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

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On behalf of the study stakeholder group

Acknowledgements

We acknowledge that some of the content of this report has been published elsewhere. These publications have been referenced in the text. Where possible, we have made changes to avoid direct duplication however the content of some tables remains the same.
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Plain language summary

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:

1. 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.

2. 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 began and completed 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.

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?
This 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.

We will also send summaries and the full report to people who might commission peer support services or those who might refer families.

We hope that the findings will help people make informed decisions about peer support.
Background and previous research

Peer support is increasingly recognised as an important part of healthcare for many different groups of patients and carers. However it is often not very well defined, and is often delivered in a variety of very different ways, making it difficult to establish if and how different types of peer support work, and to make robust comparisons between types of support.¹

For the purpose of this project we use the following definition of peer support:

“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”¹

Or more simply, emotional and practical support given by people who have had similar experiences themselves. A peer is “an individual who shares common characteristics with the ‘targeted’ group or individual, allowing her/him to relate to, and empathise with, that individual on a level that a non-peer would not be able to.”² The defining feature of peer support is that it is support offered by people who have had similar experiences. This ‘shared experience’, allows a sense that that person understands what you are going through because they have been there themselves.

There are many different types of support that fall under the umbrella of ‘peer support’ ranging from informal contact with other parents, such as chance encounters in the waiting room or at meetings, through internet and face to face support groups to one-to-one support offered by volunteer, trained befrienders. Different types of support differ in terms of the level of support for families and the investment from the person/organisation providing the support, such as the cost of delivering the service e.g. time and money to train supporters. Support also differs in terms of the provider (professionally led programmes or volunteer organisations) and the degree of structure and supervision imposed.

There is ample evidence that parents of disabled children are at increased risk of relationship problems, stress, depression and lack of sleep.³ Family relationships may suffer through exhaustion and stress and parents report feeling isolated, lonely and unsupported.⁴ Parents have reported adverse physical and mental effects which they attribute both to the actual demands of caring and to anxiety about their child’s health and future.⁵ Parents have described how they would like more contact with other parents of disabled children to share information, advice and social support.⁶ Even the opportunity to talk to other parents in the waiting room can be a valued means of support for some parents,⁷ while recurring parent groups offer a high level of support encouraging a sense of
belonging and for exchange of information and skills for dealing with day to day issues. Good leadership, local funding, practical support and flexibility to meet the needs of the participants have all been associated with successful groups.

Meeting other parents can reduce isolation and help parents feel that they belong and parents can share coping strategies and information. Being able to share their own expertise and knowledge can also help parents feel valued and more self-confident. Peer support can help parents understand what information and services are available to them as well as offering an important source of emotional support and sense of shared experience and purpose. Support groups and one to one support may vary considerably in their focus and targets. Some will focus more on emotional support whereas others may be more concerned with providing information, education or advocacy. Emotional support is proposed to reduce distress by enabling the person to speak about their feelings and restoring self esteem whereas informational support is thought to have the potential to help the person feel more in control and better able to cope with their situation.

A number of psychological theories are thought to underpin peer support, including social support, experiential knowledge, helper-therapy principle, social learning theory and social comparison theory. However the complex nature of peer support has made it difficult to use traditional research methods to test these theories. Objectively measuring the impact of peer support is challenging for a number of reasons, for example the difficulty of evaluating the intervention in isolation from the other types of social and professional support parents receive, which varies between and within the individual.

Appropriate health and social care for families of disabled children should promote social inclusion and wellbeing as key aspects of a healthy life; however, such services must provide value for money. Hence there is a need for evaluation of effectiveness and cost effectiveness. We conducted an evaluation of the one-to-one befriending service offered to parents of disabled children by Face2Face (F2F) in Devon and Cornwall. This evaluation is intended to have direct use for potential funders and organisers of this type of service by providing a detailed picture of the resources and inputs needed to deliver the intervention and their costs. Second, it sought to be a pilot to inform how the effectiveness and cost effectiveness of providing peer support to parents of disabled children might be evaluated in larger definitive studies.
Aims and objectives

This research is a pilot evaluation of a one to one peer support programme offered to parents of disabled children in Devon and Cornwall by a charitable organisation, Face2Face (F2F). Information gathered from this study will inform the development of a protocol for larger scale more definitive evaluations of the effectiveness and cost effectiveness of peer support programmes for parents of disabled children. The research explored the benefits and costs of the F2F service by addressing the following research questions:

a. In what context is peer support for parents offered?
b. What is the nature of the intervention and how is it presumed to work?
c. Who benefits from peer support?
d. What are the key outcomes of peer support?
e. What are the resources needed to provide the F2F peer support service?

We used the model of the Centre for Disease Control and Prevention (CDC) Framework for Programme Evaluation as the basis for designing the project. The CDC Framework for Programme Evaluation identifies 6 steps around which to design an evaluation, shown in Figure 1. This report presents the research using the steps outlined in the CDC framework.

Figure 1: The CDC framework for programme evaluation
Engaging stakeholders – Parent, Carer and Public Involvement and Engagement in a programme evaluation

The involvement of families of disabled children in all aspects of research is central to the ethos of the Peninsula Cerebra Research Unit (PenCRU). The idea for this research grew from a topic raised by a parent working with the unit.

At the outset of the study we formed a project stakeholder group to advise on the study design, conduct and its outputs. The members comprise the research team, 3 members of the PenCRU Family Faculty, 4 befrienders and the local coordinator from the Face2Face service, representatives from relevant local and national charities (Scope, Cerebra, Council for Disabled Children, Contact a Family, A Brighter Tomorrow), a local GP, and 2 representatives from Devon County Council. A further 4 parents from the family faculty participated in an event to develop a plain language summary of the systematic review.

The group did not receive formal training for their involvement but were supported by members of the research team. Those who were not attending in a professional capacity were offered £25 per half day in acknowledgement of their time and contribution.

The stakeholder group has had extensive involvement in the study from conception, specifically: (i) setting the research questions, (ii) contributing to the study protocol, (iii) setting inclusion/exclusion criteria and outcomes for the systematic review and writing a plain language summary of the review findings, (iv) development of participant information leaflets, data collection forms and interview topic guides, (v) as an expert reference group to advise on emerging themes from qualitative analysis, (vi) helping us to interpret the findings and deciding the key messages (vii) formulating a strategy to disseminate the findings from this research.

The impact of PPI was not formally evaluated as part of the research however during the final meeting of the stakeholder group in November 2013 we reflected on i) how the group had been involved and what impact they felt they had had on the research and ii) what, if any, impact that being involved in the research had had for them personally.

**Impact of the stakeholder group on the research**

The group felt that they brought specialised and experiential knowledge to the research, helping the research team to understand real life. They helped in the research design and to frame research questions complementing the research expertise; had the research been done in isolation from parents, it wouldn’t have been so practically useful and relevant.
The group identified several challenges such as making sure it is not always those who are most committed to the topic that drive the agenda. They also noted that, while the mix of stakeholders was important and valuable, it was disappointing and detrimental to the process that more influential professionals were not involved.

An important observation was the relationship between the research team and the stakeholder group. There can be challenges in maintaining the objectivity/independence of the researcher if working closely together over a period of time with a stakeholder group who are passionate about the topic of research.

The group were aware that group discussions can sometimes go in different directions than those planned by the research team and might lead away from the specific research/meeting agenda. The alternative view is to see this as a positive impact as it adds in richness to the discussion that can bring a different perspective on the research.

Maybe we were like the buffers on a bowling alley; keeping the content from going off into pointless areas. But then again I think we brought in a fair amount of pointless content; (I am seeing bowling balls landing with that uncomfortable thud)

There are challenges around measuring the impact of involvement and sometimes stakeholders underestimate the impact they have had on the research process. Better documentation of ‘what changed’ at each stage of the research after a meeting or email exchange may help to make it clearer to the stakeholder group the direct link between their input and changes in the research design, which might increase the value they place on their contribution. Impact is more tangible when there is a direct product or outcome from a meeting such as a questionnaire or a summary.

**Impact of the research on the stakeholder group**
The parents in our stakeholder group felt that being involved had considerable positive impact for them. Being part of the stakeholder group had helped boost their confidence. This is important to parents of disabled children who often feel that when they assume the role of parent/carer they lose confidence and a sense of having a valued role in society; often having given up their professions to care for their children.

*Becoming a parent carer is like being catapulted into a life that you just did not expect. I was a professional beforehand but that all had to be forgotten. So you end up being deskill and then no one expects anything more from you so you do not get to use the old grey cells and then you forgot how to use them. Involvement gives you a direction out of the fog; some empowerment and a change to skill up again. It is literally so exciting to ‘just get out’ for something that’s not on the child’s agenda.*
As members of the stakeholder group they felt valued and that their opinion was listened to and could make a difference. Important was a sense that their participation was not tokenistic box-ticking. As such, they felt that being in the stakeholder group for this study had led them to want to be involved in more research, time permitting.

Time was one on the negative aspects of involvement identified by the group. The stakeholder group was set up to be flexible and to allow people to dip in and out as their lives demanded. However, those members who wanted to participate as fully as possible committed considerable time to the project; other valued activities had to be missed and considerable time was spent travelling. The group described sometimes feeling guilty if they were unable to come to meetings; not because the research team made them feel that way but because they wanted to contribute to the research process.

It is important that we as researchers remember that many of the members of our stakeholder groups are talking about their own lives and experience which can sometimes be very painful for them. Some of the parents in our group acknowledge that it can be emotionally difficult to relive some of their experiences in discussions about research however it also offered a positive opportunity to recognise how far they had come.
Describing the programme

Face2Face is a third sector enterprise and forms part of the charity Scope’s Information and Support service which provides advice and information to disabled people across the country. Each local F2F scheme is run by a professional co-ordinator (usually a parent of a disabled child themselves) who has links to health and social care professionals and other relevant organisations in the area and has a group of trained parent volunteers called befrienders who support parents of disabled children. At the time this report was prepared (December 2013), plans were underway at Scope to recruit a National Parent Support Development Manager who would help to support the network of local services at a national level, be responsible for quality assurance and good practice, raise awareness of F2F and be involved in establishing new services nationally. Some of the services are directly managed by Scope. Table 1 provides details of the size and structure of the services managed directly by Scope. Externally managed services have varying levels of contact with Scope and are structured differently. There are a further 16 externally managed services listed on the Scope website. Details of these services can be found at [www.scope.org.uk/face2face](http://www.scope.org.uk/face2face).

The F2F service is accredited with the Mentoring and Befriending Foundation’s Approved Provider Standard (Table 2). This is the national quality standard designed specifically for mentoring and befriending projects ([www.mandbf.org](http://www.mandbf.org)).

Table 2: Standards for Mentoring and Befriending Foundation’s Approved Provider accreditation

<table>
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<th>Element 1</th>
<th>The project or service has a clear rationale and purpose</th>
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<tr>
<td>Element 2</td>
<td>Effective organisational and management structures</td>
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<td>Element 3</td>
<td>The competence of staff involved in the project is developed and maintained</td>
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<td>Element 4</td>
<td>There is a clear process for the identification and referral of service-users</td>
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<td>Element 5</td>
<td>Service-users are fully briefed about the project or service</td>
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<td>Element 6</td>
<td>Rigorous recruitment and selection process for volunteers</td>
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<td>Element 7</td>
<td>Safeguarding the involvement of participants in the project</td>
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<td>Element 8</td>
<td>Adequate preparation and training is in place for volunteers</td>
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<td>Element 9</td>
<td>Process in place for matching service users with mentors/befrienders</td>
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<tr>
<td>Element 10</td>
<td>Supervision and support provided for mentors/befrienders</td>
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<td>Element 11</td>
<td>Monitoring of relationships</td>
</tr>
<tr>
<td>Element 12</td>
<td>Evaluation of project effectiveness</td>
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### Table 1: Face2Face services managed by Scope.

**Face 2 Face Service Details – May 2013**

<table>
<thead>
<tr>
<th>Name of Service</th>
<th>Funder</th>
<th>Make up of area (i.e. urban or rural)</th>
<th>Number of staff</th>
<th>Number of befrienders</th>
<th>Elements of F2F Service Offered (i.e. befriending, oasis/support groups, dads groups, family days etc.)</th>
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<tbody>
<tr>
<td><strong>North Region</strong></td>
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<tr>
<td>Lancashire F2F</td>
<td>Big Lottery</td>
<td>urban and rural</td>
<td>1 co-ordinator (30 hours)</td>
<td>20</td>
<td>Befriending and support group. Enhancing service to include Sleep Solutions 121 work with families, 3 sleep workshops, 3 information days per year plus 1 family event</td>
</tr>
<tr>
<td>Wigan F2F</td>
<td>Big Lottery</td>
<td>urban and rural</td>
<td>1 co-ordinator (30 hours)</td>
<td>12</td>
<td>Befriending and support group. Enhancing service to include Sleep Solutions 121 work with families, 3 sleep workshops, 3 information days per year plus 1 family event</td>
</tr>
<tr>
<td>Alder Hey, Liverpool F2F</td>
<td>Alder Hey Charitable Trust</td>
<td>urban</td>
<td>1 co-ordinator (30 hours)</td>
<td>12</td>
<td>Befriending and support group. 1 information day</td>
</tr>
<tr>
<td>N.E. Lincolnshire F2F</td>
<td>People’s Health Trust</td>
<td>urban</td>
<td>1 co-ordinator (17.5 hours)</td>
<td>5</td>
<td>Befriending and support group. Information days and sleep work shops</td>
</tr>
<tr>
<td>Tyne and Wear F2F</td>
<td>Private Donor</td>
<td>urban and rural</td>
<td>1 co-ordinator (35 hours)</td>
<td>New service - In process of recruitment</td>
<td>Planned – Befriending and support group. Information days and sleep workshops. Family days Summer and Christmas</td>
</tr>
<tr>
<td>Halton F2F</td>
<td>People’s Health Trust</td>
<td>urban</td>
<td>1 co-ordinator (17.5 hours)</td>
<td>New service - In process of recruitment</td>
<td>Planned – Befriending and support group. Information days and sleep workshops. Family days, Summer and Christmas</td>
</tr>
<tr>
<td><strong>Central Region</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northamptonshire F2F</td>
<td>Constance Travis Trust Fund</td>
<td>Urban/rural</td>
<td>1 full time co-ordinator</td>
<td>20</td>
<td>High 5 support group Dad’s group Family days Befriending</td>
</tr>
<tr>
<td>Peterborough F2F</td>
<td>PHT</td>
<td>Urban</td>
<td>1 FT co-ordinator 1 part time worker</td>
<td>9</td>
<td>Befriending</td>
</tr>
<tr>
<td>Thurrock F2F</td>
<td>PHT</td>
<td>Urban/Seaside</td>
<td>1 FT co-ordinator</td>
<td>0</td>
<td>New service – Befriender training to start in September</td>
</tr>
<tr>
<td>Name of Service</td>
<td>Funder</td>
<td>Make up of area</td>
<td>Number of staff</td>
<td>Number of befrienders</td>
<td>Elements of F2F Service Offered</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>------------------------------------------</td>
<td>------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Face2Face Solihull</td>
<td>Pamela Green Legacy Trust</td>
<td>Mainly urban with a few small outlying rural communities.</td>
<td>1 x PT Co-ordinator (0.5FTE)</td>
<td>1st cohort - 8 trained (5 active) 2nd cohort – 7 due to complete training June 2013</td>
<td>1-2-1 befriending Parent group for parents of children with SEB difficulties Time2Behave workshops</td>
</tr>
<tr>
<td>Leicestershire</td>
<td>Peoples Health Trust (Health Lottery)</td>
<td>Both as we cover the county and city areas</td>
<td>1 PT co-ordinator</td>
<td>28</td>
<td>Dads/Grandads group, mums/Grandmas group; Support groups; workshops</td>
</tr>
<tr>
<td>Face 2 Face Sandwell</td>
<td>Local Authority &amp; PHT</td>
<td>Urban</td>
<td>2 PT co-ordinators</td>
<td>10</td>
<td>Support groups, dad’s group, stay &amp; play in summer and day trips</td>
</tr>
<tr>
<td>Face2 Face Dudley</td>
<td>Big lottery</td>
<td>Urban</td>
<td>1 PT coordinator</td>
<td>8</td>
<td>Support Groups, Stay &amp; Play in summer &amp; day trips</td>
</tr>
<tr>
<td>Stoke-on-Trent</td>
<td>LA &amp; Health Joint Commissioning</td>
<td>Urban</td>
<td>1 x 32hours 1 x 16</td>
<td>26</td>
<td>1:1 New referrals and on going 2x monthly “Carers” Drop ins Groups Male Carers/ Dads Group Monthly Evening Carers Groups Weekly station at Child Development Centre (CDC ) Multi agency pre-school assessment sessions “Discovery Group” Volunteer Support Meeting</td>
</tr>
<tr>
<td>South Region</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brighton and Hove F2F</td>
<td>Health Lottery</td>
<td>Urban</td>
<td>Part time Co-ordinator</td>
<td>New service - 12 in Training at present – finish on 10th June – launch on 26th June</td>
<td>Support group just started in March and assistance with other support groups on the island</td>
</tr>
<tr>
<td>Isle of Wight F2F</td>
<td>Legacy Funding</td>
<td>Urban</td>
<td>Part time Co-ordinator</td>
<td>6</td>
<td>Support group just started in March and assistance with other support groups on the island</td>
</tr>
<tr>
<td>North Devon</td>
<td>PHT lottery funding</td>
<td>rural</td>
<td>1 PT co-ordinator</td>
<td>9 just finished training</td>
<td>One to One befriending Support to small steps groups</td>
</tr>
<tr>
<td>Cornwall</td>
<td>Local Authority and PHT lottery funding</td>
<td>rural</td>
<td>5 PT co-ordinators 1 team manager 1 finance officer</td>
<td>79</td>
<td>Oasis support groups One to one befriending Family days</td>
</tr>
<tr>
<td>Wales</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Merthyr Tydfil</td>
<td>PHT Lottery Funding</td>
<td>Urban and rural</td>
<td>1 PT Co-ordinator</td>
<td>New service so just recruiting volunteers</td>
<td></td>
</tr>
</tbody>
</table>
The key objectives of the service as outlined in an in-house evaluation in 2009 are to:

- Improve the quality of life of disabled children and their families
- To ensure that parents who discover their child has a disability are supported through befriending to understand their child’s special needs and their own feelings about them
- To communicate the long term benefits to be derived from the empathic presence of a parent who has personal experience of disability in their own child
- To enable parents to become empowered and thereby able to manage their family’s new situation

“Our service makes a positive difference to people’s lives, enables the whole family to have more choice, to be involved in the community and have more contact with family and friends. By supporting the parent to understand their feeling about their child they become empowered and are able to manage their family’s situation and become more optimistic about their child and their family’s future”

All F2F befrienders are parents of a disabled child. Many used the service before becoming befrienders. Befrienders receive 40 hours of training delivered over a 10 week period, by counsellors registered with the British Association of Counselling and Psychotherapy (BACP) and also ongoing group support whilst befriending. Training is viewed as essential to equip volunteers with the skills to befriend to ensure no harm to themselves or the parent they befriend. The training objectives are that befrienders will have developed the communication and relationship skills necessary to support; will understand the issues facing parents around the time of diagnosis; will be able to empathise with parents who may be experiencing difficult feelings; know how to support themselves so that they can support others; understand when they need to signpost to another service.

Befrienders visit parents at their home or another convenient location. The support is informal and flexible and designed to meet individual need. The service is confidential and befrienders sign a confidentiality agreement (with caveats around the safety and wellbeing of the child and parent). Support is offered to parents of children with any type of disability or special need. Parents are able to self refer but many are referred to F2F by health and social care professionals.

Face2Face believe that the service can help to prevent families from reaching crisis point, reducing the need for additional services and family breakdown, thus having a positive impact not only on the family but on other services, professionals and the wider community. Befrienders also anecdotally report a positive impact of training and befriending. Through training and volunteering, parents gain new skills and experiences which boost their confidence and self esteem. Many befrienders have
been empowered by the training and have gone on to further training, while other parents have gone on to resume full time employment.

Parents who have used theFace2Face service have anecdotally reported:
- Improved knowledge of, and ability to access, appropriate services and benefits
- Improved partnership between parents and professionals
- Improved personal coping strategies
- Improved family functioning, and ability of the family to cope and move forward
- Improved personal quality of life, with consequent benefit for the child and siblings
- Improved mental health through reduction in stress levels for parents
- Improved access to informal supportive networks

Whilst the F2F programme has a clear mission and purpose, and the methods used by befrienders have been carefully developed, peer support is a complex intervention. Complexity arises in the F2F intervention due to the individual nature of parents’ needs, flexibility in the responsive support provided, variation between befrienders, the range of potential outcomes, and variation in the way F2F programmes are arranged in different regions.

To evaluate complex interventions it is necessary to develop a thorough understanding of how the intervention creates changes in the expected outcomes as part of any formal evaluation. We interviewed 3 local service coordinators to understand and document the nature of the intervention. Specifically, we charted how the intervention is presumed to work and developed a logic model to explain how the active elements are thought to link to expected outcomes. The logic model (Table 3) charts what the programme is expected to achieve, and how it is presumed to work, based on an expected chain of events that link the clear specification of the problem to what the organisation believes is needed to change the problem to the procedures and activities it produces to the shorter and longer term outcomes. The process model of a befriending relationship is shown in Figure 2.

There is also a need to understand the structure and processes of programmes. Factors such as awareness, referral and/or funding arrangements can influence the capacity of services to deliver outcomes efficiently. In addition, the F2F service is offered in the context of other support services both peer and professionally led. For example, at Parent Consultation events organised by Devon County Council in 3 different regions of Devon in 2011, parents were asked about what local support groups they were aware of or using. Parents identified 37 different support groups and services ranging from small school or church based parent groups, condition specific support groups, non-categorical emotional and informational support services and local authority led services. A number
of parents identified a need for more support for parents and children with additional needs and their families.
### Table 3: Logic model for Face2Face service

<table>
<thead>
<tr>
<th>Problem or issue</th>
<th>Investments</th>
<th>Procedures, activities and products</th>
<th>Short-term outcomes</th>
<th>Longer-term outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grieving process at diagnosis.</td>
<td>Service seeks to redefine normal through one to one support.</td>
<td>All befrienders are parents of disabled children to facilitate genuineness, non-judgemental acceptance and empathy.</td>
<td>Make a positive adjustment.</td>
<td>Maintaining that positive adjustment; being OK; functioning.</td>
</tr>
<tr>
<td>Parents feel that their lives are very abnormal.</td>
<td>Making positive adjustments to your child’s diagnosis providing a sense of family ‘normality’.</td>
<td>Befriending is not a mutual relationship; it is all about the parent.</td>
<td>Confidence and ability to cope with day to day. Increasing inner strength and resilience.</td>
<td>A full life for <strong>everyone</strong> in the family; quality of life for the whole family</td>
</tr>
<tr>
<td>Social isolation; embarrassed of your child; depression.</td>
<td>To support parents through the emotional journey of adapting to their child’s disability.</td>
<td>Training is critical. Befrienders share their own experiences, good and bad. Recognition of your own emotions is an important step to being able to help others.</td>
<td>Managing relationships with professionals.</td>
<td>Inner strength to face each new challenge, to know you are not the only one.</td>
</tr>
<tr>
<td>Struggling to acknowledge your child’s diagnosis and adjusting to a new way of life and the impact that having a disabled child in the family can have.</td>
<td>To empower parents to move on with their lives and enhance their family situation.</td>
<td>Training also develops supporting skills such as listening skills, body language.</td>
<td>Reducing isolation; your befriender has been there, can understand what you are experiencing and can walk alongside you.</td>
<td></td>
</tr>
<tr>
<td>There are constant challenges and adjustment is a continual process. Each new situation can set families back and in need of support. It is an emotional rollercoaster.</td>
<td></td>
<td>The content of a befriending visit is driven by the parent; there is no agreed format or specific goal for the meeting hence measuring the ‘achievement’ of a visit is difficult.</td>
<td>The measure of success is that parents feel able to end the relationship because they no longer need support.</td>
<td></td>
</tr>
</tbody>
</table>

17
Figure 2: Process model of a befriending relationship

Referral received from parent or professional
- Details entered on database

Co-ordinator contacts parent to discuss what Face 2 Face can offer

Establish if befriending is appropriate; if not signpost to other Services e.g.
- Drop in group
- Parent Carer orgs
- Parent Partnership
- Early Support
- GP

Complete referral form

Co-ordinator matches parent with befriender and discusses referral with befriender

Co-ordinator contacts parent with befriender and discusses referral with befriender

Information sheet and introductory letter is sent to parent

Befriender contacts parent to arrange first visit

Befriender completes contact log during befriending period

Co-ordinator telephones befriender and parent after first visit to check all has gone well

Evaluation sheet sent to parent

End of relationship forms and letters sent to parents

Befriending comes to an end

All activities feed into monthly monitoring reports

Befriender attends monthly support group meetings to discuss befriending

Ongoing befriending

Befriending
Focusing the evaluation design

The evaluation design was formalised through discussion and group work with the stakeholder group. Research questions were generated and prioritised on the basis of relevance, interest and feasibility. The methodology included three interrelated strands comprising: systematic review, a costing study, and qualitative research with parents, befriended and health and social care professionals. Table 4 details the prioritised research questions and identifies which part of the project addressed them.

Table 4: Overarching and specific research questions

<table>
<thead>
<tr>
<th>Overarching question</th>
<th>Specific question</th>
<th>Research stream</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what context is peer support offered in Devon and Cornwall?</td>
<td>What other forms of peer support are available in Devon and Cornwall? What are the perceptions and knowledge of key professionals regarding the benefits and outcomes of peer support services?</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>What are the resources needed to provide the peer support service?</td>
<td>How many befrienders are needed and for how much time? What is the average/typical length of time that parents are supported? How many parents are supported? What is the cost of providing the service?</td>
<td>Costing study (F2F specific) Systematic review (peer support generally)</td>
</tr>
<tr>
<td>What is the nature of the intervention, and how does it work?</td>
<td>How is it presumed to work? What elements do parents and befrienders think are most effective?</td>
<td>Systematic review (peer support generally) Qualitative research (F2F specific)</td>
</tr>
<tr>
<td>Who benefits from peer support?</td>
<td>Does peer support benefit different people under different circumstances? Why do some parents engage with peer support and others don’t?</td>
<td>Systematic review Qualitative research</td>
</tr>
<tr>
<td>What are the outcomes of peer support?</td>
<td>What are the perceived outcomes/benefits for parents, families and befrienders? What are the strengths and weaknesses of the F2F service?</td>
<td>Systematic review Qualitative research</td>
</tr>
</tbody>
</table>
Gathering credible evidence

**Systematic review**

The systematic review sought to address the overarching research questions:

(i) What are the resources needed to provide peer support?
(ii) What is the nature of peer support and how is it presumed to work?
(iii) Who benefits from peer support?
(iv) What are the outcomes of peer support?

We also sought evidence regarding costs and cost-effectiveness of peer support programmes. Initial scoping searches suggested a small and disparate literature evaluating the benefits of peer support in this context. However we found 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.

The systematic review has been published. Greater detail can be found in the published paper; therefore for the purpose of this report, the key parts of the methods are restated and only the main findings are presented.

**Methods**

*Search strategy*

We conducted a systematic search using multiple databases using a search strategy designed to include a number of search terms specific to parents and peer support. We screened over 5,000 references. We also searched the online tables of content of key journals and forward and backward citation searches of key authors and included papers. We sought grey literature (literature not published through conventional mean which can include web pages, newsletters, reports etc) through key websites.

*Study selection criteria*

Studies were included if:

The population was parents and caregivers of children with chronic disabling conditions including disabled, chronically or seriously ill children and young people. Studies about bereaved parents, parents of babies in neonatal intensive care or parents of children receiving treatment for cancer were excluded.

The support being offered was informal or formal support offered to parents by parents in the form of one-to-one or group meetings. Internet or telephone support was excluded, as were professionally led or parenting skills training interventions. We did not exclude on the basis of
comparator – hence studies comparing peer support with no peer support, those comparing between different types of support and those with no comparator group at all were eligible for inclusion.

The outcomes of interest were defined by member of our study stakeholder group. We included a broad range of outcomes; studies were eligible for inclusion if they reported on one or more of the following: psychological health of parents; experience of the person offering or receiving peer support; economic implications of peer support programmes; family functioning; accessing services and information; relationships with health professionals and long term impact of peer support.

We assessed all of the included studies for quality before data was extracted. Some studies had interviewed parents about their experiences of support (qualitative methods); other studies had tried to measure the effect of support using questionnaires (quantitative methods). We grouped the reports according to what type of information was reported in the study and then all the information about parent to parent support in each group was brought together, or ‘synthesised’. We then looked for similarities and differences in the findings within and between the groups of studies.

**Results**

Seventeen papers were included in the review, including seven randomised controlled trials that measured the effect of peer support using questionnaires; nine qualitative studies that interviewed parents alone or in focus groups about their experiences of support; and one mixed methods evaluation. Table 5 contains details of the different studies.

Several studies evaluated peer support for parents of children with mixed conditions, others targeted parents of children with specific conditions including dyslexia, limb deficiency, diabetes.

Some of the studies did not give enough detail about the peer support intervention they were studying and several studies were found to be lacking in one or more areas of the quality of methodological design or completeness of reporting. We did not exclude any studies on the basis of quality but we did bear this in mind when we were writing the results.
<table>
<thead>
<tr>
<th>Design</th>
<th>First author (year)</th>
<th>Country</th>
<th>Research objective</th>
<th>Intervention type</th>
<th>Length of intervention</th>
<th>Specific features of intervention (see footnote)</th>
<th>N Inter. Cont.</th>
<th>Children’s ages Range, mean (s.d.)</th>
<th>Children’s conditions (of primary relevance to the study)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualitative interview</td>
<td>Ainbinder (1998)16*</td>
<td>USA</td>
<td>To examine the experiences of parents participating in Parent to Parent programmes</td>
<td>One-to-one support from trained veteran parent</td>
<td>2 months</td>
<td>1,5,8</td>
<td>24 -</td>
<td>1-16yrs, 7yrs</td>
<td>Mixed disability including cerebral palsy, epilepsy, developmental delay, learning disability, hearing/visual impairment and chronic illness</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Bull (2003)17</td>
<td>UK</td>
<td>To identify the principal reasons why parents of dyslexic children attend support groups</td>
<td>Support groups</td>
<td>Variable by parent</td>
<td>1,8</td>
<td>25 -</td>
<td>Not reported</td>
<td>Dyslexia</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Kerr (1999)18</td>
<td>UK</td>
<td>To explore the impact of parent to parent support when a child is born with a disability</td>
<td>Mixture of support types around contact with parents of children with the same condition</td>
<td>Variable by parent</td>
<td>1</td>
<td>63 -</td>
<td>6mth-16yrs</td>
<td>Congenital upper limb deficiency</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Law (2001)20</td>
<td>Canada</td>
<td>To explore the benefits and limitations of participation in a parent support group</td>
<td>Parent-led support groups for parents of children with disabilities</td>
<td>Variable by parent</td>
<td>1</td>
<td>20 -</td>
<td>0-18yrs</td>
<td>Mixed disability including cerebral palsy, communication disorder, acquired brain injury, Duchenne muscular dystrophy, global delay, autism, lupus and seizures</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Lo (2010)21</td>
<td>USA</td>
<td>To explore why Chinese parents of disabled children participated in parent support group and their perceptions of the helpfulness of the support group</td>
<td>Support groups specifically for Chinese families of disabled children</td>
<td>Variable by parent</td>
<td>1</td>
<td>15 -</td>
<td>Not reported</td>
<td>Mixed disability, predominantly ASD but also cerebral palsy, Hunter syndrome, specific learning disability and hearing impairment</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Rearick (2011)24**</td>
<td>USA</td>
<td>To describe parents’ perspectives of the social support provided in the STEP programme</td>
<td>One-to-one support from trained veteran parent</td>
<td>12 months</td>
<td>2,4,5,7,8</td>
<td>21 -</td>
<td>Not reported</td>
<td>Type 1 diabetes</td>
</tr>
<tr>
<td>Design</td>
<td>First author (year)</td>
<td>Country</td>
<td>Research objective</td>
<td>Intervention type</td>
<td>Length of intervention</td>
<td>Specific features of intervention (see footnote)</td>
<td>N Inter. Cont.</td>
<td>Children’s ages Range, mean (s.d.)</td>
<td>Children’s conditions (of primary relevance to the study)</td>
</tr>
<tr>
<td>------------------</td>
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<td>-------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------</td>
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<td>-------------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td>Qualitative interview</td>
<td>Sullivan-Bolyai (2011b)25 **</td>
<td>USA</td>
<td>To describe the parent mentor perspectives of providing social support</td>
<td>One-to-one support from trained veteran parent</td>
<td>12 months</td>
<td>2,4,5,7,8</td>
<td>6 -</td>
<td>Not reported</td>
<td>Type 1 diabetes</td>
</tr>
<tr>
<td>Qualitative focus group</td>
<td>Kingsnorth (2011)19</td>
<td>Canada</td>
<td>To describe the impact of a family facilitator led transition peer support group</td>
<td>Support group led by family facilitator with a disabled child</td>
<td>12 month intervention</td>
<td>2-4, 6-8</td>
<td>8 -</td>
<td>16-21yrs</td>
<td>Communication impairment</td>
</tr>
<tr>
<td>Qualitative focus group</td>
<td>Solomon (2001)23</td>
<td>UK</td>
<td>To describe what parents of children with disabilities and special needs find helpful about participating in mutual support groups</td>
<td>Support groups</td>
<td>Variable by parent</td>
<td>1</td>
<td>43 -</td>
<td>1-26yrs 9yrs (5.5)</td>
<td>Mixed disability: 3 groups targeted “all special needs”, 2 Autism and ASD and 1 dyspraxia</td>
</tr>
<tr>
<td>RCT</td>
<td>Ireys (1996)29</td>
<td>USA</td>
<td>To evaluate a social support intervention for parents of children with JRA</td>
<td>One-to-one support from trained veteran parent</td>
<td>15 months</td>
<td>2-8</td>
<td>25 20</td>
<td>7.7yrs</td>
<td>Juvenile Rheumatoid Arthritis</td>
</tr>
<tr>
<td>RCT</td>
<td>Ireys (2001)28</td>
<td>USA</td>
<td>To evaluate maternal outcomes of a support intervention for families of children with selected chronic illnesses</td>
<td>One-to-one support from trained veteran parent</td>
<td>15 months</td>
<td>2-8</td>
<td>86 75</td>
<td>7-11yrs</td>
<td>Diabetes, sickle cell anaemia, moderate to severe asthma, or cystic fibrosis</td>
</tr>
<tr>
<td>RCT</td>
<td>Silver (1997)32</td>
<td>USA</td>
<td>To assess psychological outcomes of a support intervention for mothers of children with ongoing health conditions</td>
<td>One-to-one support from trained veteran parent (not condition matched)</td>
<td>12 months</td>
<td>2-7</td>
<td>183 182</td>
<td>Int. Cont. 7.2yrs 7yrs</td>
<td>Ongoing health conditions predominantly asthma, sickle cell anaemia, epilepsy or congenital heart disease</td>
</tr>
<tr>
<td>RCT</td>
<td>Singer* (1999)31</td>
<td>USA</td>
<td>To evaluate parent to parent programmes for parents of disabled children</td>
<td>One-to-one support from trained veteran parent</td>
<td>2months</td>
<td>1,5,8</td>
<td>56 72</td>
<td>Int. Cont. 6.9yr 7.7yr (4.69) (7.8)</td>
<td>Mixed disability: not described in paper but see Ainbinder et al (1998)11</td>
</tr>
<tr>
<td>RCT</td>
<td>Sullivan-Bolyai (2004)30</td>
<td>USA</td>
<td>To examine the feasibility of a post diagnosis parent mentoring intervention for mothers of children with type 1 diabetes</td>
<td>One-to-one support from trained veteran parent</td>
<td>6 months</td>
<td>2,4,5,7,8</td>
<td>22 20</td>
<td>1-10yrs 5yrs (3.0)</td>
<td>Type 1 diabetes</td>
</tr>
<tr>
<td>RCT</td>
<td>Sullivan-Bolyai (2010)27 **</td>
<td>USA</td>
<td>To test the efficacy of a social support intervention for parents of children newly diagnosed with type 1 diabetes</td>
<td>One-to-one support from trained veteran parent</td>
<td>12 months</td>
<td>2,4,5,7,8</td>
<td>30 28</td>
<td>1-12yrs 6yrs (2.86)</td>
<td>Type 1 diabetes</td>
</tr>
<tr>
<td>Pilot study nested in RCT</td>
<td>Sullivan-Bolyai (2011a)26**</td>
<td>USA</td>
<td>To pilot test a social support intervention for fathers of children newly diagnoses with type 1 diabetes</td>
<td>One-to-one support from trained veteran parent</td>
<td>12 months</td>
<td>2,4,5,7,8</td>
<td>19 9</td>
<td>1-12yrs 6 yrs (2.86)</td>
<td>Type 1 diabetes</td>
</tr>
<tr>
<td>Design</td>
<td>First author (year)</td>
<td>Country</td>
<td>Research objective</td>
<td>Intervention type</td>
<td>Length of intervention</td>
<td>Specific features of intervention (see footnote)</td>
<td>N</td>
<td>Children's ages Range, mean (s.d.)</td>
<td>Children's conditions (of primary relevance to the study)</td>
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</tr>
<tr>
<td>Mixed methods</td>
<td>Nicholas (2007)</td>
<td>Canada</td>
<td>To evaluate a dyadic peer support intervention for caregiving parents of technology assisted children with chronic lung disease</td>
<td>One-to-one matched parents for mutually beneficial information sharing and support</td>
<td>4 months</td>
<td>2,3,8</td>
<td>34</td>
<td>- 2mth-6.5yrs 2.2yrs 2mths</td>
<td>Chronic lung diseases</td>
</tr>
</tbody>
</table>

Features of the intervention explicitly stated in paper:
1. Study is of existing support group/service
2. Support was designed by the researcher
3. Number of contacts is largely predetermined by the research
4. Content of contacts is to some degree predetermined by the researcher
5. One to one supporters/group leaders have training
6. One to one supporters/group leaders are paid
7. One to one supporters/group leaders have professional supervision/coordination
8. Parent and supporter/support groups are matched for diagnosis
**Table 6: qualitative study findings**

<table>
<thead>
<tr>
<th>Synthesis theme</th>
<th>First author (year)</th>
<th>Author theme</th>
<th>Key message from author theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>health benefits of social identity</td>
<td>Aibinder (1998)</td>
<td>Perceived sameness</td>
<td>The importance of the shared experience, an understanding and compassion without judgement that does not exist in other relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>In the most successful matches, parents perceived sameness in their situations but also in their personalities and backgrounds</td>
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<td></td>
<td></td>
<td></td>
<td>Availability of support</td>
</tr>
<tr>
<td></td>
<td>Bull (2003)</td>
<td>The availability of informal support for parents</td>
<td>Parents described varying levels of stress that were not related to the child’s degree of learning difficulty, rather, to the level of informal social support they perceived, or lack of, within their existing social network</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emotional support for parenting a child with learning difficulties</td>
<td>Stress, a sense of not coping and a perceived lack of informal social support led many parents to seek emotional support through the group, sometimes triggered by a specific event such as the experience of obtaining a statement</td>
</tr>
<tr>
<td></td>
<td>Kerr (1999)</td>
<td>The realisation that you are not alone</td>
<td>The knowledge that other people are in the same situation can reduce feelings of isolation and can represent a turning point for parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Someone who understands</td>
<td>People who are not in a similar situation were deemed not able to truly understand</td>
</tr>
<tr>
<td></td>
<td>Kingsnorth (2011)</td>
<td>Personal challenges</td>
<td>Group participation allowed parents to make social comparisons and feel ‘sameness’ with other parents in similar situations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experiential knowledge</td>
<td>Parents saw each other as expert and valued the different perspectives each could bring to a situation, which fostered a sense of belonging, mutual support and empowerment within the group</td>
</tr>
<tr>
<td></td>
<td>Law (2001)</td>
<td>Developing a sense of belonging</td>
<td>Support groups provide parents with a secure environment in which to share experiences and concerns, providing an emotional support and understanding often not available in other areas of their lives – thus reducing the sense of isolation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Knowing that support was on hand at any time if needed provided security. This could result in a sense of loss if a group disbanded</td>
</tr>
<tr>
<td></td>
<td>Lo (2010)</td>
<td>Meeting other Chinese parents of children with disability</td>
<td>Acceptance of disability was difficult for parents and the group offered a safe environment where they were not “different” and were able to share frustrations and challenges and seek help. Disability is particularly marginalised in the Chinese community</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Development of a sense of trust and belonging</td>
<td>Participants broadened their social and support networks, meeting outside of the group with and without their children. This social contact was important even to families who did not find the support group itself beneficial</td>
</tr>
<tr>
<td></td>
<td>Nicholas (2007)</td>
<td>Impacts of support</td>
<td>Parents valued the opportunity to share with someone who could really understand – in contrast to their normal social network. This was seen to be beneficial to the parents’ sense of coping</td>
</tr>
</tbody>
</table>

25
<table>
<thead>
<tr>
<th>Synthesis theme</th>
<th>First author (year)</th>
<th>Author theme</th>
<th>Key message from author theme</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Elements of support</td>
<td>Parents actively sought to identify commonalities to strengthen the relationship</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rearick (2011)</td>
<td>Availability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Availability</td>
<td>Parents took comfort in the knowledge that help was on hand – which contributed to reducing feelings of stress and being overwhelmed. This knowledge continued to offer support even when parents needed less help over time.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Common ground</td>
<td>Common ground</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Parents felt that only parents with similar children could truly understand – mentors had been there before, struggled with diagnoses and moved on. Interactions with mentors increased confidence and validated emotions – providing a sense that they weren’t the only people going through this</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Solomon (2001)</td>
<td>Community/belonging</td>
<td>Group membership enabled parents to overcome feelings of isolation, loneliness and guilt through acceptance, value and understanding from people with a shared experience and expanded parents social network through a sense of sameness and belonging rather than trying to “fit”</td>
</tr>
<tr>
<td>Learning from others/building hope for the future/practical info but also inspiration/empowerment/wisdom</td>
<td>Ainbinder (1998)</td>
<td>Learning practical skills and useful information</td>
<td>Peer support enables parents to learn about themselves and their child through comparison with parents who have been in the same situation. This can provide not only practical information but reassurance and confidence for the future.</td>
</tr>
<tr>
<td></td>
<td>Bull (2003)</td>
<td>A recent diagnosis of a learning difficulty</td>
<td>Some parents joined a support group as part of a more general information seeking activity around the time of diagnosis.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expectations and satisfaction with the support group</td>
<td>Parents who sought information were generally satisfied, being able to glean knowledge from other parents. Those seeking emotional support had often attended at a time of crisis seeking the sympathetic ear of similar people.</td>
</tr>
<tr>
<td></td>
<td>Kerr (1999)</td>
<td>A glimpse into the future</td>
<td>Meeting other parents enabled them to develop a more positive outlook for the future and assurance that their child, like others people’s, would cope.</td>
</tr>
<tr>
<td></td>
<td>Kingsnorth (2011)</td>
<td>Personal challenges</td>
<td>Social comparisons and shared situations empowered parents to tackle specific concerns and anxieties around transition and transition planning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Shifting viewpoints</td>
<td>Group membership enabled parents to think more positively about their child’s future and what they might achieve. Parents benefited from each other’s viewpoints and experiences.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge building</td>
<td>Sharing of concrete information was a primary focus as well as topics relating to participation and independence. The shared experience and knowledge raised awareness of these issues and opportunities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Experiential knowledge</td>
<td>“expert” parent provided a motivational role model; parents were able to benefit from expertise but still experience the ‘sameness’ validation and comfort of another parent that was not the same with professionals.</td>
</tr>
<tr>
<td></td>
<td>Law (2001)</td>
<td>Developing a sense of belonging</td>
<td>Commonality enabled parents to learn from each other’s current and past experiences and work in partnership to deal with issues.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>A way of dealing with the world</td>
<td>The shared experience and problem solving with other parents was as important as the advice of professionals.</td>
</tr>
<tr>
<td></td>
<td>Lo (2010)</td>
<td>Feeling empowered and confident</td>
<td>Parents reflect and reappraise their own situations and challenges through comparison with others, this gave parents greater confidence in themselves and their children’s future.</td>
</tr>
<tr>
<td>Synthesis theme</td>
<td>First author (year)</td>
<td>Author theme</td>
<td>Key message from author theme</td>
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</tr>
<tr>
<td>Availability</td>
<td>Rearick (2011)</td>
<td>Practical tips</td>
<td>Parents valued the availability and knowledge of their mentors and would sometimes contact them with questions and concerns rather than the health care team.</td>
</tr>
<tr>
<td>Informational support</td>
<td>Sullivan-Bolyai (2011b)</td>
<td>Mentors viewed informational support as a key part of their role drawing on examples from their own experiences and expertise to help parents to gain confidence to resolve their own issues in the future.</td>
<td></td>
</tr>
<tr>
<td>Affirmational support</td>
<td>Sullivan-Bolyai (2011b)</td>
<td>Mentors were able to reassure and validate parents feelings and concerns and offer hope for the future.</td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td>Sullivan-Bolyai (2011b)</td>
<td>Many interactions focused on providing emotional support, allowing parents to simply talk without judging.</td>
<td></td>
</tr>
<tr>
<td>Personal growth/self-actualisation</td>
<td>Ainsbinder (1998)</td>
<td>Personal growth</td>
<td>Support led to life changes for some parents including enhanced feelings of empowerment, a reduced sense of isolation and improved personal well-being.</td>
</tr>
<tr>
<td>Shifting viewpoints</td>
<td>Kingsnorth (2011)</td>
<td>Actions taken</td>
<td>Parents described an increased awareness of the personal challenges such as isolation and stress but also affirmation of their own expertise as parents.</td>
</tr>
<tr>
<td>Group legitimacy, recognition and power</td>
<td>Law (2001)</td>
<td>Parents took strength from the group; it empowered them to work together for change. Parents felt that they had developed new skills for the future in this endeavour.</td>
<td></td>
</tr>
<tr>
<td>Control/agency in the world</td>
<td>Solomon (2001)</td>
<td>The shared knowledge and experience of the group enabled parents to overcome uncertainty, regain control and have confidence.</td>
<td></td>
</tr>
<tr>
<td>Self-change</td>
<td>Law (2001)</td>
<td>Group membership provided parents with an environment in which they developed personally, growing in confidence and strength, feeling less depressed, guilty and more accepting of themselves leading to changed views on their relationship with their child and disability more generally.</td>
<td></td>
</tr>
<tr>
<td>Mutuality of support</td>
<td>Ainsbinder (1998)</td>
<td>Many referred parents felt that support was mutual and that giving support was as important and helpful as receiving it. Helping other parents feels good and validates their own expertise as parents of disabled children.</td>
<td></td>
</tr>
<tr>
<td>Coming full circle</td>
<td>Kerr (1999)</td>
<td>Part of the adaptive process for some parents was to move from being the supported to the supporter – this was perceived as mutually beneficial.</td>
<td></td>
</tr>
<tr>
<td>Lessening need</td>
<td>Law (2001)</td>
<td>Those who were more ‘seasoned’ members of the groups, who felt that they had benefitted from other’s experience were keen to share theirs with new participants.</td>
<td></td>
</tr>
<tr>
<td>Obtaining and providing resources and supports to fellow group members</td>
<td>Lo (2010)</td>
<td>Parents were able to share their expert knowledge with other parents in the group, which validated their own expertise and increased their self worth.</td>
<td></td>
</tr>
<tr>
<td>Synthesis theme</td>
<td>First author (year)</td>
<td>Author theme</td>
<td>Key message from author theme</td>
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<tr>
<td></td>
<td>Nicholas (2007)</td>
<td>Elements of support</td>
<td>Parents felt supported and affirmed by the relationship and expressed a motivation to help others and a future commitment to the peer support process</td>
</tr>
<tr>
<td></td>
<td>Solomon (2001)</td>
<td>Control/agency in the world</td>
<td>Some parents reported satisfaction in and a desire to help others, experienced as personal growth from the helped to the helper</td>
</tr>
<tr>
<td></td>
<td>Sullivan-Bolyai (2011b)</td>
<td>Affirmational support</td>
<td>Mentoring others could bring back parents’ own experiences at diagnosis but rather than being upsetting this was seen as empowering; seeing how far they had come</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gratification and learning</td>
<td>Mentors gained personally from the experience and described feelings of reciprocity, empowerment, personal gratification and an opportunity to acknowledge their own expertise. Mentors also described their own shared identity as a group</td>
</tr>
<tr>
<td>Barriers to a successful supportive experience</td>
<td>Aibinder (1998)</td>
<td>Situational differences</td>
<td>Just as perceived sameness is key to a successful match, perceived differences can cause a match to fail. In this study, difference between the children’s day to day challenges could hinder the relationship – upwards and downwards comparisons can provide challenges</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Individual preferences and values</td>
<td>If parents differ in personality, communication style or core values such as parenting, views on disability and their child’s future potential, the match was unlikely to succeed</td>
</tr>
<tr>
<td></td>
<td>Nicholas (2007)</td>
<td>Elements limiting benefit</td>
<td>A lack of situational or personal commonality was often given as a reason by parents who did not experience benefit from peer support</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Some parents were disinclined to make contact for fear of upward and/or downward comparisons between their children leading to pain or concern for themselves or the matched parent</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Some parents found it difficult to divulge personal information to an unknown person and an initial face to face meeting was important to avoid awkwardness and make it easier to sustain the relationship</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Some parents had a limited amount of time for themselves, prioritising the care of their child</td>
</tr>
<tr>
<td></td>
<td>Aibinder (1998)</td>
<td>Logistical barriers</td>
<td>Parents being too busy, living too far away, a limited number of supporting parents or lack of follow up from the supporting parent were all named barriers to a successful match</td>
</tr>
<tr>
<td></td>
<td>Bull (2003)</td>
<td>A specific recommendation to join by an educational professional</td>
<td>Without which some parents would not have considered joining and those who felt pressured to attend expressed less satisfaction and did not intend to maintain regular attendance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Expectations and satisfaction with the support group</td>
<td>Those who were dissatisfied with the level of emotional support they received experienced high levels of stress and may have benefitted from a more individualised professional intervention</td>
</tr>
<tr>
<td></td>
<td>Kingsnorth (2011)</td>
<td>Personal challenges</td>
<td>Many parents found it difficult to maintain group membership because of the commitment of looking after their child which was prioritised over self</td>
</tr>
</tbody>
</table>
Qualitative synthesis

We identified four main themes across the papers that had interviewed people about their experiences of peer support. They were: (i) shared social identity, (ii) learning from the experience of others, (iii) personal growth, and (iv) supporting others. Four papers also identified when and why peer support does not work. (Table 6)

Shared social identity was the most common theme.

- Parents/carers thought people not in a similar situation couldn’t understand their experience.
- The shared social identity included a sense of belonging, support and empowerment, reduced feelings of isolation, loneliness and guilt.
- Parents felt better able to cope when supported by other parents with similar experiences.

Learning from the experience of others:

- Parents felt supported by being able to share useful, practical information and being able to learn from the experiences of others.

Personal growth:

- Several studies described how parents gained strength and were empowered through peer support.
- This enabled them to develop new skills and to feel motivated and confident parents.
- Parents described feeling more in control and less isolated or guilty.
- This in turn had a positive impact on their child.

Supporting others:

- Parents reported a sense that peer support was a two way process and felt that giving support was as important as receiving it.
- Giving support and sharing experiences validated their expertise as parents.
- Mentoring others enabled parents to see how far they had come in their own journey.

Four papers also identified some situations when peer support did not work, although no harmful effects were reported:

- Some parents found it difficult to give personal information to a stranger.
- Some were frightened of comparisons between their child and others.
- Parents who felt pressured by a professional to attend a group or those who felt the support they received did not match the level they expected or hoped for were less satisfied.
- For some parents, a lack of time to meet other parents can get in the way of successful peer support.
**Quantitative synthesis**

Psychological health:
- Eight studies measured the effect of peer support on parents’ psychological health.
- Some studies reported benefits of peer support relating to anxiety, concern, confidence and coping.
- However, the findings were inconsistent. Some studies measuring anxiety, concern, confidence, coping and other aspects of psychological health did not report strong evidence for the benefit of peer support.
- In some studies, peer support appeared to be more beneficial to those with high stress and anxiety, poor maternal health or lower coping skills; but we would need more research to be more certain that this is true.

Family function:
- Five studies measured the effect of peer support on family function.
- One study reported evidence of improvement on a measure of acceptance and family adjustment to disability, but four studies showed little or no change on a different questionnaire measuring the impact of their child’s condition on family life.

The experience of parents receiving support:
- Five questionnaire studies measured the experience of parents receiving support.
- One study found that 89% of parents receiving peer support had found the support helpful.
- Four studies looked at how much social support parents felt they had.
- Only one 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:
- Only one study measured the impact of peer support on accessing services and information.
- There was weak evidence that parents receiving peer support increase their use of community services, but no drop in Emergency Department or acute care visits or calls to specialists was reported.

**Key findings**

The qualitative synthesis highlights important characteristics of peer support including the benefits of finding a shared social identity; the opportunity to learn practical information and also be inspired by others; going through a process of personal growth; and finally finding the ability to support others. This is consistent with research in other groups. However, the quantitative studies did
not substantiate these perceived benefits. Although the general trend on measures of psychological health favoured peer support, few studies reported strong evidence and, in the only study to measure it, no difference in the use of community or health care resources was observed.

This review also shows a need to look more closely at peer support services and the methods used to study them. Better designed studies are necessary to help people make informed decisions about peer support.

In particular, the following issues should be a focus for further research:

- Are appropriate questionnaires used, are they sensitive to detecting relevant important health changes?
- When is the right time to measure the effect of support – for example how do we know when a parent has had ‘enough’ support to have an effect?
- What are the differences between the effects of one-to-one support and group support, and how important is it to match support by diagnosis in these different types of support?
- What is the impact of other types of support that parents might access at the same time of the study? Is it right or necessary to prevent parents from seeking other types of support while they are taking part in a study?
- Is it appropriate to ask parents to wait for support so that studies can compare them with parents getting support (control group)?

**Strengths and limitations**

The review was conducted using guidelines for narrative synthesis. The robustness of the synthesis may have been influenced by the study selection. Because we had very strict inclusion criteria, it is possible that some of the excluded papers may have provided additional insight.

Another limitation relates to grey literature. We searched for grey literature using relevant websites we are familiar with in the UK, Canada and Europe. This returned no additional new papers, but we cannot be certain that a worldwide search of grey literature would have a similar outcome.

Overall, the methodological quality of the quantitative studies was acceptable but some were limited by small sample sizes. In addition, the authors did not state how much change in scores on the questionnaires they would have considered important. This means it may be possible that studies failed to identify a positive impact where in fact one did exist.
Some of the qualitative studies were of poorer quality than others. Because there was a high level of agreement in the findings of the qualitative studies, we do not think that these studies affected the overall shape of our analysis.

Overall it was not possible to fully answer the review questions. None of the studies included an evaluation of cost-effectiveness or included any details regarding financial costs. Very few studies interviewed parents who had had a negative experience of support hence this perspective is underreported. This is an artefact of the type of study whereby those actively engaged in a support service are likely to have a positive view of it; this, however, places limitations on the implications that can be drawn from the review.

Peer support interventions included in the review varied in the quantity and content of parent interactions, the duration of the intervention, and whether or not the supporting parents were trained. These components varied across studies and limit the inferences we can make.

Typically the interventions delivered as part of a trial were more tightly defined than in observational studies. It is unclear whether manipulating the supporting relationship for the purpose of research may influence the nature of a complex intervention such as peer support.
Qualitative study

Rationale
The qualitative study had two strands: (i) interviews with parents and befrienders, and (ii) interviews with relevant key professionals.

The qualitative research with parents who have used the F2F service and befrienders who deliver peer support through F2F explored which elements of the programme are perceived to be having an effect, how and why these active elements are effective, and what outcomes are achieved. The qualitative research addressed the overarching research questions identified in the protocol (i) what is the nature of the intervention and how is it presumed to work (ii) who benefits from peer support and (iii) what are the key outcomes of peer support?

The views of professionals were important to capture as part of the evaluation. The stakeholder group identified key professional groups who would be potential users of the evaluation findings, such as service commissioners and chairs of charities that fund peer support as well as professionals working closely with families who might refer to F2F.

The purpose of interviewing these professionals was to gain insight and understanding, of the knowledge and views that professionals have of peer support. In particular, exploring what value they place on formal peer support, and any outcomes that they think peer support might produce. Professional groups may use evaluation findings in their decision making; knowing what outcomes they consider to be important is clearly helpful in knowing what outcomes to measure.

Methods

Recruitment and sampling - parents and befrienders
Local coordinators of the Face2Face service used service records to identify eligible parents. The coordinators used their discretion to ensure that families in crisis were not approached to avoid additional stress and overburdening vulnerable families. All other parents who had used or had been offered the service in a 12-month period were eligible to receive an invitation to the study. All befrienders who had contact with the service in the same period were also sent an invitation.

The invitation letter contained a reply slip and a freepost envelope, which interested participants returned directly to the research team. A member of the research team contacted the parent/befriender directly to discuss the study further and to arrange to take informed consent and conduct the interview. The researcher explained her independence from Face2Face and other services and emphasised that participation was voluntary, that participants have a right to withdraw
at any time, and that they would not be identified in any reports or have quotes attributed to them in any identifiable way.

One reminder letter was sent to parents/befrienders who did not respond to the initial approach. After this, no further contact was made regarding the study.

Sampling was constrained by the available pool of parents who had used the F2F peer support service locally and as such our sampling strategy was limited. Recruitment was conducted first in Devon. 29 parents were identified as having had contact with the service in the specified 12 month period and were sent invitation letters. 6 parents responded and were interviewed. 20 befrienders were approached, either in person or by post. 16 consented to be part of the study; 1 later withdrew. 15 participated in the costing study and 11 were interviewed for the qualitative study.

We sought to interview a number of families who were offered peer support but declined or who received very few visits; withdrawing from the service is a potential indicator that the parent was unsatisfied with the service or the pairing with their befrinder although equally may suggest that the parent needed only minimal support. To attempt to address this recruitment gap, we specifically asked the coordinators in Cornwall to target these families when they posted out invitation letters. Each coordinator sent 20 invitation letters. Eight parents responded and six were interviewed. 33 befrienders in Cornwall were invited to participate, 9 took part in focus groups, 2 had individual interviews and 1 responded by post. A further 3 befrienders in Cornwall participated in the study, completing work sampling for the costing study, but did not take part in the qualitative study.

We gathered demographic information from participants in order to acknowledge any sampling biases. This included the child’s age and condition and postcodes were used to calculate Index of Multiple Deprivation (IMD) scores, used as indicators of deprivation in small geographical areas. IMD scores enable ranking of deprivation in areas based on a combination of domains comprising income, education, health, housing, services and living environment. In order to understand the context of their experiences of the Face2Face service, we also asked parents to tell us about the types of health and social services they access and how often and whether they participate in other forms of support, such as support groups or internet forums. Although we were not able to control for these potentially confounding variables, gathering this information enabled us to account for them in our interpretation of the evaluation findings.

Recruitment and sampling - professionals
We conducted 10 interviews with a purposively sampled group of professionals working with disabled children and their families. We first approached professionals that we were already aware
of within organisations such as Local Authorities. We also asked participants to propose other relevant professionals to approach. We interviewed 2 members of staff from different Children’s Centres, two representatives from children’s services at different Local Authorities, a GP and a consultant paediatrician, a learning disability nurse and a children’s community nurse, a special educational needs coordinator (SENCO) and a late school provision coordinator/teaching assistant. Professionals were contacted by email with the information sheet, either directly by the research team or forwarded to them by a colleague. Professionals who were interested in learning more about the project contacted the research team to discuss the study further and to arrange to meet to document informed consent and conduct the interview.

**Interviews and focus groups topic guides**

Interview topic guides were developed with members of the Peninsula Cerebra Research Unit Family Faculty and the study stakeholder group. Many of the topics discussed with parents, befrienders and professionals overlapped, though the focus of specific question was sometimes different in the parent/befriender interview to those with professionals.

All participant groups were asked to discuss issues around:

- Why there might be a need for parent to parent support
- How this type of support might meet parents’ needs and how it differs from other types of support
- The timing of this type of support and its appeal (or not) to different people
- Structural aspects of the service: how the service is run and the befriending relationship conducted (including the matching of parents and befrienders)
- Suggestions for how this type of service might better meet their needs/those of the people they support/those of the families they work with
- Any effect, positive or negative, of support in the short and long term for the parents receiving and giving support (parents and befrienders were asked to consider impact for the other person as well as for themselves, professionals were asked to consider both parties)

Parents receiving support were also asked to discuss issues around:

- Reasons for seeking support, hopes and expectations from the service
- The impact of being befriended on their lives
- Strengths and weaknesses of the Face2Face service

Befrienders were also asked to discuss issues around:

- The decision to become a befriender, hopes and expectations
- The impact of befriending on their lives
• Strengths and weaknesses of the Face2Face service

Professionals were also asked to discuss issues around:
• Where they thought voluntary peer support services sit in relation to other health and social care services
• What information they would want to know about a service to help make a decision on commissioning/referring
• What they considered to be important elements of a “good” service (that they would refer to) and what the barriers to success might be

Interview procedure
Interviews with parents and befrienders took place at the participant’s home; professionals were interviewed at their place of work or at their home depending on their preference. Interviews began with reiteration of the researcher’s independence from Face2Face and other services, the voluntariness of participation, the right to withdraw and anonymity in any report or publication. The researcher then confirmed that the participant was happy for the interview to be recorded before starting the interview. Two parents wanted to take part in the research but were not comfortable with the conversation being recorded; notes of the participant’s responses were made during the interview instead.

The researcher ensured that interviews were conversational in tone and that the pace and duration was guided by the participant. On average, interviews lasted 45-60 minutes. Demographic information was collected during the same visit.

Interviews were transcribed verbatim and transcripts were continually reviewed and used to inform subsequent interviews. Interview guides were adapted to reflect and test the developing analysis. Reflexive notes were kept by the interviewer to record systematically the contextual details of the interviews.

Focus group procedure
Focus groups were only used with befrienders in Cornwall. The befrienders in each area are established groups that meet monthly for mutual support and discussion therefore only a brief introduction was necessary to familiarise the group with the researchers (including their independence from Face2Face and other services), the aims and objectives of the group (including the voluntariness of participation, the right to withdraw and anonymity in any report or publication), to check that all members of the group were happy for the discussion to be recorded and to establish ground rules. Ground rules included respecting others’ right to speak (not over speaking).
and confidentiality under the Chatham House rule. The groups were facilitated by a member of the research team and followed the same topic guide and structure as the one-to-one interviews.

**Analysis**

Interviews and focus groups were audio-recorded and transcribed verbatim. Analysis followed the Framework Approach\(^2^3\) which was developed as a systematic and rigorous methodology for applied qualitative research. In the Framework Approach data collection is more structured and analysis is more explicit and more transparent than some approaches to qualitative data analysis.\(^2^4\) Framework analysis involves five distinct stages: (i) familiarisation with the data – immersion in the raw data (listening to recordings and reading transcripts) to gain an overview of the whole; (ii) identifying a thematic framework – identifying the key concepts and issues both a priori and those emerging from the data of individual respondents and recurring concepts; (iii) indexing – applying the framework to the transcripts, annotating the transcripts with identification codes referring to themes and subthemes; (iv) charting – extracting data from its original context, summarising and grouping it in chart form according to the thematic reference (v) mapping and interpretation – reviewing the charts and research notes to compare and contrast, search for patterns and connections and provide explanations for the findings. Some issues will emerge as more salient than others and the interpretation of findings is influenced by the original research objectives as well as the themes emerging directly from the data. Two members of the research team read the transcripts and developed the thematic framework. One researcher (VS) indexed and charted all of the material and 25% of material was also indexed by a second reviewer (SB). This allows for checks to be made for comprehensiveness of data extraction, and consistency in the application of the index. Differences in interpretation were resolved through group discussion. Data from focus groups were coded at the group rather than the individual level. During the mapping and interpretation stage, we convened an expert reference group of befrienders from Face2Face to discuss the developing analysis.

In the following findings section, extracts from parents’ interviews are followed by identification codes beginning ‘P’, those from individual befriender interviews beginning ‘B’, from befriender focus groups ‘FG’ and those from professionals, ‘PR’. For all extracts, square brackets containing three dots [...] indicate short sections of omitted speech; square brackets containing text indicate explanation added during transcribing or analysis, usually to replace a name. While original transcription recorded hesitation, overlapping speech and disfluency, for ease of reading we edited out most of these markers from the excerpts that we present. To improve readability, the majority of excerpts are presented together in a box at the end of each section.
### Participant characteristics

#### Table 7: demographic information

<table>
<thead>
<tr>
<th></th>
<th>Parents (12 families, 14 young people)</th>
<th>Befrienders (23 families, 24 young people)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child</td>
<td>Median age 7.5 (range 3.5 – 14 years)</td>
<td>Median age 12 (range 4-22 years)</td>
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<tr>
<td>Gender of child</td>
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<td>5 female, 19 male</td>
</tr>
<tr>
<td>Primary diagnosis*</td>
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<tr>
<td></td>
<td>ASD 2</td>
<td>ASD 12</td>
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<td>ADHD 2</td>
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<td></td>
<td>CP 1</td>
<td>CP 2</td>
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<td></td>
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<td>Complex additional needs with sensory issues 1</td>
</tr>
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<td></td>
<td>Congenital heart disease 1</td>
<td>Developmental delay 1</td>
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<td>Partial trisomy 15 1</td>
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<td>2-5 years 3</td>
<td>2-5 years 5</td>
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<td></td>
<td>Over 5 years 6</td>
<td>Over 5 years 17</td>
</tr>
<tr>
<td>Number of siblings**</td>
<td>Median 1, range 0-2</td>
<td>Median 1, range 0-4</td>
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<td>6/23 single parent households</td>
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<td>Age of parent</td>
<td>Median age 39 (range 29-45 years)</td>
<td>Median age 45 (range 27-59)</td>
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<td>(where the least deprivation is quintile 1 and the highest, quintile 5)</td>
<td>quintile 2 6</td>
<td>quintile 1 1</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td></td>
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<td>Ethnic background</td>
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<td>2 others 5</td>
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<td>5 or more services 10</td>
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<tr>
<td></td>
<td>1-4 services 6</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Not applicable 1</td>
</tr>
</tbody>
</table>

*As identified by the parent. 7 of the 14 young people in the parent group had multiple difficulties; 14 in the befrienders group had multiple difficulties.

** 1 family in the parent group had 3 children with additional needs. 2 families in the befriender group had 2 children with additional needs.

The group of parents offering support were older than those receiving it, as were their children. A greater proportion of this group (70%) had received their child’s diagnosis more than 5 years previously, compared to 50% in the parent group; although time since diagnosis is not necessarily a
good marker of adjustment as many parents whose children have less visible disabilities may have been struggling for many years to get a diagnosis.

The ethnicity of both groups is almost entirely white British. This is representative of the parents and befrienders that use the service and the demographic of the South West has a higher proportion of white British citizens than England and Wales as a whole. The role of ethnicity in the take-up of support services may be a consideration for future evaluation in more ethnically diverse regions.

Around half of parents and befrienders were not participating in any other form of parent support at the time of interview. Of the 12 parents that participated, seven were currently receiving befriending whilst five had ended their befriending relationship. Of the 23 befrienders, 4 had never befriended a parent; a further five had befriended just one parent.

Five of the ten professionals we interviewed were not familiar with the Face2Face service specifically; however all were familiar with the practice of peer support in general. We found relatively little difference in the tone of their views on many of the issues discussed by parents and befrienders. As such their perceptions of the benefits and outcomes of support services were considered alongside those of the other groups, though where notable differences occur they are highlighted throughout the chapter.

**Qualitative findings**
The findings of the qualitative study have been synthesised and presented here to address specific research questions.

- What is the nature of the intervention and how does it work?
- What elements of peer support do people think are most effective?
- What are the perceived outcomes of peer support?
- Who benefits from peer support?
What is the nature of the intervention and how does it work?

Formal structures – training, supervision and delivery

The structural organisation of the service had different levels of importance for different groups. Professionals looked for reassurances that training and boundaries are in place which may give them the confidence to recommend to parents. These are critical to give the service credibility and validity in the eyes of professionals. These reassurances were also important to parents; enabling those with less confidence or concerns about confidentiality to access a one-to-one service at home.

Before they would consider referring to or funding a service, all professionals needed reassurance around the structural elements of the service and the procedures in place to protect both parties. Important reassurances for professionals included: knowledge of the principles of support – i.e. is it built on enabling and empowering parents; professional structures around – training, supervision and support; boundaries, recruitment and selection; confidentiality; safeguarding, risk management, linking with other services; quality assurance framework to reassure commissioners and families; and information about accountability.

The professional group felt that training was essential. Without training there were concerns that a befriender might make the situation worse for the parent and potentially damage the families’ relationships with professionals working with them. Training was seen as essential to ensure not only up to date knowledge but also key skills such as listening skills and boundaries such as how much to share. Befrienders too felt that the training was extensive and required a large time commitment but was essential not only to teach them the boundaries and how to conduct a session but also to give them the confidence to go out and do it.

While training is essential, ongoing support and supervision was also seen as crucial by professionals and befrienders. Knowing that they could call on the coordinator at any time for help with befriending issues offered reassurance to the befrienders. The befrienders are also able to discuss these issues with the befriender mutual support group. This was seen to provide a necessary debrief for the emotional content they take on board during a befriending visit, a conversation they wouldn’t be able to have with their own family. Like any other group though, support groups can be dominated by particularly needy people, personality clashes and dominant personalities or overrepresented groups which can leave other participants frustrated if they haven’t been able to have their issues heard. The training and mutual support that befrienders receive convey specific benefits which are discussed later in the chapter.
The service is distinct from many other forms of support in that it offers a highly personalised, flexible, one-to-one at home service. The one-to-one nature of the service was of great importance to parents. It was viewed as something that was relaxed, informal, and there just for them. They valued the flexibility of the service in terms of making appointments around their needs, be that the time or location. Though some parents and befrienders still found it difficult to fit in around work and/or the befriender’s free time and would have liked support in the summer holidays. Flexibility also has relevance to befrienders who, as parents themselves, sometimes need to “dip in and out of it” (B35) as their lives demand.

Befrienders too felt that the fact that the meeting takes place in your own environment can make it easier for parents to relax, feel in control, confident and able to say how they feel. As well as feeling more relaxed at home the importance of home visits was also stressed because there isn’t the added inconvenience of having to travel, which they often have to do attending appointments. Although there are logistical complications in delivering an at home service, particularly in rural areas and considerable time can be wasted travelling if a parent can no longer make an appointment (which they are unable to cancel because they do not have direct contact with befrienders).

Professionals also recognised the importance of flexibility, time constraints and an environment that parents are comfortable in. Although these were seen as desirable elements of the service, it was noted that the voluntary nature of peer support may mean that support isn’t necessarily available when needed, referring both to time of day for a specific conversation or a waiting list for initial access to support – both of which could make parents less likely to engage with the service.

The professional group, more than any other, talked about the structure of the service and the process of service delivery. In particular the formal elements of training and supervision were seen as critical to provide them with reassurances that a service was appropriate to refer parents to and was, on balance, more likely to do good than potential harm. They also identified that impact and cost effectiveness must be fully evaluated if services are to be seen as credible. Professionals valued a service that was parent led but professionally delivered. Getting the balance between these elements is essential to maintain credibility with professionals without losing the parent identity.
Formal structures:

I would want to know, um, what the principles of the support service were, and the way in which parents were recruited, parents were trained, and parents were supervised, supported and managed, led to a more formal helping relationship being achieved. PR01

The quality assurance has to be, match the feedback. It’s not just like here you are there’s a contract, very good, off you go, with all these vulnerable families. It’s actually, you know, what’s, what are you, what are you getting and how can you be assured that it’s, that it’s quality, it’s safe, um, so on and so forth? PR02

Does it work, does it have any side effects, and what does it cost. And, and it’s fit with current child services generally, and with all the other NHS services, and social services, social care services that are going on. Would somebody commission it in this brave new world that we are coming into, would it be commissioned. And those things are all related to that. You don’t commission something that isn’t effective. PR04

Training and support:

I feel much more confident since I’ve done the training course. Because it’s good to know that you’re saying the right thing and, you know, you’re not getting too involved [...] So for me I suppose I needed that to feel confident that I was doing the right thing. B16

It’s not just them as a supporter, they’ve also got to have the support to be able to... if they need to, share any, you know, offload as well. PR05

Flexible, tailored service:

They try and be as flexible as possible and they’re happy if you’re not comfortable in your own home, they’ll meet on mutual ground somewhere. You know, it is all sort of aimed around you really, and, and your needs P8

I guess, I mean being at home isn’t it, being in your own home so you, you’re more able to be yourself and so you’re more in a control in a way maybe to say how you feel. B3

So if they’re unable to be flexible then that would definitely be a barrier to access. [...] And then if they can’t help quite soon, then I think you’ve lost your moment and erm they’re less likely to, to actually engage with it. [...] It’s hard I know because if they don’t have the capacity. (PR08)

Rules and boundaries

The befriending relationship is not a friendship and therefore rules and boundaries are essential to maintain a degree of professionalism and to protect both the befriender and the parent. Though the importance of boundaries is recognised by all group, some befrienders felt it can be difficult to maintain that separation when someone is very emotional and boundaries could become blurred as relationships develop and become more like friendships (though there is general recognition
amongst befrienders that if the relationship becomes too much like a friendship it must come to an end).

There appeared some conflict around how much information is appropriate for befrienders to share about themselves; some sharing is helpful for parents and can facilitate the relationship but befrienders must be conscious not to divulge too much of their own lives, particularly given that the confidentiality agreement with parents is one way. Confidentiality was raised by all participant groups as a highly prized element of the service yet it is only the befriender group that raises their potential vulnerability because whilst they sign a confidentiality agreement (with caveats around the concerns for the safety of the child or parent), the parent does not.

Although parents and befrienders recognised the importance of rules and boundaries in this type of service, in some cases there seemed to be a separation of the recognition and application of them to a participant’s own situation, as if the rules didn’t apply to their particular circumstances. Of particular note is the rule that befriender’s should not share their telephone numbers with parents. All groups recognise the importance of this to protect the befriender from becoming too involved however a number of parents and befrienders had shared telephone numbers. Some justified this pragmatically, because the system for cancelling appointments via the coordinator can results in wasted journeys for befrienders if parents aren’t able to contact them.

Some befrienders describe a tension between what they know to be the ‘rules’ of a befriending visit and how the interactions actually take place in a relationship. For example it can be hard to maintain the distinction between being friendly and being friends; some find it hard not to give and opinion or advice. All befrienders know that the objective of the services is to empower parents; to help them come to their own answers not tell them what to do, however it can be challenging for befrienders not to intervene. Some befrienders specifically described themselves as ‘fixers’ and were not entirely comfortable with offering support but not advice.

Participants made a number of suggestions regarding the day to day running of the service which are listed in appendix 1.
I think maybe as the relationship grows though, as you, as you, you sort of relax into one another perhaps the edges fuzz a little bit anyway because you, you become a friend as well. It’s not like a business sort of relationship. But you have to still be aware I suppose … yes that’s it, you … there are boundaries that you, you don’t cross. B2

Um, well I actually gave her my mobile quite early on because then I thought well if you’re really desperate, but then that’s the sort of person I am. I don’t know whether that’s right or wrong. It may not have been professional but um that’s the sort of person I am. B35

Also, I think sometimes peer support can be, there is a very fine line between peer support being kind of a professional approach, because they have got to be and they have got their boundaries, turning into a friendship and sometimes that can be hard. Whether it is boundaries from the peer supporter or the parents. PR03

Um, but I think um everyone that does this counselling needs to be, needs to be clear how far they can and can’t go in terms of um boundaries you know, because it’s too easy to get too involved because it’s such an emotional thing quite often. PR07

With befriending, you can share, but really you have to think quite closely about whether it’s appropriate, whether you are sharing because you’re trying to show empathy or to help illustrate a point and not sharing for your own purposes because you’re wanting to get something off your chest or wanting to talk about yourself. B17

Obviously they didn’t often talk about themselves. I mean, I asked, and some were prepared to talk about their experience and some weren’t, but just knowing that they had been through that helped anyway. P2

There’s a few of us in the group that are fixers, in the sense of, we like to fix peoples’ worlds, technically we can’t but we like to offer advice and there’s a few of us that have decided that we’re not going befriend, because for that simple fact that we like to fix everyone’s life, perhaps it’s not appropriate. B9

Putting the right people in the right place

Readiness and suitability to befriend
Befrienders are trained to be able to listen empathically and without judgement but both parents and befrienders felt that it takes a certain type of person to want to be a befriender and to do it well. Training can help, but participants felt that befrienders had to be naturally very giving, caring people to begin with. This can make it difficult for them to take off their befriending ‘hat’. It is part of the role to help parents to feel relaxed, comfortable and to trust the befriender to enable them to speak freely, and both groups recognised the importance of a rapport between the two people if befriending is to be successful.
There is potential for harm to either party if the befriender is not ready to befriend. Participants felt that ‘readiness’ has two levels; readiness in terms of having the appropriate training and information and readiness in terms of being in the right place emotionally to be able to support someone else.

It can be difficult for befrienders to overcome natural tendencies to give their opinions and advice, and sometimes not to judge if people’s lives are very different to their own. This was recognised by all groups but professionals in particular saw this as a concern, and emphasised the need for befrienders to understand the role they are undertaking and to be supported with the skills and tools to fulfil it. Their focus was on the delivery of a safe service and they were clear that being a parent isn’t sufficient to ensure you will be good at supporting another parent. There was concern amongst professionals that if befrienders got this wrong, it could be very damaging for families but also that there was a risk that befrienders who were not ready could become too emotionally involved in families problems if they resonated with their own experiences.

*Immediately I opened the door she just looked a very open person. I don’t know what it was, she just had a lovely air about her, um, instant really. Um, and I did think, you know, when she had left I thought, you know, she must be a really nice person to come and sit and listen to a total stranger blub and whinge for an hour.* P10

*It is about you as much as who you are befriending, you know, ‘cause you’re no good to them if you’re not in the right place* B15

*I think you have to be in the right place yourself to be that kind of person that can be a befriender, because you have to be strong yourself. I’d want to just cry with them. [Laughs] Do you know what I mean? I know I’m not out of the other side yet, so I think you have to be in the right place as well.* P2

*I would hope that a person who is going into a befriending role would understand what the point of that befriending role is. They would be supported to develop skills in engaging, in helping a parent, maybe, through difficult times, and be equipped with skills and tools that are available to help that happen.* PR01

*Just because you’re a parent of a child who might have gone through that doesn’t necessarily mean that you’re able to go and be perceptive and intuitive and whatever with another family.* PR02

*I think again it depends on the parent that’s providing the support. As long as they’ve either, either they’ve got support themselves as well, or it’s got to be the right personality. Somebody that like I said, will go there, will, will be caring and is interested in how they are, but can also back off and say [...] I’m not going to get heavily involved, otherwise you’re going to get bogged down.* PR09
Parent or professional?
All participant groups value the formal structures in place that ensure the safety and quality of the service however there is a potential cost of the professionalisation of parent supporters. Parents described some blurring of the lines between parent and professional when they described the befriender role. The service itself was seen as more friendly and relaxed than other services, but more controlled and professional than talking to a friend. Befrienders were described as parents, but knowledgeable parents who were trained to be professional. One parent described ‘professionalism’ not ‘professional’ (P5). It was important to families that their befriender was a parent first, even though they behaved in a professional manner, this was important to put them at their ease.

The professionals we spoke to recognised the importance of the special relationship one parent could have with another and that it would be easier for a parent to discuss their emotions with another parent. However, befriending is not a friendship and should have a level of professionalism, for which befrienders had been trained. Elements of that training, such as establishing appropriate boundaries are there to protect both parent and befriender. In terms of raising the profile of the service with other professional groups, emphasising this level of professionalism (including training, boundaries and formal structure of the service) may be key.

Befrienders too expressed mixed views on their position between parent and professional. They felt it was paramount that they were not professionals; it is the very fact that they are parents not professionals that enables them to fulfil their role. However the formal structures in place and the way the service is intended to be delivered does make it more professional and may lead parents to think of them in that way; they requested a service and the befriender is there to deliver it. However they viewed their own role, befriender were clear that they did not feel they were viewed as professional or equal by professional groups.

I wouldn't class her in the professional level [...] I don't think that's the style they're going for. Um, they are just parents and that's, that's the whole point of it, that's where they're coming from P8

They need to be looking at this as a professional role, so they, they undertook some training. PR05

And some of the things that you have to say to them made me feel that it made me sound like a professional talking to the people, you know saying things like, well how did that make you feel. B11

It's difficult, because I don't really see myself as the professional, because I am a parent. But she sees me as the professional, because I've gone to her house to offer her support. B4

We are seen as just parents; our expertise, or our knowledge is not acknowledged as being [...] on a par with their professional qualifications. FG1
Matching families

A key role of the service coordinator is to identify a suitable match to befriend a parent. The basis of this matching was one of the more divisive topics discussed in the study. All participants agreed that parents of disabled children have a wealth of shared experience which enables them to speak openly with each other and give support (see section: Shared Experience) however it was universally recognised that the journey families go on is very different for different diagnoses, and there was no clear resolution of how much similarity between diagnoses is required to provide parents with a sense of shared identity. There was contradiction within and between participants, who were sometimes inconsistent on this point in the course of the interview. Overall there may not be a resolution to how much is ‘enough’ similarity between families and it is likely to be context and person specific.

On the one hand, participants argued that a shared experience of the world of disability is sufficient commonality. The service is there to provide emotional support to the parent, not the child. Empathy and emotional support is common across diagnoses and therefore it is as important to match the parents who will get on, to facilitate trust and ease of conversation.

The counter argument holds that matching families on diagnosis to a degree is essential. Families with very different diagnoses such as those with a hidden disability contrasted to those with a visible, physical disability have a very different journey and very different interactions with society hence some level of similarity is needed for a real connection.

Having a close match was seen as most useful for sharing information and specific experiences – some befrienders expressed anxiety around their ability to befriend ‘properly’ if they weren’t closely matched because that hadn’t lived that particular experience and wouldn’t have in depth understanding.

Close matching by diagnosis may be a double-edged sword. On the one hand parents may benefit from the experience of others who have been in a similar situation however there are issues around the comparisons parents may make between their own and their befrienders children; there is a potential danger that parents might base their expectations for the future on their befriender’s experience. Parents may learn things about their potential future that they don’t want to know or aren’t ready to deal with yet. Alternatively if they perceive their befriender’s situation to be more challenging than their own they may feel they shouldn’t be asking for support. There is huge variation within diagnosis so matching does not guarantee similar experiences or viewpoints.
The practicalities of delivering a service like Face2Face mean that it isn’t always possible to match families by diagnosis, even if the parent would like such a match.

<table>
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<tr>
<th>Statement</th>
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<tr>
<td>You’re there to support and they want support so that’s the common denominator isn’t it? B5</td>
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<tr>
<td>I don’t think that they need to have a child with a similar, you know, because I think everybody’s individual and, and such needs vary so greatly. PR05</td>
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<tr>
<td>It’s more about how you feel inside and how you feel accepted or don’t feel accepted sometimes by the community and, you know, you have got a lot of common issues. B16</td>
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<td>You’ve got to be able to get on though, that’s... you know, one thing that... you know, because it’s not... just because you’re a parent of a child with a learning disability, it doesn’t mean that you’re going to get on with another parent does it PR07</td>
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<td>The support I had wasn’t, um, support for like, understanding his conditions. It was support for accepting them. P2</td>
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<td>I do feel that it is good to pair you up... I know what you’re saying, you’ve got to be a little bit... pair you up with someone who's in the same condition and the fact that it flows more because you... you're there, you're living the, not the dream, but you're living the life you know. B20</td>
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<td>What the befriender lives within behaviour, disability, I think that matters because at least then, they've got a real connection, they know what you’re on about P4</td>
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<td>Matching me with a parent whose child, you know, suffered more on the autistic spectrum, I don’t think would be a good match because I wouldn’t feel comfortable that I was really giving them much support because I wouldn’t really be able to relate to their problems, you know, their everyday problems of what they were going through. B17</td>
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What makes F2F different to other forms of support?

Friends and family

Relationships with friends and family are complicated. Because parents inevitably compare their children with others that don’t have additional needs; spending time with friends and family, however well meaning can actually make parents feel more isolated. Parents and befrienders described the difficulty of making and maintaining friendships. Even when friends try to be supportive they aren’t fully able to understand. Going out with friends whose children are not disabled can make parents feel bad or resentful. Some described backing away from friendships to avoid this resentment whilst others have lost friends and felt excluded. Family members were often seen as being too close to the situation to be able to talk openly with them, and it is easier to talk to someone who is not emotionally involved.

I think they thought they were being helpful but actually it just made me feel even more lonely and even more unsupported and I try... I started to avoid going around there, avoid them B1

so we either avoid that situation or I go, but I actually then just feel really crap because I'm watching all the things he can't do while they sit down and have a chat, and I'm having to help him on everything. Um, so as much as they want to, they don't get it, they don't get what you're really feeling. P8

some find it difficult to talk to their friends with normal children[...] they would find it difficult to speak about, you know, their real feelings, and some people aren’t comfortable in talking about the problems that the disabled child might have. PR08

And I, they probably share lots with their families, but it's difficult because even your own family has no idea of what you're going through as a parent, I don't think. PR02

Professional support

Many parents and befrienders have had unsatisfactory encounters with a professional or professionals. These experiences influence the impression they constructed of ‘professionals’ as a group and the corresponding perceptions of their ability and willingness to help them and their family.

Like friends and families, professionals are seen as unable to fully comprehend the parent’s point of view because they haven’t been through it. This was contested by one professional who felt that lots of parents are dismissive of professionals and don’t give them credibility, despite the fact that they may have many years of professional experience, because they don’t have the lived experience.
Some professionals in our study were also parents of disabled children and they described a perceptible change in parents’ interactions with them if they disclosed this.

In discussions of the Face2Face service, participants stress the importance of being able to speak freely in a non-judgemental environment. One of the most commonly mentioned issues around interactions with professionals was that parents from both groups felt judged and blamed for their parenting skills. Some also felt that professionals were patronising and used deliberately exclusive language. How well a parent would be able to cope with these things was felt to be linked to where they were on their journey. Being judged was much more than being made to feel bad for these parents. There was a very real concern around potential consequences of how the professional viewed them, such as children being taken into care.

Although parents and befrienders were not always happy with the service they received from professionals, they did acknowledge that they did not always have the time or the remit to give them what they want. It was felt that there was a tendency to focus too tightly on a specific problem rather than consider the parent and the whole family, let alone emotions. This focus left parents feeling let down at the way professionals delivered a diagnosis, apparently without either understanding or engaging with the impact that they are having on families with this news. Perhaps because encounters with professionals were sometimes experienced as negative, ‘good’ professionals were singled out for specific praise.

The professionals that we spoke to were not negative about their interactions with parents however they had an awareness of the limitations and boundaries around what they were able to offer. There was recognition that their role was more specific whereas peer support takes a holistic view and that the voluntary service may be able to step into the gap no longer filled by some services. The benefits of parent support were seen to lie in the fact that it is not just another professional to deal with as parents have seen so many, but professionals did mention that they struggle to know what support is available for parents and if they don’t know about it they can’t refer or signpost.

I think you have seen enough of professionals and you don’t know, you don’t always like them, you don’t always trust them. P8

And what happens often is people perpetuate that ‘us and them’. And despite, you know, I’ve worked with some absolutely brilliantly, um, intuitive and in touch people that still the family would just not accept. PR02

I hope they realise that you’re not judging them, which quite often a professional does, they’re there taking notes and you know making sure you haven’t got toast in your hair B16
you’re not afraid to say, you know, “I could really strangle them one day”, but then if you’re talking to a professional, in no matter what capacity they’re in, erm you then worry that you said the wrong words and you’re going to have social on your door. B9

I mean something that I felt very strongly about, um, when [my daughter] was diagnosed was that the message needs to be, to get through to consultants and the people who are giving parents a diagnosis that comes totally out of the - can come totally out of the blue, um, and without giving them sort of proper warning and without giving them details of, um, you know, some kind of support that is available. B17

you go to, to like a clinic and it's all about the child, you know, there's never like the clinic where the parent goes to offload. You know, it's, or, you know, I sometimes think it is all about the child, and then the parent’s quite often forgotten B5

Sometimes you get the impression that they just, I don’t know, that everyone’s disgruntled (laughter) and everyone’s cynical towards what you can offer. But genuinely sometimes you just can’t achieve what they, what they need.PRO8

Support groups

A number of parents and befrienders had some experience of attending a parent support group. Professionals, parents and befrienders identified positive elements of the group environment as an opportunity for making friend and meeting people (hence helping to tackle isolation) and as a source of information sharing as well as support.

The primary differences identified between group support and the type of individualised support offered by Face2Face is that the group environment lacks privacy and confidentiality and is not always conducive to sharing emotional stories. This view was not held universally though, as some felt that even if you didn’t share your own story, listening to other people’s can help you realise that you are not alone and that it is perfectly normal to be emotional. There can be issues around the regulation of groups which can be cliquey and dominated by a few; if they are not well run they can put people off groups altogether. It also takes a lot of confidence to walk into a support group whereas a more individualised service allows less confident people to access a one-to-one service, at home reassured that the conversation will be treated in confidence. Comparisons between children can be more pronounced in the group setting, particularly where children attend, and it can be difficult for parents to see children with more serious conditions, particularly in the early stages. Equally, parents can feel that their child “isn’t bad enough” (B20) to attend, which is unhelpful when they themselves are struggling.
And it’s not until you actually go to these groups and listen to other stories that you feel that actually, I’m not on my own. But it’s that first step to go into that room with these people, it’s completely daunting, it really is. P12

I think you can speak more openly on a one to one rather than you know, people wouldn’t want everybody, don’t often want everybody knowing your business, you know. Or yeah, so. And it’s like anything, it takes time to build up trust doesn’t it. B6

You know you’re just like every single one of us and it’s probably quite nice for us to see everybody...you know, you know your first time going there or your second time or whatever, when you’ve sort of gone, [expression] I can’t cope with this anymore, and then you’ve got a new mum that’s come in the door and done exactly the same. You think oh you see, I am normal you know. B20

A room full of people you don’t know. Not everyone’s got the nerve to do that, or got the fight to do that B35
What elements of peer support do people think are most effective?

Shared experience

Shared experience is the central theme to the study and a topic on which all participants speak. Parents of disabled children feel different to people who do not have disabled children. This can lead to feelings of extreme isolation and a sense that other groups of people simply cannot understand what life is like. By contrast, parents identify with other parents of disabled children. The shared experience that parents of disabled children have with each other facilitates open conversation; parents describe not only a sense of understanding and empathy from other parents but also highly value not having to explain about their child and not being judged by other parents.

This contrasts with a perceived inability to talk to family and friends, and the broader community such as other parents at the school. To some extent there is a sense of exclusion from the “normal community” and participants have spoken about the loneliness and isolation before meeting with other parents of disabled children.

The opportunity to meet and talk with a person/people who, by the nature of their own experiences can have a sense of understanding of your situation, helps parents to realise that they are not alone – that they are in fact members of a community who, at the very least, share an identity as parents of disabled children, and a sense that this somehow separates them from the rest of society. Importantly, this identification with the ‘community’ can be achieved by parents who may not interact with other parents in a group or social setting. Even if the only other parent a supported parent meets with is their befriender, it seems that the provision of reassurances from the befriender that many other parents are going through the same problems and experiences can engender a sense of community; it is enough to know that other families are out there. It provides parents with reassurances that what they are feeling is normal and that they are not a bad parent, when processes such as diagnosis can make families feel very different to everyone else. There is a potentially negative side to this sense of social identity in that it may reinforce the differences parents perceive between themselves and others that do not have disabled children – “outside, no one understands” (FG2).

The effect of shared experience seems to operate on two levels. There is the sense of providing a social identity, of being part of a community; the second level is in the permission it gives parents and befrienders for the negative feelings they may have about their child, and the corresponding guilt they may have about that. Not everybody speaks about feeling guilty or failure but all talk to some degree about the need to be able to speak freely and not be judged.
The professional group talked readily about the importance parents place on shared experience with other parents in terms of being easier to talk to and being able to understand their situation. They also noted that befriending parents may have more credibility than professionals, because they are coming from a similar position, and that this may affect how the offer of support and the support itself is received. Whilst recognising the importance of shared experience, only one professional linked shared experience specifically to guilt and negative emotions.

Befrienders and parents both recognised the importance of the befriender seeming to have ‘come through the other side’. They have shared experience, they understand what you are going through but they can also present as a role model of someone who has learnt to cope and can potentially help you to do the same.

An important recognition is that while shared experience is necessary for effective support it is not sufficient. Some parents will not be good listeners and others will not find it easy to talk even to other parents. As discussed with regard to matching families shared experience was perceived as necessary to facilitate the other active ingredients of befriending but how much shared experience is ‘enough’ was not a consistently shared view and may depend on the parents involved and what they are hoping to get from the befriending relationship. All groups of participants recognised that shared experience between parents of disabled children provided a critical starting point on which other elements of the intervention could build.

Unless you’ve got a disabled child, you don’t get it, you can - you think you do. It’s like anything, isn’t it? You can’t understand someone unless you walk in their shoes. P2

I had lots of supportive people around me but that’s not the same as having someone who actually understands what you’re going through. B17

There’s a whole other community that opens up to you then, of um, other parents with children with disabilities, um and it just makes you feel like you’re not alone. P8

I don’t feel like it’s a job. I feel like it’s a welcoming into the fold […] you’re welcoming someone in from the isolated out there, on their tod, struggling to come into the fold FG2

The parent said that, um, it’s like being in a club […] people who have children with special needs are in that club and they know; and people that are outside aren’t in the club. I thought it was quite a confrontational thing, but I think that that sort of signifies that sort of divide between professionals and families. PR02

So the need for somebody to understand, I certainly felt, for me, the, um, to be able to say the awful things that I was feeling to somebody that wasn’t going to judge me P10
If somebody has gone there already, been through it already, and been there and got the t-shirt and would like to share that t-shirt with other people, you know PR04

So it’s actually having somebody that gets what you’re going through, but someone that’s also gone out the other side [...] So you actually see that there is light at the end of the tunnel, cos sometimes you don’t - it’s very bleak and you don’t see a light, you just see darkness. P2

I believe the shared experience is the foundation of then empowering a parent to be the family they want to be PR01

*It’s all about me*

Both parents and befrienders talked extensively about providing parents with a safe and supportive environment in which they feel comfortable to speak freely about whatever is most important to them. Important to establishing this environment is continuity and trust within the befriending relationship. The focus of the relationship is specifically on the parent, who may be confronting their emotions for the first time – the ease with which rapport can be established will depend on the individual personalities and the needs of the parent.

The importance of not feeling judged was reiterated. Parents value the opportunity to speak honestly about their feelings in a way that they cannot to other people. The language used by parents and befrienders to describe this release of emotion indicates the extent to which these feelings are usually repressed because it is in some way not ‘normal’ to feel this way about your family. Words used include offload, download, relief, let off steam and weight lifted off your shoulders. The importance to parents of not being judged is absent in the accounts of the professional participants.

This group of parents spend a lot of time thinking about their children, attending appointments and meetings. They highly valued the fact that the service is designed to be one way; that befrienders are there purely to listen to them and that the meetings are guided by their needs and are all about them.

*It grows over time, and you get to a point where you feel you really know them, and then they can tell you anything* B4

*You hope as the weeks go by the sort of layers break down and you actually get to what they do want to talk about* B16

*It’s all about me rather than the children. Um it’s about my support* P1

*I think they were the first pers-, people that actually asked about me* P4
Learning from the experience of others

Learning is both an active ingredient of the service and at the same time, a partial outcome because parents ‘take away’ knowledge. What is key to this element of the intervention is the credibility that parents give to other parents because they are speaking from experience, rather than just passing on information as a professional might. This contrasts with the lack of trust and shared experience some participants expressed for professionals and participants may be willing to trade a degree of professional training for the credibility of another parent’s experience.

Hearing how another parent has encountered and tackled a similar problem reaffirms that the parent is not the only person dealing with these problems, which can help build confidence and reassurance to explore new solutions. Parents were conscious of the fact that the journey was something they had to do for themselves, but with the support of someone who had been there, who understood and could give them pointers to be able to do things for themselves. The sharing of knowledge between people in similar situations is empowering. All participant groups describe the concept of a journey on which befrienders are further along than the parents they support, allowing them to reflect back and make suggestions without being in the midst of the emotion themselves. Befrienders were mindful of the responsibility that this conveyed and the importance of not saying the wrong thing.

Whilst professionals recognised the wealth of knowledge and experience held by the community of parents, some expressed concern that parent-supporters might inadvertently give wrong advice and signposting or might inadvertently or otherwise try to influence parents to follow a particular path.

I think it’s for parents, isn’t it, by parents and I don’t think you can get that wrong. Even if you get it wrong you don’t mean to B15

You are passing on a kind of knowledge experience. B3

And also give me strategies at times if I needed it. Like, not strategies, but, you know, like suggestions or tips or, you know, or just to know that you’re normal. You’re not a lunatic. P2

She could provide, not necessarily a solution, but she could say what she had done. So then you could make your own mind up then can’t you? So it’s information, again, that you can do something with. P11

And of course they might give the wrong advice and it is always the problem [...] peer support that they can give the wrong advice – and one hopes that that would not happen. PR04

It can be a bit of a challenge when people are very set on a certain, you know, a certain like agenda or certain idea and then they’re, they’re influencing others. PR06
What are the perceived outcomes of peer support?

Challenges of measuring support

All groups identified potential benefits and potential negative impacts of peer support programmes but a number of participants reflected on the difficulties of a) measuring these impacts and b) demonstrating that they are attributable to Face2Face.

Not all parents describe the impact of being befriended as life-changing, and spoke about other changes in their life happening at the same time that also had impact. Parents recognised that where you are in your journey may affect what you get out of being befriended, but all described being befriended as a positive part of that journey.

A number of befrienders and professionals (but only one parent) described the impact of befriending as measurable in terms of services not used by parents for example potentially avoiding crisis may reduce parents need to access mental health services. Befrienders and professionals also described how empowering parents to go out and do things for themselves could reduce their reliance on other services.

*I think on paper it doesn’t look like much. If, if you just said to people on paper what we do, people would go, “oh, okay” Whereas when you talk to these families and you see what a difference it’s made [...] you get thrown that lifeline and you grab it and i just think it just doesn’t show itself on paper compared to the effect it actually has*  

FG2

*Certainly emotional ones; you can say you are hot or you are cold, but the whole emotion side, I think that is quite hard to pinpoint what is beneficial [...] I don’t know whether I could be that specific really.*  

P10

*Um, I mean Face 2 Face is just a very small part of a bit jigsaw puzzle isn’t it, you know I mean there’s no miracle and it’s just offering a service that just might make that little bit of difference to someone’s life.*  

B16

*It seems to be mainly wellbeing and it’s the emotional support. I would have thought they’re happier people all the way around would, would be happier and easier on the NHS service.*  

PR05
What are the perceived outcomes for parents?

Emotional stability and personal growth
In earlier stages of analyses we considered emotional stability and personal growth to be distinct outcomes however, through discussion with our expert reference group we realised that in this group these two constructs were so interrelated that it was more appropriate to consider them together. For example, receiving support from a befriender can help a parent to gain a degree of emotional stability and acceptance of their family situation, which then allows them to develop in confidence and move forward to make other positive changes in their life. This in turn can feed back to have positive impact on emotional state.

Befrienders described how parents carry a lot of emotion with them and that being able to offload that emotion impacts on their mental health. However, they note that emotional stability is something of a misnomer, that their lives are often an emotional rollercoaster and what the service really offers parents is about developing the confidence and ability to cope with the ups and downs. The service isn’t about fixing things; it is about providing parents with the tools and confidence to do things for themselves. Professionals too, talked about supporting parents to build resilience and explore their own solutions within the safety net of support. This could positively impact on mental health and wellbeing, including reduced stress, anxiety, depression, increased self-esteem and confidence.

This is very much reflected in the accounts of parents who talk about how their lives would probably take the same course without F2F but that it has provided them with an emotional outlet that has helped them understand their situation and learn to accept and cope with it.

The confidence that parents describe is two-fold; the confidence and courage to deal with services and professionals but also the confidence and reassurance that you are doing a good job, and are not a bad parent. A key function of the support offered is to scaffold parents through this change.

We could hypothesise that positive impacts on the parents’ mental health might spill into their wider life, but this was rarely discussed, although all participants were asked to reflect on the broader impact on their lives. One potential explanation is that befriending is very much viewed as for the parent, their own time and specifically not for their children; it is possible that most of the outcomes described by parents have more focus on themselves than broader family life as a result.
And there’s always something going on still. It’s never ending when you’ve got a child with a disability, it is it’s never ending and you do go up and down like a rollercoaster you really do. Because there’s things that bite you back and, you know, it’s, yes it is a hard job but that’s bringing up children for everyone B3

And, you know, you suddenly see that it’s like, “Oh, no, it’s okay, I’ve booked myself on it.” And you’re like, “Wow, that’s amazing.” Um, and I think that’s when you know it’s time to start backing off and saying, “Right, she’s got the tools now. She doesn’t need me in place. I can back off and support someone else.” FG2

Yeah, and that, that all starts with the emotional stability, doesn’t it? Which I guess is what Face 2 Face do a lot of is providing that, that, you know, constructing that framework around families in the initial period, to give them that emotional stability. To then to be able to say, right, okay, yeah, this is the way we’ve, we’re going to be and we’ve got to get on with it. PR02

Um and sometimes when you talk about it you kind of realise it, it’s real, it’s happening and, and everything else. So, so no, they didn’t change my life, but they certainly helped me cope with it better P4

Reduced isolation
The sense of reduced isolation described by parents is not necessarily related to physically being with or close to other people, rather the knowledge that they are not the only people dealing with these problems and that their feeling are normal. There is a clear relationship between talking to someone who has shared similar experiences, realising that you are not alone with your problems and that what you are feeling is normal and the resulting reduction in isolation described by both parents and befrienders. The overlap with ‘shared experience’, which is the precursor to reduced isolation is significant. Feeling less isolated can also feed into other aspects of growth such as an ability to cope.

Um, I felt, um, I was, I was finding it quite hard to cope about a year ago but generally it’s … it’s helped I would say. Um, makes me feel not so much on my own as I was. P3

It shows parents that they are not alone; they can discover there is a large group of people that have gone through the same thing. Isolation can be the biggest hurdle that parents face and this service helps them to overcome this. B32

But if all they do is make your life easier to cope with, and realise you’re not alone and what you’re feeling is very normal - cos you don’t feel normal - then it works, doesn’t it? If it stops you from popping pills, then it works. P2
**Ending the relationship but maintaining the safety net**

There are cost implications if relationships are allowed to go on for too long; one professional identified a clear “exit strategy out of the service to independence” (PR01) as an important commissioning consideration because it is important that such services encourage empowerment not dependency.

However, some participants told us that ending a befriending relationship can be difficult for both parties. Difficult as it may sometimes be, befrienders were clear that they had to make a judgement on whether a parent still needed their support or whether in fact it had become more social and their help could be better placed elsewhere. It is an important and satisfying part of the befriender’s role to see the change in the parents’ behaviour, to be better able to cope and do things for themselves. At that point they described scaffolding the parent’s move towards ending the relationship and reducing the number of visits.

All groups discussed the potential to become dependent on the service and the emotional conflict this might cause for befrienders who may experience discomfort at moving on a parent who did not want to let go of the service, while at the same time recognising that dependency is not in the best interest of the parent. Dependency was linked to capacity; some befrienders were conscious that there were other parents that needed support and that maintaining a relationship where the parent no longer needed them or was not engaging fully in the service was preventing them from helping other families. Amongst the group of parents still receiving support there was also a recognition that they were part of a broader community, that there were other parents in need ‘out there’ even if they didn’t know them. This was sometimes reflected in the way they discussed drawing their own befriending relationship to an end, in the context of moving on to allow others to have the help they were benefitting from and sometimes in a feeling of guilt or selfishness that the fact that they did not feel able to end their relationship might be preventing others from having support.

An important aspect of ending the befriending relationship is the knowledge that parents can access the service again if they need it. From parents’ and befrienders’ description of the dynamics of the befriending relationship, it seemed plausible that this knowledge gives parents the confidence to move on from the service and develop their self-reliance and coping skills, akin to stabilisers on a child’s bike. Parents readily talk about being better able to cope; one consideration is how much this kind of growth is only possible because parents know that there is a safety net there if they wobble.

The emotional rollercoaster described by parents and befrienders means that being able to return to the service at any time is a crucial part of a parent being able to move on. You may end your befriending relationship in a good place but circumstances change and new challenges arise. Parents
sometimes feared letting go of their relationship in case their circumstances changed and they needed it again.

<table>
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<tr>
<th>I also felt I’d done what I went to do. I was the companion that she obviously sort of wanted and that’s what she was looking for possibly. Um and, and I … but I was also always a little bit aware that there were probably other people out there that probably needed the service more than she did. B2</th>
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<td>Um, and I think that’s when you know it’s time to start backing off and saying, “Right, she’s got the tools now. She doesn’t need me in place. I can back off and support someone else.” FG2</td>
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<td>But yeah, I guess probably relying on it a bit too heavily might, could be a downside, um, because really you have to, like, well you can’t rely on anything, you have to be able to rely on yourself to get through it. It is down to you to get through it. P2</td>
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<td>Because there are lots of people out there that need help and if you can only… you know, if the relationship was carrying on and I don’t need her as much anymore, then that’s robbing another family then, that are crying out, that need that help. P5</td>
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<td>Sometimes just having that is enough, you know, you feel like you can cope because there’s always that in the background, there is somebody there if you need them FG1</td>
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<td>Which is really nice, it’s not a case of like okay, I’ve finished with that, it’s gone forever, you know. I mean if anything happens um and life does go down again, I can always pick up the phone to them and know that, that it’s still there, so yeah. P4</td>
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What are the perceived outcomes for befrienders?

**Training**
The positive outcomes described by befrienders begin before they start to support another parent. The training that befrienders undertake is extremely influential, both in equipping them with the necessary skills and associated personal development to befriend, and in providing a new and supportive social network. The training is designed to target a core skill set including listening skills, empathy, understanding and non-judgemental behaviour, recognising that in people suited to befriending, these are qualities to be developed rather than new skills to be learnt. These are generalisable skills that befrienders report can have impact on broader aspects of life such as relationships with families and friends and in their working environment.

In many ways befrienders’ description of training is similar to the way befriended parents talk about the befriending experience; it is a process that is painful and emotional but that helps you to have a greater understanding of yourself and your journey. In the case of befrienders, this process is necessary as well as beneficial; it is essential to work through your own emotions before you are in a position to help anyone else.

Although there are similarities between a parent talking to a befriender, the fact that the group go on this journey together, sharing the stories which they may never have told anyone, establishes a special connection between the group and puts in place the friendships that will continue when, as befrienders, they are supporting each other.

Parents who complete befriender training are under no obligation or pressure to befriend. Training is a painful process for most parents and not everyone wants to, or feels ready to take the next step to befriending. If peer support is viewed purely as a straightforward intervention and befrienders as the people responsible for delivering that intervention, it may seem counter-intuitive to train people without expecting them to assume that role. It is only when the training and the ongoing mutual support between befrienders are viewed as part of the intervention as well that the complex nature and multiple levels of support being provided by the service become clearer. For example, some direct impact reported from the training course included a boost in confidence and self-worth, and a more positive view of your child.

Several participants felt that the process of sharing personal stories in training was extremely beneficial, so much so that a tailored version of the training programme might be appropriate for parents who had recently received a diagnosis or indeed anyone who had major life adjustments to make.
It’s invaluable at even the training, just to teach you to not judge, to listen, to….you know, all the tools you have, but to know how to put them together and it does, it changes you I think. B15

It was a such a journey over a period of months that you don’t realise you’re changing, but you obviously are. B2

Most of us didn’t know each other at all and the bond that we got was amazing. I’ve never known, I’ve never known a bond like it. It was quite uncanny, quite scary uncanny. It was like you could go and just open up your soul in that room and know that it stayed in that room. B35

I did the befriending course, so I’ve got that little monthly group, and if you don’t actually befriend or you don’t want to befriend or you’re not ready for it, you can’t do it, even though we’ve done the training we can still, we can still be a part of that group so that’s really lovely. B3

It’s given me the confidence to say to my friends, well actually he is like any normal little boy, he just has a few issues that he can’t control. B9

Feeling that you have helped someone else
There is a well established literature around the benefits associated with feeling that you have helped someone else, and this was clearly identified by the befrienders as a positive and important outcome for them. In a sense, this provides befrienders with their job satisfaction and it would be frustrating to feel that they weren’t helping the parent in some way. Particularly rewarding was seeing parents make progress and knowing that they had played a part in that progress.

An important subtheme which appears in a number of different areas of the befrienders’ discussions is ‘so that they don’t have to’. In this context, there is great satisfaction for befrienders in knowing that their experiences and knowledge, which were often very difficult for them at the time, can be passed on for someone else to use, without having to struggle themselves. Although befrienders gain personal satisfaction from helping other parents, notably in the opportunity it provides to recognise where they are in their own journey (see personal-growth and self worth) there is a strong desire in the motivations of befrienders to protect other parents from the struggle that they have been through, and in this way build a stronger network of parents that are better placed to help themselves, and potentially to move on to help others (see sustainability of the Face2Face model).

All groups of participants also noted that a negative experience a befriender had in their own life could be used as a learning experience for parents; potentially helping them to avoid a similar struggle and at the same time having a positive resolution for the befriender if they are able to see some good come from their experience.

Some befrienders also expressed a more general sense of enjoyment and interest from the process as much as the outcome and it is important to recognise the value of the social interaction in its own
right in addition to the longer term outcomes. Professionals acknowledged that there is a reciprocal benefit and that it can be as therapeutic to give support as it is to receive it, but were clear that this is not the main purpose of the service.

I feel like oh you know, I see someone down the street, I think oh I helped them you know. I quite like that [...] Knowing that you’ve helped, yeah definitely. Knowing that you’ve made a difference in their life. B20

So I think that’s invaluable for people to know that they’re actually helping. Um, and it’s probably quite frustrating if they feel they’re not B15

You can feel that all that you’ve learnt, all that knowledge that you’ve acquired, that you didn’t necessarily think you were ever gonna have to acquire, actually is of some use. B1

So maybe even where people have had a negative experience in the past, being able to turn that into something positive, um, for themselves, but also for somebody else, I think has a good effect. PR01

Perhaps that opportunity to give back a little bit would be quite good for the person giving the support. That feeling of value and, erm giving back would be quite good. PR08

**Personal growth and self-worth**

Confidence is key to the accounts of befrienders. Whether it is the confidence to take your child to a restaurant, to stand up and speak at a meeting or to say that you think a professional is wrong; there was a general consensus that being part of Face2Face, through the training and ongoing support, had increased their confidence with a wealth of positive outcomes. Increased confidence enabled befrienders to operate more effectively in a number of roles: on behalf of their own family, on behalf of the service and therefore parents who might need support or on behalf of the broader community of parents of disabled children by joining committees, attending meetings etc.

Befrienders did not suggest that they had always lacked confidence; rather that since becoming carers for their children, often giving up work to do so, their confidence had been eroded but their involvement with F2F had helped to restore that confidence. This was strongly associated with a feeling of a sense of purpose and doing something worthwhile, with a corresponding restoration of one’s own self-worth.

Befrienders’ personal development continues throughout their involvement with Face2Face. They describe many of the same benefits that befriended parents do, such as feeling stronger for their own journey and empowered to try new things because of the realisation that they are not the only ones that are going through this experience. Because befrienders are further on in that journey, they also described how befriending others had helped them to reflect on and accept their own situation.
This may be linked to the benefits of being able to use your own experiences to help another, even, and perhaps more so, if the experience was very negative at the time. Being able to share negative experiences and turn them into a positive outcome for the parent can help befrienders to feel that what they have been through was not in vain and can help them see how far they have come in their journey.

*My world opened up completely, from being completely isolated, quiet, shy, wouldn’t say boo to a goose, to someone who is now about four years down the road is not only befriending but involved in steering groups, er, talking with, um, er, what do you call them, um, commissioners, um, er, advising and supporting lots of different person... not advising so much as signposting on to other services. I know a heck of a lot more now that I do and my world just completely opened up.* FG2

*I think it gave me back my self worth, after, you know, sort of, after having the diagnosis, and being shoved into parenting classes, it was the thing that – it sounds a bit dramatic – it was the thing that saved me, that gave me back my self worth.* FG1

*It was the first time really since [my daughter] had been diagnosed that I was able to get out of the house and do something for me and learn something and feel like I was participating in society again, in a separate role, you know, not as a mother.* B17

*For the person who gives support? Well, I suppose a really positive outcome for me, that I think parents would get, was, sort of, an increased confidence, you know, sort of, self esteem and confidence in their own ability to, um, use their skills.* PR01

*Um because one thing is they realise actually how far they’ve come, what experts they’ve become, if you like.* PR06

**Mutual support**

Crucial to understanding the importance of mutual support to this group, and the amount of time the group spend engaged in support activities, is the understanding that the division into ‘parents’ and ‘befrienders’ is a false one. Befrienders are also parents and while they are likely to have come further in their journey, the nature of changing family life, children’s health and major transitions such as changing schools, means that befrienders too are likely to go through many emotional ups and downs – emotional stability is a fluid state of affairs. The support that befrienders offer each other is important to maintain their emotional stability, for the sake of their own well being but also crucially for the service, to keep them in a place where they are able to support other parents.

As in their interactions with the parents they support, the support befrienders give each other is defined by their shared experiences and the ability to speak freely in a non-judgemental, safe environment. They too learn from each others’ experiences and support and encourage each other and benefit emotionally from the group.
Alongside permission to express their negative feelings, befrienders talk about the opportunities support groups provide to celebrate the positive steps their children make, things that might be considered too small to mention to a different group of peers, such as tying a shoelace for the first time. Humour is a feature in these groups. Again the link is to a safe environment and being given permission to speak freely but in this context befrienders describe being able to laugh at their situation with other parents and make jokes and comments about their children that would be considered un-PC in other environments. This not only provides a necessary release for what could otherwise become negative feelings, but it also serves to strengthen the sense of group/community.

The support befrienders give each other does differ from that they offer parents however; it is more like a friendship in that it is two-way and open and befrienders are there for each other. It was felt important to maintain that friendship through attendance at the support group and social events.

There is a very real and palpable sense of community in the support groups, particularly where the group has trained together and shared their most difficult experiences– some befrienders expressed a reluctance to join or merge support groups that had not trained together. This is not necessarily a negative reflection of other befrienders, rather a statement of the bonds built up within the training groups. Not all befrienders saw combining groups as a negative, viewing the new contacts as a positive learning experience. Befrienders who are not befriendng still give and receive support in the groups. They do not feel in any way that they are not part of the group because they don’t befriend and feel they have an important role to support the other befrienders.

One of the more striking contrasts between the accounts of professionals and befrienders is around mutual support for befrienders. The need for support from the coordinator and network of colleagues is discussed by professionals in the context of professional supervision. Like training, support for befrienders was considered essential for the safety and well being of both parents and befriender – particularly around managing the emotional burden of this type of work. Though the importance of support is considered essential in this context, there is no knowledge or expectation of the much more personal support that befrienders give each other, which is sometimes hard to distinguish from the kinds of support parents describe receiving from their befrienders.
But another thing as well worth pointing out is unless you have these groups like these, these little steps you have to celebrate on your own, you know. You celebrate it with somebody else and it’s that affirmation back and you’ve got, yeah. You know, you know that the other parents realise how momentous it is. FG2

You know and I still feel I have, I don’t feel as if, I don’t feel that because I’m not befriending that I haven’t been able to be helpful, because actually it’s nice because three or four of us get together reasonably regularly and support each other outside of that [...] And so it’s been really very good, even if I haven’t done the befriending really. B11

I think you are more open, and more, um, particularly emotionally, within the support group than you would be. Because when you are with a parent it’s not about you, it’s about them. Um, so it’s, I think, yeah, you are much more open. FG1

Expanding social networks for both parents and befrienders
Engaging with the Face2Face service also serves to expand the social networks of parents and befrienders. A number of participants made reference to the social and support benefits of training as a befriender in terms of broadening their social circle and becoming part of a bigger community and meeting other families similar to their own. Several parents describe the social benefits for them of having a befriender and some befriending relationships develop into friendships after the formal support, broadening both people’s social network.

I enjoy seeing [my befriender] as much as I benefit from seeing her P9

And I think, on the selfish side, I thought how that could help me, by meeting other people, more people like me, um, that have, you know, difficult children, whatever their disability, whether it be, you know, whatever [...] that’s going to grow my friendship circle P10

I think what it means to me really is that it’s nice to meet with parents who have a understanding of how, how difficult it can be to have a child with support needs really B6

Educating the professionals and, and also bring parents together because before Face 2 Face, before Parent Carer Council, before the Oasis groups and everything, you were isolated, on your own, nobody understanding you or your situation at all. Er, now we have, like, it’s like a, a subculture almost. FG2

It was a nice feeling to be part of sort of a local community sort of feel about it P8

Well if there’s a positive relationship that’s, that’s struck up, um then there could very well be a friendship between the, the adults, possibly then broadening into the children and maybe the family PR10
**Negative impact for befrienders**

Potential negative outcomes for parents, such as the potential effects of seeing and hearing what the future might hold for your child, or the potential for harm to vulnerable parents without the proper training and boundaries have been discussed. In our conversations with befrienders we identified a number of potential areas of negative impact, which reinforces the need to look at volunteer outcomes in any evaluation as well as those of the service user.

Befrienders identified themselves as naturally caring and wanting to help. These characteristics underlie some of the potential negative impact of befriending. Befrienders described the emotional drain of befriending, which they felt to be underestimated by professionals. This view is at odds with the concerns that the professional group expressed around the emotional burden placed on befrienders and the necessity for appropriate supervision and support network to ameliorate this.

Befrienders found it difficult to switch off after befriending, which was sometimes constructed as a commitment to the family and service rather than necessarily a negative impact for them. Professionals however were concerned that befrienders may have difficulty maintaining their distance from a family’s situation, particularly if they had been through similar experiences themselves and there is a risk of befrienders becoming emotionally overburdened as it is harder to maintain boundaries around the relationship than it would be for a professional.

Professionals identified that the time and energy required to deliver the service well has implications for the befriender’s own family. Some befrienders confirmed that they had a tendency to take on too much, leaving little time for their own family but can feel bad about letting people down if they need to back away from a relationship, describing obligation and responsibility.

Many, though not all, befrienders described varying levels of anxiety before a first visit; whether they were going to ‘get it right’, whether they would get on with the parent. This is linked to the greatest negative impact for befrienders – the worry they feel about their own impact on the parent. Befrienders were concerned whether they would do any good or that they might even make the parent feel worse. One befriender described feelings of inadequacy and the huge difference between role play and the real life situation. Others expressed frustration that they wouldn’t be able to ‘fix’ things for people (even though this isn’t the objective of the service) and that there are some people that you just won’t be able to help. Finally, one befriender described feelings of guilt at letting her parent down through an unavoidable cancellation, even though she knew that the parent would understand. This feeling of guilt was specifically linked to not wanting to appear like just another professional that lets parents down.
Emotional and time commitment:

Um, and again, it must be really hard to stop your emotional side kind of taking over, especially when you are seeing a parent who is really distressed. It is quite hard to switch off if you have been in that situation, and also, again, becoming over reliant on you. PR03

So you have to be very, you have to be very clear and you have to be quite disciplined I would imagine, to, to do it as a parent. I can do it because I am a professional and do that, but um I... that's one of the things I would find difficult to do. PR07

I've got to make sure that I don't take on too much, because I'm the sort of person... yeah I'll do that, I'll do that, and I think, oh my god I'm going to have to like slow down a bit, you know, because else the home life just gets too [expression]. B35

And also I think it’s a good thing, but also a negative aspect of it is the amount of responsibility you have towards that person. [...] you feel responsible because you’re that emotional support for that parent. FG2

Concerns that you might make things worse:

I think then it's really important to all know that you're getting it right, hugely important. Um, so I think, yeah, I think, I think you get even the brief bit of befriending I did, you want to know you kind of come out thinking oh did I say the wrong thing, did I upset her, did I make it worse? B15

Feelings of inadequacy:

And I was just like, it doesn’t come out when you’re suddenly in this situation, and you think, oh gosh, I'm supposed to be saying something! And it's just really hard, it doesn’t happen like it did. And, um, yeah, so just because I just felt inadequate it wasn’t anything she’d done, it was just that I just didn’t feel that I knew what to say, or how to move it to where we should be. B4

Frustration at not being able to ‘fix’ things:

I want things fixed, I don’t like things being, for anybody you know upsetting I want it resolved for them really. Maybe that will be hard for me if I was in a house befriending and then I had to leave that person, because I’d think oh I don’t know if I can leave you in that, I want to help so it would be quite hard really, I don’t know. B11
Who benefits from peer support?
Parents arrive at the service with a range of emotions. Some describe guilt and shame, depression and a tendency to turn blame in on themselves. Many perceive a struggle to get things done for their family and feel disappointment and loneliness that they can’t do what other families are doing, when other parents exclude their family or when their child doesn’t meet the same milestones.
Attempts to fit in be ‘normal’ can be exhausting and frustrating. It is important not to lose sight of the fact that befrienders bring all of this to the relationship with them as well as parents on “the rollercoaster of up and down and coping and not coping” (B11)

Parents’ gave a variety of reasons for seeking support. Although several felt they needed emotional support from someone who had been in the same situation, two parents expressed an interest in very practical/information driven support, and two wanted to meet other parents with children similar to their own. It is often very hard for parents to actually ask for support and it may take them a long time; they will access support at different stages in their journey.

A number of parents said that they didn’t have any expectations of the service they just knew that they wanted help; some parents indicated that in their experience expectation could lead to disappointment. While all parents were positive about the service as a whole, a number had perhaps hoped for a little more than was possible. For example, support with marriage difficulties, to be put in contact with other families, disappointment at the length of time it took to be matched or wanting the relationship to be more two way and learn more about their befriender.

Timing of support
The timing at which support is offered, needed and accessed (or not) is something of a paradox. Befrienders and parents speak of their desperate need for help early on but at the same time, not being ready for support. This was most often articulated by befrienders. The most common reason

I would just, just want to just come home from school, school drop-off, lock the door, pull the curtains and just go back to bed and hide from the world, and never speak to anybody, do anything... the amount of times I didn’t wanna go and pick them up from school ‘cause it had got that bad. P4

I don’t really think I had a lot of expectations; I think you learn not to have too many expectations because with things you just take it for what it is. P11

Before I saw them, I thought that they would have all the answers and that would be finished, but what the service has allowed me to do is to realise that in some respects there isn’t any answers and it is a rollercoaster, but that’s okay and to use them when you need it, and to accept that. But actually, by realising that, that is actually like, like a conclusion. P2
befrienders give for volunteering is so that other parents do not have to go through what they have been through, yet this is hard to reconcile with the suggestion that people are not in a place where they are able to access or seek support when they are at their most desperate.

All participant groups recognised that early intervention might be of most benefit to prevent families reaching crisis or struggling through on their own however many felt that it was simply too much to cope with early on and that parents needed to build a degree of confidence themselves before they could talk to someone else. Befrienders and professionals noted the potential dangers of early intervention when parents are very vulnerable and the skill needed to do no harm. Some also noted that when in the midst of dealing with things may not be the best time for parents to have support and that it is most needed and helpful when parents are looking back and reflecting.

It was not felt possible to know when the best time to offer support would be. All parents are different and it has to be the right time for the individual; some people will never be ready, or wish, to talk. All groups agreed that an appropriate compromise is to give parents the option and information about support right from the start so that they would be aware that support was available when they were ready.

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**Maybe a piece of paper won’t help but you know what I mean, erm when you’ve just been told something you don’t shut down, you just, you don’t listen. but at least if you’ve got a piece of paper there or a leaflet that says, you know, these are the services that you can access, then you can read it later when you’re in a better place, as I say to take away with you.** B9

**So I can see that some people might need it when it’s more catastrophic in a way. It was like everything’s coming at you and you just think, “Hey, I need to talk to somebody.” But I always find when everything’s going mad, that’s when I cope better than, it’s when things are a bit more calm, you just think, “Oh well what about this?” You have more time to think and you ... and therefore you want to say ... talk to somebody. Whereas when it’s happening you just have to deal with it.** P1

**So when they kick in, it’s really individual. It’s when the parents are ready to open up, because some of them are not going to be, and might never be. And that’s going to be really difficult because they all suffer. So it depends on the child, it depends, every one of them.** PR09

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**Not the right service for everyone**

Not all parents of disabled children require this type of emotional support to adjust to their child’s diagnosis. Participants described a number of reasons why some people who might benefit from support, may choose not to engage with the service. Some parents find it very hard to accept their situation and are not ready to process what is happening. Unless they are able to acknowledge that they have a need, they will not engage with the service. All groups noted that this may be
particularly difficult for dads. Not everyone wants to share their emotions and prefer to keep their
difficulties from other people, coping in their own way. People differ in how much they want to talk
and how they cope; some people may never be able to open up even to another parent and this may
be particularly true of families with hidden disabilities who may feel that they should struggle on.

It requires courage and confidence to admit that you need help and parents may not have the
emotional capacity to do it hence the very people that may desperately need it, may not be able to
ask for it. How the discussion around support is introduced is of vital importance; if not well
managed it could be seen as a criticism of parenting or ability to cope. It is important that those
suggesting support recognised that families may have had negative experiences of others services
and may be anxious about engaging with a formal service if they have concerns around being
judged.

Although all of the parents we talked to had engaged with the Face2Face service, we can
hypothesise that some of the anxieties they had before meeting a befriender might be sufficient
cause to put some people off accessing the service at all. Most parents said that they felt nervous
before the first visit. Some also noted that their befriender was also nervous as it was the first time
they had befriended. Parents described a host of reasons for feeling nervous; concerns around
talking to a stranger, that the befriender might try to tell them what to do, concerns that they might
not really need the service and would be using up valuable resources or that their child wasn’t
‘disabled enough’. Parents were aware that they could pull out if they decided they didn’t want to
see the befriender again, which helped them to overcome their initial nerves but this may not be
enough reassurance for those who chose not to access the service. Because we were unable to
interview any parents or befrienders that had not engaged with the service we are only able to
speculate using the views and suggestions of those who did chose to use or offer the service.

Many participants commented that the reason why some people do not engage with the service is
inextricably linked with the timing of when support is offered. It is not necessarily that the service is
wrong for some people full stop, but that it might not be the right service at that particular time for
that family.
Because the other thing is, in many ways, the parents who most need help don’t get it. So when you, the parents that... ‘cause, ‘cause I think a lot of parents can be quite defensive and feel that maybe they’re being criticised um and that, or the implication is that you are not a good mother or you don’t love your children. So it does, does need to be carefully handled. B1

Um, I think some people um could possibly be in denial. [...] Um, some people are just loners and just want to get on with it themselves, they don’t you know, want to go and chat to people. Um, and I think some people may not have the courage to go. B35

I mean there are some families who I think probably would just ring anybody, because they’re desperate for anybody to offer them something, but there are some where that would be kind of an admission of not coping and that would be a, quite a hard thing for them to do. PR08

So, you know, I think if it hasn’t worked for some people, it isn’t cos the system doesn’t work, it might be cos it just didn’t work at that time for that person cos it is very much the time that... the right time for you, the type of person you are, the person you get, do you know what I mean? It’s the combination of all, of everything. It’s not just one thing. P2
**Summarising the processes in peer support**

In describing the processes involved in delivering the service, we have identified a number of key factors that can help or hinder a successful befriending relationship, which have been discussed throughout the chapter. These suggest a much more complex set of processes and outcomes than originally conceived, in particularly highlighting the impact, both positive and negative, for those offering the service as well as for those who receive it. A visual representation of these factors is shown in Figure 3. The process model begins with the structural elements of the service put in place to ensure that the service is delivered safely and within boundaries. Elements included here, such as training and supervision, were particularly valued by the professional group. Participants also identified a number of factors that could either help or block a successful befriending relationship including the matching of parent and befriender, whether the timing is right for the parent to be able to benefit from support and intrinsic and extrinsic factors relating to the befriender.

Shared experience was the central theme to the study, seen as a necessary component of peer support. If shared experience is in place, other active ingredients of a befriending relationship are enabled, such as learning from the experience of others, support and encouragement, and the ability to speak freely in a non-judging environment. Things can also go wrong at this stage and we have identified a number of factors that can result in a negative experience for parents and befrienders which have the potential to put the parent back to the beginning, or potentially to withdraw from support altogether. Befrienders too are at risk of a number of negative experiences, most notably from the emotional burden they take on and concerns around whether they are doing a good enough job.

If the befriending relationship is successful, participants told us about a number of short-term outcomes for parents, instant impacts such as a feeling of emotional release or a piece of practical information they could use. Longer term outcomes for parents included a reduced sense of isolation, emotional stability and personal growth particularly increased confidence and coping ability. For befrienders too, confidence and self-worth are important outcomes as is the knowledge that they have been able to help someone else. For befrienders though, perhaps the greatest benefits described were around the mutual support they give and receive from their fellow befrienders, often the group they trained with and established such strong bonds.

Participants, both parents and befrienders, described the skills and confidence they had gained through their involvement with Face2Face. These skills and behaviours carry over into participants lives outside of the service and have potential impact in the broader community. For example, some participants described becoming active in local parent organisations, being part of council
committees or being involved in training professionals. Interventions such as peer support although designed primarily to impact on the wellbeing of the individual may also have the potential to impact at a broader level which should be considered in service evaluations. A representation of the service is shown in figure 4.

Since becoming a befriender, now I work for the Parent Carer Council, [...] I went to London all on my own [...] and I went to this conference and I talked to these people and I could've never have done that a few years ago. FG2
Figure 3: Processes and outcomes of peer support

**Intervention:**
- Structure of service
- Rules and boundaries
- Training
- Service objectives

**Moderators**
- Matching parents and befriender
- Timing of support
- Extrinsic qualities of befriender (e.g. training, rules and boundaries, professionalism)
- Intrinsic qualities of a befriender (e.g. empathic, understanding, knowledgeable, non-judging, readiness and suitability, motivations to befriend)

**Mediators**
- Significant blockers can put parents back to the beginning (e.g. request new befriender, come back at a later time) or withdraw from services entirely

**Active ingredients**
- Learning from the experience of others
- Support and encouragement

**Shared experience:**
- operates on two levels
  - Social identity, not being only ones going through this, normalisation of feelings
  - Permission for negative feelings about your child (and associated guilt) – because befriender has experienced these too, changes dynamic of interaction

**Mediators**
- All about me – ability to speak freely in a supportive non-judging environment “emotional download”
- Permission for negative feelings about your child (and associated guilt) – because befriender has experienced these too, changes dynamic of interaction

**Potential negatives for parents**
- e.g. unfavourable comparisons between children, seeing what lies ahead, inappropriate/unprofessional befriender, unmatched hopes and expectations

**Potential negatives for befrienders**
- e.g. emotional burden, concerns around impact, unmatched hopes and expectations

Not the right service for everyone – some people are not able to engage with this type of service e.g. not in the right place emotionally, prefer (or think they prefer) to manage alone, previous negative experience with this or other service

Ark},
Short-term outcomes: such as sense of relief, “emotional download”, practical suggestions that can be implemented, social interaction. These are indicators that the relationship is functioning and that parent may go on to “get something” out of support. The balance of practical and emotional benefit may reflect the parents’ priorities.

### Parents
- Reduced isolation
- Emotional stability
- Personal growth: e.g. increased confidence, ability to cope

### Befrienders
- Satisfaction of helping others
- Impact of training
- Personal growth: confidence, self-worth and perspective on own situation

### Long term outcomes
- Personal growth:
- Maintenance and sustainability
- Community resilience
- Mutual support network
- Ending the relationship
- Maintaining the safety net
- Moving from parent to befriender
Figure 4: model of peer support within the community

- Individual parents in need of support
- Parents may train to become befrienders themselves
- F2F train other parents to provide peer support
- Befrienders benefit from training in terms of their personal journey and the bonds formed with their training group
- Some people leave the service at this point but have still benefitted and take those skills into the community with them
- Befrienders offer one-to-one emotional support to parents for a period of time
- Stronger, happier, empowered parents
- Befrienders support each other and place great value on this support. Some will never befriend but give and receive support at these meetings and feel valued
- Stronger, happier, empowered befrienders

- Role models
- Social network
- Advocacy, other parent organisations, joining committees
- Delivering training to professionals

Potential benefit to the broader community of parents of disabled children
Sustainability of the Face2Face model

Much of the discussion with participants highlighted the artificial distinction between supporter and supported and we extrapolate from these conversations to think of both groups as members of a community who understand and want to help each other. This is keenly identified as the main motivation for becoming a befriender; wanting to help other parents through the difficulties that befrienders had been through themselves, so that they didn’t have to go through the same struggle.

A number of befrienders described becoming a befriender as almost a natural progression for someone who felt that they themselves had benefitted from the service, as a way of giving something back and maintaining the continuity of the support cycle. Many comments from parents who are potential befrienders reflect the same motivation; they felt they had turned a corner themselves and wanted to help other parents so that they didn’t struggle in the same way.

There is a recognition that not everyone is in the right place to move directly between the two roles; being in the right place to let go of the supporting relationship does not necessarily mean that a parent is in the right place to help someone else. Training was sometimes seen as a transitional state between the two roles, conveying the benefits of mutual support and continuing personal growth without the obligation to take on other people’s problems.

The process of transition from being the supported to being the supporter was not discussed by professionals. Given the importance of this transition for the self-sustainability of the service it may be beneficial to promote the continued involvement of families after the end of their formal befriending relationship to help potential funders and referrers understand the sustainability of the service.

I think I’d just got to that stage where I though, gosh I’ve been through so much and it’s been such hard work and I think I can probably help some other people so that hopefully it won’t be quite such hard work for them. Hopefully at an earlier stage, they might have some realisations that I only reached much later because of, you know, not really having that kind of support. B17

It does pass on. I think when you realise what you get out of it you really, you really do want to pass on that and then I think they feel the same. They think, wow, I’m like a different person. I want to help other people now. And I think there’s... it’s only good can come out of that. I can’t see anything detrimental to that at all, building up your social circle of likeminded people. FG2

I have heard parents say that [...] if their experience could have been different earlier on then it would have been easier for them [...] they want to offer that to other parents. But I have also heard parents say that they want to give something back; because they have had a positive experience, they want to be able to help other people have a positive experience too. And other people say they have learnt so much through the process that they don’t want that to be lost knowledge; actually
they want to be able to use their expertise that they have developed as being a parent, and help other parents benefit from that. PR01

They know what it’s like to be in that place of isolation, and, and fear and whatever. And they also probably know what it’s like to feel better about that, and I think that the motivation is not one of anything other than, um, what is good about humans which is about sharing, um, that lessening of, of the burdens, I suppose, on other people. PR02

One day I would like to be able to return the favour if you like and do the same thing for someone else P6

I felt that it was so valuable to me, having befrienders, and it helped me through a difficult time, that I really wanted to put something back […] I just thought that I wanted to help parents like I had been helped really. P11

Links with professionals and other organisations

The most significant difference between the views of professionals and parents/befrienders was around the perceived value of the service. Overall, professionals thought highly of the potential benefits of parents helping other parents and the impact that these programmes could have in terms of the use of services in general and the possible collaboration with more ‘professional’ services to provide a whole family approach. Linking in with other services was viewed as a potential way to spread awareness and provide opportunities to combine with other voluntary services to have greater impact.

This contrasts with the perceptions of befrienders who felt that they are not valued at all by professionals. A number of befrienders and parents had specific concerns around the need for more referrals from professionals, particularly those that go into people’s homes and concerns around the future of the service and its funding. Both of these concerns were linked to the sense that professionals do not value the service and a need to demonstrate to decision makers that the service is beneficial. Discussions around family interactions with professionals in general tended to be negative (see section: Professional Support). These negative personal experiences likely contribute to the way befrienders perceive that professionals view the service and their role.

Like professionals, befrienders and parents agreed there was a need to work together with other organisations and professional services however there was some concern that closer integration might change the nature of the service, as informality is so important to parents and befrienders. The fact that the organisation is a charity rather than accessed through a service such as the NHS can reassure and instil trust in families who have not always had good experiences – one parent
described F2F as filling a gap, providing a port of call when you have been let down by other services.

There appears scope for closer working between voluntary organisations such as Face2Face and professionals that might refer to the service. The interviews conducted in this study would suggest:

1. Professional groups are not always aware of peer support services and what they offer. While there is a need for services to raise awareness with relevant professional groups the limitations of coordinator and volunteers’ time is recognised.

2. The value placed on peer support by professionals was far higher than perceived by the parents and befrienders in this study. For closer working to succeed, it will be necessary to address this potential misunderstanding, while recognising that the views of the professionals interviewed in this study may not be representative.

Professional:

I think there is a huge value in, in voluntary help and a lot of volunteers are really expert and really good at what they do. Um and I think that they are, as well, very committed. PR06

So it would be possibly erm, it would be sitting alongside but possibly, maybe the professionals could also gain some insight and support from the people that have been there and done that. PR09

Parent/befriender:

A1 I don’t think..... My perception is that we are not taken seriously enough, and our work isn’t valued enough. Um, I don’t know how.....

A3 Yeah, I would agree, yeah. It’s, um.....

A2 I am not even sure they know we exist. FG1

I genuinely think its invaluable. I think it’s, um, something that would probably be bottom of the list, but it probably should be top of the list. Um, I don’t know how well perceived it is, you know, from the right kind of bodies that can get it out there. B15
Key findings

- Parents identify with other parents of disabled children in a way that they can’t with other people because they have had similar experiences. How much shared experience in terms of the similarities between children and parents is unresolved in this piece of work and may be context and person specific. The importance of shared experience to this group is rooted in social identity theory.\(^{19}\)

- The shared experience between parents of disabled children is a necessary component of peer support. It enables parents to speak freely and not feel judged. This is what differentiates peer support from the kinds of interactions parents have with professionals and even with their friends and families. The one-to-one, confidential and professional nature of the Face2Face service sets it apart from the support parents can access in support groups. A potential danger when a group sees themselves as very different to other groups is that they can become quite inward focussed, promoting an ‘us and them’ division.

- Important to understanding the impact of peer support is to grasp that there is no fixed endpoint where the parent is ‘better’ – the service is about helping parents to have the confidence and ability to cope with the emotional ups and downs, scaffolding this change with support and encouragement, and providing the safety net that support will be available as and when needed. The fluctuating nature of parents’ and befrienders’ emotional wellbeing presents challenges for how and when to measure the impact of peer support.

- A number of positive outcomes were also identified for the parents offering support; particularly from the training and ongoing mutual support they receive from other befrienders. There were however some concerns around potential negative outcomes including emotional burden, time commitment and concerns around doing a good job.

- Professionals highly valued the support that services such as Face2Face can offer parents however they need reassurance that the formal structure is such that the service is safe for both parent and befriender. Parent support services must present as a parent-led but professionally delivered service if they are to meet the needs of both parents and satisfy professionals.
Strengths and limitations

- A key strength of this study is that it enables the views of service users, service providers and professionals that might commission or refer to the service to be considered alongside each other. This has highlighted similarities and differences between the groups which have the potential to inform service delivery and promotion, and to foster stronger ties between the service and professional groups.

- The close involvement of the study stakeholder group was central to the success of the qualitative study. The group were instrumental in setting the research questions, preparing information leaflets and designing the topic guides. At the analysis stage we convened an expert reference group who advised us on the emerging analysis and highlighted gaps in our interpretations and alternative ways of thinking about the data.

- A significant limitation of the study lies in the potential bias due to sampling. We sought to interview families who were offered peer support but declined or who had received very few visits. Withdrawing from the service is a potential indicator that the parent was unsatisfied with the service or the pairing with their befriender although equally may suggest that the parent needed only minimal support. We were not able to recruit any parents who had declined or who had withdrawn from the service because they had a negative experience or were unhappy with the service. The coordinator from the service in Devon informed us that, during the 12-month period only two parents would fall into this category. One parent withdrew because she wanted a different type of support and was not happy to explore difficult emotions. A second chose not to have a befriender, deciding that she did not need one after an initial visit with the coordinator.

- We also sought to recruit befrienders who had withdrawn from the service. We were able to interview a number of befrienders who had never befriended, or who were currently not befriending however most had maintained regular contact with the service via the coordinator or support groups. Only two of the 23 befrienders we interviewed no longer had regular contact with the service. We acknowledge therefore that there is a positive bias in both the parent and befriender groups, although both groups were still able to identify some potential limitations and suggestions for improvement of the service.

- Our participant group was entirely white British. This was representative of the service locally, however cultural and social considerations around the uptake of this type of peer support service would be a potential area for future research.

- We interviewed a purposive sample of professionals from health, social care and education. We recognise the limitation of this sampling strategy; however i) we did not seek to recruit a representative sample of professionals. This preliminary piece of work sought to gauge the
opinions of a small group of professionals to guide the development of future evaluation ii) the pool of professions that have contact with families of disabled children is large and diverse. In selecting such a small group to interview it would be impossible to represent this diversity in any meaningful way. As such we aimed to represent health and social care and educational support and took guidance from the study stakeholder group as to which key professions would be potential users of the evaluation findings.

- A more notable limitation is the potential bias of attitude in this group; a group of professionals willing to set aside an hour to talk about parent support may not be representative of the group that parents encounter on a daily basis and arguably may hold more positive views.
- Parents and befrienders also found it challenging to discuss topics around how support might work, or not, for different people under different circumstances, and why some people don’t engage with peer support at all. This was difficult for participants to think about because it is not about their own experiences; rather it is asking them to try to imagine other people’s experiences. These topics were more easily discussed in the focus groups with befrienders.
- Similarly, parents and befrienders seemed to find it hard to verbalise negative impacts of the service and barriers to support. Again, this may reflect the participant group who might find it hard to think of negative impacts if they had not experienced them. An alternative consideration is that participants were reluctant to say anything negative about the service either because they were concerned how the information would be used (a number of participants discussed concerns around future funding of the service at points in their interview) or because they were concerned that their comments might be made known to the coordinator (despite repeated reassurance to the contrary).
- These questions would have been better addressed if we were able to talk to parents and befrienders who had either chosen not to be involved or who had withdrawn from the service.
Costing study

The aims of this costing study were to provide a detailed picture of the resources needed to provide a peer support service for parents of disabled children, to estimate what these resources cost and to calculate the cost of the service per parent who receives it.

The peer support services

The F2F services in both Devon and Cornwall were used as separate case studies for the costing analysis. These two models of service provision formed the basis of the costing exercise, with the intention of estimating the full resource consequences of providing a peer support intervention for parents of disabled children.

Literature on costing other forms of peer support interventions has informed the methods used in the current study. However, no previous studies were identified which have provided a systematic costing of a peer support intervention for parents of disabled children. (Search of databases provided by the Centre for Reviews and Dissemination).

Research questions

- What resources are needed to provide a peer support service (as the F2F model) for parents of disabled children?
- What are the costs of providing such a service?
- What is the cost per parent who receives the service?

Methods

The method for costing the peer support service was to:

- identify the resources needed to provide the intervention;
- measure the amount of resource use;
- value, or cost, this resource use;
- provide a cost per parent who uses the service.

All data collection was conducted between February and December 2011.

Identification of resources

From programme documentation and initial conversations with service providers, the main expected cost drivers in providing the peer support service were the time of the volunteers who provided support (befrienders), and the time and cost of the service co-ordinators and managers. Befriender training was also anticipated to be a significant cost as all befrienders receive 40 hours of training including elements of counselling such as active listening skills, prior to starting in the role (see pages
The intervention offers one-to-one peer support mostly in parents’ own homes, resulting in travel costs and related expenses.

**Service provider meetings**

Discussions were held with service co-ordinators, managers, administrative support staff and accountants in both Devon and Cornwall to determine the infrastructure of the services in more detail and other resources needed to provide them. These meetings were focussed around the following, but also enabled other resources to be identified:

- Direct service costs (e.g. staff type and grades, management structure, administrative support, training, travel, consultant payments, venue hire);
- Indirect service costs (e.g. befriender’s time);
- Direct overheads (e.g. accommodation, telephone, postage, printing, stationery, other consumables, transport, heating, lighting, email);
- Indirect overheads (e.g. accommodation, central operating costs, human resources, audit and financial services);
- (Both fixed and variable costs were considered).

**Measurement of resource use**

**Work sampling**

As befriender time was anticipated to be the key resource in providing the service, this was assessed in some detail. The technique of work sampling was used for this purpose.

Work sampling is a measurement technique that allows the proportion of time spent by people on particular activities to be estimated.\(^\text{32}\) It has been used in a variety of ways to research the delivery of health care services.\(^\text{33}\) Work sampling can ‘provide important insights into the cost analysis of complex interventions’\(^\text{12}\) and can be used to determine staff resource needs, as well as identifying how time is spent.\(^\text{34}\)

Work sampling had two purposes. First, to estimate, in a systematic manner, the amount of time that befrienders spent in befriending activities, and to estimate the amount of time that befriending co-ordinators actually spent in work-related activities as compared to their contracted hours. (People working for voluntary organisations may give more of their time). Second, to give a detailed picture of how befrienders spend their time, and how they divide their time between different activities in providing the service.
Two focus groups were held with the Devon service co-ordinator, befrienders, the lead researcher for the project and the project health economist to identify the main befriending activities (e.g. visits to parents, making phone calls on behalf of parents, paperwork, travelling). Based on the outcomes of these meetings, a form was created for anonymous completion by the befrienders, and a separate form for the co-ordinator, regarding the amount of time they spent on each of these main activities (Appendix 2). The co-ordinator and befrienders were asked for feedback on these forms prior to their use.

Each befriender was provided with information about the work sampling (Appendices 3 and 4) and asked to take part by keeping a record for a three month period of the amount of time they spent befriending and how they spent their befriending time.

**Valuation of resource use**

**Unit costs**

Estimated resource use was combined with unit costs (e.g. salary costs) or actual expenditure (e.g. service overhead costs) to calculate the expected total annual cost of providing a peer support service.

The valuation of resources was, as far as possible, based on national unit costs of social and voluntary care resources (e.g. Unit Costs of Health and Social Care\(^{35}\) and National Joint Council Salary Scales\(^{36}\)) in order to maximise the generalisability of the costing analysis findings. Where such national costs were not available, local cost data was applied.

**Cost data from service providers**

Financial accounts from both the Devon and Cornwall F2F services were obtained for the year April 2011 to April 2012.

**Valuation of befrienders’ time**

There is no consensus in the research literature as to how to value or cost the time given by volunteers in providing a peer support service to parents of disabled children, or indeed in providing any form of voluntary service. As such, alternative approaches were taken for valuing the time that befrienders spent in befriending activities.

a. No monetary valuation
The base case chosen was not to assign a monetary cost to the befrienders’ time. The rationale was that befrienders freely chose to become befrienders and volunteered to partake in befriending activities. Therefore, they may have obtained personal value from this role and the tasks they took part in, and no financial reward was expected, provided or received.

The following methods for costing befrienders’ time were additionally explored in scenario sensitivity analyses:

b. Opportunity cost method

In this approach, the opportunities foregone by befrienders as a result of spending their time befriending were valued. This is based on the premise that befrienders’ time could be spent in other activities. Wilson and colleagues\textsuperscript{25}, and Patel \textit{et al.}\textsuperscript{26} have used this approach in costing peer support services. Wilson \textit{et al.} used the gross hourly wage rate for women and men, and Patel \textit{et al.} used the UK minimum wage as proxy valuations of volunteers’ time. Both approaches were used here.

c. Replacement cost method

This method considers the potential cost of the service if befriending was provided by paid social care or health staff, rather than volunteers. Previous studies that have costed peer support services have used replacement costs of a NHS counsellor\textsuperscript{37} and of a home care worker from social services,\textsuperscript{26} and both these approaches were adopted here.

\textit{Service activity}

For the base case, it was intended that the activity of the service would be defined as the number of ‘complete befriending cases’ in one year. This was the number of parents who were referred to service and completed using the service in the year period. This was estimated using service data and based on discussions during service provider meetings. However, during the course of the research, through service user and provider involvement, the concurrent qualitative study, and work sampling data, it became apparent that parents who received the service were not the only beneficiaries of the service (please see qualitative findings for further details). Befrienders themselves clearly also obtained substantial personal value from their involvement with the service. This implied that considering the costs solely according to the number of parents befriended was too limiting a viewpoint. Therefore, the costs were also considered against the number of befrienders involved with the service during the year period, and the cost per parent who received the service was not directly estimated.
**Scenario sensitivity analyses**

Sensitivity analyses were conducted to explore the impact on the intervention costs of aspects of service provision around which there was some uncertainty.

**Results**

**Service configuration**

The meetings with service providers found that the infrastructure of the services differed between Devon and Cornwall and, therefore, they are described and costed separately.

Table 8: models of service provision

<table>
<thead>
<tr>
<th>Individual co-ordinator model: Exeter, Mid and East Devon</th>
<th>Multiple co-ordinator model: West, Mid and East Cornwall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Approximately 20 befrienders at any one time</td>
<td>Approximately 63 befrienders at any one time</td>
</tr>
<tr>
<td>One co-ordinator who is contracted to work 21.5 hours per week, works from home and also befriends</td>
<td>Three co-ordinators (one for each of the regions), who work 20, 17.5 and 17.5 hours per week</td>
</tr>
<tr>
<td>Supervision by an area manager who manages F2F services across the south west of England</td>
<td>One area manager who manages F2F services across the south west is based here, and works 28 hours per week for the Cornwall service</td>
</tr>
<tr>
<td>Two co-ordinator and befriender support group meetings each month for 2.5 hours</td>
<td>Weekly to monthly meetings to which parents can drop in</td>
</tr>
<tr>
<td>New befriender costs</td>
<td>New befriender costs</td>
</tr>
<tr>
<td>No office premises</td>
<td>Single office premises</td>
</tr>
<tr>
<td>-</td>
<td>Three administrative staff, who are employed 20, 12 and 10 hours per week</td>
</tr>
</tbody>
</table>

**Figure 5: Individual co-ordinator model of peer support service for parents of disabled children**
Figure 6: Multiple co-ordinator model of peer support service for parents of disabled children

**Work sampling**

The focus groups held to explore the main areas of activity of the befrienders identified the following categories:

- Meetings with parents;
- Other contact with parents;
- Non-contact time on behalf of parents;
- Individual contact with service co-ordinator;
- Mutual support (e.g. group meetings);
- Training/continuing professional development;
- Travel;
- Record keeping/admin;
- Delivering training;
- Other
**Individual co-ordinator model**

Sixteen of the 20 befrienders agreed to take part in the work sampling. One person withdrew prior to completing any forms, and the remaining 15 all provided information for each of the three months. The co-ordinator also completed work sampling forms for the three month period.

Across the three month period the estimated total time spent in befriending activities by the 15 respondents was 204.7 hours. (This excludes the activities of the co-ordinator which are reported separately). Befrienders are not in generally in contact with those they befriend over the summer holiday period, so extrapolating this figure to the five additional befrienders provided an estimate of approximately 1,000.9 befriending hours in a year for the service.

The proportion of the total time (over the 3 months) spent in each of the specified befriending activities is shown in Figure 7.

The pattern of befriending varied considerably between the befrienders, and according to the types of befriending activities they took part in. This is shown in Figure 8.

Over the three month period the co-ordinator worked approximately 4.0 hours per week in addition to the contracted hours. (Based on annual leave being taken in the school summer holidays, and assuming 8 statutory leave days pro-rata and 10 days sickness leave pro-rata). This equates to an adjustment factor of 1.186 to be added to the co-ordinator’s salary costs. The pattern of the co-ordinator’s activities is shown in Figure 9.
Figure 7: Percentage of total befriending time engaged in specified activities (individual co-ordinator model)

![Graph showing percentage of total befriending time engaged in specified activities.]

Figure 8: Time (minutes) spent in befriending activities by befriender (individual co-ordinator model)

![Graph showing time (minutes) spent in befriending activities by befriender.]

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Multiple co-ordinator model

Befrienders from Mid and East Cornwall took part in the work sampling. Fifteen consented to take part, and 12 forms were returned each month. Work sampling data was not available from service co-ordinators in Cornwall.

Across the three month period the estimated total time spent in befriending activities by the 12 respondents was 381.6 hours. Excluding the summer holidays, and extrapolating this figure to the additional befrienders, gave an estimate of approximately 7,345.2 befriending hours per year for this service.

The proportion of the total time (over the 3 months) spent in each of the specified befriending activities is shown in Figure 10.
Figure 10: Percentage of total befriending time engaged in specified activities (multiple co-ordinator model)

Unit costs

Salary costs were estimated from National Joint Council Salary Scales. For the opportunity cost method of valuing befrienders’ time, both the UK average hourly earnings of £12.62 and the minimum hourly wage of £6.08 were used. For valuing befrienders’ time using the replacement cost approach, the hourly unit costs of a counsellor in primary medical care (£51) and a home care worker from social services were used (£18). All unit costs were for the year 2011.
Cost of the interventions

The estimated costs of the two models of peer support service for parents of disabled children are given in Tables 9 and 10.

Table 9: Estimated annual cost of a multiple co-ordinator peer support service

<table>
<thead>
<tr>
<th>Resource used</th>
<th>Cost (2011 values)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct costs:</td>
<td></td>
</tr>
<tr>
<td>Area manager’s salary (including oncosts &amp; superannuation, (28 hrs per wk, equivalent to NJC* Point 35)</td>
<td>£23,877</td>
</tr>
<tr>
<td>Co-ordinator’s salary (including oncosts &amp; superannuation) (20 hrs per wk, equivalent to NJC* Point 23)</td>
<td>£11,783</td>
</tr>
<tr>
<td>Co-ordinator’s salary (including oncosts &amp; superannuation) (17.5 hrs per wk, equivalent to NJC* Point 23)</td>
<td>£10,310</td>
</tr>
<tr>
<td>Co-ordinator’s salary (including oncosts &amp; superannuation) (17.5 hrs per wk, equivalent to NJC* Point 23)</td>
<td>£10,310</td>
</tr>
<tr>
<td>Administrator’s salary (including oncosts &amp; superannuation) (20 hrs per wk, NJC Point 13)</td>
<td>£9,009</td>
</tr>
<tr>
<td>Administrator’s salary (including oncosts &amp; superannuation) (12 hrs per wk, equivalent to NJC Point 13)</td>
<td>£5,406</td>
</tr>
<tr>
<td>Administrator’s salary (including oncosts &amp; superannuation) (10 hrs per wk, equivalent to NJC Point 13)</td>
<td>£4,505</td>
</tr>
<tr>
<td>Area manager &amp; co-ordinators’ travel</td>
<td>£424</td>
</tr>
<tr>
<td>Area manager’s expenses</td>
<td>£1,500</td>
</tr>
<tr>
<td>Befrienders’ expenses</td>
<td>£7,396</td>
</tr>
<tr>
<td>Training</td>
<td>£1,507</td>
</tr>
<tr>
<td>Consultant payments</td>
<td>£166</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£86,191</strong></td>
</tr>
<tr>
<td>Indirect costs:</td>
<td></td>
</tr>
<tr>
<td>Befrienders’ time</td>
<td>£0</td>
</tr>
<tr>
<td><strong>Overheads:</strong></td>
<td></td>
</tr>
<tr>
<td>Direct (Postage, Telephone, Insurance, Water, Stationery, Printing, Maintenance, Equipment, Electric)</td>
<td>£7,594</td>
</tr>
<tr>
<td>Indirect (Accommodation, HR, IT, Payroll)</td>
<td>£21,736</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£29,330</strong></td>
</tr>
<tr>
<td><strong>Total per annum</strong></td>
<td><strong>£115,521</strong></td>
</tr>
</tbody>
</table>

*National Joint Council
Table 10: Estimated annual cost of an individual co-ordinator peer support service

<table>
<thead>
<tr>
<th>Resource used</th>
<th>Cost (2011 values)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Direct costs:</strong></td>
<td></td>
</tr>
<tr>
<td>Co-ordinator’s salary (including oncosts &amp; superannuation) (21.5 hrs per wk, equivalent to NJC* Point 30)</td>
<td>£15,663</td>
</tr>
<tr>
<td>Supervision</td>
<td>£3,000</td>
</tr>
<tr>
<td>Co-ordinator’s travel</td>
<td>£1,698</td>
</tr>
<tr>
<td>Befrienders’ travel</td>
<td>£993</td>
</tr>
<tr>
<td>Training</td>
<td>£4,416</td>
</tr>
<tr>
<td>Venue hire</td>
<td>£507</td>
</tr>
<tr>
<td>Support group expenses</td>
<td>£190</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td>£26,467</td>
</tr>
<tr>
<td><strong>Indirect costs:</strong></td>
<td></td>
</tr>
<tr>
<td>Befrienders’ time</td>
<td>£0</td>
</tr>
<tr>
<td><strong>Overheads:</strong></td>
<td></td>
</tr>
<tr>
<td>Direct (IT, Telephone, Stationery, Insurance)</td>
<td>£1,302</td>
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<tr>
<td>Indirect (Accountancy)</td>
<td>£540</td>
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<tr>
<td><strong>Sub-total</strong></td>
<td>£1,842</td>
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<tr>
<td><strong>Total per annum</strong></td>
<td>£28,309</td>
</tr>
</tbody>
</table>

*National Joint Council

**Service activity**

The fact that befrienders themselves obtained significant personal value from providing the service and their links and connections with it, was substantiated by the work sampling data, which indicated befrienders spent the largest proportion of their befriending time engaged in mutual support activities (39.2% and 27.3%). This was the case for both the individual co-ordinator and the multiple co-ordinator models (Figures 7 and 10). This implied that considering solely the cost per parent befriended was too narrow a viewpoint. (This also supports the base case approach taken of not costing the befrienders’ time). Therefore, the costs were considered against the number of ‘completed befriending cases’ and the number of befrienders involved with the service during the year period, as shown in Table 11. The number of ‘completed befriending cases’ in one year was estimated to be 12 for the individual co-ordinator model and 26 for the multiple co-ordinator model. On average, parents were supported for approximately six months.

Table 11: Annual intervention costs and service activity

<table>
<thead>
<tr>
<th>Peer support model</th>
<th>Annual intervention cost (2011 values)</th>
<th>Number of completed befriending cases</th>
<th>Number of befrienders involved with service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual co-ordinator</td>
<td>£28,309</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>Multiple co-ordinator</td>
<td>£115,521</td>
<td>26</td>
<td>63</td>
</tr>
</tbody>
</table>
Scenario sensitivity analyses

Co-ordinator’s additional hours

The effect of the additional hours that the co-ordinator actually worked on the overall cost of the intervention was estimated by applying the adjustment factor of 1.186 to the co-ordinator’s salary. This resulted in the estimate that the individual co-ordinator model would cost £31,222 per annum.

Use of alternative methods to value befrienders’ time

Using opportunity cost and replacement cost methods to value befrienders’ time resulted in substantial differences in the cost of providing the peer support services, details of which are given in Table 12.

Table 12: Use of opportunity cost and replacement cost methods to value befrienders’ time

<table>
<thead>
<tr>
<th>Method of costing befrienders’ time</th>
<th>Individual co-ordinator (1,000.9 befriending hours)</th>
<th>Multiple co-ordinator (7,345.2 befriending hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No monetary valuation</td>
<td>£28,309</td>
<td>£115,521</td>
</tr>
<tr>
<td>Opportunity cost:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK median hourly earnings (£12.62)</td>
<td>£40,940</td>
<td>£208,217</td>
</tr>
<tr>
<td>Minimum hourly wage (£6.08)</td>
<td>£34,394</td>
<td>£160,180</td>
</tr>
<tr>
<td>Replacement cost:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hourly cost of counsellor in primary care (£51)</td>
<td>£79,355</td>
<td>£490,126</td>
</tr>
<tr>
<td>Social services home care worker (£18)</td>
<td>£46,325</td>
<td>£247,734</td>
</tr>
</tbody>
</table>
**Summary of findings**

This report gives details of the resource requirements and costs of providing a peer support programme for parents of disabled children. Costs are given for two different configurations of service provision. One model has an individual co-ordinator who also befriends, approximately 20 befrienders who provide one-to-one support to parents, with new befrienders being trained on an annual basis, no office premises, and supervision provided by an area manager. The second model has three co-ordinators who do not befriend, an area manager, approximately 63 befrienders who provide one-to-one and group support, with new befrienders trained annually, and an office base. The individual co-ordinator model was estimated as costing £28,309 per annum and the multiple co-ordinator model was estimated to cost £115,521 per annum.

Befriending activities varied considerably between volunteers, with large proportions of time spent travelling and in mutual support activities. The most frequently used approach for presenting the cost of an intervention is as a ‘cost-per-case’\(^3\). Here, costing the interventions according to the number of ‘completed befriending cases’ appeared too limiting given findings from the work sampling and the results of the parallel qualitative research. As such, the annual costs of providing the interventions were given alongside the number of befrienders who were involved with the service, as well as the number of ‘completed befriending cases’. These costs should also be considered alongside the spectrum of potential benefits identified by the qualitative research (Please see qualitative research findings).

Initially, in the base case, a monetary value was not applied to befrienders’ time, given the personal value they appeared to obtain from being involved with the service. Using opportunity cost and replacement cost approaches to befrienders’ time results in substantial increases in service provision cost. For the individual co-ordinator model the costs rise to £40,940/£34,394 (opportunity cost method) and £79,355/£46,325 (replacement cost method), and to £208,217/£160,180 (opportunity cost) and £490,126/£247,734 (replacement cost) for the multiple co-ordinator model.

It should be recognised that local circumstances and funding structures are likely to have led to the evolution of these peer support service models in their particular form. This study provides details of the infrastructure, resource use and costs that can be drawn upon in establishing or commissioning peer support services for parents of disabled children elsewhere, in a manner tailored to the specific local context. The focus on external validity means the findings given here should be broadly applicable to other places and other settings. It should be considered that the information presented is based on services provided in predominantly rural areas, with parents mostly visited in their own homes (perceived to be a particular strength of the service as identified in the qualitative findings).
Therefore, befrienders spend significant amounts of their time travelling, and incurred substantial travel expenses. This time and expense is likely to be much reduced in an urban setting.

The approach taken of not applying a monetary value to befrienders’ time was substantiated by the finding that befrienders spend a good proportion of their time in mutual support activities, and by the results of the parallel qualitative study that befrienders obtain a great deal of value from their involvement with the service. Therefore, in many ways it seems inappropriate to ‘cost’ their time. In addition, the qualitative findings indicate that the shared experience that the befrienders offer is critical from the point of view of parents, befrienders and professionals, i.e. that they have ‘walked in their shoes’. Parents are seen as more credible sources of learning than professionals. However, from a commissioning, and funding, perspective it is useful to consider the cost of the service if it was provided by health or social care service providers and delivered by health or social care professionals. The additional ‘replacement’ cost of the interventions being provided by home care workers is substantial, and this cost is greater still if support were to be given by primary care counsellors. Indeed, this latter replacement cost substitute might be the most appropriate given that befrienders receive 40 hours training which includes elements of counselling skills). However, neither of these ‘replacements’ could deliver the intervention as a peer, unless they were also the parent of a disabled child.

Strengths and limitations

To our knowledge, this is the first time that the detailed resource requirements and costs of providing a peer support intervention for parents of disabled children have been described in such a systematic manner. However, inevitably, there are some limitations to this work.

This section of the report is a cost analysis of the peer support intervention. It draws on other parts of the report in discussing the possible outcomes and impact of the service, but the outcomes are not considered here in a cost-effectiveness (CEA) framework, whereby costs and benefits would be ‘weighed-up’ in contemplating the potential value for money that the intervention offers. This was not the intention of the project described here, and the cost effectiveness of a peer support programme needs to be considered in future research.

At the outset of this research, it was intended to follow a case series of new referrals to the peer support service over a three month period to explore, in more detail, service activity and the nature of the intervention that parents received. However, given the very heavy workload of the service coordinators this was not viable, and further discussion with the service providers suggested that a three month snapshot was unlikely to have been a sufficient time to gain a representative picture of
the number of people coming in to the service, the length of their intervention, and the inputs they received.

The Cornwall service co-ordinators and the West Cornwall befrienders did not take part in the work sampling and, therefore, the work sampling findings from East and Mid Cornwall were extrapolated to West Cornwall. This approach was deemed appropriate given there was no expectation that the West Cornwall volunteers befriended to a greater or lesser extent. This was supported by the finding that befriender expenses for West Cornwall were broadly equivalent to those of befrienders in East and Mid Cornwall on a pro-rata basis.

In addition to one-to-one support, the multiple co-ordinator (Cornwall) model of providing peer support consisted of group meetings between befrienders and parents. These were intended as a means of supporting more than one parent at a time, and for parents to be able to gain support from each other. It would be anticipated that for the work sampling, befrienders would categorise these meetings as ‘contact with befriendees’. However, they may have categorised them as ‘mutual support’, leaving some ambiguity regarding how befrienders may have described their time in relation to these meetings. Given that the work sampling was self-report, if befrienders consistently allocated their categorisation based on whether they felt they attended the meetings to help the befriendees or to gain mutual support, this would not be a methodological issue, but it is not possible to determine whether they did consistently use such an approach.

Service activity was very difficult to define. ‘Completed befriending cases’ was decided on as the unit of measurement in order to be able to give a cost per unit of output of the service. However, this metric was limiting. The befriending services are tailored very flexibly to the individual needs of the parent and his or her family. As such, parents may be in contact with the service just once, for over a year, or their contact may be as and when needed over a short or long period of time.

Probabilistic sensitivity analyses (PSAs) were not used to estimate the effect on overall service costs of varying input parameters. Data were not available on the extent to which intervention costs might alter, or the degree to which they might be inaccurate. Therefore, the assumption of variance around point estimates would have been entirely arbitrary, resulting in potentially misleading estimates of uncertainty around the intervention costs.

One of the key strengths of this research programme, exploring both the costs and benefits of a peer support intervention for parents of disabled children, has been the strong service user and service provider (PPI) involvement, and the concomitant qualitative research. The in-depth perspective that this provided gave context and understanding regarding the resources used to deliver the service. It
provided an explanatory framework as to the costs of implementing such a complex intervention in a complex system.
Discussion

This research aimed to identify the benefits and costs of providing peer support to parents of disabled children through the one-to-one befriending service provided by Face2Face in parts of Devon and Cornwall. The research was made up of three studies:

1. A systematic review of quantitative and qualitative studies of peer support for parents of children with chronic disabling conditions
2. Qualitative research with parents and befrienders from the Face2Face one-to-one befriending service in Devon and Cornwall and professionals from health, social and education services
3. A costing study of the same service to determine what resources are needed to provide the service.

The findings from each research stream are summarised in the corresponding chapter. In this chapter, we highlight the implications of these findings for practice, policy and research and also discuss the dissemination of these findings to ensure use.

Justify conclusions: implications for practice, policy and research

Implications for practice and policy

The impact and outcomes for people delivering the service must be fully considered in an evaluation. Befrienders in this study described long term benefits and costs of training and ongoing mutual support as well as the benefits and costs they experience from befriending parents. A cost consideration of this for future research is how much support (mutual support for befrienders) is enough to maintain a good service not just the benefit to the befriender.

The qualitative findings describe the risk of emotional burden for befrienders which may imply the need for the degree of mutual support that is identified via the work sampling. Funders may be willing to cover the costs of formal mutual support activities, but less willing to fund some types of more informal mutual support, and yet these may be part of the ‘glue’ that consolidates the service in functioning and delivering its outcomes.

As well as a direct personal impact on the people involved in the service, the skills and confidence parents and befrienders attributed to their involvement with Face2Face have the potential to impact on their broader community for example, by sitting on committees to represent parent carers. We
propose that these broader ‘unintended’ (in the context of the intervention) effects should be considered in service evaluations.

Commissioners and professionals may benefit from some clarity around elements of the service in order to explain the associated costs. For example the service is available for parents to access again at a later stage if they feel they need it. The cost associated with allowing repeated use of the service may be considered against the security that this knowledge provides parents with, which may give them the confidence to develop and try new things. Similarly, the transition from parent to befriender was not discussed by the professional group; yet maintaining parents within the service and developing them into supporters themselves has implications for the longevity and sustainability of the service. Finally there is a cost associated with training a parent who then does not go on to befriend. However, our findings suggest that befrienders benefit from training and from giving and receiving support in meetings with other befrienders even if they never go on to befriend.

It is important to remember that this evaluation is of a specific one-to-one peer support service in a particular region of the UK. We are not able to definitively say that the findings are generalisable to different types of services in different regions. Even within the network of Face2Face services at a national level it is possible that differences may exist. For example some services are managed centrally by Scope while others are externally managed. While this may not be significant it is important to be aware of the many differences in service structure when using the findings from this evaluation.

Evidence from this research suggests:

- Impact and outcomes for people delivering the service must be fully considered in an evaluation
- Indirect impact on the broader community of parents of disabled children should also be considered
- Greater transparency around elements of the service may help commissioners and professionals understand the costs associated with the service
Implications for research

How should we measure the impact of peer support

When conducting the systematic review we were aware that the included studies had differed marked in their methodology which made it difficult to draw conclusions across studies. The peer support offered to parents in the different studies varied in terms of, amongst other things, how many interactions with their supporter and the content of these discussions, how long they received support for in total and whether or not the supporting parent was trained.

In the real world, parents engage with peer support to the extent that they feel they need to, rather than having a ‘prescribed dose’ determined by a researcher. An important consideration for researchers is whether these attempts to control different elements of peer support may actually change the nature of the interactions between the two parents. Another is whether it ethically right to ask parents to abstain from other types of support to ensure the reliability of the research?

In consultation with parents we found that the types of questionnaires typically used to assess impact on psychological health and well being were not well received. This echoes research we have recently conducted on measuring health outcomes for disabled children. A large number of questionnaires have been used to measure well being in this group of parents however:

i) The variety of measures used makes it difficult to compare across studies and hence more difficult to draw conclusions

ii) The questionnaires selected by researchers may not be measuring the things that parents think are most important

We propose a separate piece of work with parents to discuss what outcomes in terms of their well-being they think are important to measure and to examine different ways of measuring these outcomes; perhaps not exclusively through questionnaires. The benefits perceived may not fit neatly into what would traditionally be considered ‘health gain’ therefore we must address what are the appropriate outcomes to measure and how.

Who should be included in the qualitative elements of evaluation?

The qualitative research explored important processes and outcomes for parents and befrienders. However, a limitation of the research was that we were unable to speak with parents and befrienders who had an unsatisfactory experience of the service. Future research should focus on these groups as it is likely they have a different perspective on support in general and the service in
particular. A greater understanding of when and why peer support doesn’t work would provide us with a more rounded view of the service as a whole.

Similarly our sample was entirely White British. This reflects both the demographic of parents and befrienderes using the service in Devon and Cornwall and indeed the demographic of the South West in general. Future research in more ethnically diverse regions should consider the role of ethnicity and community in the take up of support services.

This research has also highlighted a number of potential methodological challenges for future work aimed at estimating the cost effectiveness of a peer support intervention for parents of disabled children.

*What should, and should not, be included when costing this type of volunteer-based intervention?*

One of the questions raised in the costing study was how best to cost the time of befrienders. Initially we did not apply a cost to befrienders’ time given the personal value they appeared to obtain from being involved with the service. However, we also considered how much the service would cost using two other approaches. The opportunity cost approach recognises that befrienders are actively choosing to be involved with the service, whilst also representing the fact that befrienders could be engaged in other activities if they were not providing the service. The opportunity cost approach uses the UK minimum wage and the UK median wage to estimate service costs. We also present the replacement costs; how much the service would cost to deliver if provide by professionals. However, it should be noted that ‘replacement’ professionals could not deliver the service as a peer, unless they were also the parent of a disabled child. This raises the issue of the most appropriate perspective to take in a cost-effectiveness analysis of this form of intervention; perhaps the most valid description of costs is given by the opportunity cost approach. The perspective of a Third Party Payer (or commissioner) would not include a ‘cost’ of befrienders’ time, but a societal perspective would. Both perspectives should be considered in future cost-effectiveness analyses.

*Which outcomes, and also whose outcomes, should be considered in a future cost-effectiveness analysis?*

In the UK, decisions about the funding of treatments and interventions relating to health and social care are often founded on the cost-per-quality-adjusted life-year (QALY). The QALY is an outcome
measure which combines both length and health-related quality of life in a single outcome, with the ‘quality’ weight based on general population preferences for particular health states that people might experience. Limiting outcomes for parents to QALYs, and estimating the cost-per-QALY of the intervention is likely to be too narrow a framework for picking up the potential benefits of support for parents of disabled children. There may well be outcomes other than those which can be captured by the generic preference-based health-related quality of life measures used to estimate QALYs. This seems key as the qualitative research suggests a web of effects driven by combinations of moderators and mediators which have unexpected unintended consequences. These include potential benefits to people other than those who have received the intervention, be they befrienders or others who may have benefitted from the strong social networks and communities of parents of disabled children that have evolved from the peer support programmes. The benefits to befriendees also appear broader than health-related quality of life which is considered within the QALY framework. The intervention may well impact on participants’ sense of social identity and social role, and well-being more generally.

A future cost-effectiveness analysis of peer support for parents of disabled children would be wise to consider the cost-per-QALY of such an intervention, as this can be fed into UK health policy decision-making. In addition to using the preferred outcome measure of the National Institute for Health and Care Excellence, the EQ-5D (5L), a measure that considers well-being more generally and can be used in economic evaluations, such as the ICECAP-A, could be included. However, the most valid approach for assessing the cost effectiveness of this type of programme is likely to be a Cost-Consequences Analysis (CCA). This methodology assesses both the costs and possible multiple outcomes of the intervention in a disaggregated form.

How best to capture potential ‘downstream’ costs and benefits?

Such an intensive support service, often provided in times of crisis, may well impact on the health, social care, and other voluntary sector resource use and the health and well-being of families of disabled children over the longer-term. The peer support services are often provided over approximately six-month periods, and yet this initial investment may have far-reaching economic and cultural impacts. Therefore, careful consideration is needed regarding a sufficient follow-up period to capture potential benefits and costs. Only this way can commissioners be given a clear picture of what they are funding the service to achieve, for whom, and over what period of time.
Evidence from this research suggests:

- Greater consistency is needed in the methods employed to measure the impact of peer support to allow for comparison across studies.
- Researchers must work with parents to establish what are the important outcomes for them and how we could go about measuring them.
- More research is needed with parents and befrienders who have had a negative experience of peer support and in more ethnically diverse regions.
- Carefully consideration is needed when designing a costing study of such a service with particular regard to:
  - If and how to cost volunteers’ time.
  - Whether traditional measures of health gain are appropriate.
  - When is a sufficient follow-up period to capture potential benefits and costs.
**Ensure use and lessons learnt**

*Academic output*


Papers from the qualitative and costing study are being prepared for submission to academic journals. A plain language summary is prepared for all academic papers. These are available at [www.pencru.org](www.pencru.org).

*Output with relevance to policy and practice*

The dissemination of research findings to non-academic audiences was the agenda for the final stakeholder group meeting. This was of particular importance to the parents involved in this and other projects with the research group. Parents get involved in research because they want to help change things for other parents in the future; publicising research findings widely is important to achieve this and to ensure their contribution has an impact. The stakeholder group felt that the research findings have potential to raise the profile and value of the service with other organisations and professionals which may in turn impact on referrals. They also saw the potential to impact on the commissioning of support services more broadly and to be of potential use to other groups or parents considering setting up a peer support programme.

Members of the stakeholder group who are part of the Face2Face service also felt that the research findings gave them greater confidence in what they are doing and may be of practical use in terms of writing referral guidelines, the training of volunteers, how the services is offered to families and general PR and marketing of the service.

Issues around broad dissemination included:

Different groups will need to access the findings, dividing loosely into those who might use the service, those who might refer to it and those who might fund it be they charities, commissioners or commissioning groups.

The nature of families’ interactions with professional services means that the list of potential referrers to the service is almost inexhaustible. However, GPs were identified as a particular target because parents would be more likely to access GPs if they were looking for help themselves so GPs may be more likely to refer than a paediatrician for example, whose primary focus is the child.

As highlighted in the qualitative study, the timing of the offer of support can be critical in determining whether a parent engages with the service or not and should be made more than one.
As such, the stakeholder group felt that the research findings should be made available to professionals that come into contact with families at different stages of their lives, starting with midwives and health visitors.

The full report will be made immediately available to local authorities to aid decision making. The plain language summary will be made available to families and those who may commission or refer to the service first through our website (www.pencru.org) and through those of Cerebra (www.cerebra.org.uk) and the Mentoring and Befriending Foundation (www.mandbf.org). The plain language summary has a link to the full report so that anyone wishing to read further can do so.

In accordance with the suggestions of the study stakeholder group, we will distribute the plain language summary to professionals whose contact with families makes them potential referrers to the service, such as GP’s and those working in Children’s Centres. We also plan to develop a more accessible video summary of the research which will be available via YouTube and explore opportunities to talk directly to professionals about the research, such as at GP training events.
References

3. Contact a Family. No time for us: relationships between parents who have a disabled child: Contact a Family, 2003.

## Appendices

### Appendix 1: Suggestions for change

#### General service:

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>B’ders</th>
<th>Parents</th>
<th>Profs</th>
</tr>
</thead>
<tbody>
<tr>
<td>More widely available and better publicised (but how to expand without overstretching the service – B9)</td>
<td>B1/4/6/15/16/35</td>
<td>P1/2/6</td>
<td>PR01/8</td>
</tr>
<tr>
<td>More referrals from professionals particularly those that go into people’s homes e.g. health visitors and schools but ....</td>
<td>B1/4/6/20/FG1*</td>
<td>P12</td>
<td></td>
</tr>
<tr>
<td>Professionals can’t refer unless they know about it</td>
<td>P1</td>
<td></td>
<td>PR01/2/4/6</td>
</tr>
<tr>
<td>Changes to leaflets – greater clarity that service open for all and testimonials from parents who have used the service (for reassurance)</td>
<td>B3/6</td>
<td>P10</td>
<td></td>
</tr>
<tr>
<td>Rolling welcoming us training out to schools – train education professionals to be more aware of the impact of their interactions with families</td>
<td>B3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Train more and greater diversity of befrienders so parents don’t have to wait for a match</td>
<td>B5</td>
<td>P6</td>
<td></td>
</tr>
<tr>
<td>Different types of supporters for different parents e.g. dads, very young parents</td>
<td></td>
<td></td>
<td>PR03</td>
</tr>
<tr>
<td>Ensure parents told about the service at diagnosis</td>
<td>B5/17</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leaflets and posters in more general places e.g. libraries and schools</td>
<td>B5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A version of befriender training could be used to help boost confidence in parents</td>
<td>FG2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More social events for parents and befrienders – would feel less professional, more part of a community and might encourage more people to befriend</td>
<td>FG2</td>
<td>P4/5/8</td>
<td></td>
</tr>
<tr>
<td>allow exchange of mobile numbers with agreement that both sign at the start that they won’t ring or text inappropriately</td>
<td>FG2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attend meetings with parents for support</td>
<td>P2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Checking on the day of appointments to see still convenient</td>
<td>P3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change process for cancelling through coordinator</td>
<td>P6/8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>quick access service for “a little bit of, um, almost sort of parental boosting”</td>
<td>P10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Closer working between different parent organisations to build a framework of services for families – different skills across different organisations</td>
<td></td>
<td></td>
<td>PR02/8</td>
</tr>
<tr>
<td>Use of different media such as text and email to develop and maintain relationships</td>
<td>P4</td>
<td></td>
<td>PR04</td>
</tr>
<tr>
<td>Support for siblings</td>
<td></td>
<td></td>
<td>PR09</td>
</tr>
</tbody>
</table>

* in FG1 there is a particular frustration that, in their opinion, professionals do not pass on information about the service enough. This links to the feeling in this group that the service is not valued and respected by professionals “how difficult is it just to pass a leaflet over?”

#### Befriender/coordinator specific

<table>
<thead>
<tr>
<th>Suggestion</th>
<th>B’ders</th>
<th>Parents</th>
<th>Profs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less frequent support groups</td>
<td>B2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More support for overstretched coordinator</td>
<td>B2/3/15</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refresher training on things like endings to be separate to support groups</td>
<td>B4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 2: work sampling form

**Face 2 Face - Work Sampling Sheet** - *There is no need to put your name on this form*

Number: _______  
Month: __________________

<table>
<thead>
<tr>
<th>Work Activity / Category</th>
<th>Amount of time (minutes)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meetings with befriendees</td>
<td>Total:</td>
</tr>
<tr>
<td>Other contact with befriendees</td>
<td>Total:</td>
</tr>
<tr>
<td>Non-contact time on behalf of befriendees</td>
<td>Total:</td>
</tr>
<tr>
<td>Individual contact with</td>
<td>Total:</td>
</tr>
<tr>
<td>Mutual support</td>
<td>Total:</td>
</tr>
<tr>
<td>Training /</td>
<td>Total:</td>
</tr>
<tr>
<td>Travel</td>
<td>Total:</td>
</tr>
<tr>
<td>Record keeping / Administration</td>
<td>Total:</td>
</tr>
<tr>
<td>Delivering training</td>
<td>Total:</td>
</tr>
<tr>
<td>Other</td>
<td>Total:</td>
</tr>
</tbody>
</table>

If you have used the ‘other’ category, please briefly describe what you did in this time
Appendix 3: work sampling information sheet

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

Work sampling – Information Sheet

As part of this research study, we are estimating the resources used and the costs associated with delivering a peer support service to parents of disabled children. To help us to get a picture of the true resources that are used in providing the service (and to establish their cost), we ask that you provide us with some information on your befriending activities.

We are using an approach called Work Sampling. For days/times that you act as a befriender, we would like you to record the amount of time you spend on each of the activities listed. An explanation of these categories is given on the back of the sheet.

Throughout the day, please jot down amounts of time (in minutes) that you spend on the activity categories. At the end of the month, please add up the number of minutes spent on each category and enter it in the ‘Total’ box in the right-hand corner of that category. For example:

<table>
<thead>
<tr>
<th>Activity / Category</th>
<th>Monday</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Amount of time (mins)</td>
</tr>
<tr>
<td>Meetings with befriendedes</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>25</td>
</tr>
<tr>
<td>Total: 125</td>
<td></td>
</tr>
</tbody>
</table>

Do not worry about keeping the sheet tidy, but please do try and give an accurate estimate of the amount of time you have spent on befriending and each of the categories. We would prefer that you scribble amounts of time on the sheet throughout the day and give us a realistic estimate of the time you spend on each of the categories, rather than completing the sheet tidily at the end of the day when it may be harder to remember how much time you have spent on different activities.

We are collecting this information for research purposes only – please rest assured, it is not for any sort of assessment or appraisal of your befriending activities. Your work sampling record sheets are anonymous and will only be looked at by research staff at the Peninsula College of Medicine and Dentistry. Our aim is that this research will aid the development of local befriending services, and guide new befriending service planners, both locally and nationally. We are very grateful for your help.

If you have any questions or queries, please contact:

Val Shilling on 01392 726041 (val.shilling@pcmd.ac.uk) or
Annie Hawton on 01392 722284 (annie.hawton@pms.ac.uk)

Thank you.
## Appendix 4: work sampling definition of categories

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Meetings with befriendees</strong></td>
<td>This category includes meetings with befriendees in person i.e. face to face contact, e.g. in their own homes or other settings.</td>
</tr>
<tr>
<td><strong>Other contact with befriendees</strong></td>
<td>This includes non-face to face contact with befriendees by telephone, email, letter etc.</td>
</tr>
<tr>
<td><strong>Non-contact time on behalf of befriendees</strong></td>
<td>This includes gathering information for befriendees, or finding details to pass on to them. It also includes time spent considering and ‘thinking through’ befriendees’ circumstances and how they might be helped.</td>
</tr>
<tr>
<td><strong>Individual contact with service co-ordinator</strong></td>
<td>This category includes one-to-one contact with the service co-ordinator in person, by telephone via email etc, for supervision, support or signposting.</td>
</tr>
<tr>
<td><strong>Mutual support</strong></td>
<td>This refers to activities whereby befrienders support each other, and includes support group meetings and informal (e.g. social) events in groups or between individuals.</td>
</tr>
<tr>
<td><strong>Training / Continuing Professional Development</strong></td>
<td>Both initial training and ongoing training from Face 2 Face and other providers.</td>
</tr>
<tr>
<td><strong>Travel</strong></td>
<td>This includes all travel time related to your role as a befriender e.g. to and from visiting befriendees, to and from meetings, to and from training.</td>
</tr>
<tr>
<td><strong>Record keeping / Administration</strong></td>
<td>For example, keeping contact logs, other befriendee notes/records, completing expense forms and other administrative tasks and paperwork.</td>
</tr>
<tr>
<td><strong>Delivering training</strong></td>
<td>e.g. to new befrienders, other volunteers/professionals.</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>Please use this category to include anything else you did in your role as a befriender that you do not feel fits under the headings above e.g. being a member of a committee, promoting the service.</td>
</tr>
</tbody>
</table>