

Peer support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study

V. Shilling, S. Bailey, S. Logan and C. Morris

Peninsula Cerebra Research Unit and NIHR PenCLAHRC, University of Exeter Medical School, Exeter, UK

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Abstract

Background Parents of disabled children are encouraged to seek peer support. Delivering one-to-one support requires resources; therefore, investigating how these services may impact on families and those providing the service is important when evaluating such services.

Methods We carried out a qualitative study involving semi-structured interviews and focus groups. Participants were 12 parents and 23 befrienders who had contact with the Face2Face one-to-one befriending service in Devon and Cornwall during a 12-month period, and 10 professionals from health, social care and education services.

Findings Shared experience was perceived central to successful peer support and was a catalyst for other elements of support, enabling parents to (i) learn from the experience of others; (ii) speak freely in a safe and non-judgemental environment; and (iii) receive support and encouragement from their befriender. These elements underpinned perceived outcomes for both parents providing and receiving support. Outcomes for parents receiving support centred on emotional stability, personal growth and reduced isolation. Supporting parents experienced positive outcomes through their training, mutual support and the feeling that they were helping others. Parents and befrienders appeared to benefit through expanding their social network. Nevertheless providing support was reported to create emotional burden and concerns for befrienders around their performance, and also required a substantial time commitment.

Conclusions Befrienders as well as parents perceived positive outcomes from their involvement in peer support although there is also potential for less positive impact on those offering support.

Keywords

childhood disability,
emotional well-being,
parents, qualitative

Correspondence:

Valerie Shilling, SHORE-C,
Brighton and Sussex
Medical School,
University of Sussex,
Falmer, Brighton BN1 9RX,
UK

E-mail:

v.m.shilling@sussex.ac.uk

Data sharing statement:

Additional data extracts
and full topic guides are
available from the
corresponding author:
v.m.shilling@sussex.ac.uk

Introduction

There is ample evidence that parents of disabled children are at risk of physical and psychological health problems, which are both pervasive and likely to worsen over time (Brehaut *et al.* 2009, 2011; Gerstein *et al.* 2009; Emerson *et al.* 2010; Miodrag & Hodapp 2010). Parents often seek support from their peer group; health services in United Kingdom and United States actively encourage peer support (Committee on Early Childhood Adoption and Dependent Care 2011; NHS

Choices 2011; HM Government 2012). Peer support is a complex intervention and this influences approaches to evaluation (Craig *et al.* 2008). Our recent systematic review reported that peer support in this context was highly valued and perceived as beneficial; however, quantitative studies that tried to measure specific impacts on parent health and well-being were less consistent in reporting positive effects (Shilling *et al.* 2013).

Previous research on peer support has focused more on the recipients of support as the primary beneficiaries. However,

findings from our systematic review (Shilling *et al.* 2013) and the helper therapy principle (Salzer & Shear 2002; Solomon 2004) suggest potential benefits for parents providing the service. Furthermore, health service providers and researchers increasingly appreciate that patients and carers are experts in their own lives. Recognizing the expertise of parents of disabled children is a fundamental concept in family-centred services (Rosenbaum *et al.* 1998) and is linked with better psychosocial outcomes for parents (King *et al.* 1999). Involving patients and carers as partners in research to utilize their expertise has also been shown to have positive impacts on their self-esteem and confidence (Staley 2009). Parents are often keen to be involved in improving services and feel empowered through peer-led initiatives (Goldbart & Catons 2010; Briton 2014). Thus, we anticipate that benefits for providers of peer support may stem from these same underlying constructs.

We conducted an evaluation of a peer support service offered in South West England by Face2Face (Scope 2014). Trained parent volunteers called befrienders offer one-to-one emotional support to parents of disabled children. All befrienders are parents of a disabled child. Each local scheme is run by a professional co-ordinator (usually a parent of a disabled child themselves). The support is informal and flexible and designed to meet individual need. Support is offered to parents of children with any type of disability or special need (see Supplementary file S1 for further details of the service). The aim was to understand perceived outcomes and identify influential components of the intervention. We sought both parent and professional perspectives regarding peer support as, although the service is provided by and to parents, professionals are influential stakeholders; they signpost and refer parents to services and are often involved in decisions to commission and provide funding for such services. The value of including their views in the evaluation is to highlight where consistencies and inconsistencies existed in the opinion and understanding across the different participant groups. In this first of a pair of papers we explore what are the perceived outcomes of peer support in this context and for whom.

Methods

Ethics statement

The study received ethics approval from the Peninsula School of Medicine and Dentistry research ethics committee (ref: 11/12/130). Signed informed consent was obtained from all participants.

Patient and public involvement

We convened a stakeholder group to advise on all aspects of the evaluation. The group included parents of disabled children, members of Face2Face and representatives from local and national charities, local authorities, and a general practitioner (GP). Members of the group contributed to (i) setting the research questions; (ii) developing participant information leaflets, data collection forms and interview topic guides; (iii) suggesting key professions to interview; (iv) advising on emerging themes from analysis; (v) interpreting the findings and key messages; and (vi) disseminating findings.

Recruitment and sampling

Local co-ordinators of two Face2Face services, in Devon and Cornwall, identified eligible parents through case records. Families in crisis were not approached to avoid overburdening those who were vulnerable. For reasons of confidentiality, this judgement had to be made by the local co-ordinators based on their knowledge of the family situation. All other parents and befrienders who had contact with the service in a 12-month period were eligible and invited to participate in the study. We purposively sought to interview parents who were offered peer support but declined or received very few visits. In addition, we recruited a purposively sampled group of professionals working with disabled children and their families.

Interview and focus group procedure

Interview topic guides explored areas pertaining to the specific research question discussed here, and other questions addressed within the broader evaluation. All participant groups were asked to discuss, for example, how this type of support might meet parents' needs and how it differs from other types of support; about any impact, positive or negative, for parents receiving and giving support; and the importance of structural and delivery aspects of the service. Some specific topics were directed only to the relevant participant group, for example, parents were asked about their reasons for seeking support. Further detail can be found in the summary of topic guides (Supplementary File S2). 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 were audio-recorded. 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.

Interviews were conversational in tone, and the pace and duration was guided by the participant. On average, interviews lasted 45–60 min. Focus groups were used with befrienders in Cornwall to enable us to include the views of a much larger group of befrienders than would otherwise be possible, given the logistical challenges of running the project across Devon and Cornwall. The groups were facilitated by a member of the research team and followed the same topic guide and structure as the interviews. The content of the data collected in focus groups did not differ from the data collected from individual interviews with befrienders.

Interviews and focus groups were transcribed verbatim, and transcripts were reviewed and used to inform subsequent interviews. Topic guides were adapted to reflect and test the developing analysis. Reflexive notes were kept to record systematically contextual details of the interviews.

Analysis

Analysis followed the framework approach (Ritchie & Spencer 1994) that 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 (Pope *et al.* 2000), and allows the researcher to incorporate key concepts and issues identified *a priori* from the literature alongside those emerging from the data. From the literature we anticipated that several themes were included in the framework *a priori*. These were shared social identity, learning from the experience of others, personal growth and supporting others.

Two members of the research team (VS/SB) read the transcripts and developed the thematic framework. The framework was then applied to the transcripts that were indexed by themes and subthemes using NVivo10 (QSR International Pty Ltd, Victoria, Australia). Data from the focus groups were analysed at the group rather than individual level, that is, each utterance was indexed and attributed to the group rather than an individual speaker within the group. VS indexed and charted all of the material; 25% of material was also indexed by SB to check for consistency in the application of the index. Themes and subthemes with greater than 2% disagreement between reviewers and where kappa was <0.4 were considered to have unacceptable reliability, indicating that the particular theme/subtheme was not functioning as intended or was being interpreted differently by the researchers. This is part of the quality assurance in the process of fully developing the thematic framework. The content of the themes and subthemes identified in this process was reviewed by VS/SB and differences in interpretation were

resolved through discussion. In some cases subthemes were deemed to be redundant and were merged with other themes. The data were then extracted and summarized in charts, grouped by themes and subthemes and incorporating field and reflexive notes. The charts were used to compare and contrast across groups and explore relationships between outcomes and aspects of peer support. During the later stages of mapping and interpretation of the data, we convened an expert reference group of befrienders from Face2Face to discuss the developing analysis. The emerging themes and illustrative quotes were discussed, links between themes explored and the group discussed how themes related to the befrienders own experiences. This was a collaborative process between the researchers and befrienders, and no tension was experienced between researcher and befriender priorities. Some issues were perceived to be more salient than others; hence, our interpretation of findings was influenced by the original research objectives as well as the themes emerging directly from the data.

Findings

Participants

A total of 69 parents and 53 befrienders from Devon and Cornwall were invited to participate. Of the 69 parents, 14 responded and 12 were interviewed. Of the 53 befrienders invited to participate, 23 took part; 13 had individual interviews, 9 took part in focus groups and one responded by post, providing written responses to the same topics discussed in the individual interviews. These data were coded in the same way as the manuscripts from interviews and focus groups. Participants were parents of children with a range of 15 different diagnoses, including no diagnosis $n = 5$. The most common diagnosis was autistic spectrum condition, $n = 14$. For those parents who had a diagnosis, time since diagnosis ranged from 1 to 12 years in the parent group and 18 months to 16 years in the befriender group. Length of involvement in the service ranged from less than 6 months to 2 years in the parent group and less than 1 year to over 5 years in the befriender group (Table 1).

Ten professionals were interviewed: two members of staff at different children's centres, two senior staff from integrated children's services at different local authorities, a GP and a paediatrician, two community nurses, and two school-based educational support staff. Half of the professionals were not aware of the Face2Face service specifically; however, all were familiar with the concept of peer support. We found little difference in the attitudes to peer support expressed by professionals, parents and befrienders. This is not to suggest that the views

	Parents (12 families, 14 young people)	Befrienders (23 families, 24 young people)	
Age of child	Median age 7.5 (range 3.5–14 years)	Median age 12 (range 4–22 years)	
Gender of child	4 females, 10 males	5 females, 19 males	
Primary diagnosis†	No diagnosis	4 No diagnosis	1
	ASC	2 ASC	12
	ADHD	2 ADHD	2
	CP	1 CP	2
	Auditory processing disorder	1 Complex additional needs with sensory issues	1
	Congenital heart disease	1 Developmental delay	1
	Currarino triad	1 Down syndrome	1
	Severe learning difficulties	1 Dyslexia	1
	Spina bifida	1 Partial trisomy 15	1
		Semantic pragmatic disorder	1
		Missing	1
Time since diagnosis	No diagnosis	4 No diagnosis	1
	Less than 2 years	1 Less than 2 years	1
	2–5 years	3 2–5 years	5
	Over 5 years	6 Over 5 years	17
Length of contact with service	0–6 months	2 0–6 months	0
	7–12 months	6 7–12 months	1
	12–18 months	3 12–18 months	4
	>18 months	1 18–24 months	6
		2–5 years	10
		>5 years	2

Table 1. Demographic information, parents and befrienders

†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 multiple (3) children with additional needs. 2 families in the befriender group had multiple (2) children with additional needs. ADHD, attention deficit hyperactivity disorder; ASC, autism spectrum condition; CP, cerebral palsy.

held by the different groups come from the same experiences of peer support. Rather than when asked to discuss specific topics around peer support the opinions expressed across the groups were broadly aligned. As such, professionals' perceptions of the intervention and outcomes were considered alongside those of the other groups; we highlight in our findings where notable differences occurred.

What are the perceived outcomes of peer support?

In the following sections we will explore the outcomes for parents receiving support and for befrienders delivering support as perceived by the three participant groups. In our analysis we identified key elements of peer support that appeared to act together to enable these outcomes to be experienced. Although distinct, these components are related and appeared largely dependent on the perception of shared experience between befriender and parent. Figure 1 illustrates the link between the mediator 'shared experience' and the active ingredients and outcomes of peer support.

Key outcomes for parents receiving support

Reduced isolation

All participant groups discussed the isolation experienced by parents of disabled children and the potential for peer support to reduce this feeling. Parents of disabled children reported feeling 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. Conversely, participants told us that they identify with other parents of disabled children in a way that they cannot with other people. They differentiate this support from that received from friends and extended family or professionals which, however well meaning, can lead to feelings of resentment and increased isolation because parents inevitably compare their children with others who do not have additional needs.

Physically being with a group of other parents of disabled children was not seen as a necessary prerequisite of reduced isolation. Rather, the knowledge and reassurances provided by

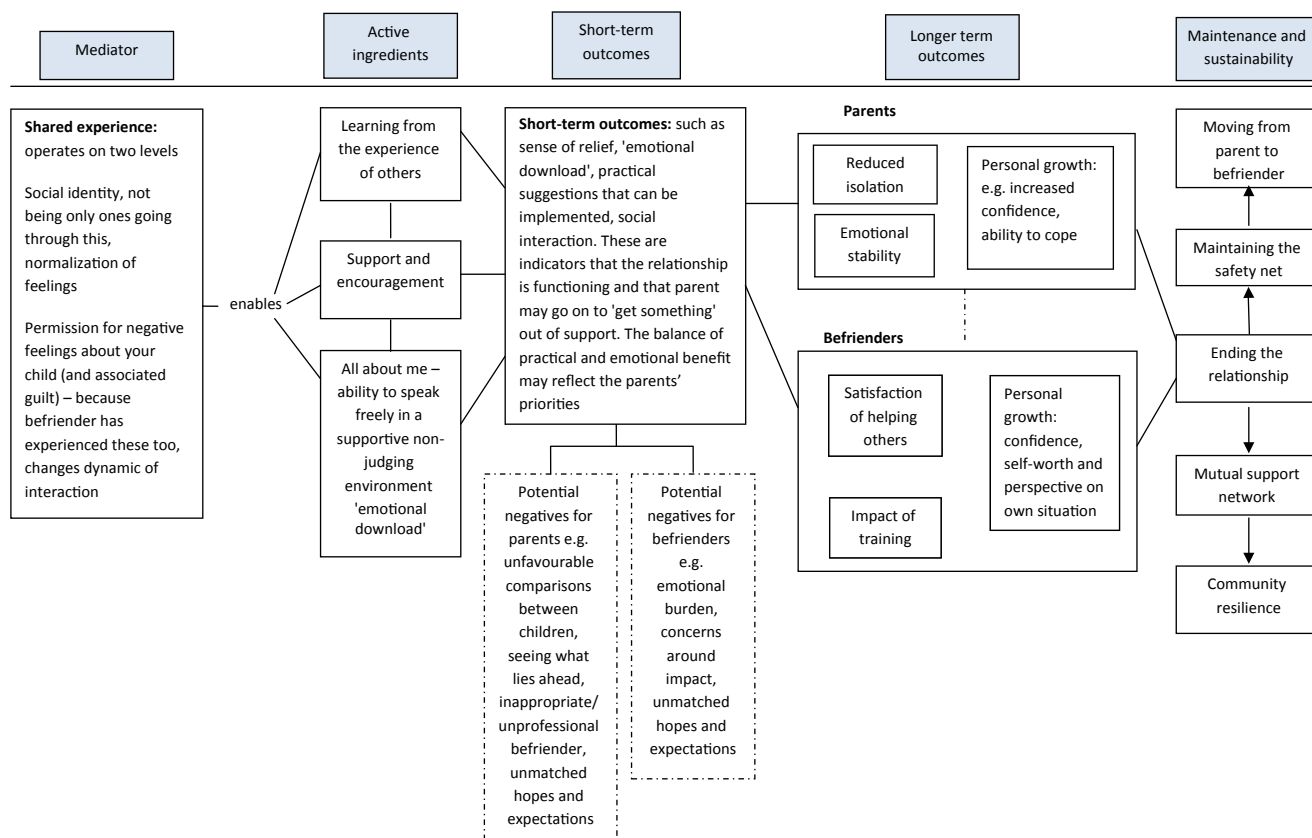


Figure 1. Active ingredients and outcomes of peer support.

the befriender that many other parents are going through the same challenges and feelings could engender a sense of virtual community. The befrienders provide a link to that community by offering the opportunity to meet and talk with someone with 'shared experience', who can comprehend the situation first hand and thus may help parents to feel that they are not alone.

Shared experience was seen by all participant groups as a necessary component of peer support. Opinions on 'how much' shared experience, in terms of matching by diagnosis, is sufficient for effective support were divided. All participants agreed that parents of disabled children have a wealth of shared experience that enables them to speak openly with each other and give support. An adjunct to shared experience, facilitating reduced isolation, was the importance of a safe and supportive environment in order for parents to feel comfortable to speak freely; continuity and trust seemed vital components.

Parents valued the opportunity to speak honestly about their feelings in a way that they cannot to others for fear of being judged. This, 'permission' for the negative feelings they may have about their child and the corresponding guilt they may have about that was linked to the knowledge that other parents

may have felt the same way. Only one of the professionals we spoke with linked shared experience specifically to guilt and negative emotions. 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. Phrases used to express this included 'offload', 'download', 'relief', 'let off steam' and 'weight lifted off your shoulders'. The importance of 'not being judged' as a key component of peer support was not evident in the interviews with professionals.

Several parents and befrienders also made reference to broadening their social circle, meeting families similar to their own and becoming part of a community. Parents described the benefits of social as well as emotional and practical support from meeting their befriender (Box 1).

Emotional stability and personal growth

The outcomes of emotional stability and personal growth were strongly interrelated. The service provided parents with the support to offload some of their emotional burden (emotional

Box 1. Reduced isolation*

Linked to shared experience:

I'm not on my own; I'm not the only one with difficulties. Sometimes you do feel very alone, very isolated as a mum of a disabled child. P6

just trying to get them ready for school in the morning you know, without a tantrum, without throwing things, without hitting you, and then another parent saying well that happens to me as well, I understand exactly how you feel, it's always . . . you feel as if you're not on your own. P12

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

And I mean just constantly reiterating to them, you know, it is really hard, you know, and this is a normal response. And I think because often families feel like they're the only ones in this place, you know, and I think that really, really helps them. B6

But the element that we just can't give as professionals is, is, is the reality you know, the day to day of, of either going through something or, or living with a child with, you know, with that disability or whatever. PR06

Linked to matching by diagnosis:

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

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

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

Linked to 'it's all about me':

I think they were the first pers-, people that actually asked me about me. You know, um you go to the hospitals, you go to school, you fill these forms in, it's all about [my child]. P4

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

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

Linked to expanding social networks:

There's a whole other community that opens up to you then, of um other parents with children with disabilities. P8

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

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

*In all boxes, 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.

support), which was seen as important for their mental health. This then enabled the service to support parents in developing the confidence and ability to cope with the emotional ups and downs for themselves. Parents were helped to achieve these outcomes by learning from the experience of their befriender

(informational support) and the support and encouragement of their befriender (affirmational support); both of which are underpinned by shared experience.

Parents have credibility with other parents because they are speaking from experience rather than simply passing on infor-

Box 2. Emotional stability and personal growth

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

I think I feel more confident with dealing with it all really and I've sort of like learned to accept you know, that that's what it is. P5
it's really important that you are able to get rid of some of that emotion because it really does store up inside you and if you bottle it up it can manifest into all sorts of illnesses and how you are with your children, how you view everything, your mental health, you know, it has such a bit impact. Emotion is something that affects everything. B16

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

Linked to learning from the experience of others:

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

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 [. . .] I needed to know that I could cope further down the line. And also, cos they've got experience, they can suggest things to you, like places to go or things. P2

You hear her ideas or whatever, that's worked for her and you think, oh okay I'll try it. We might have to tweak it, or it might not work at all. So it's definitely had an impact on us, definitely. P5

You are passing on a kind of knowledge experience. B3

And I think it's also something about how you then receive that um you know, that support or information because you see that person with a level of credibility because they obviously have come from a similar place. PR06

Linked to Support and encouragement:

She encouraged me to fight for the statement, [. . .] it made me realise well yeah, I've got to take control as well. They don't get to dictate to me, it's my son and I know what's best for him at the end. P5

It's like no one can make you, no one can . . . it has to come from within you. You have to rebuild yourself and repair yourself and accept your situation, but you do need support while you're doing that. P2

mation as a professional might. Hearing how another parent has encountered and tackled a similar problem assures the parent that they are not the only person dealing with such problems, which can aid their confidence to explore new solutions. Befrienders were conscious of the responsibility that this conveyed and the importance of not saying the wrong thing. Professionals in the group recognized the knowledge and experience held by the community of parents but some expressed concern that befrienders might give wrong advice or signposting, or unduly influences parents' decisions.

The support and encouragement that befrienders give to parents contribute to their development in areas such as confidence and knowledge. Providing enough support that the parent feels secure and able to challenge themselves, and positively reinforcing progress, enables parents to help themselves

(also known as 'scaffolding'). Parents were conscious of the fact that the journey was something they had to do for themselves, but they benefited from the support of someone who had been there too, and who understood and could give pointers to be able to cope and do things for themselves (Box 2).

Key outcomes for befrienders

Specific outcomes for befrienders were identified by parents delivering support and professionals but were rarely discussed by parents receiving support.

Feeling that you have helped someone else

Befrienders clearly identified that feeling that they had helped someone else was a positive and important outcome for them.

Particularly rewarding was seeing parents they support making progress, and knowing that they had played a part in that progress. A particular motivation for becoming a befriender was to protect other parents from the struggle that they had been through themselves.

Personal growth and self-worth

Befrienders described an increase in their own confidence through training and ongoing support. Feeling more confident enabled befrienders to operate more effectively in their own family and in relationships outside of the service, as well as with parents they supported. This was strongly associated with having a sense of purpose and doing something worthwhile, with a corresponding restoration and maintenance of their own self-worth.

Part of personal growth was the recognition of how far they had come in their own journey. Befrienders were able to gain strength from using their own negative experiences in a positive way to help other parents avoid the same problems or pitfalls, or at least to know what to expect. Befrienders described ways in which changes in their confidence and self-worth, which they ascribed to their involvement with the peer support service, affected their willingness to engage in activities such as becoming active in advocacy and other parent organizations, joining committees or becoming involved in training professionals (Box 3).

Training

Training undertaken by befrienders in this service was extremely influential, both in equipping them with the skills to befriend and contributing to their personal emotional development but also in creating a supportive social network. Training groups go on an emotional journey together, sharing stories that they may never have shared with anyone else. This establishes a special and close connection between the group members and puts in place the friendships that often appear to continue when, as befrienders, they are supporting each other.

Those who complete training are under no obligation or pressure to befriend. Training was described as a painful process for many befrienders. The process of sharing the details of one's emotional journey while therapeutic was difficult for many trainees. Subsequently, not everyone wants to, or feels ready to, take the next step to befriending, although they remained part of the network. Training was viewed by professionals as a critical component of a well-run service; however, they seemed

Box 3. Positive outcomes of befriending

Feeling you've helped someone else:

I just feel really, really glad within me that I can help somebody else, that there is, that there would have been somebody else there to, to pour it all out to. B5

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

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

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

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 persons. FG2

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

unaware of the personal impact on befrienders, beyond equipping them with the skills to befriend.

Mutual support

Befrienders highly valued the support they offer to each other. This mutual support was not described by the other participant groups in the same way. The importance of the co-ordinator and befriender network was discussed by professionals in the context of professional supervision as essential for the safety and well-being of both parents and befriender. However, professionals seemed unaware of the personal and emotional support that befrienders described giving each other. Befrienders described the support they offer each other in similar ways to parents, defined by their shared experiences and the ability to speak freely in a non-judgemental, safe environ-

Box 4. Training and mutual support**Training:**

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

Err so if somebody hasn't had the training I would worry that inappropriate err misguided help may be on offer and then making it worse. PR10

Mutual support:

It's just a sharing session with the group. [. . .] it just gives me an opportunity really to hear what other people are up to and then try and bring that into our family life. B16

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. B11

I think they need a sort of support network so that they know themselves you know, what they feel happy with and if they don't you know, feel happy because it is a bit of risk that you might get sucked in if you're working very much on your own. PR06

ment. They spoke of learning from each other, supporting and encouraging each other, and gaining emotional benefit from the group. Mutual support was seen as important to maintain their emotional stability for the sake of their own well-being but also crucial for the service to sustain their ability to offer support to others (Box 4).

Negative outcomes for befrienders

A number of potentially negative outcomes for befrienders were identified, both by befrienders and professionals. Befrienders described the emotional drain of befriending, which they felt to be underestimated by professionals. However, professionals did express concerns regarding the emotional burden on befrienders and the importance of supervision and support to protect them.

Box 5. Potential negative impacts for befrienders

Sometimes they feel a bit helpless, the actual befriender, that they can't help. P11

There seems to be some kind of perception that we just go in and have a nice little cup of coffee and a chat. And I would like them to realise how, um, emotionally and mentally, you know, taxing it can be. FG1

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

I just feel that we'd need to know what, you know, and what supervision they've got, what support have they got as well? Because if they have got a lot of burden of all of this from another person, they could actually get deeply emotional with them. PR05

Befrienders often found it difficult to switch off after befriending, which was sometimes constructed as a commitment to the parent they are supporting and to the peer support service rather than a negative impact. Professionals were concerned that befrienders may have difficulty maintaining their distance from another family's situation and might be less able to maintain boundaries around the relationship than a professional.

Many, although not all, befrienders described varying levels of anxiety before a first visit, whether they were going to 'get it right' and whether they would get on with the parent. Befrienders were concerned whether they would do any good or whether they might even make the parent feel worse. One described feelings of inadequacy; others expressed frustration that they would not be able to 'fix' things for people even though this is not the objective (Box 5).

Discussion

Participants identified a number of important ways in which support impacted on parents: a reduced sense of isolation, emotional stability and personal growth. For befrienders, personal growth was also an important outcome in association with increased self-worth and a sense of having helped someone else. The befrienders, but not the other participant groups, also stressed the positive impact of the training and ongoing mutual support. Potential negative outcomes for befrienders, such as emotional burnout and anxieties around personal effectiveness, were identified by all participant groups. Befrienders and parents appeared to benefit through expanding their social network.

We are not aware of other research in this context and population that has identified such strong, positive impact of the training and ongoing support between befrienders. Training and ongoing befriender support are integral features of the Face2Face service and may be less prominent or even absent in less formal organizations. 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 your journey. In some sense, the training is itself another form of peer support and like the support offered to parents is founded on shared experience.

Failure to acknowledge the impact for befrienders has potential implications for whether the service is considered value for money. For example, the service does not require parents who complete training to go on to befriend. If the service is viewed purely for the benefit of the recipients, the parents receiving support, this would seem to be a waste of money. It is only when the combined benefits of training and ongoing mutual support to befrienders are viewed as outcomes of a community-based service that the complex nature, and multiple levels, of this model of peer support become clearer.

Previous qualitative research in this population has also reported outcomes relating to emotional and personal growth for parents receiving support (Ainbinder *et al.* 1998; Kingsnorth *et al.* 2011). For parents who support others, the satisfaction gained from helping other people (Lo 2010; Sullivan-Bolyai & Lee 2011) and the desire to give something back (Solomon *et al.* 2001; Jenkinson *et al.* 2013) has been highlighted and is consistent with research in other populations on the benefits derived from offering support to others, known as the helper therapy principle (Salzer & Shear 2002; Solomon 2004).

Shared experience was key to the success of this particular support and distinguished it from other types of support such as that received from professionals or family and friends. We interpret shared experience to be the overarching theme linking, if not actually enabling, other aspects of the peer support to be effective, thus leading to the perceived outcomes. The findings support those of previous studies highlighting the importance of shared experience (Law *et al.* 2001; Nicholas & Keilty 2007) and learning through the experience and support of others (Kerr & McIntosh 2000; Bull 2003). These themes reflect the informational, affirmational and emotional support described elsewhere (Ireys *et al.* 1996). The findings are also consistent with research in other populations on the positive and protective effects of a shared social identity (Haslam *et al.* 2009).

Consideration of the outcomes for parents receiving support and those offering support in the same study high-

lights two issues. First, that there are important parallels between the two groups. Like parents receiving support, befrienders benefit from the support of other befrienders that is centred on the same sense of shared experience that is key to the success of the support they offer parents. They too experience personal growth through their involvement with the service, continuing to grow in confidence and perceived ability to cope. This should not be surprising given that befrienders are parents of disabled children too, coping daily with challenges in their family's health and well-being; however, it does highlight that viewing parents and befrienders as entirely distinct groups is artificial. This distinction speaks to the second point that it is important to raise the profile of outcomes for befrienders particularly around ongoing mutual support, which was not strongly recognized by professionals but is an important part of ensuring the well-being of befrienders and ensuring that they are equipped for the role they are taking on. Future programme development should strongly consider the importance placed on training and mutual support in this study.

A strength of this study is that it enabled the views of service users, service providers and professionals who might commission or refer to the service to be considered alongside each other, thus enabling us to highlight here areas of consistencies and inconsistencies in the opinion and understanding across the different participant groups. It is important to remember that half of the professional group did not have familiarity with the specific service, although all were familiar with peer support services more generally. Gauging the opinion of this group about peer support is perhaps more informative in terms of highlighting understanding and knowledge gaps about the potential benefits of peer support than professionals who already refer to such services.

Specific outcomes for befrienders were identified by parents delivering support and professionals but were rarely discussed by parents receiving support. We did not explore this in depth at interview with parents receiving support unless discussion was forthcoming as (i) they have no direct experience and (ii) we did not wish to elicit discussion where there was potential to impact on how these parents might behave with their befriender.

The close involvement of the stakeholder group was a key strength. 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. This was a collaborative process between the researchers and befrienders that helped us to understand the emerging themes. The activity was wholly constructive and no tension was experienced between researcher and befriender views on the themes.

Limitations of the study include potential sampling bias as we were not able to recruit any parents who had declined or who had withdrawn from the service because they either had a negative experience or were dissatisfied with the service. Similarly, only 2 of the 23 befrienders we interviewed no longer had regular contact with the service. All participants were White British, which was representative of the service locally; however, ethnic and cultural factors may well influence the uptake and implementation of peer support and merits further research. Groups that aim to support families from specific ethnic groups and marginalized communities exist in the United Kingdom (Include Me Too 2014). We also recognize the limitation of our professional sample as there is a potential positive bias in this group who were willing to set aside an hour to talk about parent support.

Future research

Our analysis has led us to question whether there may be potential impact of this type of service on the broader community of parents of disabled children as well as on those directly involved with providing and/or receiving support through the service. This may present an unexplored avenue for future research. The perspective taken by the researcher on what the intervention 'is', 'does' and 'for whom' will determine the nature of the evaluation (Petticrew 2011) and, logically, will also impact on the value perceived in both monetary and societal costs and benefits.

The importance of shared experience between parent and befriender is central in our study and in the work of others. Creating that sense of shared experience, however, may not be straightforward. Peer support is a complex intervention with a number of factors relating to the organizational structure of the service, the parents offering support and the parents receiving support that have potential to impact on the effectiveness of the intervention. The growing emphasis on process evaluation in trials of complex interventions (Craig *et al.* 2008) highlights the need for a greater understanding of the organizational and process factors that may help or hinder the establishment of a sense of shared experience between parents. We unpack and explore these factors in the second of these linked papers (Shilling *et al.* 2015).

Key messages

- Shared experience between parent and befriender underpinned the outcomes of peer support.
- Important outcomes for parents included reduced isolation, emotional stability and personal growth.
- Befrienders also experienced positive outcomes from training, mutual support and the feeling that they were helping others, but were also at risk of emotional burden and concerns around their performance and the requisite time commitment.
- Capturing all potential beneficiaries of a peer support service is important in evaluations and will influence their perceived value.

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References

- Ainbinder, J. G., Blanchard, L. W., Singer, G. H., Sullivan, M. E., Powers, L. K., Marquis, J. G. & Santelli, B. (1998) A qualitative study of parent to parent support for parents of children with special needs. Consortium to evaluate parent to parent. *Journal of Pediatric Psychology*, 23, 99–109.
- Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F. & Rosenbaum, P. L. (2009) Health among caregivers of children with health problems: findings from a Canadian population-based study. *American Journal of Public Health*, 99, 1254–1262.
- Brehaut, J. C., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., Rosenbaum, P. L. & Kohen, D. E. (2011) Changes over time in the health of caregivers of children with health problems:

- growth-curve findings from a 10-year Canadian population-based study. *American Journal of Public Health*, 101, 2308–2316.
- Briton, C. (2014) *Engage, enable, empower: progress report of the National Network of Parent Carer Forums*. Available at: <http://www.nnpf.org.uk/wp-content/uploads/2014/07/NNPCF-Report2014-Low.pdf> (last accessed 20 August 2014).
- Bull, L. (2003) The use of support groups by parents of children with dyslexia. *Early Child Development and Care*, 173, 341–347.
- Committee on Early Childhood Adoption and Dependent Care (2011) The pediatrician's role in family support and family support programs. *Pediatrics*, 128, e1680–e1684.
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*, 337, a1655.
- Emerson, E., McCulloch, A., Graham, H., Blacher, J., Llewellyn, G. M. & Hatton, C. (2010) Socioeconomic circumstances and risk of psychiatric disorders among parents of children with early cognitive delay. *American Journal on Intellectual and Developmental Disabilities*, 115, 30–42.
- Gerstein, E. D., Crnic, K. A., Blacher, J. & Baker, B. L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 981–997.
- Goldbart, J. & Catons, S. (2010) *Communication and People with the Most Complex Needs: What Works and Why This is Essential*. Mencap, London, UK. Available at: http://www.mencap.org.uk/sites/default/files/documents/2010-12/Comms_guide_dec_10.pdf (last accessed 13 August 2014).
- Haslam, S. A., Jetten, J., Postmes, T. & Haslam, C. (2009) Social identity, health and well-being: an emerging agenda for applied psychology. *Applied Psychology: An International Review*, 58, 1–23.
- HM Government. (2012) *Support groups for parents of disabled children*. Available at: http://www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10026501 (last accessed 8 August 2014).
- Include Me Too. (2014) *About Us*. Available at: <http://www.includemetoo.org.uk/about-us> (last accessed 1 September 2014).
- Ireys, H. T., Sills, E. M., Kolodner, K. B. & Walsh, B. B. (1996) A social support intervention for parents of children with juvenile rheumatoid arthritis: results of a randomized trial. *Journal of Pediatric Psychology*, 21, 633–641.
- Jenkinson, C. E., Dickens, A. P., Jones, K., Thompson-Coon, J., Taylor, R. S., Rogers, M., Bambra, C. L., Lang, I. & Richards, S. H. (2013) Is volunteering a public health intervention? A systematic review and meta-analysis of the health and survival of volunteers. *BMC Public Health*, 13, 773.
- Kerr, S. M. & McIntosh, J. B. (2000) Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health and Development*, 26, 309–322.
- King, G., King, S., Rosenbaum, P. & Goffin, R. (1999) Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology*, 24, 41–53.
- Kingsnorth, S., Gall, C., Beayni, S. & Rigby, P. (2011) Parents as transition experts? Qualitative findings from a pilot parent-led peer support group. *Child: Care, Health and Development*, 37, 833–840.
- Law, M., King, S., Stewart, D. & King, G. (2001) The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 21, 29–48.
- Lo, L. (2010) Perceived benefits experienced in support groups for Chinese families of children with disabilities. *Early Child Development and Care*, 180, 405–415.
- Miodrag, N. & Hodapp, R. M. (2010) Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry*, 23, 407–411.
- NHS Choices. (2011) *Parent support groups*. Available at: <http://www.nhs.uk/carersdirect/guide/parent-carers/pages/parentsupportgroups.aspx> (last accessed 8 August 2014).
- Nicholas, D. B. & Keilty, K. (2007) An evaluation of dyadic peer support for caregiving parents of children with chronic lung disease requiring technology assistance. *Social Work in Health Care*, 44, 245–259.
- Petticrew, M. (2011) When are complex interventions 'complex'? When are simple interventions 'simple'? *European Journal of Public Health*, 21, 397–398.
- Pope, C., Ziebland, S. & Mays, N. (2000) Qualitative research in health care. Analysing qualitative data. *British Medical Journal*, 320, 114–116.
- Ritchie, J. & Spencer, L. (1994) Qualitative data analysis for applied policy research. In: *Analyzing Qualitative Data* (eds A. Bryman, R. Burgess), pp. 173–194. Taylor & Francis, London, UK.
- Rosenbaum, P., King, S., Law, M., King, G. & Evans, J. (1998) Family centred service: a conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics*, 18, 1–20.
- Salzer, M. S. & Shear, S. L. (2002) Identifying consumer-provider benefits in evaluations of consumer-delivered services. *Psychiatric Rehabilitation Journal*, 25, 281–288.
- Scope. (2014) *Face 2 Face – the one-to-one befriending service for parents of disabled children*. Available at: <http://www.scope.org.uk/face2face> (last accessed 8 August 2014).
- Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M. & Logan, S. (2013) Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine and Child Neurology*, 55, 602–609.
- Shilling, V., Bailey, S., Logan, S. & Morris, C. (2015) Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health and Development*, 41, 537–546.
- Solomon, M., Pistrang, N. & Barker, C. (2001) The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29, 113–132.

- Solomon, P. (2004) Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 392–401.
- Staley, K. (2009) *Exploring impact: public involvement in NHS, public health and social care research*. Available at: http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf (last accessed 13 August 2014).
- Sullivan-Bolyai, S. & Lee, M. M. (2011) Parent mentor perspectives on providing social support to empower parents. *The Diabetes Educator*, 37, 35–43.

Supporting information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Description of peer support service.

Appendix S2. Summary of topic guides.

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