclusion. Between March and June 2010 F2F provided support to approximately 16,000 families.

F2F also has an online and telephone befriending service which complements the F2F schemes and offers the same support primarily for those living in geographical areas where there is no appropriate F2F group and those who prefer these methods of communication.

The provision of peer support has the potential to mitigate some of the problems faced by families of disabled children and to have a significant positive impact on later outcomes.

The Health Problem:
According to Contact a Family (www.cafamily.org.uk) there are 770,000 disabled children under the age of 16 in the UK. This equates to one child in twenty. Devon County Council reports that there are10,900 children in Devon who have special educational or additional needs and receive support paid for by DCC. Most (98%) of disabled children live at home and are supported by their families. Families of disabled children face considerable challenges. For example disabled children are more likely to live in poverty than non-disabled children; families have lower than average incomes yet the cost of raising a child with additional needs is up to 3 times higher. Families of disabled children commonly experience relationship problems, stress, depression and lack of sleep. Disabled children often have problems at school and are up to 13 times more likely to be excluded. Many of these problems are related to lack of awareness of appropriate services and benefits and lack of access to appropriate supportive networks. With substantial cuts in social services planned these pressures and difficulties are likely to become worse.

Estimates suggest that approximately 5% of school children in England and Wales have some form of ADHD; significant numbers of these children will be undiagnosed. The prevalence of autism spectrum disorders in the general population is believed to be approximately 1 in 100.

Guidelines:
We were unable to find any NICE guidelines on the use of peer support for parents with disabled children.

The new Government has committed to joining up commissioning of health and social care and creating and Outcomes Framework to hold commissioners to account. Explicitly, the framework will include children, and there is commitment to 'support local health, education and social care services to work together for children and families'. Appropriate health and social care for families of children with chronic lifelong disability should improve social inclusion and wellbeing as key aspects of a healthy life.

NHS Priority:
Regional
SW SHA Priorities framework 2008-11
The SW SHA recognises that the children of the South West are its future, and good health, unhindered development and a healthy environment are the right of every child. Therefore one of the priorities for improving health in the South West is Children and Young People.

Local
- Improving mental health and wellbeing is a priority for Plymouth PCT and Cornwall and Isles of Scilly PCT.
- Carers support is a priority for Cornwall and Isles of Scilly PCT and NHS Devon.
- Improving mental health and learning difficulties is a QIPP priority.

Existing Research:

Published research
We were not able to identify any published evaluations of the F2F service nor did we find any existing systematic reviews of peer support for parents of disabled children delivered on an individualised, flexible and informal basis. We found four studies of peer support delivered by matched, trained supporting parents; a qualitative studies in parents of children with congenital upper limb deficiency[3], one mixed methods study in parents of children with chronic lung disease requiring technology assistance[5], one study of parents of children with cerebral palsy[6] and a comparative trial of parents with children in a neonatal intensive care unit[4] 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.[4] Benefits reported in other studies include the provision of much needed emotional, social and practical support[3], reduced feelings of isolation, increased knowledge and an important sense of feeling understood[5] and improvement in parental mental health[6].

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.[1]

Another mechanism for providing peer support might be via online or virtual communities. A systematic review of health-related communities and electronic support groups identified six evaluations of peer-to-peer online communities. Most of the studies included other programmes within complex interventions, preventing any conclusions on the effectiveness of electronic support groups or online communities to be made.[2]

Ongoing research
No ongoing research on this topic was identified.

<u>**Feasibility:**</u>
This question has been developed from an idea suggested by parents who are part of the Cerebra Research Unit.

There are several F2F groups within the Peninsula; a large group of 70 befrienders in Cornwall, a small and evolving group in Plymouth and a group of 22 befrienders in Exeter and East Devon. The group in Exeter and East Devon is funded by a local charity called 'A Brighter Tomorrow'.

<u>**References:**</u>

1. 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." <u>J Pediatr Psychol</u> **23**(2): 99-109.
    OBJECTIVE: To examine qualitatively the experiences of parents participating in Parent to Parent programs. METHOD: Twenty-four parents of children with special needs, a subset of subjects in a larger quantitative study, participated in a semi-structured telephone interview to explore the impact and meaning of being matched with a trained supporting parent. RESULTS: Qualitative analysis reveals a successful match is contingent upon creation of a "reliable ally" in the supporting parent, comprised of four main components: (1) perceived sameness, (2) situational comparisons that enable learning and growth, (3) round-the-clock availability of support, and (4) mutuality of support. CONCLUSIONS: Parent to Parent support creates a community of similar others trained to listen and be supportive and provides an opportunity for matched parents to experience equality and mutuality in their relationship. Findings also identify the need for quality control in Parent to Parent programs and the importance of such programs as an adjunct to traditional professional services.

2. Eysenbach, G., J. Powell, et al. (2004). "Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions." <u>BMJ</u> **328**(7449): 1166.

OBJECTIVE: To compile and evaluate the evidence on the effects on health and social outcomes of computer based peer to peer communities and electronic self support groups, used by people to discuss health related issues remotely. DESIGN AND DATA SOURCES: Analysis of studies identified from Medline, Embase, CINAHL, PsycINFO, Evidence Based Medicine Reviews, Electronics and Communications Abstracts, Computer and Information Systems Abstracts, ERIC, LISA, ProQuest Digital Dissertations, Web of Science. SELECTION OF STUDIES: We searched for before and after studies, interrupted time series, cohort studies, or studies with control groups; evaluating health or social outcomes of virtual peer to peer communities, either as stand alone interventions or in the context of more complex systems with peer to peer components. MAIN OUTCOME MEASURES: Peer to peer interventions and co-interventions studied, general characteristics of studies, outcome measures used, and study results. RESULTS: 45 publications describing 38 distinct studies met our inclusion criteria: 20 randomised trials, three meta-analyses of n of 1 trials, three non-randomised controlled trials, one cohort study, and 11 before and after studies. Only six of these evaluated "pure" peer to peer communities, and one had a factorial design with a "peer to peer only" arm, whereas 31 studies evaluated complex interventions, which often included psychoeducational programmes or one to one communication with healthcare professionals, making it impossible to attribute intervention effects to the peer to peer community component. The outcomes measured most often were depression and social support measures; most studies did not show an effect. We found no evidence to support concerns over virtual communities harming people. CONCLUSIONS: No robust evidence exists of consumer led peer to peer communities, partly because most peer to peer communities have been evaluated only in conjunction with more complex interventions or involvement with health professionals. Given the abundance of unmoderated peer to peer groups on the internet, research is required to evaluate under which conditions and for whom electronic support groups are effective and how effectiveness in delivering social support electronically can be maximised.

3. Kerr, S. M. and J. B. McIntosh (2000). "Coping when a child has a disability: exploring the impact of parent-to-parent support." <u>Child Care Health Dev</u> **26**(4): 309-22.

AIM: To explore the impact of parent-to-parent support when a child is born with a disability. DESIGN: The research approach was qualitative. Data were collected retrospectively and were derived from in-depth interviews with parents. The audio-taped interviews were transcribed and then analysed using constant comparative procedures. SETTING: Scotland. PARTICIPANTS: The parents of 63 children born with a congenital upper limb deficiency. FINDINGS: The early weeks and months following the birth of their baby was a difficult and emotional time for most parents. Feelings of isolation were common and there

was a lot of concern about what the future would hold. Although a certain amount of support was derived from contact with family, friends and health professionals, parents did not generally obtain the level of support that was required from these sources. Contact with other parents of limb-deficient children, however, clearly exerted a powerful stress-buffering influence, providing much needed emotional, social and practical support. CONCLUSIONS: This study suggests that parents of children with special needs are uniquely qualified to help each other. The challenge is to ensure that health professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about appropriate local organizations/ contacts.

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

When infants are admitted to a neonatal intensive care unit, the parents are immediately confronted with the crisis surrounding a critically ill newborn and often require additional support. Parents experience feelings of anxiety, fear, anger, and guilt over this unanticipated event. In addition, parents often describe the withdrawal of friends and the denial responses of well-meaning family members during their infant's illness. In an effort to address the NICU parents' need for support, Butterworth Hospital in collaboration with Michigan State University initiated a demonstration and research project focused on parent-to-parent support. The primary goal of the program is to improve parenting outcomes by providing emotional, informational, and role modeling support to parents of high-risk infants utilizing experienced volunteer parents. The program model includes professional program coordinators who recruit and train volunteer parents with past NICU experience. Volunteers are then matched to new NICU families based on infant's diagnosis, similar geographic location, and other characteristics. Volunteers provide support through hospital visits, phone contact, and home visits during the infant's hospitalization and throughout the infant's first year of life. The program was evaluated by analyzing the differences between a treatment group and a comparison group of parents. Significant differences between groups were found on measures of maternal mood states, maternal-infant relationships, and home environment. Services to over 900 families by 110 volunteer parents have convinced staff that the volunteer parents are a valuable and indispensable component of the services at Butterworth Hospital and that families of high-risk infants benefit from past experiences and ongoing support of volunteer parents.

5. 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." <u>Soc Work Health Care</u> **44**(3): 245-59.

This study evaluated a dyadic peer support pilot intervention for parents of technology-assisted children with chronic lung disease. These medically-fragile children, living at home in the primary care of their parents, require continuous or intermittent assistance from technological support such as home oxygen, respiratory or cardiac monitors and/or mechanical ventilators. The intervention

consisted of matching parents with similar caregiving responsibilities, in order to reciprocally engage in parent-to-parent support. Results identified mixed outcomes based on quantitative and qualitative methods. Participants conveyed benefits and limitations of this modality of peer-based support. They generally favoured peer support as a clinical resource for caregiving parents as the intervention offered a valued opportunity for mutual sharing with another parent who could understand the unique realities particular to caring for a medically-fragile child. Sharing daily experiences was reported to reduce isolation, increase knowledge, and provide an important sense of feeling understood. Challenges associated with peer support included scheduling difficulties and personality incompatibility. Recommendations for program development in clinical settings are described.

6. 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." International Journal of Rehabilitation Research **29**(4): 281-8.