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

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ABSTRACT:

Background: Parents of disabled children often seek support from their peers. The shared experience between parents appears to be a crucial mediating factor. Understanding how a sense of shared experience is fostered can help to design and evaluate services that seek to provide peer support.

Methods: 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.

Findings: Formal structures and processes in place such as training and ongoing supervision and support were highly valued, as was the highly personalised, confidential, flexible, one-to-one at home nature of the service. Crucial to establishing rapport was putting the right people together; ensuring a good match between befrienders and parents. Clearly, the befriending parent has to be emotionally prepared to provide help. However, if the parent being offered support was not ready to accept help at the time it was offered or the type of support was not right for them, they are less likely to engage with the service.

Conclusion: Organisational and process factors as well as characteristics of the parents offering and receiving support contribute to the sense of shared experience in one-to-one peer support. These factors interact to influence whether peer support is effective, and should be explicitly considered when designing and evaluating services.

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Key messages:

Shared experience is central to successful peer support but a number of factors may contribute to a relationship that engenders the sense of shared experience.

Facilitating factors include organisational and processes aspects of the service, such as training and ongoing supervision and support, and also characteristics relating to the parents who offer and receive support.

The impact of each of these factors may be context and person specific and research should identify and measure how they influence the outcomes of peer support.

INTRODUCTION

A large body of research has identified the potential benefits of peer support across a range of health care and promotion contexts (Hoey et al. 2008, Repper and Carter 2011, Charlesworth et al. 2008, Jolly et al. 2012), including parents of disabled children (Ainbinder et al. 1998, Law et al. 2001). In our recent systematic review (Shilling et al. 2013), qualitative studies reported that parents experienced peer support as extremely beneficial, although this was not consistently supported by quantitative studies examining changes in psychological health or family function. The most coherent theme across qualitative studies was that the crux of successful peer support was a sense of 'shared experience' between the two parties. The person offering support could identify with and understand the issues of the person receiving support because they had been in a similar situation themselves.

Several studies identified situations where peer support was not successful. In some situations practical factors such as time and logistics interfered with the supporting relationship (Ainbinder et al. 1998, Kingsnorth et al. 2011). There were also suggestions that some parents may find it difficult to share personal information with a stranger (Nicholas and Keilty 2007), that some were frightened of comparisons between their child and others (Nicholas and Keilty 2007), and that parents did not like to feel they were being pushed into accepting peer support (Bull 2003). Different factors are likely to contribute to whether a parent, when matched to another parent feels that bond and understanding of perceived shared experience. These may include whether their children have similar diagnoses and severity of condition as well as family, social and environmental factors. (Ainbinder et al. 1998)

This study forms part of a programme evaluation of a one-to-one peer support service offered to parents of disabled children in South West England by Face2Face (Scope) (see

supplementary file S1 for further details of the support service). In the first of this pair of papers we described the perceived outcomes of a one-to-one peer support service for parents of disabled children (Shilling et al. submitted). We reported, as have others (Ainbinder et al. 1998, Bull 2003, Kerr and McIntosh 2000, Kingsnorth et al. 2011, Law et al. 2001, Lo 2010, Nicholas and Keilty 2007, Rearick et al. 2011, Solomon et al. 2001), that shared experience between parents of disabled children was crucial to the success of the support relationship. Shared experience enabled other elements of the supporting relationship, such as learning from the experience of others, support and encouragement and the opportunity to speak freely in a non-judgemental environment. In this paper we explore organisational and process factors that were perceived necessary or influential in building that sense of shared experience between befrienders and parents.

METHOD

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). The patient and public involvement in the design and conduct of this research is described in more detail in the related paper (Shilling et al. submitted).

Participants

Parents (excluding those perceived by the service coordinator to be in crisis) and befrienders who had contact with the Face2Face service in Devon, Mid or East Cornwall Face2Face services in a 12 month period were invited to participate in the study. We purposively sought to interview parents who were offered peer support but declined or received very few visits.

A total of 69 parents and 53 befrienders from Devon and Cornwall were invited to participate. Of these, 14 parents responded and 12 were interviewed. Twenty-three befrienders participated; thirteen had individual interviews, 9 took part in focus groups and one responded by post. We conducted 10 interviews with a purposively sampled group of professionals working with disabled children and their families: 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.

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 (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 with the exception of two, where detailed notes were taken. Focus groups were used with befrienders in Cornwall. The groups were facilitated by a member of the research team and followed the same topic guide and structure as the interviews. 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 and Spencer 1994, Pope et al. 2000) Two members of the research team (VS/SB) read the transcripts and developed the thematic framework – incorporating key concepts and issues identified a priori from the literature and those emerging from the data. The framework was then applied to the transcripts which were indexed by themes and subthemes using NVivo10. 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. The content of these themes and subthemes were reviewed by VS/SB and differences in interpretation were resolved through discussion. 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.

Where direct quotes are presented, 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.

FINDINGS

We identified several key factors that contributed to a relationship that engendered the sense of shared experience, thereby enabling the other active ingredients of support. Though interrelated, these factors divide into those concerning organisational aspects and standard

processes of the service, those relating to the parents delivering the service and those relating to parents as potential users of peer support services.

Organisational aspects and processes

FORMAL STRUCTURES AND PROCESSES – TRAINING, SUPERVISION AND DELIVERY

All participant groups discussed how the service was organised and delivered, but gave different weight to different elements. For parents and befrienders the focus was how the organisation of the service helped to create an environment where the parent has trust and confidence in the befriender from the start, thus facilitating the initial meeting.

Face2Face offer a highly personalised, flexible, one-to-one at home service. This was seen as particularly important to enable those with less confidence or concerns about confidentiality to access support. Confidentiality for parents was raised by all participant groups as a highly valued element of the service. The flexibility of the service; being able to access support at home at a convenient time on a one-to-one basis, ensured that the service was viewed by parents and befrienders as relaxed and informal, enabling parents to feel in control, confident and able to say how they feel.

Professionals also recognised the importance of flexibility and an appropriate environment, but they specifically valued the more formal processes of befriender training (including safeguarding and risk management) and ongoing formal supervision and support. These were perceived by professionals as giving credibility to the service as appropriate to refer parents to, with procedures in place to protect both parties.

Training was seen as essential by professionals and befrienders 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 also valued the confidence it gave them, which in turn could help them to put parents at ease.

The formal structures in place to ensure the safety and quality of the service sometimes resulted in a blurring between the perception of the befriender as a parent or professional. The service itself was seen as more friendly and relaxed than other services, but more controlled and professional than talking to a friend. It was important to families that their befriender was a parent first, even though they behaved in a professional manner, this helped to put them at their ease. Befrienders too 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.

Box 1: Organisational aspects and processes

RULES AND BOUNDARIES

The importance of boundaries, and rules around those boundaries, to maintain a degree of professionalism and to protect both the befriender and the parent was recognised by all groups. However boundaries were sometimes viewed by befrienders and parents as a barrier to establishing a 'safe' environment and sense of shared experience; formal boundaries would recommend that befrienders do not share too much about themselves however some sharing is helpful for parents and can facilitate the relationship. Some befrienders felt it can be difficult to maintain that separation particularly when a parent was very emotional, and many described how boundaries could become blurred as relationships developed. While all parents

were positive about the service as a whole, the boundaries around the relationship occasionally led to disappointment when parents hoped for more than could be provided. For example, support with marriage difficulties, to be put in contact with other families, or wanting the relationship to be more two way and learn more about their befriender.

Box 2: Rules and boundaries

Putting the right people together

READINESS AND SUITABILITY TO BEFRIEND

Befrienders are trained to be able to listen empathically and without judgement but participants felt that befrienders had to be naturally very giving, caring people to begin with. This is implicit in the main motivation stated for becoming a befriender; wanting to help other parents through the difficulties that befrienders had been through themselves, so that parents didn't have to go through the same struggle. However, there is potential for harm to either party if the befriender is not ready to befriend; 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.

MATCHING FAMILIES

Matching parents and befrienders in a one-to-one service is a key role of the service coordinator but is not straightforward. There was variability within and between the accounts of different participants as to the importance of different matching 'criteria' including personality, age and social background. Most commonly discussed however was the relative importance of matching parent and befriender by their child's diagnosis. There was no clear

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resolution of how much similarity between diagnoses is required to enable parents to feel a sense of shared experience.

Some 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. The need for 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. Others argued 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 may have a different journey and different interactions with society hence the belief that some level of similarity is needed for real connection.

Box 3: Putting the right people together

Parents as potential users of peer support

When parents first become aware of peer support, they bring a range of emotions and prior experiences and often have a variety of support needs. Two themes relating to the parent and how they might respond to the initial suggestion of peer support were repeatedly discussed across participant groups; the timing of the suggestion and reasons why parents in need might not access the service.

TIMING OF SUPPORT

The timing at which support is offered, needed and accessed (or not) was considered critical to the uptake of support, but was not straightforward. 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. There are potential dangers inherent in early intervention when parents are very vulnerable. 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.

NOT THE RIGHT SERVICE FOR EVERYONE

Participants described a number of reasons why some people who might benefit from support, may choose not to take up the offer. 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. People also differ in how much they want to share their emotions and how they cope; some people may never be able to open up even to another parent.

Participants across all groups acknowledge that 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 most need help may not be able to ask for it. Other, potentially more easily modifiable anxieties, included 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'.

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.

Box 4: factors relating to the parent seeking support

Figure 1 illustrates the moderating service and personal factors that precede the mediator 'shared experience'.

Figure 1: Factors contributing to shared experience

DISCUSSION

We have reported several key factors that can contribute to or inhibit the establishment of a sense of shared experience in which parents are likely to feel at ease and able to talk openly. These include organisational elements and processes of the service put in place to ensure that the service is delivered safely and within boundaries such as training and supervision. Participants also identified the importance of matching a parent and befriender and choosing the timing which is right for the parent to be able to benefit. It is crucial that the befriender him/herself has the emotional and personal capacity to support another parent. These factors were important to the participants in this study but we do not suggest that this list is exhaustive or necessarily applicable to all peer support services.

Participants recognised the complexity of this type of intervention and identified a multitude of variables that effect on the befriending relationship. How these factors may interact and the corresponding effect on outcomes is unclear as are the potentially ameliorating effects of other factors, such as perceived support from family, friends and professionals.

The complexity is further increased by the fact that the impact of some of these factors is person and context specific. For example, some parents in our sample wanted a close match by diagnosis, for others it was more important that they were similar in personality to their befriender. These, factors are illustrated in Figure 1 in this paper which should be viewed alongside the figure presented in the first of this pair of papers (Shilling et al. submitted), which shows the links between the mediator 'shared experience' and the active ingredients and outcomes of peer support.

There are a number of challenges for evaluating the impact of peer support; for example parents may seek and/or receive other types of peer or professional support, which varies between and within the individual (Silver et al. 1997). Other challenges relate to implementation and maintaining the fidelity of the intervention in a trial (Craig et al. 2008). While there may be a clear mission and purpose, and the methods used carefully developed, a service offering one to one emotional support is intentionally delivered with a high degree of flexibility. This was highly valued by parents and befrienders however the nature of the service makes it challenging to address issues such as intervention fidelity; the 'what and when' of measuring impact; and demonstrating that any change is attributable to peer support. Peer support is a highly complex intervention, and appropriate evaluation requires specific considerations including monitoring whether key components are compromised or otherwise modified (Craig et al. 2008).

Not all parents of disabled children require this type of emotional support to adjust to their child's diagnosis, however there may be specific reasons why parents who would benefit choose not to access the service. A limitation of the study is that we were not able to

interview any parents who had been offered services but chose not to take them up. Participants highlighted the timing of the approach and a number of anxieties that they themselves had experienced to some degree, which may be sufficient to put some parents off accessing the service.

CONCLUSION

Previous research, our own included, has reported that a critical factor in the success of a peer support intervention is a sense of shared experience between the parent and befriender. This paper identifies some of the key preceding factors that can help or hinder the establishment of that rapport and highlights the need for evaluative research to explore how these factors act and interact to influence the success of the befriending relationship.

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Box 1: Structures and processes

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

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

Parent or professional?:

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

Box 2: Rules and boundaries

*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 wan*ting to get something off your chest or wanting to talk about yourself B17

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, 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

Box 3: Putting the right people together

Readiness and suitability to befriend:

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 […] 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 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

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

Matching parent and befriender:

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

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

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 real*ly *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

Box 4: factors relating to the parent seeking support

The timing at which support is offered and accessed is critical:

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

And any one particular service may not be the right thing for everyone:

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